DOCTOR OF HEALTH (DHEALTH)

The role of diet in palliative care as perceived by patients, carers and healthcare professionals

Holdoway, Anne

Award date:
2020

Awarding institution:
University of Bath

The role of diet in palliative care as perceived by patients, carers and healthcare professionals.

Anne Holdoway

A thesis submitted for the degree of
Professional Doctorate in Health

University of Bath
Department for Health

28th February 2020

Copyright notice

Declaration of authorship

I declare that no material in this thesis has been used in any other submission for an academic award. I also certify that this thesis has been written by myself and that any help I have received in my research work in preparation of my thesis has been acknowledged. I certify that all informational sources and literature used are indicated.

Anne Holdoway

February 2020

Table of Contents

Tables

Figures

Acknowledgements:

Firstly, I would like to express my considerable thanks to all the patients, family members and healthcare professionals who participated. I am indebted to them all for the time they dedicated to the study and without whom this study could not have happened. My life has been enriched by their insights and experience.

I am truly grateful to my supervisors, Dr Paula Smith from the Department of Psychology, University of Bath and Dr Christine Baldwin from the Department of Nutrition and Dietetics, King’s College, London. Without their support and advice, this thesis would never have been realised.

I would also like to give credit and thanks to Dr Ailsa Brotherton, a valued friend and colleague who encouraged me to embark on this journey and Dr Alan Buckingham who was key to helping me overcome my writers block during the early assignments of the Professional Doctorate programme.

In my workplace I give praise to the amazing work the palliative care team deliver day after day and whose enthusiasm for nutrition in palliative care inspired me to focus on this as my research topic.

A special thanks to Helen De Renzie-Brett, whose calmness and experience in the palliative care sector supported me in the early phases of the research until sadly cancer took her life.

My thanks to all my family and friends, especially Hilary Franklin, for their tolerance when listening to me talk about nothing else over the years and in providing the laughter and camaraderie to keep me going.

And finally, a huge thank you to my children Will, Katie and John and my husband Lindsay. Your patience and advice have been above and beyond anything I could wish for. I could not have completed this thesis without you, and I owe you much for the immeasurable ways you helped me throughout my doctorate journey.

Title: The role of diet in palliative care as perceived by patients, carers and healthcare professionals.

Abstract

Amongst patients with incurable cancer, many will experience unintentional weight loss, loss of appetite and a range of symptoms that adversely affect the ability to eat and drink.

This thesis explores the role of diet and nutrition in the palliative phase of cancer care as perceived by patients and their carers and the healthcare professionals involved in providing support. The work sought to explore the views on the role of diet before cancer and once diagnosed, the experience and identification of diet-related issues, what mattered and why and the suitability and adoption of management strategies.

To explore the issues and complexities, a qualitative approach using case study methodology was considered the most appropriate. Semi-structured interviews were the primary source of data with secondary sources including medical records, policies, training and resources. Interviews and data collected was thematically analysed.

Patients with incurable cancer, deemed palliative, were purposively sampled to include a variety of cancer types likely to experience diet-related issues. Each patient was asked to nominate a family member or friend, and two healthcare professionals who had been, or were involved in their care, to participate in the study.

4 patients, 3 carers and 7 healthcare professionals participated. Patients had the following cancers: melanoma with brain secondaries; head and neck with lung secondaries; pancreatic cancer; lung cancer with liver metastases.

Several overarching themes were identified which included: the complexity of diet, cancer and symptoms; disruption and distortion: the altered meaning of food and preservation of self; identification of what mattered through nutrition conversations and observations; strategies to deal with diet-related issues including adaptations, adjustment, acceptance of a new norm; facilitators of nutritional care including knowledge acquisition, culture and environment.

The findings have offered new insights into the identification and management of diet-related issues, weight loss and cachexia in advanced cancer and been used to develop a framework for training and clinical practice. It is hoped dissemination of the findings will assist in shaping strategies to improve nutritional care and provide advice for the growing numbers of patients receiving palliative care.

Abbreviations

AHP - Allied healthcare professional

GP - General practitioner

HCA - Healthcare assistant

HCP - Healthcare professional

MDT - Multidisciplinary team.

UK - United Kingdom

WHO - World Health Organisation

GLOSSARY OF TERMS

For the purpose of assisting the reader's understanding of this thesis some medical and dietetic terminology is outlined below. The definition of palliative care, end of life care and palliative medicine is included to facilitate an appreciation of how care and the focus of care, may change as a patient reaches the end of life.

Anorexia - The loss of desire to eat (Wholihan & Kemp, 2010)

Body Mass Index (BMI) - calculated by dividing weight in kg by height squared in metres squared, the normal range for adults is 18.5 - 25 kg/m^2

Cancer cachexia - a complex, multifactorial wasting syndrome involving loss of skeletal muscle and fat caused by the metabolic response to a tumour or tumour factors. (Fearon et al., 2011)

Clinically assisted nutrition and hydration – nutrition support provided via the gastrointestinal tract (tube feeding) or via a vein (parenteral nutrition) to provide essential nutrients when the ability to meet nutritional requirements via the oral route is not possible.

Complex palliative care problems - those that are severe and intractable, involving a combination of difficulties in controlling physical and/or psychological symptoms, the presence of family distress and social and/or spiritual problems. They exceed the resources of the generalist palliative care provider to meet the needs and expectations of the individual/carer/family.

Constipation – reduced frequency of passage of stools

Diarrhoea – frequent passage of stools

Diet-related issues – a term designated to encompass the effect of cancer, cancer treatment and symptoms on the ability to eat and drink and consume a diet.

End of life care - a continuum of palliative care used to describe the care that is offered during the period when death is imminent, or life expectancy is likely to be a short number of weeks, days or hours.

Fatigue - a persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.

Family members and carers - those who are closest to the individual in knowledge, care and affection. The family may include the biological family, the family of acquisition e.g. related by marriage, and the family of choice and friends

Hospice care – a term that may be used to describe both a place of care (i.e. institution) and a philosophy of care, which may be applied in a wide range of care settings. The term is often used interchangeably with 'palliative care'.

Life-limiting - a condition, illness or disease which is progressive and incurable

Malnutrition - a state of nutrition resulting from lack of uptake or lack of intake of nutrition leading to altered body composition (decreased fat free mass) altered body cell mass, diminished physical and mental function and impaired clinical outcome from disease (Sobotka, 2012)

Multidisciplinary team - A team of health and social care professionals who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified needs of the individuals and families being care for. A multidisciplinary team typically includes members from the following disciplines: Medicine (doctors), Nursing, Social Work, Occupational Therapy, Dietetics, Physiotherapy, Psychology, Chaplaincy, Pharmacy, Volunteers, Speech and Language Therapy, Complimentary and Creative Arts Therapy

Nutrition impact symptoms - a term that has evolved to describe the cancer related symptoms specifically associated with interference of nutrient intake which in turn can adversely affect nutritional status.

Palliative care - The World Health Organisation (WHO) defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. (WHO, 2008). The discipline of palliative care is intended to help individuals to live well until they die whenever that occurs. 'Palliative care' as opposed to 'end of life care' is the preferred term when describing care which is supportive and focused on improving the quality of life of individuals and their families facing the problems associated with life-limiting and life-threatening illness.

Palliative medicine - the appropriate medical care of individuals with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the individual's death.

Parenteral nutrition - the provision of liquid nutrition via a tube directly into a vein

Palliative rehabilitation - care aimed at helping individuals gain opportunity, control, independence and dignity, setting the pace with the individual. The focus of palliative rehabilitation is on enhancing function, adaptive coping and independence within progressive disease constraints. Tailoring rehabilitation goals to the stage of the disease, prognosis and personal meaning of quality of life allows for the establishment of realistic, attainable and often short-term goal. This is achieved through a multidisciplinary, patient and family centered approach. The provision of rehabilitation care encompasses open communication, continual review and adjustment of therapeutic goals.

Specialist palliative care teams - Professionals working in partnership in both inpatients and outpatient settings within hospices, secondary care settings such as acute hospitals and the community e.g. homes, care homes and nursing homes.

Steatorrhoea - diarrhoea due to fat malabsorption usually secondary to pancreatic insufficiency which can occur in pancreatic cancer

Specialist nurse - A senior nurse appointed to a specialty, with a minimum of five years post-graduate experience including post-registration qualifications

Specialist palliative care services - services with palliative care as their core specialty, which are provided by an interdisciplinary team, under the direction of a consultant physician in palliative medicine.

Texture modified diets - A diet that contains carefully selected foods of an appropriate consistency which can be more easily chewed and managed by a person with dysphagia (swallowing problems).

Themes - patterns of explicit and implicit content that capture something important about the data in relation to the research question (Richards, 2015).

Tube feeding – the provision of liquid nutrition via a tube into the gastrointestinal tract

Unless otherwise indicated by a reference, the terminology above is adapted from the Health Service Executive (2014) Glossary of terms https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/glossary/palliative-care-glossary.pdf

Chapter 1

Background to the research

In this chapter I introduce the reader to the background to the research including insights into my career and the personal journey that led to this research.

Years of dietetic experience culminating in a position in palliative care

After 30 years as a registered dietitian and having previously undertaken a range of small-scale clinical studies, I felt drawn to pursue work at an academic level that would not only add to the evidence-base for nutrition and dietetics but would support my development as a researcher.

Shortly after commencing a dietetic post in palliative care, I was asked by the Director of Nursing and Medical Director, at the Hospice in which I was employed, to evaluate the acceptability of a screening tool; the Malnutrition Universal Screening tool ‘MUST’. ‘MUST’ had been integrated into the holistic assessment as a result of the Hospice needing to demonstrate meeting the standards of both the Care Quality Commission and NHS provider standards. Preliminary discussions with the healthcare teams, highlighted concern that ‘MUST’ failed to fit with the philosophy of palliative care. As a result, a study using focus groups and a survey to further investigate the concerns was undertaken. This confirmed concerns regarding the objective nature of ‘MUST’ which relies on the recording of weight loss and body mass index (BMI). Members of the Hospice healthcare team who participated in the study felt ‘MUST’ accentuated concerns about weight loss rather than alleviating concerns. The nurses acknowledged that diet-related issues and weight loss commonly experienced by patients and carers, were important and needed to be identified. Participants felt that an assessment tool to help identify the issues would be beneficial, but the majority felt ‘MUST’ did not fit with the holistic principles underpinning and guiding palliative care. The study was presented as a poster at the 2013 BAPEN annual conference (Czerwinska et al, 2013). Subsequent contact with several Hospices across the UK showed only a small handful were using ‘MUST’, a few had created their own tools for nutrition screening in palliative care in an attempt to identify nutritional issues. Although it is well documented that nutritional issues should be anticipated and identified early, this did not appear to be happening consistently in practice.

Recognising the need to have a nutrition screening tool in place in the Hospice but acknowledging the potential limitations associated with the use of ‘MUST’ in a palliative patient population, a multiple stakeholder group was formed to explore the possibility of finding or creating a more bespoke nutrition screening/assessment tool.

As part of the development, a literature review was undertaken by myself to scope what was available, assist in the development of the tool and shape clinical practice to provide the care needed. The review identified that very little existed on how patients and families dealt with the issues, potentially overcame them and whether healthcare professionals were skilled to deal with the diet-related issues.

The project work and clinical experience illustrated to me how little we understood of our patient's drive and motivation to eat and drink when appetite may be abolished and during periods when symptoms interfered with diet and dietary choice. Within the literature and resources available, the management and role of nutrition in palliative care was also contradicted, key messages comprised 'focus on calories' and 'eat what you like', but this approach failed to resonate with patients I saw in practice who wanted to 'eat well'.

Whilst data on how cancer and life-limiting conditions adversely affected the ability to eat and drink and pleasure associated with it, there seemed limited understanding on how patients and carers coped and adapted and whether advice given was helpful.

In tandem with my clinical work at the Hospice, I was studying research methodologies in the early phase of the professional doctorate programme, this had sparked my interest in qualitative research. Greater knowledge in qualitative methodologies, emphasised on a personal level how I interpret the world and experience of my patients and carers and how this, in turn, influenced the care and advice I delivered. Over time, I was aware that this enhanced knowledge began to subtly influence my approach to patient consultations. I began to encourage patients to share with me their description of the circumstances in which they found themselves in and what was important to them. I believed this helped determine what advice they truly needed to make a difference to their lives.

Working in the multidisciplinary healthcare team, I began to observe that views pertaining to the role of diet in palliative care varied considerably even at a local level. An exchange between a doctor and a nurse in a ward meeting exemplified a stark difference in attitudes towards diet - when a nurse raised the topic of diet in the ward handover, the Doctor said; *'nutrition – it doesn't matter at this point'* to which the nurse replied, '*it might not to you, but it does to that patient'*. I reflected deeply on this exchange and contemplated how this created the potential for inconsistencies in our management and messaging on diet for patients and carers. Where dietary advice was provided, I noted patients were given dietary advice by one professional for it then to be contradicted by others they came into contact with. These experiences in the Hospice setting, made me wonder how we might be more cohesive in our approach to provide 'patient-centred nutritional care'.

As my role as a dietitian specialising in palliative care developed, I was conscious that an understanding of the difference between end of life care and palliative care was crucial in tailoring care. Not only was this relevant for my own position in delivering care but I felt it was also important for members of the healthcare teams and care staff to appreciate the difference in the courses I ran on nutrition in palliative care. A lack of understanding of palliative care also became evident in my meeting with the ethics committee who perceived the patient group to be end of life as opposed to palliative. The confusion associated with use of palliative care terminology and the meanings attached to certain words appeared common in clinical practice and indeed led to the Health Service Executive for the National Programmes Strategy to develop a glossary of terms for palliative care, to ensure consistency in understanding of the terminology. It is for this reason the definitions of end of life care and palliative care are included in the glossary of terms in this thesis (pages 11 - 13).

The culmination of these observations, conversations with colleagues and preliminary work in stakeholder groups, were pivotal in fueling my desire to understand more about the role of diet in palliative care as perceived by patients, carers and healthcare professionals. This became the focus of my research for the professional doctorate programme. In the next chapter I explore the literature, which led me to develop the research aims and questions for this thesis.

Chapter 2

Review of the literature

2.1 Introduction

In this chapter I provide a review of the literature that populates the main themes associated with the current provision and understanding of symptoms, nutrition and diet in cancer and palliative care. These important publications alongside my professional experiences, as a dietitian, practicing in the field of palliative care, provided the entry point for me to undertake research into the role of diet in palliative care as experienced by patients, carers and professionals.

The purpose of the literature review was to examine the literature relating to symptoms, diet, nutritional status and diet in palliative care. Material was identified through extensively searching electronic databases including CINAHL, Medline, EMBASE, PsycINFO and Web of Knowledge. Search terms included: nutrition, diet, cancer, advanced cancer, palliative care, adults, carers, family, symptoms, nutrition screening, malnutrition, nutrition impact symptoms, perceptions, coping, communication, knowledge, adaptation and qualitative research, in various combinations. Additional material was identified through books, grey material, and references in the literature identified. The findings of the literature review are presented in this next section.

2.2 The changing face of cancer care

Cancers are now one of the leading causes of morbidity and mortality worldwide. Current data suggests that 1 in 2 will have cancer during their lifetime (Ahmad et al, 2015). Significant funds have been invested into treatments and potential cures resulting in greater precision and sophistication in the range of treatments offered. Surgery, chemotherapy, radiation therapy and more recently immunotherapy now offer a greater chance of cure and even in the absence of cure, many cancers can be classed as ‘chronic disease’ as patients can live with the cancer for many years.

2.3 Incurable cancer

Although some cancers are curable and survival rates have improved, there are many cancers that are incurable either because the cancer recurs at the original site or secondary cancers develop. Cancer is described as advanced when it is unlikely to be cured or controlled with treatment. The cancer may have spread from the primary site to nearby tissue, lymph nodes, or more distant parts of the body. Treatment may be given not with intent to cure but to help reduce the tumour size (particularly if the tumour interferes with bodily functions), slow the growth of cancer cells, or relieve symptoms (Cancer Research UK, 2020)

If the cancer becomes incurable the patient is considered palliative. Treatment does not necessarily stop despite recurrence or recognition of the cancer becoming incurable but may continue during the trajectory of disease. As the cancer progresses and symptoms increase, the need for supportive, palliative care arises.

In the UK, hospices have grown out of the recognition that the needs of cancer patients, and increasingly other life-limiting conditions, could not be appropriately met in an acute hospital setting particularly towards the end of life. In 1967, Dame Cicely Saunders, founded the modern Hospice movement and over the past 50 years, Hospices have been instrumental in changing expectations of a different type of end-of-life care and death.

Historically hospices provided support for those with end-stage cancer, however many Hospices in the UK, including the Hospice where this research took place, have expanded their remit over time to care for a variety of patient conditions, and support patients, carers and family members not just in end-of life care but as soon as a palliative diagnosis is made. This means that the care of patients may extend over many months and in some cases years.

2.4 Palliative care - guiding principles

The guiding principles of palliative care is captured in the WHO definition (page 13). In brief, palliative care focusses on living well with life-limiting conditions such as incurable cancer, but also seeks to prepare individuals and their families for a good death. Care aims to address psychosocial concerns of both the patient and their family. With an ageing population and increasing complexity of patients with multi-morbidities, palliative teams often find patients have a number of medical conditions. The palliative care team often assist patients and families navigate the complicated healthcare system by co-ordinating care and communicating across care settings (Hospice UK, 2020) at a time when health is compromised, and resilience challenged.

2.5 How effective is palliative care and what is the focus?

A systematic review by Higginson and Evans (2010) sought to evaluate the effect of palliative care teams in both hospitals and the community. As the population under study was heterogeneous, Higginson and Evans used regression of combined data to explain heterogeneity, a meta-analysis using a Cochrane method and methods synthesis involving descriptive and interpretive methods, to determine the effectiveness of the care. Outcomes included management of pain, symptom control, quality of life, death, patient family satisfaction, morbidity and pre-and post-bereavement counselling offered.

Overall the review by Higginson and Evans, supported a positive effect of palliative care teams in chronic care situations. The strongest evidence was for pain and symptom control but many of the quality-of-life measures failed to capture aspects important to the patient. The review did not cover aspects of nutrition and diet on symptom control or evaluate the impact of diet-related issues on the patient. In the next section I therefore consider what we know about symptoms in cancer and advanced (incurable) cancer, how they might impact on diet and nutrition and what we understand about the role of diet in alleviating symptoms.

2.6 The prevalence and impact of symptoms in advanced (incurable) cancer.

With regard to our knowledge of the impact of symptoms in advanced cancer, a systematic review by Teunissen and colleagues (2007) identified that amongst the range of symptoms that could affect dietary intake; fatigue, lack of energy and loss of appetite occurred in more than half of the patients. Fatigue, weight loss, lack of energy, loss of appetite, dry mouth, constipation, nausea, dysphagia, diarrhoea and urinary symptoms had the greatest prevalence. Gastrointestinal symptoms including dry mouth, bloating, constipation and nausea affected a third of patients. Early satiety, taste changes, sore mouth, dysphagia affected about 1 in 4 patients and diarrhoea affected 1 in 10 patients. As these symptoms can interfere with dietary intake it was not surprising that weight loss was highly prevalent, reported in 46% of patients with the prevalence rising to 86% of patients in the last few weeks of life.

The review included a range of cancer types - brain, head and neck, lung, breast, gastrointestinal, gynaecological, prostate and genitourinary, skin/melanoma/sarcoma, haematological and non-specific. As the data was captured from 46 different studies and included 26,223 patients in a variety of settings - hospice in-patient and out-patient settings, home and general outpatients - the large sample size in diverse settings suggests the estimations of symptom prevalence were likely to be as reliable as possible. As patients did not spontaneously mention all the symptoms, Teunissen and colleagues emphasised the need for standardising assessments to comprehensively and routinely enquire about the range of symptoms possible so that symptoms can be better identified, treated and alleviated. As symptoms changed during the trajectory of disease, the authors also recommended timely reviews were needed if healthcare professionals are to provide care that makes a difference to the patient experience.

Teunissen recommended that further studies to evaluate symptom severity, burden and impact of symptoms on quality of life were necessary to facilitate the tailoring of treatment to an individual in the last phase of life.

In 2014, Deshields undertook a longitudinal study in cancer patients to track symptom experience over time, evaluate the degree of burden and effect on quality of life (QoL). Using several tools validated in the oncology population, Deshields captured information on symptom experience in 542 cancer patients with one of five cancer types; breast, colorectal, gynaecologic, lung, and prostate cancer. Co-morbidities were accounted for. Participants completed surveys at baseline, 3, 6, 9 and 12 months. 89-93% reported at least one symptom in each time period studied with individual symptoms varying at the different time points. The ten most prevalent symptoms varied by cancer diagnosis hence suggesting standardised assessment of symptoms might need to be adjusted for cancer type. There was a significant decline in symptom severity and symptom burden over the various time points. The highest symptom burden arose in those with cancer of the lung whereas the least arose in the cancer of the prostate. Overall, quality of life scores were stable over time except for the physical sub-scale which showed significant improvement. Quality of life correlated with symptom burden. Although Deshields' study was undertaken with cancer survivors and not those deemed palliative, it provided considerable insights into the symptoms associated with cancer that need to be considered in planning care, suggesting some groups such as those with lung cancer, older clients and those with more symptoms require more intense support. Deshields concluded that the communication between clinicians and patients regarding symptom experience was an area ripe for further research.

2.7 The burden and suffering associated with symptoms.

To further understand the patient experience of symptoms, Al-Shahri et al., (2012), explored 'suffering' amongst 124 patients with advanced cancer. Suffering was defined as a 'negative and undesirable experience'. Whilst Shahri reported pain as one of the most significant factors, there was a significant association between suffering from a variety of symptoms and the performance status of patients.

In 2013, Oeschle et al., prospectively studied dimensions of symptoms that included the frequency, intensity, distress and treatment requirement of the patient's physical and psychological symptoms. In addition to the patient's experience, they also evaluated the perspectives of family caregivers and the palliative care team involved. They aimed to better understand factors that lead to decision-making in treatment, what to treat and when. Oeschle asked about nine symptoms: pain, shortness of breath, tiredness, lack of energy, dry mouth, lack of appetite, nausea, constipation and difficulty sleeping. They assessed frequency, intensity (how severe it was), and distress (how much it bothered patients) and how important it was to the patient to have that symptom treated. A scoring system was used for all assessments with zero representing no bother at all and four reflecting the symptom was there constantly. 98% (n=39) suffered from at least one symptom frequently or constantly. The most frequent symptoms were lack of energy (95%), tiredness (88%) and pain (80%). Oeschle found significant differences in symptom burden between patients, family caregivers and healthcare professionals. Healthcare professionals under-estimated 60% of symptom dimensions. In contrast caregivers over-estimated 77%. Some patients were still receiving palliative treatment; four were receiving palliative chemotherapy, one radiotherapy and one anti-hormonal therapy. Symptom distress was higher for symptom intensity than for frequency for pain, shortness of breath, lack of energy, dry mouth, lack of appetite, nausea, difficulty sleeping, anxiety and sadness. Exceptions were tiredness and constipation where frequency rather than intensity correlated with symptom distress. Overall physicians underestimated the impact of symptoms.

Similar to Shahri's findings, Oeschle concluded that level of distress should be used to guide treatment and relieve the suffering of the patient. Oeschle's inclusion of the subjective perspective added valuable information to our understanding of symptoms and distress from the patient's perspective and is of merit in directing what we need to do to address what matters to the patient, as opposed to what we think or assume we need to do. It would be interesting to know if the same could be drawn out in relation to nutrition and diet.

2.8 The impact of symptoms on diet and nutrition

Although considerable data has been cited above exploring the prevalence, frequency and intensity of symptoms in cancer, data on diet-related symptoms were absent in the above-mentioned studies. Numerous studies have however evaluated the relationship between poor nutritional state and outcomes in cancer (Argiles et al., 2005, Van Cutsem and Arends, 2005, Ravasco 2019) and over the past 20 years, our knowledge and understanding of the role of nutrition in cancer has been expanding. Much of this knowledge has been derived from studies involving patients who are being treated with curative intent (Capra et al., 2001, Ravasco et al., 2004, Ravasco et al., 2007, Baldwin et al., 2012). Although the studies involved patients who were curative, there is much we can learn from these studies as symptoms and issues are likely to persist in the palliative care phase.

In the systematic review and meta-analysis by Baldwin et al. (2012), the impact of oral nutrition interventions in cancer patients was evaluated. The review demonstrated that whilst oral nutrition interventions were shown to be effective in increasing nutritional intake and improved some elements of quality of life, they did not improve mortality. Whilst this latter finding is of merit, one needs to consider that the aims of nutrition therapy may be multiple and if we are to provide patient-centred care, we need to establish what is important to the patient and their carer as weight, function and other aspects of nutrition such as socialisation, may be important and potentially more important, than an end point of mortality.

If symptoms alter across the trajectory of disease, then it is also important that we understand the impact of changing symptoms on individuals and their dietary intake. A longitudinal study by Tong et al. (2009) assessed the prevalence and levels of distress caused by nutrition impact symptoms in 219 medical oncology patients at 3 time points across a year (1 month., 6 months and 1 year). Patients had stage II and III disease. The five most commonly reported nutrition impact symptoms in patients with a range of cancers (including head and neck, gastrointestinal, solid tumours and haematological malignancies) were dry mouth (38%), belching (36%), nausea (35%), bad taste (28%) and constipation (27%). The most distressing symptoms were dry mouth, nausea, belching and constipation. The prevalence of nutrition impact symptoms was high with 79% of patients experiencing at least one symptom at 1 month and 72% at 6 months. Even at 12 months, when the majority had finished treatment, 46% continued to experience nutrition impact symptoms. These figures compare with data from Olsson's study in patients with upper gastrointestinal cancers who continued to experience discomfort related to diarrhoea, reflux and constipation, which interfered with intake and adversely affected nutritional status 12 months after surgery. Tong's study was important as it illustrated the impact of symptoms on quality of life over time and whilst the patients were not palliative, the duration of symptoms after treatment ended, provides insights into the persistence of symptoms.

Despite the high prevalence of nutrition impact symptoms, Tong (2009) noted that the number of patients who had seen a dietitian (the professional able to advise on managing the symptoms), was half of that expected.

2.9 Nutrition screening and symptom assessment

As a result of nutrition impact symptoms associated with cancer, multiple cancer sites, and the side effects of treatment, individuals are likely to experience diet-related issues which can put them repeatedly at risk of malnutrition.

The European Society for Parenteral and Enteral Nutrition (ESPEN) guidelines (Arends et al, 2017) provide a clear steer on the role of nutrition in cancer and palliative care and cite the range of symptoms that may be amenable to dietary modification, including lack of energy, fatigue, appetite, nausea and constipation. Combined with Teunissen's systematic review comprising large patient numbers, this suggests there are many patients who experience diet-related issues who may potentially benefit from attempts to address them through dietary advice and nutrition support.

Screening for malnutrition is recommended (Arends et al., 2017, Flynn et al., 2018) in both curable and incurable cancer and is considered the first step in determining those deemed to be at risk of malnutrition in whom one would then identify and assess factors that may interfere with food intake.

In everyday practice, a range of barriers can impede the successful implementation of both screening for malnutrition (Green et al., 2014, Harris et al., 2018, Flynn et al., 2018) and the implementation of guidelines (Churn et al., 2009, van Wayenburg et al., 2010, Attar et al., 2012, Hebuterne et al., 2014, Spiro et al., 2016). Arends et al. (2017) suggested that failures to adopt guidance is in part due to the '*frequently only moderate interest of clinical oncologists in nutritional aspects of cancer care*' but also arises as a result of lack of understanding of cost-benefit analysis, current financial incentives to limit nutrition support to contain costs, a lack of training in the medical curriculum and the sparse availability of evidence for diagnostic and therapeutic nutritional and metabolic markers to monitor interventions.

The work by Spiro et al. (2016) adds to this in acknowledging that Oncologists not only need to value nutrition as an integral part of treatment in attenuating and preventing weight loss that can affect outcome and response to treatment, but they also need to recognise the importance of alleviating eating related distress and the anxiety relating to unintentional weight loss.

In palliative care, the survey by Flynn et al. (2018) sheds light on inadequacies in undertaking nutritional assessment of cancer patients admitted to a hospice. Flynn and colleagues suggested '*implementation of a nutritional symptom checklist and nutrition* *screening tools, along with enhanced physician education and multidisciplinary nutrition care, could improve the identification and management of cancer cachexia in the palliative care setting'*. In the Hospice setting where I worked, we had extensively contemplated these issues relating to nutrition screening and the provision of nutritional care. Through a multiple stakeholder project, a nutritional symptom checklist and screening tool was co-created, piloted, tested, updated and embedded into routine practice via the electronic patient record and the approach supported by training and education (Souter et al., 2015, Holdoway et al., BAPEN conference abstract 2018). What remains to be established is whether the tools and education put in place to identify diet-related issues have benefitted patients and carers or been futile.

2.10 The changing role of diet in palliative care

Historically the role of nutrition in palliative care focussed on comfort eating and alleviating hunger and thirst if they were present (Royal College of Physicians, 2010, Acreman, 2009). With the evolution of palliative care commencing as soon as a patient is deemed incurable but who may still live for many months and possibly years, the role of nutrition in palliative warrants revisiting.

2.11 Weight loss and cachexia

It is estimated that 10-20% deaths of patients with cancer can be attributed to malnutrition rather than to the malignancy itself (Pressoir et al., 2010, Wie et al., 2010, Sesterhenn et al., 2012) and hence management of nutritional status and the prevention of malnutrition should be an important component of care. Despite this data, European studies reported that only 30-60% of patients received nutrition support who needed it (Hebuterne et al., 2014, Planas et al., 2016)

Although advances in technology have facilitated the provision of clinically assisted nutrition to support patients when they are no longer able to manage a diet to meet their nutritional requirements, the benefit may be out-weighed by the burden associated with the additional care required and potential complications. Conducting randomised controlled trials (RCTs) to evaluate the impact of food-based interventions and clinically assisted nutrition in palliative care are lacking, not least because in undertaking trials that might 'withhold' nutrition in a control group is deemed unethical. In the absence of RCTs, it is not surprising that there are many mixed views arising. A degree of nihilism may exist in practice where the lack of evidence is quoted as a reason not to feed rather than focusing on the individual receiving the care at that moment in time. In my own clinical experience spanning 30 years, opposing views have arisen where a patient may be asking for clinically assisted nutrition to alleviate the burden associated with eating and drinking when problems are present, whilst the doctor has considered it not appropriate to provide clinically assisted nutrition due to fears that it might prolong discomfort in those who have a life-limiting condition.

Recognising some of these dilemmas, the Royal College of Physicians (RCP) published guidance to assist healthcare teams in addressing the challenges in oral intake when difficulties exist and facilitate decision-making for the use of clinically assisted nutrition and hydration in end of life care (Burnham et al., 2010).

In some cancer types such as head and neck cancer, the use of clinically assisted nutrition has become routine (Belwar et al., 2016). Reviews to determine the optimal method of delivering nutrition support, have been attempted. Due to small sample sizes results of assessing the optimal method have been inconclusive (Nugent et al., 2013). In palliative care there remains no consistency in the provision of clinically assisted nutrition. The reasons for the indiscrepancy can perhaps be part explained by the limitations of studies including heterogeneous populations. Of equal relevance is Eliot and Olver's observations (2009) who identified that the charged emotions present amongst palliative patients and their carers, meant decisions were often sought under stressful circumstances and at a time of considerable uncertainty around life. Advanced directives for patients on clinically assisted nutrition have been developed to try and give control to the patient's decision-making in advance of a deteriorating condition. Early learnings suggest however, that we have to be cautious in the way that we deal with these decisions as the decision made by an individual in advance of experiencing the situation, may be very different to their experience when the situation arises (Nolan and Mock, 2004).

In palliative and end-of-life care a whole new meaning around nutrition and clinically assisted nutrition may arise. In my own clinical practice, members of the healthcare team have expressed concern that even suggesting clinically assisted nutrition to patients and carers offers false hope. This risks denying patients and carers the opportunity to determine from their own perspective, the burden versus the benefits and explore with them how this may, or may not, give false hope but could alter quality of life in either a positive or negative way. This was the basis for the Cochrane review by Sowerbutt et al., (2018) on the use of parenteral nutrition in mechanical bowel obstruction. The review was inconclusive but identified the need for further research to elucidate potential benefit or harm.

The gaps in our knowledge on the management of weight loss and cachexia, raise the opportunity for further research on the attitudes and experience of weight loss and the role of not only clinically assisted nutrition and hydration, but also less invasive oral nutrition support measures, in palliative care.

2.12 The meaning of food and the impact of weight loss in palliative care

Concerns regarding weight loss have been consistently reported in the literature. Hopkinson and colleagues (2006, 2006a, 2006b, 2010, 2013, 2018) have provided the most prolific data on the effects of late stage cancer on the ability to eat and drink with a particular focus on weight loss, eating related distress and the psychosocial impact on both patients and family members.

In 2005 Souter, conducted a small-scale qualitative study to explore the meaning to patients and their carers of the loss of appetite whilst under the care of the community-based specialist palliative care team. A poetic transcription of participants' words was created from semi-structured interviews to capture the experience of the patient and carers involved. Overall, Souter described the lack of understanding by patients and carers of the underlying factors contributing to loss of appetite. In the absence of interventions to effectively reverse poor appetite, Souter raised the importance of facilitating patients and carers understanding and adjustment to the condition and help them reflect on the reality particularly in advanced disease. It would be of interest to evaluate whether Souter's recommendation on improving the understanding of weight loss amongst patients and carers, including explaining the physiology underlying appetite loss, have been adopted in everyday practice.

In 2006, Hopkinson and colleagues reported the prevalence of concern regarding weight loss and altered eating in people with a range of advanced cancers. Of 199 patients who participated in a survey, 79% reported weight loss and 76% were eating less. A third of patients were concerned about the weight loss and reduced amount of food eaten. Two thirds of patients expressed concern where weight loss or altered eating had occurred, suggesting this is an important aspect to patients. Concern was not confined to those who had lost weight or experienced altered eating but was also present in patients who had had no weight loss or had to alter their eating, thus suggesting the cancer itself created concerns about what they felt they should be eating. Amongst palliative patients, concern arose at various points in time and was not restricted to the last few weeks of life or proximity to death. As concern about loss of appetite and weight were greater amongst family members the authors recommended that mitigating concerns amongst family members was important especially in the absence of being unable to effect an improvement.

Building on this work, Hopkinson et al., (2007) investigated how people with advanced cancer managed changes in eating habits. Hopkinson concluded that patients 'can and do' find their own solutions. It was not established whether greater knowledge amongst the HCPs supporting these patients could have expedited the time between experiencing the problem and in identifying the solution. Whether the problem experienced and the distress it creates could be minimized, through enhanced knowledge amongst the healthcare professionals supporting the patients, presents a gap in the research that warrants further investigation.

Based on the lack of solutions to manage cancer related weight loss, Hopkinson and MacMillan, created and tested a framework including training for nurses named the 'Macmillan Approach to Weight and Eating' (MAWE). The uptake and value of 'MAWE' was evaluated in a cluster randomised study in the South of England (Hopkinson et al., 2013) but whether the tool or similar has been more widely adopted is unclear. It would therefore be of interest to know if the principals of 'MAWE' have extended beyond the area in which the evaluation took place and been adopted elsewhere.

It is evident that Hopkinson and colleagues (2006a, 2006b, 2007, 2010, 2013) have contributed a wealth of understanding to the diet-related issues in palliative care and insights into the distress associated with unintentional weight loss amongst patients and carers including family members. Research to date has identified the need for comprehensive nutritional assessment to identify the issues contributing to the weight loss and the distress but also the dietary beliefs held by the patient and caregiver. In addition, Hopkinson and colleagues work concluded that in the management of cancer induced cachexia: a 'healthy diet' as currently defined in our UK culture (low fat, high fibre, 5 portions of fruit and vegetables daily) is of unproven benefit for someone with advanced cancer, that patients will typically eat more of the things they enjoy or find easiest to eat, that cancer causes metabolic change that suppresses appetite and disagreements over food are common between patients and caregivers. What is evident is there is, as yet, no agreed successful nutritional intervention for cancer induced cachexia.

2.13 How cancer affects metabolism, function and body structures

Whilst weight loss can be measured and visibly noted, cancer related weight loss can also have profound effects on function. This is due to the derangements in metabolism in cancer which result in muscle breakdown including the effect of cancer on metabolic pathways that govern cell turnover, and the metabolism of substrates including protein, fat and carbohydrate (Fearon et al., 2011).

As far back as 1998, Schuit reported that increased nutrition symptom scores correlated with poorer function. This was further supported by the published literature review by Caro et al. (2007) who demonstrated that nutrition impact symptoms reduced performance status and quality of life. If functional status plays a significant part in determining quality of life in those living with an incurable cancer, then identifying and where possible correcting nutritional issues to preserve muscle is a key component of supportive care for those who are palliative.

For effective treatment and management of diet-related issues and function in cancer, healthcare professionals need an awareness and an understanding of their role and overlapping responsibilities in addressing the nutritional issues and promotion of physical activity that can affect response to treatment, function, outcomes and survivorship. Research to date has primarily involved nurses and dietitians. As we move into an era where other members of the MDT care for patients with cancer, including palliative care, it would be of interest to know if other members of the multidisciplinary healthcare team such as physiotherapists and pharmacists, appreciate the role of nutrition and indeed whether they utilise knowledge to advise patients and families on diet and activity, to optimise nutrition, function and quality of life.

2.14 The need for an individualised approach to managing diet-related issues and nutrition

International (Arends et al, 2017) and national guidelines (GMC 2010, NICE 2010) have called for an individualised approach in palliative care. With palliative care patients now surviving months to years in the palliative state, nutrition could take on an increasingly important presence.

This literature review along with personal experiences reported in practice, illustrates that many patients experience profound symptoms during and after treatment, and as a result of the cancer itself, which adversely impacts on their ability to consume and enjoy a normal diet and continues into the palliative phase of care.

With limited training in diet for many healthcare professionals (Morris, 2014) and nutrition barely being represented in the curriculum of nurses, doctors and allied healthcare professionals (De Souza et al., 2015), the role of diet and nutrition in life-limiting conditions and chronic diseases and decisions to use nutrition support, may be undermined by the lack of knowledge and capability of those involved in decision-making.

Although over the past four decades our understanding of the impact and distress caused by cancer cachexia and diet-related issues has been enhanced (Hopkinson, 2018), our knowledge of the advice offered to patients and carers and whether it is acted upon, remains limited.

Registered dietitians who have been specifically trained in nutrition and dietetics utilise skills to assess and plan nutritional care. In the UK, and across Europe, the appointment of dietitians and the provision of dietetic care in palliative setting remains limited (Hospice UK data 2017, BDA Correspondence 2017, European study 2018), this is despite the recommendations from NICE (2004) that cite dietitians as part of the multidisciplinary palliative care team. With insufficient dietitians to meet the needs of the palliative population, it may be that other members of the healthcare team need to address diet-related issues in meeting the holistic needs of patients and their families.

Concluding remarks

This literature review has highlighted that patients with cancer experience discomfort, anxiety and distress arising from unintentional weight loss and diet-related issues. It identifies the opportunity for members of the healthcare team to get involved in managing the nutritional needs of patients. How effective the healthcare team is in identifying the issues and handling them across the trajectory of palliative care, remains poorly understood. As life-limiting conditions requiring palliative care services are predicted to increase (DoH, 2018), the need to investigate the potential role of diet and perception of diet amongst all those involved represents a key area for further investigation. An understanding of how issues are identified and acted upon and whether dietary advice provided for patients and family members and carers is acceptable, and answers their concerns, became the underpinning foundation for my research.

In the next chapter I outline how the literature informed my research aims, research questions, my consideration of a variety of methods and methodologies, why case study method of research was chosen and the background to informing me of my own position as a researcher.

Chapter 3

Methodology

3.1 Introduction

In this chapter I introduce the research questions and the aims of the research determined by current knowledge and research. I focus on clarifying my rationale for the grounding of the research on the role of diet and nutrition in supportive palliative care, the theoretical perspectives that I used to guide key concepts resulting in the use of case study design and my reflections on my position as the researcher.

3.2 Methodology

Studies over several decades have explored the dietary issues and challenges faced by patients and carers during cancer treatment including up to one year after cancer treatment. There is however a general lack of studies observing the impact of diet-related issues beyond a year of treatment or observing the impact of diet-related issues that can occur and change over time in the palliative journey.

Whilst Hopkinson and colleagues (2006, 2006a, 2006b, 2010, 2013), have contributed a wealth of understanding and knowledge of the impact of diet-related issues in end of life care, the focus has largely been on loss of appetite and unintentional weight loss and not the wide range of issues that have been reported that can persist after cancer treatment such as taste changes, diarrhoea, constipation, dry mouth, fatigue and issues relating to clinically assisted nutrition and swallowing problems.

Studies have often involved the patient and carer perspective or the healthcare professionals experience. None to date have studied the experience of a broad range of agents involved within one study. There therefore appeared a gap in the literature that studied the experiences of patients and their families and their interactions with HCPs, over time, in various contexts and for the duration of their illness.

A host of literature over the past four decades has improved our understanding of the prevalence and impact of symptoms including diet-related issues (often referred to as nutrition impact symptoms), in cancer and palliative care. Information on managing the issues, advice given and whether acted upon, and the extent of coping and adapting during times when issues and prognosis may be changing, is less well understood. In addition, studies have not explored the similarities or differences in the way diet is viewed before and after the cancer diagnosis and how its value and relevance may change across the trajectory of disease.

3.3 Research questions

As a result of the literature review the following research questions were developed:

- How do healthcare professionals, patients and families currently perceive the role of diet in palliative conditions?

- What has been the experience of patients, carers, family members and healthcare professionals in dealing with dietary challenges during the patient journey?
- Which dietary interventions or advice were adopted by patients and families and carers and how were they managed? What were the barriers and facilitators to identifying, adopting and implementing the nutritional interventions recommended?

As I wanted to explore, gain insight and understand the role of nutrition in symptom management and nutritional status, there was the need to take into account the complexity of the individuals, the healthcare settings and the support that was given to patients, carers and healthcare professionals, including how knowledge was gained (from whom, what and where).

To meet the aims of the study and answer the research questions, I was conscious of the need to select a method most appropriate to answering the research questions.

3.4 Qualitative research

In the last century, modern healthcare has evolved and benefitted from knowledge ascertained predominantly from biomedical research utilising quantitative approaches and RCTs (Coates, 2004). Post-positivists have criticised the use of qualitative research viewing it as soft approach when compared to the use of rigid protocols and questionnaires designed to eliminate bias that are frequently used in quantitative research (Coates, 2004). With an increasing emphasis on patient-centred care, the value in considering views of patients and carers has been elevated and the value of qualitative enquiry to elicit descriptive accounts in healthcare has become increasingly popular (Greenhalgh and Papoutsi, 2015).

Qualitative research is an umbrella term that describes a diverse set of techniques and philosophies (Silverman, 2005). Often utilising words and descriptions the researcher uses a fundamentally inductive and interpretive approach to generate meaning and interpretation amongst natural social settings. As highlighted by Bowling (2002), qualitative research offers the vehicle to explore, discover, describe and understand the experiences of those involved. In undertaking qualitative research, the researcher attempts to make sense of, or interpret phenomena, in relation to what it means to the participants who were involved (Denzin and Lincoln 1994, Van Manen 1990) and in the context in which they happen.

A strength of qualitative research is its ability to focus in on the human experience using methods that seek to enhance understanding of complex phenomena and the participants experience. On this basis and in light of the research questions, I concluded that qualitative research would provide the insights into the perceptions of the role of diet amongst patients, carers and healthcare professionals and fitted well with the patient-centered, holistic philosophy that underpins palliative care.

3.5 Epistemology

I was conscious of the need to understand my epistemological stance that would not only influence my decisions to determine what knowledge I could gain through the qualitative research but also guide me in how I might ensure adequacy and legitimacy in my research findings (Krauss, 2005). My epistemological stance is one in which I believe people cannot be viewed separately from the multiple influences that contribute to constructing their reality. Influences can include culture, history, personal values and beliefs, social interactions and language and an individual's perception of reality can be shaped not only by past and present experiences but also determine future experiences. This belief, that truth or meaning comes into existence through engagement with the realities of our world, is described by Crotty (2004) as constructionism. The philosophical approach for my research therefore lies in the spirit of constructionism. With a constructionist understanding of knowledge, different people may construct meaning in different ways in relation to the same phenomena and hence the constructionist approach is often described as interpretative. As I believe reality is socially constructed and social phenomena exist in the minds of participants, I acknowledged interpretation would be necessary for me to understand the many facets and multiple constructions of participants' experience.

3.6 Case study research

I considered a variety of qualitative methods that might suit my research aims. Of particular relevance was my desire to understand the phenomena from those involved, in both receiving care and delivering care, namely patients, carers and health care professionals.

Whilst I was familiar with case histories in healthcare, it was in reading Denzin and Lincoln's review (1994) and reference to the use of case study in offering 'a quiet methodological revolution' that I considered this method further. As the case study approach is one that lends itself well to evaluating complex healthcare innovations in specific contexts it seemed suited to undertaking research in the palliative care arena where care can be complex. With case study research being available in health care (Dowell et al., 1995) and medicine (Greenhalgh and Taylor, 1997, Greehlagh and Paoutsi, 2018) I was able to review examples and consider how I could adopt this approach.

As case study research retains a holistic and real-world perspective (Yin, 2014) and given the complex situation facing those living with incurable cancer identified in the literature, case study research was considered well suited to the focus of this study to understand the complex social phenomenon and clinical condition that influences the diet of a patient. As case studies can offer insights that may not have been achieved with other approaches, and take into account the prior development of theoretical propositioning, I also felt that case study research using interviews and other data including local policies, could fill the 'gaps and holes' (Ridder, 2017) that I had identified in the literature search, thus building on the knowledge to date in the field of diet in palliative care. Discussion with my lead supervisor confirmed that case study research fitted well with my research aims in providing the framework to understand complex interactions in nutrition and diet in palliative care following a rigorous methodological plan.

A multiple case study approach incorporating one to one interviews with key players; the patient, family members and healthcare professionals, was considered to be the most viable means to explore this area and the anticipated open style of questioning was considered consistent with the holistic philosophy of palliative care (WHO, 2002).

Patients were recruited if they were considered palliative and in the last year of life but not the last few weeks of life. This was to avoid the burden of being involved in research amongst those very unwell at the end of life but include patients who had, and might still be experiencing issues, to establish and identify the issues and time points where interventions could be offered in the future, to make a difference to patient care.

3.7 Defining the case

With case study research, the object of the case is the focus of interest in its own right. At the heart of the case studies in this research was the patient. However, as the care experienced and the diet chosen, or consumed, by patients who are palliative, could be influenced by family members and healthcare professionals, it was felt crucial to involve representatives from these groups. By asking patients to nominate a family member or friend (from hereon defined as a 'carer'), and two healthcare professionals, from amongst the healthcare teams who cared for them, it was felt the case would remain patient-centred. This would enable me as a researcher, to explore potential differences between the perceptions of the patient, their carers and the healthcare professionals involved.

Confident that the case study research would enable me to focus on the range of problems faced, the process by which participants might cope, the support available and provided, and the variations in their experiences, semi-structured interviews were chosen as the primary source of data. Working in settings where the research took place and with ethical approval, I was also able to review patients' medical records, policy documents, resources and teaching available.

I anticipated that using a case study approach with the patient at the centre, along with nominated carers and HCPs, would allow me to explore the interconnections between patients, carers and HCPS during the patients' journey. Asking the patients to choose members of their healthcare team and a carer to be interviewed, was considered to be the most effective method to reveal reflexively the everyday lived experience of patients, the carers involved and the influence of the healthcare team.

Whilst I did not feel a single case could achieve external validity or generalisability, one could argue that multiple cases, carefully chosen to reflect different cancer types and where themes might be repeated across cases or differ, might be more generalisable and replicable. Although Dyer and Wilkins (1991) criticised the multiple case study approach on the basis the researcher is less likely to pay attention to the way the cases compare and contrast, Stake (2003, 2005) argued that multiple case studies, by the very nature of enquiry, can be more robust and the evidence more compelling. These published opinions influenced my approach from the outset in both creating and conducting the research and in the subsequent analysis.

Based on my clinical experience, I strategically chose to recruit patients with specific cancers including secondaries, where I anticipated there would be differentiating features and a variety of dietary issues. The four patients who consented to participate represented four different cancer types. As the cancer types differed and the patient and carer participants differed, it was anticipated that the HCPs nominated by the patients would differ. I foresaw that a variety of HCPs were likely to be invited but would remain connected by the patient at the heart of the case. I hoped this would enable me to explore a range of perspectives but also the levels of knowledge that might be associated with life experiences, varying levels of experience gained in clinical posts and include HCPs from a variety of environments (acute and community).

The number of cases deemed sufficient at the outset (four patients and four participants per case) was based on discussions with my supervisors, the range of cancer types the Hospice cared for and insights gained from the literature. My intention with the number of cases and participants was to explore contrasts for predictable reasons (theoretical replication) and also identify similarities (literal replications). Due consideration was given to recruiting more cases if the data collected was not considered rich enough.

The exploratory and inductive approach aimed to be grounded in the goals of qualitative research strategies, with an emphasis on developing a rich theoretical framework based on the analysis of data and interpretation of themes.

3.8 Positioning myself as the researcher

The more familiar I became with the literature on qualitative research methodology, the more conscious I became of viewpoints suggesting that qualitative research, by the very nature in which data is collected and interpreted, carries risk of bias. Aware that I would be collecting and interpreting data from interviews, I acknowledged the risk of interviewer bias and participants saying what they thought I might wish to hear, in them knowing I was a healthcare professional. As a caring professional I was also conscious that I might respond to comments with empathy in interviews with patients and carers that might lead to participants responding in a certain way. Inherent in my nature I was aware that it might be difficult to adopt a change of approach and my demeanour. I aimed to counter this through the use of semi-structured interviews, avoidance of pre-set questions but also through making a conscious effort to act in a neutral non-judgemental manner during interviews (Bowling, 2002). Being comfortable in the environment and aware of potential patient characteristics such as the adverse impact of cancer on symptoms and possessing skills in compassion and empathy, I felt this would act in a positive way by helping the participants feel relaxed and more likely to open up to talk about their experiences and how they felt.

Former experience in the field of oncology had made me very aware of the impact of treatments on the ability to eat and drink. As quality of life (QoL) and symptom control is at the heart of palliative care, I felt my experience in oncology placed me in a good position to both hear and understand some of the symptoms and management of symptoms that my patients and carers and HCPs might describe in relation to diet, and the impact of those symptoms on a person’s ability to eat and drink. I believed this would assist in not only obtaining and assimilating rich quality data through qualitative research methods but enhance my understanding of their reality. In interviewing the HCPs I worked alongside, I was aware of the need to retain a consciousness of my insider knowledge to avoid influencing the interviews. Overall, I felt the positives outweighed the negatives in my acting as the researcher and that I could embrace my experience in that it enabled me to make observations of the environment at ease and served a purpose in providing an in-depth knowledge to help interpret, and analyse, the data from participants.

3.9 Reflexivity

Aware that my theoretical assumptions, my choice of the topic and my ethical framework influenced not only my choice of methods but also the relationship with my participants (whether it be the patient, the carer or the HCP), I undertook reflective activities to consciously compartmentalise, deal with and set aside knowledge that I knew might cloud my interpretation of the data. Such reflective activities were undertaken regularly when pursuing all aspects of the research, from contemplating and designing the methods and methodology, completing the interviews and throughout the entire analytical phase and writing up.

3.10 Ethical issues

The board of ethics raised concerns regarding the potential harm in interviewing patients who were palliative and end-of-life and sought assurance that patients would not feel obliged to participate nor coerced. The ethics committee also raised concerns relating to the fact that patients may not themselves benefit from the research outputs as they were likely to die beforehand. The ethics committee’s concerns were addressed by informing them of the approach taken, in which the specialist nurses broached potential participation with participants as opposed to the researcher. In practice, the specialist nurses have a very close relationship with patients and carers and through their holistic approach, are very aware of the need to avoid burdening patients and carers in asking them to participate in a study. It was felt the specialist nurses were best placed to act as the primary identifiers of suitable patients. The specialist nurses made the initial contact to discuss the study and seek potential participation before any contact by myself as the researcher was made. This allowed the patient to hear about the study, what the study entailed and allowed them time to give it due consideration before potentially agreeing and consenting to participate.

As a practitioner with 30 years clinical experience and as a duty of care as a researcher, I was also very aware not to impose a significant burden on a patient or carer and ensure that all involved were familiar with the benefits of participating and the potential downside. Several patients commented that they would be happy to participate to enhance the lives of others even after they had departed this life, this supported my belief and consciousness of the research process offering those involved an opportunity to have a voice.

In the hospice within which I am employed, there exists an ethical framework to protect the vulnerable and as part of my reflective practice and approach to the research, I drew on the ethical knowledge I had gained as part of my professional doctorate and previous clinical studies I had undertaken. I also interacted with and sought advice from experienced practitioners in this field including the Hospice counselling services and the Head of Education, research and development at the Hospice.

As the semi-structured interviews were led by the participants, they were provided with the opportunity to freely withdraw at any time. I asked during interviews whether an individual wished to continue or discontinue, particularly when emotional matters were being shared. As a skilled practitioner in this field, I felt I was sensitive to note cues from the patients and carers if any distress or emotional anxiety arose and I always asked the participant if they were happy at various points in time to continue, making it clear that I would not wish to induce any further anxiety associated or contributed to by their continuation. In practice, when undertaking the research, the need to stop was rarely observed (one participant only). Some interviews lasted beyond an hour due to the keenness of the participant in sharing their experiences.

Concluding remarks

In this chapter I have clarified the research questions and contextualised my work by placing the study in epistemological and ontological frameworks. I have attempted to justify why multiple case study research is suited to the research aims and questions.

Based on 30 years in clinical practice and an understanding of qualitative methods of research, I felt the multiple case study approach suited the research questions and aims which was to capture the complexities of the patient carer and healthcare professional experience and the services, that intended to meet the needs of patients and carers.

the collection of data to investigate phenomena in real life contacts. Simons (2009) emphasises the value of case studies for in-depth exploration from multiple perspectives in a real-life context to generate in-depth understanding of specific topics that are too complex for the survey or experimental strategies.

The aim of the case study approach was to present a rich portrayal of nutrition and dietetics in palliative care to inform practice. The case study method was seen as a flexible method to explore the topic in-depth. I hoped that by involving multiple players in a unique case study design not previously undertaken in the field of palliative care, involving those who receive care and those who influence care, a fresh perspective would be achieved. From multiple sources of data, I hoped I would be able to interpret events and analyse patterns within and across case studies, using inductive reasoning, to shed new understandings on the role of diet in palliative care (Simons 2009).

In the next chapter I introduce elements of the practical methods employed in undertaking the research.

Chapter 4

Methods

4.1 Introduction

In this chapter I introduce the practical elements of the research methods, the sites that interviews were undertaken including recruitment, operational processes including data collection, the management of data, analysis and interpretation. I present the approach for analysis of data including the reflexivity I employed as the researcher and the value of interactions and discussions with peers to develop concepts.

4.2 Research Design

In answering the research questions, a multiple case study approach was employed which utilised semi-structured interviews in the field. The semi-structured interview aimed to seek the views of patients, carers and healthcare professionals regarding the role of nutrition and diet in the place of care. The interview was based on the available literature and the previous projects undertaken in the hospice setting (Czerwinska et al., 2013; Souter et al., 2016)

Other sources of data included the medical records of patients and relevant policies (appendix 1, pages 153 - 168) and assessment tools used within the care settings where the nominated HCP was employed. Medical records were checked prior to consent to ensure participants met the inclusion and exclusion criteria and were also checked on the day of the interview to ensure the patient was in a suitable condition to participate. After the interview the medical records were reviewed to triangulate the information from the interviews and provide validation of some of the symptoms experienced over time.

4.3 Defining the cases

Since one cannot separate the care given and the patient experience from the relationships and support from family members and friends, multiple participants for each case, specifically including a family member or friend, and up to two healthcare professionals, reflected the diverse and holistic approach that underpins palliative care.

As the patient participants were asked to nominate carers and two HCPs they came into contact with, this led to a variety of HCPs participating in the study, giving breadth of insight according to different HCPs. Figure 4.3 illustrates the participants and relationships in each case.

As active treatment may play a part in palliative care, patients and carers may be receiving care simultaneously from the hospice as well as acute setting. In asking the patient to nominate two HCPs involved in their care it was hoped a variety of HCPs would participate to capture the experience in both the hospice or community setting and the acute setting, and indeed this proved to be the case.

I used purposive sampling in the selection of patients to intentionally include patients with four distinct primary diagnoses. Cancer types were specifically chosen for their diversity based on the current knowledge of the physical impact of different types of cancers and treatments on ability to eat and drink. I anticipated that this would provide rich and varied data on the impact of different tumour types and secondaries on symptoms, treatments and physical aspects that might impact on diet and food related experiences.

All but one HCP who participated had spent time in their training and after qualifying in both acute, community and latterly in a palliative care setting which enabled them to compare and contrast experiences according to care settings. Years since qualifying are indicated in Table 1 (chapter 6, pages 62 – 63)

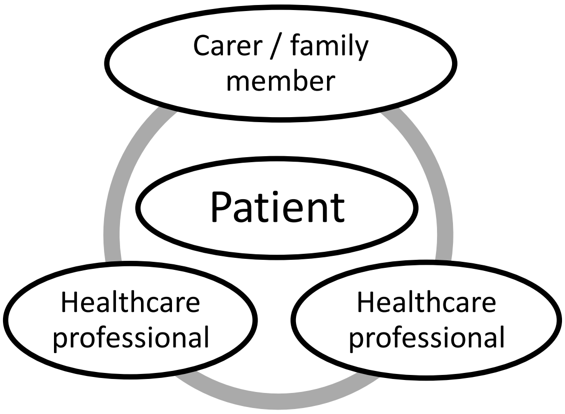


Figure 4.3 – visual representation of a case

4.4 Patient participant criteria

Sampling aimed to recruit a diverse group of adult patients with different advanced cancer types, of differing ages, in whom it was anticipated that dietary choice and eating habits would be affected. Participants had to be able to understand what was involved, have mental capacity and be willing to consent.

4.5 Developing the interview guide

The interview guides for patients, carers and healthcare professionals was initially drafted from the findings of the literature review. The draft interview guide was then discussed with experts in the field and colleagues including the Head of Education and Research and Audit at the Hospice, the Hospice nutrition steering group which included patients, carers and volunteers, and my academic supervisory team.

A pilot interview was undertaken with a patient and their family member. Using the learnings from the pilot and following subsequent discussions with the academic supervisory panel, the interview guide was modified to allow greater freedom of the participants to direct the flow of the interview and reduce prompts that might bias the interview. The interview guides for patients, carers and healthcare professionals were finalised and are included in the appendices (appendix 2, pages 169 -174). The rationale for inclusion of the specific semi-structured questions in the final interview guide is included in the appendices (appendix 3, pages 175 - 176)

It was during the piloting of the interview that the use of terminology was raised. The patient and carer who volunteered for the pilot commented that ‘nutrition impact symptoms’ meant very little to them and that ‘diet-related issues’ was much more understandable. Although ‘nutrition impact symptoms’ have previously been used in the literature, I chose after the pilot to consistently use the term ‘diet-related issues’ as it appeared more meaningful to patients, carers and also the HCPs and I was keen to use a term that resonated with participants.

4.6 Field Sites

Suitable participants were drawn from the patient and carer population under the care of a Hospice in the South West of England, providing palliative care services which include rehabilitation, respite and terminal care. To access these services patients are registered with the specialist palliative care service via a formal referral made by the patient’s General practice or from the acute hospital Trust. The care is offered on an in-patient and out-patient basis and also includes group support sessions, for patients diagnosed with life-limiting conditions and their carers.

Interviews with patients, carers and HCPs were undertaken in a place of their choice which included the patient’s home, carer’s homes, outreach centres and outpatient settings. All participants were given a full choice with regard to the date, time and preferred location.

4.7 My relationship with the field sites

I drew upon existing relationships and contacts to gain access to all participants. As I was working in the setting, I had access to both the in-patient unit and out-patient settings and caseloads. As some of the palliative care staff knew me, this did mean there was an element of trust in allowing me to access the patients. As my clinical time working at the Hospice was part-time (0.2 whole time equivalents) and delivered on one day a week, I was able to establish myself in the role of a researcher on other days distinctive from my clinical role. Being there on a part-time basis managing the dietetic service did however legitimise my presence and fostered relations with staff. Through briefings undertaken, particularly with the nurse specialists and the therapies team, I was able to put into context for staff, the purpose of the research project, what was expected and also have access to the medical notes and data on participants who met the inclusion criteria. Patients and carers were initially identified and approached by the nurse specialists employed by the Hospice, to avoid any risk of coercing them to participate by myself as the researcher.

4.8 Ethics

The study was approved by the local research ethics committee (appendix 4, pages 177 - 181), the Hospice research and ethics committee and the University of Bath research committee. The study conformed to local healthcare research governance requirements and University governance. The University of Bath, Hospice and NHS standards for ethical research, were followed and acted upon to protect the rights of participants during the interviews and throughout data management. The Hospice standards primarily related to the nature of palliative care work, which is known to be demanding from an emotional perspective, particularly when end-of-life is imminent. Consideration was given to the sensitivities around research involving patients who are palliative and in whom it was important to consider how easily they could participate if very unwell. Access to the Hospice psychological support and counselling services was granted for all participants if needed. The patients GP was informed in writing of the patient's consent to participate (appendix 5, 182)

All individuals who took part were provided with a participant information sheet (appendix 6, page 184 -190) to ensure they understood what was involved. Information included key contact numbers and email addresses to ask further questions beforehand. All participants had to agree to signed consent (appendix 7, page 191) prior to the interview. Consent included permission to undertake and record the interviews and in the case of the patient record permission to access their medical records. Participants were made aware of the purpose of the research including potential dissemination of the findings and assured that all information would be confidential and identifiable data would be removed. Identifying information was deleted from audio recordings, notes and records and replaced with an identifier code. Names used in the results and analysis to identify quotes are pseudonyms.

I attended the ethics committee in person to ensure that any questions raised could be answered at the time. Members of the ethics committee questioned whether involving those who were deemed 'palliative and end-of-life' might be inappropriate. I was able to reassure them from the literature and my own experience in the clinical setting, that patients and carers were often very keen to share their stories for the purpose of 'giving back' and sharing their experience for the future care of others. I sought to instill confidence in the committee that I would be able to recruit participants who could comfortably participate and that I had mechanisms in place to ensure that patients in the end of life phase would not be asked to participate and came under the exclusion criteria. Ethical approval was awarded, and I commenced my research to explore the role of diet in palliative care as perceived by patients, carers and healthcare professionals.

4.9 Participant recruitment

HCPs with whom I worked with, or with whom I was in contact with intermittently, were asked to identify suitable participants from both the out-patient clinics or attending the courses provided. Adults over the age of 18 years, who were able to converse in English and who were able to understand the requirements of the research, give informed consent and comfortable to participate, were provided the opportunity to hear more about the study. A telephone conversation or face to face conversation was provided by the Hospice nurse specialists to explain the research if a patient expressed an interest to be involved. The relevant participant information sheet was provided by the specialist nurse if interest was expressed and time given to allow the patient to read the sheet and ask any questions. Once the patient participant was recruited, the carer and HCPs they nominated were approached by the researcher to seek their participation. Participant information sheets for the carer and HCP (appendix 6, pages 186 - 190) were provided so that all participants could gain an understanding of their involvement and what was expected. Written consent was obtained from all participants by the researcher prior to interview.

4.10 Interviews

Each interview began by inviting participants to talk about their views on diet and nutrition in the absence of a cancer diagnosis. The aim with this question was to help put participants at ease, gain insights into previous dietary habits and routines and obtain views relating to diet and health to then understand how this might differ in the presence of disease. Participants were then asked semi-structured questions about diet-related issues and their perception and experience of diet in the presence of cancer. Strategies to manage issues and advice offered or received was also explored. All participants were asked if they thought anything was missing that could help deal with diet-related issues. Healthcare professionals were encouraged to draw on other examples, if they saw it appropriate, to help the purpose of the research. The flow and length of time spent on each area was led by the participant. The interview was not restricted to the semi-structured questions as the intention was for the participant to lead on what they felt was important.

The series of questions were used to guide the interview but not restrict the interview so that the participant shaped the conversation. The structure and style of the semi-structured interview aimed to ensure that participants were able to express their stories and experiences in their own time, in a relaxed environment of their choice and in their own words. The aim was to capture what was important and relevant to them as an individual and how they viewed the effect on those around them.

All participants agreed to one interview. The duration of the interview was led by the participant. The shortest interview was twenty minutes and the longest one and a half hours, the majority were of fifty - sixty minutes duration. Length was guided by the participant and I gently encouraged participants to share what they felt was important. Non-verbal cues, for example evidence of fatigue - a feature common to many patients who have a palliative condition - were observed for as a sign of a need to draw an interview to a close. I drew on my experience and clinical judgement to determine whether the participant gave cues to freely continue to speak on the subject matter or move on. The semi structured interview required little if any additional prompts to the main open-ended questions. In later interviews, questions were specifically pursued if they added to the knowledge.

4.11 Data handling

Data from the interview took the form of audio recordings but were supported by notes and reflections. All data remained in my possession throughout the field work and subsequent analysis. All data was stored electronically in a password protected computer that only I as a researcher had access to. All transcriptions were anonymised at the point of creating the typed word document. When sharing data for analysis (for example with my supervisors), all accounts were anonymised and only details on the primary diagnosis and social circumstances of the patient were shared. Only I as researcher knew of the identifier codes. Back-up drives were held in accordance with data protection in place at the Hospice and in accordance with the Health and Social Care Professions Council, the ethics committee and University research standards on the handling and storage of patient data and research files.

No identifiable participant data was stored out-with the electronic patient record. In accordance with University of Bath standards, all data (transcriptions) will be held securely for a period of seven years after which all data will be destroyed.

I explained to participants prior to consenting, and reiterated at the start of the interview, that their recordings would be transcribed i.e. typed up as passages in their entirety but excluding any personal identifiable data such as names. I outlined to all participants that the research would be used in several different forms to educate and inform a range of audiences including HCPs, those commissioning services and colleagues at research symposia. I explained there might be some unexpected dissemination opportunities that would arise that I may have not anticipated but that all data would remain anonymised.

As the patients were in the palliative care phase then it was inevitable that some of the patients would die before I completed the thesis.

4.12 Addressing potential ethical concerns arising during interviews

Whilst the therapeutic benefit of qualitative research is a highly contested area (Kohn, 2008) my approach was explicit in that the purpose of the qualitative interview was not one of therapeutic intent. The nature of the interview was to facilitate active listening of the participant with minimal interruption.

It was evident that participants not only wanted to participate in research towards the end-of-life as part of sharing their story but patients recognised and acknowledged that engagement in research could assist HCPs to understand what they were feeling; what experiences were good but also what could be improved upon. Many said at sign-up to participate in the study that they felt information on diet could have been better. This appeared to be a motivational factor in driving their enthusiasm to consent and participate as they felt their story could help others.

For some patients I was aware that in sharing their story it brought to them a sense of relief. The emotional demands that arose during the interviews and transcriptions induced a strong element of sadness at times, in particular in relation to patients and family circumstances, for example where young children were to be left without a parent.

As patients were at various stages of wellness, I used my clinical skills and interpretation of body language to consider whether it was appropriate to continue with an interview or offer to end the interview, particularly if I sensed distress or fatigue. It was my clinical skills that I drew upon to help determine whether a patient appeared well enough to continue in the interview and if I sensed distress or fatigue, I would subtly ask, in a natural pause, if they wished to continue or were happy to leave it at that point, being positive about stopping, so they would not feel under duress to continue. Overall there was only one interview with a patient that was relatively short (22 minutes), the majority exceeded an hour due to the enthusiasm of the participant.

Although I had to avoid giving advice at the time of participation in the study, after the interviews had been recorded and transcribed, I went on to provide advice to several patients and staff at a later date where gaps in their knowledge or the service provided were identified.

4.13 Data analysis

A descriptive framework was used to organise the cases making use of all the relevant evidence; interviews, policies, environmental observation. The interviews contributed the majority of the data and were transcribed, coded, and analysed using the principles of thematic analysis as informed by Braun and Clark (2006), Spencer et al’s framework (2014) and insights into handling qualitative data by Richards (2015). My overall intention was to interrogate the data with the research questions in mind and create categories (often referred to as codes) derived inductively. Once sections of the transcribed interviews were coded, I methodically studied the words and the context to interpret the meaning. I went back and forth over the data, the transcriptions, revisited codes, grouping codes and seeking patterns and meaning that I felt was significant and new. My aim was to present aspects of the cases that generated new understandings which I could relate back to the research questions and the literature including new literature searches that were needed to determine if the phenomena was novel and new.

Typing up each interview myself, checking for accuracy, reading and re-reading the transcripts enabled me to gain a holistic overview of the participant’s experiences. I found listening over and over to the interviews to type them accurately very powerful in transferring me into their world. Becoming so familiar with the data meant that I could recall from memory the spoken narrative and the situation at the time, including the environment. As I transcribed, I reflected on the participant's mood and their emphasis placed on words in expressing their experience and I noted these elements in the transcripts. I paid meticulous attention to ensuring that I placed emphasis on features that seemed important to the participant to avoid being drawn to my own bias as a dietitian.

As the majority of the interviews were an hour's duration I also summarised each case in essay format to create a document to give an overall feel to each participant's interview and each case. The summary served the purpose of capturing my overall thoughts about the case and was helpful to revisit when I felt overwhelmed with the amount of data I was handling. It also helped me to not lose sight of any striking content that was specific to a singular case when I undertook the cross-case analysis.

4.14 Coding

Taking each transcript, I selected and marked up passages and assigned initial codes. For first level coding I used descriptive low inference codes, in some cases these were one or two words such as 'weight loss' or 'appetite', others included short descriptors such as 'impact of treatment'. Examples of the codes and a section of a coded transcript is included the appendices (appendix 8, page 192). Codes were developed sequentially, then revisited, refined, renamed, building codes within the case and then across the cases. Coded data was then sorted into broader categories and the broader category was given a title or theme that aimed to capture the essence of the content. Data and coding were continuously reflected on in line with the research questions and literature.

Due to the large volume of data accumulating with each interview (some interviews had a wordcount of 20,000 words), I adopted the use Atlas Ti 8.4.2 to manage the coding and interpretation. The programme was helpful in highlighting selected narratives along with the codes and descriptors, and commentary that demonstrated complimentary experiences of participants and contrasting experiences or views. I utilised all of the data (interviews and field observations) to explain the differences. I explored content that reflected the patients voice as a whole, the carers as a whole and the HCPs as a whole and then as one case and then across the cases. This assisted in discussions with supervisors, my writing, reflexivity and comparison with previous work published in the field.

I reviewed the data with coding and without coding, the latter to identify emerging themes without losing connections. Many cycles were repeated to develop my understanding of the data and meaning intended. To assist in identifying new insights into the phenomena being studied new codes and new and unexpected themes led to new literature searches.

Meetings with supervisors were invaluable and took place repeatedly throughout the coding of the data and analysis. Both supervisors coded sections of the transcriptions early in the analysis to compare and discuss interpretation of the data. One supervisor coded in full several transcriptions to further compare coding and our understanding of the narratives. The meetings with my supervisors were reflective in nature and provided an opportunity to study the codes, critique the analysis and meaning and begin to develop the themes and sub-themes. Together with my supervisors we explored what we believed a narrative was saying, what we were interpreting from it, to whom we felt the narrative was directed and if there was anything hidden within the narrative. Definitions and meanings became sharper when the differences in the use of codes were discussed. This inevitably resulted in codes that best fitted the section of text.

A framework from the initial coding in the first round of familiarisation is included in appendices (appendix 9, pages 193 - 195). Following numerous iterations, this was replaced with emergent themes and sub-themes.

4.15 Deriving meaning from the data

By cross referencing comparing and questioning the transcribed data, I began to feel it was possible to begin to make inferences and explanations. After I completed initial coding of the interviews, I returned to the transcripts, immersing myself once again in the words and their inferred meaning. I drew diagrams and flow charts to represent potential frameworks and connections. As some of the interviews were an hour's duration and transcripts exceeded 20,000 words, I also produced written descriptive summaries of the cases to capture the overall messages and initial meanings.

The fieldnotes were also referred to repeatedly in the process of analysis to remind me of the setting and the atmosphere of the environment in which the interviews took place which were primarily in patients and carers home settings or the workplace where the healthcare professionals worked. Being so familiar with the interviews I was at times transferred back to the moment at which the interview took place, this enhanced my understanding of the feelings I felt the words evoked in the storyteller.

The process of analysing the rich data aimed to draw out themes and sub-themes which pointed to a more latent level of meaning. At times, I struggled with this process, feeling overwhelmed with the data, at such times the descriptive summaries and replaying the audio-recording helped me re-focus on what each case was telling me. I found the guidance from Richard's textbook (2015) on handling qualitative data helpful in providing a more structured approach to the process. Elliott's guide on the coding process (Elliott, 2018) was published in the latter stages of my analysis and I found this an invaluable and instructive guide to make sense of the 'semantic mire' that Elliott refers to in the search for precision and clarity in method. Of greatest value was spending considerable time writing and reflecting followed by discussions with supervisors and colleagues who questioned my thinking. Whilst I found the discussions challenging and uncomfortable at times, the process helped me distil my thoughts. As I began to write about the meaning of the data I found I relabelled sections of data, modifying the codes and categories to give a more symbolic meaning (Miles, Huberman and Saldana 2014, p 71).

With repeated cycles of coding, re-coding, deriving meaning and analysing the data, salient points rose to the surface. To provide an example, David's wife described how the children 'took daddy breakfast in bed' by placing his tube feeding equipment and feed on a tray, covered with a tea towel and took it to their father's room before leaving for school. At first reading this seems like a thoughtful gesture by the children, but as I analysed the transcripts of all the participants in David's case, I realised this gesture carried considerable meaning: it reflected the impact of the cancer in disrupting family life, the inability for David to eat which brought a sense of loss but also represented adaptation by family members that facilitated the move towards a 'new norm'.

Over time and through the cycles of analysis, some codes became redundant as overlap was identified, and new ones emerged. As noted by Richards (2015), codes also changed with the higher level of thinking. I refined my coding to allow condensation of data, as Miles and colleagues highlight in their text (Miles, Huberman and Saldana, 2014, p.73), this also facilitated the process towards discovery of meaning. As the analytical process progressed, I was able to group codes under new headings that became the themes and sub-themes. With time and considerable reflection, the themes became more solid and I felt more confident that they portrayed the meaning behind the participant's stories in their own right.

In the final stages of analysis, I undertook a further review of the literature to check whether concepts were new or built on existing theoretical ideas (Boyatzis, 1998). I was able to conclude that the data offered a mixture of established themes but also rich, new themes.

Concluding remarks

In this chapter I have provided a detailed account of the methods used and how data was managed and analysed. I have attempted to describe in detail the approach to provide a clear understanding of how the analysis was undertaken. I believe the strategies used to analyse the data, coupled with a reflexive approach and a conscious recognition of my own strengths and limitations led to the discovery of new insights that are valuable and trustworthy.

In the next chapter I introduce the patients who participated, the carers and healthcare professionals they nominated and introduce the initial findings relating to the meaning of food and role of diet in health prior to a palliative diagnosis.

Chapter 5

Findings – Part I

The meaning of food

(before cancer)

5.1. Introduction

In this chapter I introduce the patient participants and the carers and healthcare professionals that the patients chose to nominate for inclusion in the research. I start with an introduction to the patients to assist the reader in gaining a sense of who the patient is, their character, situation and the involvement of those around them. The vignette is intended to act as an anchor point for the reading of subsequent analyses. The chapter also explores the meaning of food and diet before cancer. Throughout the results section, narratives from participants are indicated in italics and in quotation marks.

5.2 Introduction to the cases - patient participants and the carers and health care professionals the patients chose to nominate for inclusion in the study.

5.2.1. Case one - David

David was a 54-year-old night-time security guard. He lived with his wife Susan and 2 children, a son aged 9 years and a daughter aged 6 years.

David was diagnosed with carcinoma of the tonsil. He had smoked for many years. Surgery was not an option, so he received radiotherapy and chemotherapy in an attempt to eradicate the cancer. The cancer recurred infiltrating the base of the tongue, tonsil and on a subsequent scan he was found to have lung secondaries. The tumours were considered unresponsive to radiotherapy and chemotherapy and David was informed his condition was incurable and any further treatment would be palliative. David was referred to the Hospice for ongoing support. David's interview took place 2 years after his cancer was diagnosed.

David embraced the opportunities to engage in the activities offered by the Hospice. As a family man he was very involved with his young children even during the periods when he was unwell.

David nominated his wife, the hospital dietitian (hospital A) and a palliative care multidisciplinary (MDT) assistant to be interviewed, all of whom were, or had been, involved with his care.

5.2.2. Case two - Martha

Martha was an 83-year-old lady who lived in the annex of the property occupied by her daughter and son-in-law. Martha's own husband had died from cancer 20 years prior. Martha was diagnosed with cancer of the bowel in her late 70's. The tumour was surgically excised. Martha had 2 cycles of chemotherapy following surgery which she found challenging due to the symptoms and side effects that arose. Once recovered from the surgery and chemotherapy, Martha enjoyed good health for several years. Cancer of the pancreas (a possible secondary from the primary in the colon) was diagnosed when she was 82 years of age. Surgical removal was not an option and

Martha’s condition was deemed palliative. Previous medical history included a cholecystectomy (removal of her gall bladder) performed in her 60’s and a history of hypertension.

Martha had swum several times a week throughout her life to keep fit. After her husband died Martha’s social life very much revolved around swimming and she often enjoyed a lunch out with her swim ‘buddies’ after a swimming session.

Martha nominated her daughter, a hospital dietitian (hospital B) and a palliative care nurse specialist from the Hospice, to be interviewed.

5.2.3 Case three - George

George was a 71-year old gentleman who had worked for much of his career in the drinks industry. The nature of his work and the environment meant there was a considerable amount of socialising and entertaining in his working life. After retiring from the drinks industry in his 60’s, George set up a home refurbishing business. He was also a musician, song writer and played in a local band. George had divorced from his wife when their two children left home, the separation was amicable, but George saw little of his ex-wife after the separation except for family gatherings. George’s 2 children were now in their 40’s. Although George lived alone his daughter and her family lived locally.

George had a zest for life, a large circle of friends and the entertainment that had been a part of his career in the drinks industry had spilled into his home life where he enjoyed entertaining and cooking lunches and dinners for friends and family. He played golf several times a week and his social life revolved around the golf and meals with golfing friends.

George had a malignant melanoma diagnosed and removed from his upper back when he was 67 years old. 3 years later brain metastases were identified on a CT scan and an MRI scan. The brain tumours were treated with stereotactic radiotherapy and George commenced immunotherapy. Steroids were prescribed for a period of several weeks to reduce the inflammation post-stereotactic radiotherapy. George experienced recurrent disease a year later and was referred to the Hospice team for palliative support whilst continuing treatment at the acute hospital to contain the disease.

George chose not to nominate a family member or friend to participate. He explained that whilst he had a daughter nearby and a close group of friends that were aware of his health issues and from whom he drew support, he did not wish for them to be approached. His wish as respected. He nominated a Physiotherapist and a multidisciplinary team assistant (MDT), both employed by the Hospice, to be interviewed.

5.2.4. Case Four – Tom

Tom was a 76-year old male with lung cancer. Tom had worked all his life as a maintenance engineer. Despite being in his 70's he had only recently retired. He lived with his second wife with whom had had a son and daughter. Prior to Tom's cancer they enjoyed an active social life which usually centred on having friends to lunch and dinner in their home.

Tom's previous medical history included a cholecystectomy performed in his early 40's. Tom was diagnosed with a squamous cell carcinoma of the lung when he was 74 years of age and myeloma was diagnosed when he was 75 years of age. He had 6 cycles of chemotherapy with mixed response and radiotherapy. A 2nd line of chemotherapy was started but had to be discontinued when Tom developed sepsis.

Their daughter lived in a nearby town and both Tom and his wife were involved with their children's lives and grandchildren deriving much pleasure from their company.

Tom chose to nominate his wife and a multidisciplinary team assistant from the Hospice to participate. Tom did not nominate another healthcare professional as the nurse from the hospital, who he would have chosen to participate in the case study research, had left her post.

5.3 The meaning of food - patient and carer views

This initial results section reports on the first phase of the interview relating to participants' views of diet, food related activities and factors they felt influenced dietary choice before the diagnosis of cancer.

I considered it crucial to understand from the patient's and carer's perspective why they ate, what they ate and how they ate before the cancer, to understand what a normal eating behaviour before cancer might be and better appreciate any adaptive eating and changes in behaviour that arose during the palliative phase.

The data was captured in the initial phase of the interview with an introductory question which served two purposes; the first to create the space for the participant and myself to come to ease with each other and secondly allowed me to gain insights into daily life, routines, motives with regards to eating, dietary habits and choices before the cancer diagnosis. Although the findings from the initial questions in the interviews are not central to the final focus of my thesis, their significance enabled me to contextualise the findings that arose during the later stages of the interviews and assisted me in determining where the emphasis was best placed.

Motives and factors relating to the role of diet, food choices and habits were grouped under several sub-themes common across the data which included body weight, health, social interactions and family routines, memorable occasions. These sub-themes are presented in the following section.

5.4 Body weight

A key element for all patient participants and nominated carers was that of body weight as a governing factor in determining dietary choices and habits in health. All 3 male patients referred to having freedom of choice, being able to eat what they wanted when they wanted, as their weight remained consistent and normal for them pre-cancer.

George - '*I could eat what I like before anything happened. I was lucky in that I never put on a lot of weight if I ate too much. I never went on a diet. I would choose to eat anything that took my fancy and I never had any dietary problems at all that I could recollect'*.

Martha recalled that prior to a palliative diagnosis, her dietary habits had, like the male participants, focussed on weight but in contrast to the male participants, Martha had to be more controlling about what she ate to avoid undesirable weight gain and keep at a weight she felt comfortable at *"I have always been careful about what I eat and I have always tried to eat healthily with lots of fruit and vegetables and I don't like fatty, rich food. I used to swim nearly every day to keep fit and watch my weight and saw my diet being a part of all of that'.*

5.5 Health as a factor determining and influencing choice

Although all 3 male patient participants felt they could eat freely in the absence of weight problems, it was evident that their partners (wives) exerted influence on the food choices to encourage a more healthy-balanced diet.

Although David's wife was a classroom assistant at their children's school she had trained and worked as a chef. David revealed how his wife had influenced his food choice after they met with his diet changing 'for the better'. David described how his wife introduced him to a new range of foods *'I had no choice really as my Mrs. would cook the meal and say this is what you have to eat, take it or leave it.'* David's recall was similarly recounted by his wife: *'healthy stuff was never high on his agenda; it was much higher on my agenda than it was on his! (laughter)'.*

Both David and his wife declared their feelings regarding a shared responsibility to set a good example to their children to make healthy food choices *'we all tried to eat a healthy diet. And I suppose encourage the children they had to try everything…… anything on their plate they had to try' (David).*

In his 40's, David developed diabetes, this too began to influence his food choices and his wife gently encouraged David to adapt his eating habits and food choices to manage his diabetes. David also highlighted how his job as a security officer warranted a high energy intake and was physically demanding *'I am diabetic, so I had that to take that into account….I had to be in good health because the job demanded it. On my patrols I walked 6 or 7 miles every night on a 12-hour shift'.* David's description of his former self (pre-cancer) 'of great stature in a very physical job', becomes more apparent later in his interview when we explore his attitudes and experience in relation to his body weight during and beyond the treatment for cancer.

Tom's wife's desire to eat a healthy diet appeared driven in part by her own avoidance of undesirable weight gain *'I've only got to look at a bar of chocolate and I put on weight so easily'*. She expressed envy in Tom being able to eat anything and everything *'I felt he was so lucky. I guess he had a physical job and he was always on the go…I was quite envious of him really as to what he could eat'*. Before the cancer diagnosis Tom's wife spent years encouraging Tom to adopt healthier eating habits '*When I first met my husband he was on full cream milk, I cut him down to half cream….before all this happened (cancer) I was very strict about diet… not too many fried foods, well not before his illness, chips once a week, yes I allowed them once a week! I guess he might have told you that!? (laughs)….and we made sure we had plenty of fish'.*

In light of family health problems, Martha's daughter, who prepared her mother's main meals each day, had adjusted the family meals over time. This was first triggered as a result of her husband having bowel cancer (survived). She took steps to improve the family meals *'I've cut out processed pretty much completely, don't buy that anymore cos I think, well I think a little of what you fancy does you good… we all know what's bad for us ….but they do sometimes taste the best but yes, I do think it is important. We try to have plenty of fibre and stuff 'cos with bowel problems in the family, because my grandmother had bowel cancer too, so you know, we've tried to eat a healthy diet'*

Meals prepared by Martha's daughter were not the only factor influencing Martha's food choices. During a period on blood pressure medication, Martha had experienced profound loss of taste. A previous cholecystectomy (removal of gall bladder) had also influenced Martha's food choices in her 30's as she became intolerant of fatty foods after the operation.

Eating as natural a diet as possible was cited as an influencing factor for choice and meal preparation by Martha's daughter who placed an emphasis on the use of 'natural foods' as a result of a strong family history of bowel cancer *'I've cut out processed pretty much completely ….and we try to have plenty of fibre and stuff 'cos with bowel problems in the family……so you know we've tried to eat a healthy diet. I'd rather have a bit of sugar than all this ruddy chemicals they put in everything'*

5.6 Food as a uniting feature in daily life

Cooking, shopping and meal preparation became a shared task for David and his wife when the children arrived. David and his wife saw meal-times as an opportunity to bring the family together:

‘*I loved my food, I loved eating and it was always a focus for our family, we’d always sit around the table together when we could, right from day one when the children arrived, the minute they were born really’.* This habit dated back even to the time the children were in highchairs, ‘*even when they were eating slop as toddlers’* (David)

Eating out was rare for David and his family due to limited finances but David described how they would sometimes enjoy a fast-food takeaway such as pizza as a treat. David reflected on these occasions as *‘happy times’*, describing how such occasions arose more often on their family holidays. He spoke about them with considerable sentiment in his tone.

Both David and his wife described the family meals were not only a time for the family to be together but also viewed them as an opportunity to shape and influence their children’s food choices and help them develop good dietary habits, an example provided was encouraging the children to eat vegetables by setting the example as parents.

Eating together was not always possible due to David’s shifts so on occasion David’s meal would be set aside to him to consume at his leisure after a night-shift. The family therefore had experience of disrupted meal patterns which plays a part later in contributing towards David’s coping strategies in the palliative phase.

Tom’s wife described how their social life revolved around dining with friends and family *‘I loved having people round to dinner, you know it was the thing I did. And I loved baking cakes too’*.

As a result of George’s principal career in the drinks industry he was very accustomed to entertaining ‘*we had a large social circle because of my occupation, there were lots of dinners in the evenings, …with or without my partner’*

Martha’s daughter referred to her mother never being a huge fan of eating out as she was a ‘fussy eater’ but recognised the considerable role lunch played in her mother’s social life. Having cared for three generations of her family including her parents, her own partner and her own children Martha’s daughter made specific reference to changing dietary habits amongst generations; how the post war generation would be expected to finish everything on their plate but that in a society of plentiful and with so many overweight, this is not now to be encouraged. This bears relevance when her mother’s appetite diminishes and food is wasted. *‘I think that’s a generational thing, ‘cos waste was you know, that wasn’t done by our parents post war era’.*

5.7 Memories

The taste, smell, and texture of food can be extraordinarily evocative, it can create memories not just of eating the food itself but also of the place and setting. A quote from George’s narrative illustrates how the role of food exceeds beyond the provision of nutrients and captures the powerful effect of food as a stimulus for deeper memories

'*Food is not just a fuel is it? I remember having a meal in a hotel in a castle in Scotland, I had this huge room, 4 poster bed, it was bloody freezing, don't think there was any heating. Venison was on the menu. I had never had venison. I had venison, I think they had literally just slaughtered it, it was so fresh. It was so fresh, so tasty, so flavoured. And when food tastes good it is very memorable…..I think with food it is all about those little memories tied in with it, why you enjoy food and why you enjoy life. Those events are very important'.*

5.8 The meaning of food - views of Healthcare Professionals (HCPs)

In contrast to patients, HCPs placed equal emphasis on dietary choices to maintain a healthy body weight but also the importance of dietary choices in preventing disease and avoiding conditions such as heart disease and diabetes. All acknowledged the pleasure associated with food.

Attitudes were consistent with regards to combining the goal of eating healthily and the pleasure associated with food, *'maintaining a reasonable weight and not overindulging but acknowledging food is there to enjoy'* (George's Physiotherapist)

Several HCPs acknowledged the difficulties in putting this into practice:

Tom's MDT assistant:

'I am aware how important diet is for good health, you know for reducing the risk of cardiac disease, reducing the risk of cancer, you know all the diseases, and so it's really important to try and eat a well-balanced nutritious diet'.

Martha's specialist nurse who struggled with her own weight, expressed how difficult it can be to follow healthy eating guidelines: '*I know how important diet is with regards to health, it might not be something I personally take on-board but I am aware about how important diet is for reducing the risk of cardiac disease, reducing the risk of cancer, you know all the diseases, and so it's really important to try and eat a well-balanced nutritious diet. I think lots of the public know how important that is but it's actually following that through and making those healthy choices I think which is what I think can be difficult for lots of people to do'*.

5.9 Reflections on the findings:

Few would contest that food possesses and serves multifunctional purposes; providing nutrients for physiological functioning but playing a central feature in relation to our activities and routines. In the pre-cancer phase, all patients and carers described situations which demonstrated how food activities connected them to people and places, had meaning in the way they expressed themselves as individuals or with their families, and acted as a social vehicle, features captured in a systematic review in similarly aged subjects by Plastow and colleagues (2015).

The role of food and its link to cultural heritage and food habits was evident amongst participants even down to details such as what food groups one should eat and whether you should eat all of the food on your plate (a factor that varies across the globe and might be generational).

Factors influencing our dietary habits, food choices and routines are well reported in the literature in health including the influence of our partners (Bove et al, 2003), how we influence our children, what motivates us to make healthy choices (Renner, 2012) and how choices may not be made on the premise of avoiding ill-health but change when we have ill-health. Across the board participants demonstrated the range of social norms, how they viewed food, along with motives for eating what they did and the environment in which they created or chose to eat.

It was interesting to observe that appetite and satiety (the feeling of satisfaction after eating) did not feature in the narratives relating to diet before cancer diagnosis. This is perhaps because hunger as a means of triggering eating may play less of a role when food is plentiful and appetite normal.

A key differentiating feature in the views of the healthcare professionals and the views amongst the patients and carers was the greater emphasis placed on food choices to preserve health and avoid disease amongst the healthcare professionals, whereas amongst patients and carers the focus was on modifying food choice only if weight or health became a problem.

The attention on body weight by all patients and carers in influencing dietary choices and attitudes to diet before cancer is particularly worthy of mention as it may have a bearing on an individual’s interpretation of weight during illness and treatment. Historically in the Hospice setting and as reflected in the palliative care literature (Hopkinson 20o6a, 2006b, 2010, Cooper et al 2015, Czerwinska et al, 2013), practitioners in palliative care often choose not to weigh patients and shy away from talking about weight because it is viewed as something they feel they cannot do anything about, particularly for those cancer cachexia. As all participants focused on weight in health, failing to engage on matters pertaining to body weight, even in the absence of being able to treat this feature in palliative care, may fail to address the degree of concern that patients and carers develop regarding their weight during their palliative journey and cancer treatment. I revisit the topic of weight later when the patient’s association between weight and the ability to eat becomes relevant in relation to physicality, strength, function and survivorship.

Whilst participants did not specifically refer to identity, food and its associated activities played a part in creating a sense of identity and for some, a sense of self and purpose. Plastow (2015) describes identity and the maintenance of identity as a ‘person’s ability to preserve a consistent and stable view of who they are across the past, present and future’.

Concluding remarks

This chapter has focused on the meaning of food and diet in health. The next chapter explores the impact of the cancer and associated symptoms on diet and everyday living as experienced by the patient and family members. As will become evident in the next chapter, food and food-related activities, weight, physicality and function and the sense of self and identity, become challenged when illness and disease are present

Chapter 6

Findings – Part II

Patient and carer experience

6.1 Introduction

The first section of this chapter summarises the diet-related issues experienced by the patient participants throughout their cancer journey, the breadth of which illustrates the complex nature of diet-related issues. I then explore how the disruption and distortion (a key theme), altered the meaning of food for patients, carers and family members.

6.2 The complexity of diet

The patient cases selected for this study were purposively sampled to include a diverse range of cancers - head and neck, brain, gastrointestinal and lung - in whom a variety of nutrition and diet-related problems were anticipated.

6.2.1 Table 1 summarises the patient demographics and cancer types, carer and HCP participant information and the diet-related issues experienced by the patients participating. The range of symptoms that were experienced were broad ranging and illustrate the complex nature of diet-related issues which can occur in tandem or singularly.

Table 1 - Participant information and diet-related issues experienced by patients participating is summarised in table 1.

	Case 1 **David**	**Case 2** **Martha**	**Case 3** **George**	**Case 4** **Tom**
Age (years)	54	83	71	76
Primary cancer	Tonsil	Colon	Melanoma	Lung
Treatment for primary	Chemotherapy & radiotherapy	Surgical resection & chemotherapy	Surgery	Chemotherapy & radiotherapy
Secondary site/metastases	Lung	Pancreas	Brain	Liver
Treatments	Chemotherapy & radiotherapy	Chemotherapy	Stereotactic radiotherapy	Chemotherapy
Nominated carer	Wife	Daughter	Chose not to	Wife
Nominated HCP, (place of work), years of healthcare experience	Multidisciplinary team assistant, (Hospice), 28 years	Specialist nurse (Hospice), 35 years	Multidisciplinary team assistant, (Hospice), 25 years	Multidisciplinary team assistant, (Hospice), 26 years

	Case 1 **David**	**Case 2** **Martha**	**Case 3** **George**	**Case 4** **Tom**
Nominated HCP, (place of work), years of healthcare experience	Dietitian, (Hospital A), 8 years	Dietitian (Hospital B), 18 years	Physiotherapist (Hospice), 31 years	
Loss of appetite	x	x	x	x
Chewing difficulties	x			
Swallowing difficulties	x		x	
Dry mouth	x			
Nausea	x	x		
Early satiety	x	x	x	x
Taste changes	x	x		x
Food aversion	x	x	x	x
Diarrhoea		x		x
Constipation				x
Unintentional weight loss	x	x	x	x
Fatigue	x	x	x	x
Intentional weight gain	x		x	x

Even though some of the symptoms had occurred in the past and not at the time the interviews were undertaken, recounting the experience provoked strong memories reflecting the significant impact that diet-related issues had on everyday living. Patients were able to recount their sequence of diet-related issues and how symptoms and dietary intake was affected over time. Although it was not possible to capture the exact time period, Table 2 illustrates how some issues occurred in tandem whilst others in isolation. Each column represents a period of time. The multidimensional issues experienced, illustrate the complex challenges that patients and carers faced in everyday living.

6.2.2. Table 2 illustrates the issues on a time continuum to illustrate the duration, those grouped together in the same column for the patient occurred at the same time.

Time continuum →

David	Pre-treatment- Teeth removed resulting in chewing problems.	Dry mouth. Oral mucositis Frequent bolus feeding exhausting Pureed diet orally Fatigue	Overnight feeding resulting in poor sleep, poor glycaemic control of diabetes. Profound weight loss >30%	Daytime intermittent tube feeding. Small mouthfuls of food for pleasure
Martha	Bowel surgery interrupting intake, diarrhoea	Nausea. Pancreatic insufficiency and small intestinal bacterial overgrowth (SIBO), undiagnosed for months resulting in malabsorption, diarrhoea, weight loss	Anorexia Poor appetite. Fear of eating. Lactose intolerance. Fatigue. Pain.	Cachexia Fatigue. Depression.
George	Drug treatment interfered with ability to swallow	Reliance on liquid diet. Weight loss	Fatigue. Early satiety.	Fatigue
Tom	Anorexia secondary to chemotherapy Fatigue	Taste changes and food aversions. Constipation. Weight loss.	Fatigue. Poor appetite.	Early satiety.

What was evident from the patient narratives was the dynamic nature of diet-related issues over time. Such changes necessitated the need for dietary changes, further adaptations, more knowledge and the need to continually seek and have access to further advice on managing the issues. The nature of the symptoms has implications for practice as they create the need for healthcare professionals to be astute and tuned in to the dynamic nature and the need to adjust advice and care according to the presentation of symptoms and issues as they arise. Rarely a ‘one off’ they triggered dietary adjustments and coping strategies at various time points across the trajectory of care.

In the next section I explore the impact of diet-related issues on patients and carers and carers

6.3. Disruption and distortion - The altered meaning of food and preservation of self

The previous section has illustrated how the patients participating in this study experienced symptoms and the complex nature of the diet-related issues. In this next section I explore in further detail, the patient and carer experience of the diet-related issues including inter-relationships. What unfolds from the combined analysis of patient and nominated carers, is how diet-related issues disrupt and distort the meaning of food, the mealtime experience, routines, physical function and socialisation amongst patients and family members.

6.3.1 Weight matters

With up to 80% of patients with advanced cancer experiencing unintentional weight loss, weight is cited as a key concern to patients and carers and a measure that carries meaning to both (Cooper et al., 2015, Hopkinson et al., 2018).

All patients recalled marked shifts in body weight that had arisen at various points in their palliative journey. Weight changes were not permanent and weight loss was at times regained contrary to the views of HCPs the patients came into contact with. The extent to how much weight mattered to patients was influenced by the stage of the disease, individual circumstances, the extent to which it affected physical functioning and their experience of illness as witnessed in significant others in their lives.

Whereas pre-cancer, the majority of patient participants did not have any concerns about their weight and were thankful that they did not have to worry about undesirable weight gain associated with overeating, it took on a new meaning with the diagnosis of cancer.

As Hopkinson and colleagues observed (Hopkinson et al, 2006) retaining weight, being a normal weight and being able to regain any weight lost was associated with survivorship, fighting the cancer and being strong enough to be active.

6.3.2 Preoccupation with weight

Several participants – patients and carers - drew on experiences of family members losing weight when they had cancer which related to proximity to death:

David 'I watched my Uncle waste away to a shadow of his former self at which time death came quickly. He became a bag of bones, I remember I could lift him in my arms'.

as well as other patients whom they met along the treatment journey who

'wasted away quickly in the last few weeks of life.'

For Martha and her daughter, lack of eating was reminiscent of previous experience with Martha's husband only eating a few mouthfuls in the last few weeks of life, reinforcing beliefs that food intake drops dramatically as death approaches.

Thus this study emanates the findings by previous research in this field (Hopkinson et al., 2013, Cooper et al., 2015) that concern is driven by a belief that weight loss reflects the cancer taking a hold and proximity to death.

Weight clearly became a preoccupation for several of the patients and their family members. That rationale varied and was linked to survivorship, tolerance to treatment and physicality.

Weight was perceived as a sign of wellness and normality by patients and family members

'I was very worried. My weight had gone up with the steroids, so I wasn't unhappy to see it coming off to begin with but after a week and a half when it was coming off, I was really worried….my daughter noticed too'.(George)

At a time when George's oral intake of food was considerably challenged and he was relying on liquids only, the loss of weight was a driver (motivator) to prompt George to make dietary changes:

'As soon as it got to the stage where I was standing on the scales and tightening my belt, I thought I am not having this'. George took matters in hand.

David's wife described David's monitoring of his weight obsessional:

'David used to weigh himself once a week, he was like a Slimming World addict in reverse, he even got a weight loss app (laughs).

She noticed a step change in David's mood and a renewed positivity, when he began to gain weight

' you usually get upset when you gain weight whereas we were 'oh my you've put weight on !! and we were like yeeees!! and the app was nooooo!!!'

Weight and the ability to eat was also used as a barometer by patients and family members, to indicate recurrence or remission of the cancer:

David *'Putting the weight on has made me feel a lot more positive, I now feel I can fight it (the cancer) for longer'*

Equally a degree of pragmatism was apparent as expressed by George who acknowledged that the absence of weight loss might raise false hopes:

'I get a bit twitchy about being too reassured when I am eating and keeping my weight on because it (the cancer) might grow and bite me in the bum'.

David expressed a wish to die of cancer and not the starvation he had observed in other family members and patients and to David good nutrition meant he had a better chance of fighting the cancer:

'*there's a 90% chance that the cancer is going to win but I'm going to fight it all the way and I can only do that with proper nutrition'.*

6.3.3 Weight and tolerance to treatment

Several patients were aware that their weight was remarked upon when it potentially impacted on tolerance to treatment but in contrast then experienced a lack of acknowledgement by healthcare staff of issues contributing or pertaining to weight. George recounted a conversation with his Oncologist about him keeping strong:

'I need you strong for when we start the drug trial and I said 'well I am not feeling very strong at the moment as I have lost a stone or more in weight very rapidly. I said I felt like death warmed up and the Oncologist seemed genuinely concerned'.

George was surprised though that having raised weight loss as an issue this concern was not followed up with advice on how he might eat to be strong:

'nothing was ever said like you need to build up with any specific dietary plan, it was just a case of if you can eat now, then eat. It was days before I could make myself a sandwich or manage toast or milk and things like that. I did start to get back to my normal weight. It was very gradual though'.

The rate of weight loss, changes in weight, whether it was intentional or unintentional were of concern to patients and family members alike, the relevance of which related to wellness, living and surviving. The lack of advice in response to patient's concerns relating to weight, weight loss and lack of strength, resonate with Amano's findings (2016, 2018) regarding the considerable concern and frustration experienced by patients when credible strategies that prevent weight loss remain absent.

6.3.4 What weight was normal?

It was evident that discrepancies arose in what patients considered was a normal weight for themselves and what HCPs viewed as normal or realistic. Considerable frustration was evident in David's recall of the experience in which he felt the healthcare team failed to acknowledge his weight goal whilst being tube fed. As a former security guard of large stature, David felt the healthcare team in the hospital failed to grasp the importance of his desire to be a weight closer to his pre-cancer weight.

'I didn't want to be eight stone I wanted to get back to the 13 stone that I was'.

David's wife described the 'battle' in convincing the healthcare team in the hospital that David was not receiving a sufficient quantity of feed via his gastrostomy tube *'If he is sat on his bum doing nothing and all he is doing is having this stuff pumped in and he is still losing weight then he surely has not got enough Calories. I am assuming that other people just accept that and go along with it and don't understand that and don't question it'.*

Reviewing David's case notes it was evident that he was not cachectic and therefore weight gain could have been an achievable goal. David described how he felt the hospital were totally unsupportive of his views on weight and what they felt was achievable.

As it transpired David proved to himself weight gain was possible when he took it upon himself to administer more feed, over and above what the hospital staff had recommended

David- *"They gave me a 1500 ml bag of feed; I was supposed to take 1200 mls a day and throw the rest away. I thought I'm not going to do that! I am going to take the whole lot, even though it was more Calories. I did it off my own back! I took more feed than they suggested and I started to gain weight'.*

Despite the inconvenience and adversity associated with tube feeding, the absence of oral intake and the time taken to feed, David viewed the weight gain as a positive reward, and whilst tube feeding is 'not normal', achieving a weight that was closer to normal brought a considerable sense of achievement and renewed confidence.

David –*'Adapting my feed made a big difference, gaining weight made a big difference. Once you understand what's going on and you are given information you can make an informed choice'.*

When asked if he could explain why the HCPs failed to take note of his own weight goal, David felt the healthcare team at the hospital set the amount of feed to maintain his weight rather than achieve a weight closer to his pre-cancer weight. Further questioning by the healthcare team to gain insights into David's perception of what was a normal body weight for him, would have revealed that the weight target set was not acceptable to him.

What was evident from David's narrative was that his diminished physique not only added to a sense of loss in being too weak to work but reminded him of the imagery of watching his Uncle die of starvation. These experiences acted as a driver for David to want to turn his weight around and gain weight even though he felt it went against what he was being told at the hospital *'The impression I was given from the hospital was that I would continue to lose weight till I'm dead basically that was my conclusion at the time that I would lose weight until I was dead!'*

When David gained weight, he felt he had 'proved them wrong' at the hospital. It proved to David that his goal to gain weight was not a false hope and despite being given a short prognosis of several months, David went on to live in the palliative phase of care for a further 18 months. For David the return to a weight closer to his pre-illness weight was viewed as a return closer to normality and a degree of recovery, 'beating the cancer' if not cure and not dying of starvation but dying inevitably of the cancer. Given the short prognosis it may be that the healthcare team had set low expectations for weight gain as they thought he was cachectic even though nothing in his blood results pointed towards that suspicion.

Whilst David and George showed a determination to gain weight, the degree of concern associated with weight loss did vary amongst participants and varied over time. Martha appeared less bothered by what she weighed on the scales but this could perhaps be explained by always striving throughout her life to keep her weight down. Tom's wife was particularly concerned by the rate of loss in treatment whereas Tom seemed less concerned.

Historically in palliative care the likelihood of weight gain was always thought impossible. In the past decade there has been a shift in our understanding that weight can be preserved and possibly gained in the early to mid-palliative phase of cancer (Arends et al, 2017). The literature has indicated that in determining goals with regard to whether weight gain or maintenance is possible, is the need to ascertain whether the patient is cachectic or not. What we might learn from the patient-carer experience in this study is that although all patients participating were palliative, cachexia was only present in one patient at the time of the interviews and the importance of understanding what weight the patient views as desirable and what concerns or anxieties may be arising amongst the patient or carer in relation to weight are of critical importance to patients and their carers. Only in doing this can we endeavour to meet or manage patients and carers expectations relating to weight maintenance, weight gain or prevention of loss of weight and jointly work on what is realistic and achievable.

6.3.5 Weight loss, weakness and disrupted function

Amongst patients and carers, the relevance of weight was not confined to beating the cancer, surviving or what was noted on the weighing scales but was also viewed as relevant to strength and function:

George: *'the weight loss can have a real impact, mine was very physical'*

A desire to be able to consume (in the case of carers encourage), sufficient intake to maintain strength to continue with everyday activities was associated with maintaining a degree of normality mirroring life pre-cancer.

For David and George, restoration of weight closer to what was normal for them, was important for enabling activity *'because I got the weight on I can now do the exercise' (David).*

Although Martha did not appear too bothered that her *'weight has probably gone down about 4, 4 ½ stone altogether'* as it was remarked on very non-chalantly, (despite it representing a very clinically significant 30% weight loss over 10 months) Martha was very conscious that the loss of weight had had a marked effect on function, dented her confidence and her ability to be independent outside of her home and engage with friends

'I'm getting a bit shaky and unsteady. I went to the hydrotherapy on Monday, you know, that was nice.. to get into the warm water. And then she said to me after we had done the exercises, she said 'would you like to swim?' And I thought 'can I?'… you know.. you lose all your confidence don't you really? I am not driving very much or anything either now.'

All patients and their carers had to accept that fatigue set in rapidly at times and therefore had to reset the pace of life:

Small steps were encouraged by the HCPs this included pacing oneself and setting realistic goals that brought with them a sense of achievement.

George's determination to continue to be active centred on remaining independent, to be able to get to his appointments, shop for provisions

'*It's only about 600 or 700 yards (to the shops and bus-stop) and I am walking pretty slowly, and it wears me out and I don't feel comfortable with that, but I use it to prove to myself, as long as I can still get my shopping, get to a bus stop, I can then get to places, I use it as a goal, that to me is self-preservation*' (George).

Tom and his wife had previously been avid walkers. Whilst Tom's weight loss and fatigue hampered activity, they were encouraged by Hospice staff to go for walks and not to be demoralised even though they found they had to be shorter.

Martha and her daughter made a trip to the supermarket an outing to make up for Martha not being able to swim but Martha described how she found the trip exhausting:

‘We might go and get the shopping and you know, have a cup of tea, but I tire very easily now. Even just going around the supermarket is tiring. I’ve got to find a seat as I am exhausted’.

Martha sighed and sadly reflected on the fact this was *‘not how I wish to be all the time’.*

Whilst George remained socially active he remarked on the contrast that he had had to become accustomed to since having cancer and going through treatment but how this did not deter him from trying to keep active and engaged:

‘*last week I managed to play golf. I walked and I pulled the trolley. I was sapped but I don’t want to give stuff up. So, I am still trying to do DIY, my music, I still try to push the envelope, but I do have huge limitations, after playing golf I slept for 2 hours in the armchair. That would never have happened before. But I need to do those things, they’re really, really important’*.

For all participants, a scaling down of activities occurred. Simple activities formerly taken for granted, such as walking to the shops, playing a round of golf, took on a new meaning providing a sense of purpose and achievement, and whilst slightly disheartening compared to their former selves, the activities represented a degree of normality at a time when their worlds were disrupted and turned upside down.

6.4 The altered food experience

A variety of strategies were evident amongst patient participants and carers to manage eating problems. Solutions included adjusting the environment, modifying routines, creating new ways of enhancing self-worth, seeking alternative means of eating at social occasions.

Perceptions of food have been shown to change considerably during cancer (Mroz et al, 2010, Bell et al, 2009) including in advanced stages of cancer (Hopkinson, 2007). In my own research, diet-related issues were experienced by all patients participating.

The impact of diet-related issues on food choice, habits and routines and their impact on nutritional status and weight was very individual in the way it was experienced. The diet-related issues were of variable duration; some were short lived, some prolonged, some irreversible and some overlapped. For all patient and carer participants diet-related issues altered the food experience.

George’s dietary issues were relatively short-lived (over several weeks) but as they were profound and rapid in onset, they took him by surprise:

‘it sort of happened in the period after my operation …I made myself a cup of tea and started drinking it and then thought ‘oh I don’t like this, it tastes horrible’. I put it down to the milk being off. I got myself some cereals, my usual Weetabix and then thought I don’t like, I thought the milk was off again but it didn't smell off. That was the start….I went to black coffee with sugar, gave up drinking tea as I don't like black tea, gave up eating Weetabix with milk. I started to look at alternatives, switched to a banana for breakfast but after a couple of days I didn’t like bananas’ (George).

During the period that George experienced taste aversions he also developed an aversion to solids: *‘The issue spread and spread until I couldn't stand anything of any solid nature in my mouth. I was chewing it but I wanted to spit it out, I couldn’t swallow It and it was like all the taste molecules had disappeared’*

As there was no physiological reason to explain George’s taste aberrations and aversion to swallowing, the effect was assigned to a side reaction to his steroid medications. Although George found the food aversion very difficult, the doctors took some convincing to reduce his steroids, George felt this was because they were very focused on a standard dose and resistant to tailoring the treatment in response to George’s adverse consequences on taste and the food experience. George felt the Doctors had good reason to resist changing the therapeutic dose of steroids, they were not forthcoming with an explanation, George ascribed this to their focus on the treatment and nutrition not registering on their agenda.

Although George was totally reliant on a liquid diet, he received minimal advice on dealing with the issue albeit his GP offered to prescribe some nutritional drinks. This was perhaps because at this time he was not regularly seeing the healthcare team for treatment nor had he yet been referred to the palliative care team. George effectively self-managed his eating issues which lasted about 4 weeks.

George’s prompt action to deal with his weight loss shares similarities with Bernhardson’s study (2012) who showed that advanced cancer patients undertook conscious cognitive processes to increase food intake despite abolition of appetite. In George’s case, despite loss of pleasure in eating and reliance on a liquid diet due to an aversion to solids, unintentional weight loss drove George to seek solutions and take in enough nutrition to maintain weight from liquids:

‘I didn’t languish at a low level for very long because I took action pretty damn immediately, once everyone realised the seriousness of it’ (George).

George felt able to regain the weight quickly as result of his actions in persuading his consultant to reduce the dose of medication which George believed was the root cause of the diet-related issues. Not all patients are as forthcoming as George in their approach with the Doctor and not all Doctors would necessarily act on the patients’ request to change drug dosage but in George's situation his actions achieved the desired goal to resume solid foods and regain weight lost.

Martha's poor appetite had persisted for months, she was overwhelmed by even small portions *'It's as if you have just eaten an* *<u>enormous</u>* *Christmas meal, and you know how that feels …. It's that sort of feeling but there all the time'.'*

She was advised to *'graze'* on small quantities of food but even a tiny biscuit made her feel full *'It's like force-feeding; it is very difficult' (Martha).*

Whilst George was able to make a conscious effort to eat more to regain weight, this was not possible for Martha. A review of her notes, blood biochemistry and physical features suggested that at the time of interview Martha was cachectic. The importance of adapting advice and expectations was relevant at this point (Arends et al, 2017) but the advice Martha had been given was not adjusted.

Martha was conscious that avoidance of eating meals with the rest of the family worried her daughter, she therefore tried to sit at the table to participate in meals to appease and manage her daughter's concerns as opposed to any desire of her own to participate:

'I don't want to worry my daughter all the time, she's watching me all the time They like me to eat with them, but I don't really want it. You have to make it look as though you're eating something, hmmm' (Martha)

Martha expressed relief in her son in law's actions '*my son-in-law finishes up when I can't eat'* partly relieving the pressure Martha felt to eat.

For all the worry that Martha felt her daughter experienced, Martha's daughter applied an element of rationality to assist herself in accepting the reduction in her mother's intake on the basis food in our society is now frequently oversized, and it was therefore not surprising her mother could only manage smaller portions

'I think there are several portions in one now. And some people think that is a normal portion, but a quarter would be more than enough. So, I know mum doesn't need to eat huge quantities (Martha's daughter)'.

George experienced the inability to manage solids for only a fraction of the time David experienced his loss but George acknowledged the wider impact of a restricted diet and the absence of solids on his enjoyment of food:

'loss of being able to manage textures was a real issue for me, I realised that it's really important, and something you maybe only notice it when you can't manage the textures. Food is not just a fuel is it?' (George).

Tom developed severe taste changes during several cycles of chemotherapy. Whilst this adversely affected Tom's pleasure in eating, Tom's wife was more distressed by the effect than Tom himself. Tom's lack of pleasure in eating the meals prepared, challenged her role as the principal cook, a feature that grounded their relationship. The issue was perhaps further compounded by their relationship and social interactions which were foundered on and previously revolved around entertaining their friends at home. Disappointment in not being responsible for, nor able to change or reinstate Tom's taste was a source of frustration for Tom's wife:

'everything I gave him was salty whether it was cereals, bread, anything, and I couldn't understand it. It was so difficult because I never put salt in anything, but he said he could still taste salt. And so, well then, he just didn't eat.

For David an inability to swallow required an altered textured diet. David rejected the idea of taking a pureed diet as he didn't want to '*eat like a baby'*. He greatly missed the oral sensation of different textures. When able to manage liquids orally he was prescribed oral nutritional supplements but struggled to take them

'I went back to work for a while and I hardly ate anything… the drinks (sip feeds) were awful… I'd have a drink on the counter at work try sitting at terrestrial or night long to try and get through a couple on the nightshift… I'm much happier now putting it down a tube'.

David therefore chose to administer more feed via his gastrostomy rather than consume a modified textured diet or take oral nutritional supplements. At times he would spend half an hour chewing a piece of solid purely to experience the texture of 'normal' food. Despite adversity of tube feeding and limited oral intake, his self-directed weight gain achieved through 'overfeeding' was a positive reward for the effort taken and partly compensated for the inability to eat normally.

6.5 Socialisation and isolation

The relevance of unresolved symptoms and diet-related issues in preventing taking meals with others or eating out adversely affected patients and carers.

In Martha's case, her unpredictable loose bowels, resulted in her becoming increasingly housebound. The stark transition for a lady who had once swum several times a week and enjoyed lunch thereafter with her friends was very evident, not only from Martha and her daughter but from the interview with the specialist palliative care nurse.

Martha's case showed inextricably how bowel function adversely affected dietary intake. At a time that Martha's diarrhoea was most problematic Martha ate less as that was the only means by which she could control the diarrhoea, she felt she had no-one who could advise her to do otherwise.

'you do feel if you don't eat or don't drink you can control it more (the diarrhoea)'. Martha also commented on how isolating this felt *'I don't know anybody else who is coping with it really'.*

The diarrhoea took its toll, resulting in further weight loss, weakness and loss of physicality and in turn greater social isolation. Although for Martha her diarrhoea, was after many months, found to be due to small intestinal bacterial overgrowth and therefore treatable, the prolonged duration of weight loss meant she never managed to regain her strength to go swimming again as she moved into the later stages of cancer and was affected by cachexia. She felt this was a huge loss.

Tom and his wife gave up hosting suppers with friends and eating out when Tom experienced his taste changes '*We couldn't go out for meals, well it is pointless isn't it, you can't go out when it's like that 'cos if we went out he would say it all tastes salty, you know, you've paid that money, you don't want to waste it, so no' (Tom's wife).*

And for David, who was dependent on tube feeding and barely able to manage any solids or liquids during radiotherapy treatment, David initially responded by not going out with the family, could not sit at the dinner table at home with the family and withdrew from cooking meals despite having previously cooked for the children and his wife.

David: 'I couldn't sit in the same room when the family were eating. I had to stand outside and have a cigarette. I couldn't stand somebody else eating, it was very annoying to say the least'

When they took a holiday at a time David could eat no solids orally, he coped by making sure that he accompanied the family to the meals but would order a drink *'that's how I managed the situation and that seemed to help the kids cope too'.*

Loss of freedom and choice was evident in the swallowing difficulties which not only impacted on David's ability to eat but also affected his ability to participate in family meals, eat outing including when on holiday. This was also true for Martha, George and Tom whose social opportunities were curtailed either permanently or temporarily.

George differed in that he remained determined to engage with friends and his social circle regardless of what he could or couldn't eat *'I still went to lunch with friends …and I said 'I've got a problem, (laughs) I can't eat anything solid? I don't mind what you are having but can I have soup?' It was important for me to go though, it was a social thing, I was hell bent on going and even if that meant taking my own tin of soup and warming it up, I would have done so'*

6.6 Tensions and adjustments created by diet-related issues

Across the cases, the cancer, but also the treatment and its consequences, not only reduced opportunities to work and engage in social activities but also extended beyond the patient, leading to a loss of confidence in roles and loss of self-esteem amongst others.

Tom’s wife referred to her concerns when weight loss arose with Tom’s distorted taste during and after his chemotherapy. She commented that none of the staff at the hospital ‘seemed bothered’ when she raised her concerns about Tom’s weight loss and taste aberrations, she felt unheard. Being a keen cook, she found Tom’s loss of interest in the food she prepared demoralising, illustrating the impact of the diet-related issues not just on the patient but also the carer.

Patients and carers also described the tensions between trying to eat a healthy diet against a tide of difficulties which prevented the patient from achieving this.

Tom’s wife felt compromised in having to alter Tom’s diet to one that she felt was less healthy but understood that it was necessary to prevent further weight loss and improve the experience of taste:

‘with my husband losing so much weight and nothing tasting right, I needed to make sure that he was getting lots of good food in him. At one stage I was feeding him anything he would eat whether it was bad or not’ (Tom’s wife).

David’s wife had previously been the driving force behind healthy eating in the family. She expressed an initial reluctance in having to make unhealthy choices for David, going against her desire to provide balanced nutrition, having to accept instead the need to get anything into David in an attempt to maintain body weight. She spoke about how she rationalised and accepted the shift away from ‘healthy’ foods during treatment as the chemotherapy was *‘poisoning him anyway*‘.

David’s wife also expressed her concern for the children. With David not participating in family meals, she felt there was one less role model at the table eating vegetables and the children would become ‘picky eaters’. She dismissed this in the next breath by putting into context against the backdrop of their father having terminal cancer

‘in the grand scheme of things, the kids eating their vegetables pales into insignificance’.

Martha’s daughter who had previously focused on providing her mother with simple, lower calorie foods to help her mother manage to *‘keep trim’* also justified a switch to higher calorie, higher fat foods, in them having less additives and therefore being better for you:

‘*You read all these low-fat labels and aspartame stuff, the weight watchers stuff and it’s all loaded with all these chemicals. I am convinced they do as much harm’* (Martha’s daughter).

Tom’s adverse taste changes and loss of enjoyment in eating also had a detrimental effect on Tom’s wife’s own enjoyment and relationship with food:

‘*I didn’t want to eat in front of him when he didn’t want to eat. When I did eat, I didn’t really enjoy what I was eating, I didn’t taste the food, I just ate. And half the time I didn’t eat it all’*

Alongside this with *'everything tasting salty*' to Tom, any pleasure previously associated with eating out was lost so Tom and his wife stopped eating out diminishing the social life for both of them.

These patient carer experiences illustrate the wider impact of diet-related issues adversely influencing the patient, the carer and the sphere of friends and interactions.

Resistance to change to foods perceived 'less healthy' has previously been reported amongst patients with advanced cancer (Bernhardson et al, 2012).With public health messages focusing on reducing fat and sugar, recommendations to switch to high Calorie foods to manage weight loss may go against long term habits and be perceived as unacceptable. It was evident from the patients and carers interviewed in this study, that resetting beliefs about the need to move to use higher calorie foods created tensions but that patients and carers found ways to self-justify the change.

6.7 Frustration and uncertainty

Penrod (2007) illustrated the considerable uncertainty patients with cancer face - uncertainty with regard to prognosis, uncertainty regarding likely response to treatment. With uncertainty comes doubt and in turn this can affect confidence and threaten one's feelings of control. Whilst there is individual variation as to how uncertainty is sensed, not having information, not knowing, can be disconcerting and discomforting in its own rights. Here I consider how lack of access to information to diet issues was disconcerting for patients and carers and in turn led to frustration of the situation.

David's situation provided an example of how swallow assessments were undertaken and yet he remained uncertain about the texture of food that he could try;

"I had no face-to-face contact with anybody who could really explain it to me, I felt I was to do as I was told but then I wasn't told what to do". What David and his wife desired was advice on alternative texture, how they could adapt meals and what foods might be suitable.

Although David's wife had formerly worked as a chef and therefore felt she had good knowledge of diet, she found the need for a modified texture diet challenging, pureed food was tasteless and unappealing and even on a soft diet the lack of ideas were disappointing:

'Adapting David's meals was a challenge and a source of frustration….pureed food was taseteless and unappealing. The whole bread thing was valid, it does stick in your throat, but maybe more advice on what you can do instead. People often have a sandwich in this country for lunch so providing ideas on what to have instead, ideas that would fill you up in place of bread, 'cos you have to eat a lot of crackers to get the equivalent of 4 slices of bread!' (David's wife)

Not only was information lacking but it was also conflicting. David's experience of what he could eat and what staff felt he could eat conflicted. David and his wife felt that rather than accept David's experience, hospital staff dismissed it.

'*Some of the things that David couldn't swallow were things that he really fancied so I would go and get it and then he would take a mouthful and sit there and go 'I can't get it down'. We'd then go to the hospital and be told 'it's a choice thing' errr well it's not a choice is it 'cos if there is something you really fancy and you get it in your mouth and you can't swallow it then that's not a choice'* (David's wife).

David's wife expressed the need for the healthcare team to acknowledge and hear the patient experience rather than contradict it *'I think the one big thing is that what one patient can do is not abnormal because it is different, it's not normal, but then the rest of life ain't normal! Instead they could say ''well that's really great you could get that down, could you try this as well?' What one can manage or chooses to try is dependent on what your palate is like in the first place'.*

Despite these set-backs by the acute team, resilience and determination to participate in some way at a meal-time to achieve some normality was evident in David's interview and his wife's. Over time David began to develop cope with others eating when he couldn't, he rejoined the family to sit at the table to administer his tube feed (with a new intermittent pump tube feeding regimen) and tried to occasionally chew a mouthful of food *'even if it took half an hour!'*

Discussions about the options for dietary modification, adjustment of meal patterns, managing the sense of loss when not able to eat and being familiar with all tube feeding methods, with ample time for patients and family members to gain an understanding, would have helped the patient and family members to work towards decisions that eased the challenges faced and allow individuals to regain control and regain a sense of purpose in relation to meal preparation and provision.

A strong message emerged from carers and patients that prescribed formulaic approaches to nutrition were not helpful and that symptoms could not be explored in isolation but needed to be placed in context with consideration given to how symptoms impacted on the individual's everyday experiences, sense of purpose and identity**.** All **c**arers remarked on the frustration created by the lack of individualised advice, an example is provided here from David's wife:

'*We were given this text book approach of people with swallowing difficulties, what people can and can't swallow …he obviously didn't fit the text book approach because things he could or couldn't swallow were not on the textbook list ..it made you feel you were swimming upstream' (David's wife)*

6.8 Self-determined adaptation

Patients and carers referred to how some of the diet-related issues both restricted but also directed choice. Much of this was achieved through trial and error, an observation made by Bernhardson (2012) in patients undergoing chemotherapy.

This was evident in how Tom's wife managed Tom's taste changes. Rather than cook meals they had habitually eaten, Tom's wife tried new recipes, new foods and experimented with the preparation of foods. She found foods that Tom had previously disliked foods were enjoyed. After Tom's taste aberrations resolved (as a by-product of a short dose of steroids for a respiratory problem) she found that Tom's diet had increased in variety compared to when they met, she was delighted with the change *'now no matter what I serve him he eats'.* Another adaptation that had a positive impact on Tom and his wife, was Tom's creation of a new routine of picking his wife up from work and taking her to afternoon tea. Tom did this to create an opportunity for social engagement in the absence of the meals with friends that had stopped because they felt they were pointless when food lacked pleasure. His wife felt this new routine was really special.

Martha's daughter was aware that Martha would rather opt out of participating in meals as she felt 'over-faced' by the plated food and self-conscious of her small appetite and inability to eat as normal. With symptoms of early satiety and loss of appetite prevailing, Martha's daughter switched to preparing a buffet or afternoon tea so that her mother could 'pick' at small amounts of food, feel less self-conscious and benefit from the company of others. Martha's daughter also took it upon herself to contact Martha's swim friends to encourage them to socialise with Martha and how they might support Martha to eat out:

'I've told them all, she (mum) is worried about when you come and get her to take her out to lunch and she'is not eating - so I said to them all please take her out and you have whatever you fancy, don't not eat cos mum's not eating or otherwise she won't go'.

David's wife gave a remarkable account of how the children found ways to make their father feel he was not missing out:

'The kids like bringing him breakfast in bed. David gets his pump on charge in the carry pack and the new tube and a pack of feed in the bag ready at night, so the kids in the morning at whatever time, unplug the bag and take the equipment on a tray covered with a tea towel. And they say to their friends 'we bring our daddy breakfast in bed every morning'… The children love doing it. I think they are pretty envious as they'd love breakfast in bed!' (David's wife)

Whilst this did not address David's issue in not being able to eat, it was a thoughtful strategy created by his young children to make up for their daddy's illness and lack of ability to participate at the family meals.

A number of strategies were adopted in order to cope with the daily struggles of being unable to enjoy food as in the past. A sense of 'just getting on with it' was captured in the interviews with several patients and carers. This gradually changed with the duration of the issue but took many months of adjustment.

As a result of profound weight loss, weakness and the side effects of treatment, David was signed off from work long term. Whilst he struggled for a while with not being able to eat and participate at meal times, eventually he galvanised enough courage to participate again including helping to prepare family meals, despite the challenge of not being able to eat himself.

David: *'my ability to eat is still a struggle, I can cope a bit better with other people around me eating and the family have adapted well…. From my point of view, they seem to have. But I've got over it with time, I feel I've come to terms with it and I feel a sense of duty to help in the home"*

With multiple diet-related issues experienced either singularly or simultaneously including loss of appetite, unintentional weight loss, fatigue, inability to swallow a range of textures, early satiety and food aversions, the nutritional issues were complex. With the diversity of diet-related symptoms and challenges, many patients and carers were caught up in seeking information that, as identified in these case studies, was neither clear cut nor existed in an accessible format.

The desire to self-act differed by age and stage of disease. One could argue that David who was given such a short prognosis survived way beyond it and that this was fuelled with determination to survive because of his young children. George had less advanced cancer and also showed a steely determination to continue but this could also have been because George was relatively symptom free at the time of his interview. Both David and George were pain-free in the palliative phase for many months and both felt they had much to live for. In contrast Martha experienced pain, was frail, elderly, cachectic and had lost her husband to cancer, during her interview I sensed that she was beginning to give up on life.

Concluding remarks

The two themes from this chapter - Theme 1, the complexity of diet and diet-related issues and Theme 2, the altered meaning of food, illustrate the multiple challenges patients and families face in dealing with diet-related issues in the incurable phase of the cancer journey. I have attempted to cast light on how patients and carers make sense of the diet-related issues and how they developed coping strategies to deal the broad ranging effects and disruption to everyday life and food-related activities. At varying points and to varying degrees, patients and carers perception of the role of nutrition and eating oscillated between eating for pleasure, eating to optimise health and function and eating for survival. All participants either made or accepted adjustments and adaptations which altered their relationship with food or helped retain the relationship with food. These findings and observations illustrate the broad impact of diet-related issues and the need for us to heed and understand the impact if we are to provide nutritional care that provides not only nutrients that nourish but address the psychosocial aspects of food and diet that impact on the patient themselves, families and friends.

In the next chapter I explore the HCPs perceived role of diet in the incurable and advanced phases of cancer, how they identified diet-related issues and what strategies they used to support patients and carers in managing the diet-related issues identified.

Chapter 7

Findings - Healthcare professionals' perceptions

7.1 Introduction

In this chapter I explore how the HCPs perceived the role of diet in palliative care, whether it was important and why it mattered. The first section provides insights into the HCPs views of diet-related issues in the cases chosen, enhanced through their recall of other experiences with other patients and carers in everyday practice. The complex nature of diet-related issues, identifying what mattered and strategies to manage the issues form the over-arching themes but are explored in more detail in the sub-themes which are indicated by the sub-headings.

It is evident from the patients who were interviewed, that weight was of particular relevance to their well-being and a key focus but an array of other diet-related issues were also bothersome and disruptive to everyday life. In my own research, all HCPs nominated and involved in the patient cases, illustrated a drive to understand the diet-related issues experienced. This understanding was a prerequisite that ultimately led on to seeking solutions where the HCPs felt things could be better. This is further explored in this chapter.

7.2 The complexity of diet

All the HCPs demonstrated an awareness of the impact of a variety of cancers and treatments on the ability to consume and enjoy diet. They saw their role as one of relieving or managing diet-related issues and considered it an integral part of care, along with other aspects of care such as management of pain or fatigue.

All HCPs interviewed felt the array of symptoms from bowel disturbances, dry mouth, physical difficulties, self-consciousness arising from not being able to participate as normal, were important to investigate and manage because of their perceived negative impact on the patients and carers quality of life in not addressing them. They recognised that as the field of palliative care has evolved, with patients surviving for longer with more advanced cancers, and a trend in the population of multimorbidities, that the patient's dietary needs were becoming more complex:

Martha's specialist nurse: *'These days diet can be complicated, it might not be just about giving information on one specific thing anymore'.*

Martha's hospital dietitian further described these challenges in 'juggling' the host of symptoms associated with Martha's pancreatic cancer including exocrine pancreatic insufficiency, steatorrhoea, possible small intestinal bacterial overgrowth (SIBO), weight loss, pain, poor appetite and potential diabetes.

The majority of HCPs talked about being on the 'look out' and opening up conversations to identify the issues which I further illustrate in this next section.

7.3 Identifying the issues

One of the key questions in this research was to explore how HCPs identify the severity and impact of diet-related issues. In this next section I explore this further.

Previous research in the Hospice setting where this research primarily took place (Czerwinska et al, 2013) identified a reticence amongst HCPs to weigh patients and use 'MUST'. In response to the research in the Hospice a nutrition assessment tool (the Patient led assessment of nutritional care' (PLANC), that was felt to more sensitively identify patient's and carer's diet-related concerns, was developed and introduced into the Hospice in 2015 (Souter et al, 2015). Primarily based on the MacMillan Durham cachexia tool, PLANC was adapted through a stakeholder engagement programme. Stakeholders included representatives from the multidisciplinary team, catering, patients, family members, volunteers and staff. The tool was intended to guide the identification of issues and concerns about diet and had been embedded in practice along with algorithms to guide interventions (Holdoway et al., BAPEN 2018). PLANC captured weight and weight history in all patients with the exception of those who were considered in the last few weeks of life or where patients declined to discuss weight. As reflected in the previous chapter weight was clearly important to all patients in this research. It was interesting to note that despite the reticence to weigh patients in the Hospice study in 2013, a review of the medical records of patients participating in this study revealed that weights were regularly being recorded and noted by Hospice staff. This may reflect the change in palliative care which now happens earlier in the trajectory of the cancer and that monitoring of weight is perceived as acceptable. The latter could be explained by the routine weighing of patients in the acute hospital whilst receiving treatments given with palliative intent, which in turn has influenced the acceptability and usefulness of weighing patients in the Hospice setting

In both hospital settings where the 2 hospital dietitians participating in the research worked, 'MUST' was in use. In addition, in hospital B, an informal set of criteria for use by the Oncologist and nurse specialists had also been created by the dietitian to facilitate identification of who would benefit from a dietetic referral. Evidence of its impact was reflected in increased referrals being received by the dietitian in hospital B.

Although screening and assessment tools were in evidence, all the HCPs who participated in this study with experience in palliative care (the Hospice HCPs and the dietitian from hospital B), described the usefulness of a combination of approaches to identify and assess diet-related issues. This comprised utilising objective measures such as weight, weight trends and body mass index, informal discussions, direct questioning and probing when they felt it was necessary.

The interviews conducted with the HCPs, combined with content from the case notes of patients, illustrated that the nutrition assessment tool (PLANC) (appendix 10, pages 196 - 198) used by the hospice staff, acted as a springboard at initial assessment. However, it was subsequent conversations with patients and carers that enabled staff, regardless of setting to deepen their understanding of the diet-related issues that mattered to patients. In the next section I illustrate how ‘nutrition conversations’ were used to identify and attain greater insight into the diet-related issues and how they affected patients and carers.

7.3.1 Nutrition conversations

Staff were conscious of the need to approach the issues in a sensitive manner and consider all the issues being experienced, with a focus on individual care and balancing the advice given in relation to benefit to be gained against the effort to adopt the action:

‘*It can be really challenging (to explore the dietary issues and weight loss) but it is all about how you address it….. it’s about breaking it down. By listening, people feel their anxieties that are being dealt with and where we cannot change the issues, we maybe facilitate acceptance’* (Martha’s MDT Assistant).

Martha’s dietitian also emphasised the importance of not viewing nutrition in isolation, nor working on it in a silo and also establishing what was relevant to the patient and family, avoiding viewing nutrition as nutrients alone:

‘Your aim might be to improve nutrition but to achieve this, it’s important to think holistically and sensitively. It’s important to have an individual approach and contact with the family’ (Martha’s dietitian).

HCPs in the hospice setting felt it was important, as part of the nutrition assessment, to ascertain more information on dietary intake through dietary recall and probing to seek out the spectrum of problems that could interfere with dietary intake. Whilst the quote below is extensive, it illustrates the level of diet-related questioning undertaken by the MDT Assistant:

Tom’s MDT Assistant *‘I ask how they are eating and drinking, how much, are you eating 3 meals a day? Or are you eating little and often? I ask if they have noticed if they have lost any weight? If they don’t know I would ask if their clothes feel looser and that type of thing. I ask if they are having any problem with swallowing or taste changes. It's a very general assessment but you are kind of trying to establish if there is an issue. And they may say ‘oh I haven’t got much of an appetite’ and you might then try and figure out a little bit more about why is that? Why haven’t they got an appetite, is it because your wife has given you a plate full of food… it’s quite off putting if someone has given you a plate full rather than just doing a tiny portion of food. And so, it’s about exploring it really …and we might go and get a leaflet and look at the leaflet whether it be they are nauseous or diet issues relating to treatment and all of those things that can affect somebody’s appetite’.*

This extensive questioning shares similarities with the ‘nutritional care process’ that has been adopted by dietitians who are skilled to undertake dietetic assessments. The extent of the questioning as part of the assessment by the MDT Assistant suggests that when HCPs, including nurses, physiotherapists, multidisciplinary team assistants, assign value to nutrition, they are motivated to spend time asking relevant questions, to identify the issues and find ways of supporting the patents and carer to deal with them.

To identify what mattered to the patient and the family members and help determine the level to pitch the dietary treatment and management of side effects of the cancer and cancer treatment, empathy and listening skills were identified as essential by all the HCPs interviewed. This undoubtedly links with the complexity previously commented on. Listening to what was important and relevant to the patient was apparent in the approach taken by Martha's dietitian, who was keen to balance the dietary advice and medication to improve digestion and absorption against the burden of taking multiple medications:

'Your aim might be to improve nutrition but to achieve that it's important to think holistically. You have to listen and think about the benefit and burden of the medication or the dietary changes for example. There are so many patients where their situation has showed me the importance of having an individual approach and contact with the family'.

Martha's dietitian who was primarily based in the acute setting, also referred to the value of thorough history-taking using prompts and visual checks, to identify the patient's needs:

'I might ask them about their taste, what their mouth is like, check for ulcers, have a look at the tongue as that might affect their eating. And then I would ask them about their digestion which would lead onto their symptoms and some people pick that up - the link between symptoms and wanting to eat' (Martha's dietitian)

She recognised that her skills in developing this approach had been influenced through her time working solo in the community as a home enteral feeding dietitian where she often didn't have access to the medical notes and so used her skills in history-taking to shape nutritional care and advice:

'I got used to asking a lot more questions, relied on history taking from the patient and would take a head to toe history to gain information'. Although not having access to medical records risks missing relevant facts, the merit in this technique is that with careful questioning one might achieve delivering goals and wishes determined by the patient rather than being distracted by preconceived ideas of medical colleagues and other HCPs.

The narrative from David's dietitian who was relatively new in post when she first met David, felt she failed to ask enough questions early on in her post and that this may have prevented her picking up the issues such as the disturbed nights arising from David's tube-feeding regimen. As she developed into the role, she learned of the importance to prompt and probe for detail to identify what mattered to patients and carers, particularly if she was to avoid preconceived assumptions on what she thought mattered:

'When the patients have their views, I hope I'm listening to them now…. you may not appreciate what's going on at home, so it's making sure you are aware of the social situation. With experience *I learned to ask, 'is this an issue?'. So, I learned to ask the right questions'* (David's dietitian).

This has implications for training and skill development and the question arises as to whether it is possible to develop advanced communication skills and a more holistic approach to identify the issues and create the right care particularly in our training and early on in our careers.

Supporting patients in palliative care, alleviating symptoms and improving quality of life cannot be achieved if we are blind to patient's needs, what is the matter with them but importantly what matters to them.

Although tools such as 'PLANC' identified the presence or absence of a range of symptoms, the binary nature of responses, risked failing to capture the impact on the individual and family, how bothersome or disruptive or concerning the diet-related issues were and provided limited information on the effort a patient and/or family member might go to, to address the issues. The nutrition conversations built on the tools and provided more in-depth information to enable the HCP to gauge the impact of the diet-related issues which in turn guided interventions.

7.3.2 Observation

Successive contact and observation were also valued by HCPs in the hospice setting where changes in body image and stature did not go unnoticed:

'*with some who come in you visibly see, you might not see them for a little while and it's quite shocking how much weight they've lost. And you're kind of thinking then what's happening? And you have that conversation with them and check the notes. It might be something that is already being dealt with and we know about it. If it's not, it's a case of having a chat and seeing whether it is something we can do and consider whether we need to step up another level and get the dietitian involved'* (Tom's MDT Assistant).

In this excerpt below David's MDT Assistant refers to identifying those who might look cachectic:

'when someone is looking quite cachectic and not interested in food and finding it really difficult to eat and losing a lot of weight, then I would definitely let the nurse specialist know and the dietetics team too'. This narrative indicates an awareness of cachexia existed amongst HCPs in the hospice setting, when asked about acquired knowledge she said she had learned about it on the Hospice training course on nutrition in palliative and end of life care (appendix 11, pages 199 - 201)

All the HCPs demonstrated how they saw it important to tune-in to what mattered to the patient and the family or caregivers. They recognised that failing to notice how the symptoms and dietary issues were impacting on an individual's way of life and way of living, hampered solutions being sought and symptoms persisting unnecessarily. It was evident from all the cases that an understanding of how diet-related issues were impacting on the patients and carers was required if they were to create the solutions and strategies to assist patients and carers to engage physically, socially and emotionally in life, despite the adversity of living with a life-limiting condition.

I now seek to explore how an understanding of the issues helped to develop the strategies to facilitate care and manage the diet-related issues.

7.4 Strategies to deal with diet-related issues

7.4.1 Managing concerns relating to unintentional weight loss

Previous research amongst nursing staff at the Hospice where this study was undertaken (Czerwinska et al, 2013) identified that nutritional screening focusing on physical measures such as weight and rate of weight loss in the palliative phase, felt futile and did not fit the palliative care philosophy. The nurses felt that the sheer action of recording weight would focus attention on weight and add to the unrealistic expectations, enhancing the gap between reality and what body weight might be feasible to achieve or maintain in end of life care.

With the palliative care services broadening to engage patients earlier in their trajectory of care, and opportunities to manage weight, symptoms and quality of life, in the mid-phase of palliative care, new updated training and new approaches to managing conversations about weight, diet-related symptoms and skills in handling difficult conversations around appetite and weight were introduced (Souter et al., 2015) (appendices 10 and 11, pages 196 - 201).

Evidence from the interviews with the palliative HCPs indicated that the training and role plays and case discussions encouraged amongst team members as well as sharing of guidance on new approaches to cancer-related weight loss (Arends et al, 2015) to address nutrition in the early to mid-stage of cachexia, were having an effect on the messages to patient and carers. Managing expectations were seen as a valuable part the HCP toolkit and put to good effect in patient and carer education. This was not however perceived as an easy task by any means.

It was noticeable from the interviews with all the palliative HCPs employed by the hospice that the matter of weight loss and poor appetite was not avoided as previously demonstrated in other studies (Hopkinson et al., 2013), but was proactively discussed. This may be unusual and be in part due to the research undertaken by several practitioners in the Hospice (Czerwinska et al., 2013, Holdoway et al., 2014, Souter et al., 2015, Holdoway et al., 2018).

What was evident from the patient stories in this research, including the recall of weight during the patient journey, was that David, Tom's and George's weight loss was due to inadequate nutrition arising from physical difficulties. Once a new and more acceptable feeding regimen was identified for David, ideas to overcome taste changes for Tom were established, and George adjusted his dietary intake to be more nutritious, weight gain was achieved, further demonstrating the patient was not necessarily in the later phase of cachexia even though the cancer was advanced and the patient's condition was classed as palliative. Determining what is possible and achievable is important if HCPs are to support patients and carers in understanding the obstacles relating to weight gain and setting realistic expectations. To achieve this requires a depth of understanding of the cachectic process and skills in communicating that to patient and their families.

Amongst HCPs employed by the Hospice, conversations with patients and carers relating to unintentional weight loss and poor appetite arising in the late-stages of palliative care, centred on alleviating the distress and facilitating an understanding of the contributing physiological factors. Similar to the findings of Hopkinson (2010) the HCPs felt explaining the underlying causes of the weight loss, alleviated the anxiety associated with the weight loss, even when the outcome could not be altered.

David's MDT Assistant *'I think you need to explain to the families, the cancer is producing chemicals that make people not like the taste of food, and don't want food…. I think if you can explain that it is part of the disease and they don't want to eat and encourage them to focus on offering a little bit of what they fancy, that can help hugely'*

All of the Hospice palliative HCPs referred to the frequency with which they dealt with weight loss and poor appetite. Several outlined that if a subtle and indirect approach was insufficient in identifying the relevance of weight loss or dietary issues, they would use more direct questioning, reflecting their determination and motivation to explore the relevance and impact:

Martha's specialist nurse *'obviously at some stage you'll need to direct that question to them and ask how is their appetite? Do you think you have lost any weight? So, you have that more direct conversation'.*

Hopkinson also referred to carers perceptions of the patient not eating as a sign of 'giving up'. The issue of family members perceiving their loved one's refusal to eat as intentional starvation was raised by all the HCPs participating in this study. David's MDT Assistant described how she would try and dissipate tensions with family members:

'when they say, 'Oh he's stopped eating, is that cos he wants to die quicker?', I say 'they're not trying to starve themselves it's just he doesn't want it.' Just making them aware of the fact that it's nothing to do with wanting to die and that they've just lost interest helps'.

Force feeding was also cited as a topic of concern and distress in previous doctorate research amongst bereaved family members, undertaken in the hospice (Newbury, 2012) and a systematic review by Amano and colleagues (2019). David's MDT Assistant described how she would discourage force-feeding by explaining to the family that in the late stages of disease the patient is not likely to experience hunger. She believed this helped discourage family members from force feeding, thereby reducing the likelihood of conflict arising between patients and family members which would ordinarily only add to the patient's distress.

7.4.2 Inter-relationships - diet and Symptoms

In George's case, the Physiotherapist and MDT Assistant strove to manage George's symptoms, primarily fatigue and food aversions, to enable him to continue to maintain some activity and socialise. The MDT Assistant and specialist nurse involved in Tom's care provided specific advice and resources to manage Tom's poor appetite and loss of taste. In the absence of Tom and his wife going out for meals, the Hospice team created an opportunity for Tom's wife to continue cooking for others by inviting her to make cakes for the coffee club, thus addressing the gap created by the absence of shared meals with friends.

The specialist nurse interviewed in relation to Martha, appreciated that faecal incontinence and urgency and loose stools severely disrupted Martha's ability to carry on with activities associated with one's own purpose and identity that were enjoyed before cancer, in Martha's case swimming, but also deterred eating and drinking as this triggered bowel actions. Wishing to improve Martha's quality of life, the specialist nurse demonstrated a determination to seek dietary solutions to alleviate symptoms, in this case managing bowel function:

'I could see that pain and the bowels were the major features for her and they were having a major impact on her life and her lifestyle… I didn't see that she was dying quickly from her illness in any other sense really, so for me there was a big part of trying to improve her quality of life of whatever life she had left' (Martha's specialist nurse)

She therefore sought advice from the specialist dietitian with knowledge of gastroenterology. The dietitian was aware of the need for pancreatic enzyme supplements which eased Martha's diarrhoea but was also conscious that Martha would benefit from possible investigations to elucidate further underlying causes of diarrhoea. Lack of access to breath tests led to Martha's diarrhoea remaining unnecessarily protracted. Although the dietitian involved with Martha recognised that bowel symptoms could be better managed through dietary adjustment and medication, she equally appreciated that imposing dietary restrictions including the avoidance of foods that might precipitate diarrhoea, might further limit Martha's choice of foods and enjoyment:

‘*I gave a bit of advice on diarrhoea and what foods might make things worse, but if people are really enjoying certain foods and like Martha, don't really want to stop eating fruit and find it refreshing, then that’s difficult, particularly for some in the end-stage of their disease as you don’t want to limit something they enjoy* (Martha’s dietitian)

Later on, when under Hospice care, Martha was able to have the necessary tests that identified small intestinal bacterial overgrowth and the need for a course of antibiotics which helped improve the diarrhoea.

7.4.3 Refining tube feeding

In this study only one patient, David, received nutrition support (tube feeding via a gastrostomy). David’s experience of tube feeding had not been positive in that he spent many months on a feeding regimen that was exhausting and very disruptive to family life. After many months of frustration administering eight bolus feeds a day, David learned about overnight feeding accidentally during a hospital stay for a chest infection. Although at the time he and his wife felt the provision of a pump ‘*was a gift’* to use to administer feed overnight at home, the noise from the pump and accidental feed leakage at night, gradually ground them down through loss of sleep. David’s diabetic control was also difficult to manage on the overnight feed combined with little nutritional intake in the day. Finally, after many months a solution was created through referral from David’s MDT Assistant to the specialist dietitian in the Hospice. David was established on intermittent pump feeding, feeding a third of his day’s tube feeding requirement over two to three hours, David did this around mealtimes to make him feel ‘more normal’ and also managed portable feeding when out and about by using a specially designated backpack that accommodated the pump, feed and equipment.

David’s dietitian who worked in the acute setting, only met David part-way through his cancer treatment. She described how prior to her appointment into the Oncology post, patients did not receive dietetic input from an Oncology dietitian who was able to anticipate the likely impact of the aggressive radiotherapy regimen that David was exposed to, an observation that did not pass by David’s wife who recognised the lack of specialist knowledge by the dietitian they first met. David’s dietitian also referred to her bias to bolus feeding after working with a senior colleague who told her ‘that’s what works for patients’ which certainly wasn't the case for David. After being in post for several months, David’s dietitian had learned the Oncology ward routines, care pathways and enhanced her knowledge and understanding through reading up on the topic. She felt better able to support patients by outlining to them the likely impact their treatment would have on their ability to eat and drink and how they would be supported with tube feeding and advice on dietary modifications. The delay in finding an acceptable feeding regimen for David does however raise the prospect that post-graduate training for dietitians could be enhanced and encourage the value of understanding the patient and family’s home situations and routines and that assessments for tube feeding should adopt a comprehensive assessment as proposed by Brotherton et al. (2006).

David's experience reflects the positive and negative experiences and impact on QoL that can occur in patients with head and neck cancer receiving tube feeding similarly reported by Ehrrson et al. (2015). It indicates the ongoing need for HCPs to work to create the most acceptable solutions for the individuals and their families when oral intake is not possible or limited, and take into consideration the psychosocial issues that patients may have to deal with.

7.4.4 Physical function and diet

In the past decade the role of rehabilitation in palliative care has been receiving greater attention through the understanding that rehabilitation can support patients and carers manage a life-limiting condition and live life to the best of their ability (Chasen and Dippenaar, 2008). Although there has been an increasing interest on the role of nutrition and resistance training in preserving muscle mass and function in a range of life-limiting conditions, we have yet to witness wide scale adoption of combined nutrition and activity/resistance training in clinical practice. An awareness of the role of nutrition in rehabilitation was however evident in the narratives of one of the Hospice MDT Assistants and the Physiotherapist, who felt that the patient's nutritional status influenced the effectiveness of the rehabilitation programme aimed at maintaining the ability to perform everyday activities:

Tom's MDT Assistant: '*many of our patients have problems like breathlessness and fatigue and if they are not taking in the nutrients, they are not going to have the energy to do the exercises that can help them with their everyday activities or breathe better'.*

The Physiotherapist felt diet went hand in hand with physiotherapy as part of a holistic approach to looking after the patient on their palliative journey:

'Our patients can struggle to eat enough, so they might need more high carb and high protein foods to help develop and strengthen their muscles. Providing them with high energy foods, might help do the basic things like washing and dressing as the illness progresses' (George's Physiotherapist).

Although the role of nutrition in cancer fatigue remains poorly understood (Baguley et al., 2017, Prada et al., 2020), several HCPs highlighted the importance of nutrition as a component in managing fatigue when discussing fatigue with patients

George's MDT Assistant '*From a team's point of view (supporting several practitioners), I highlight the importance of good nutrition as it is going to help manage patients' fatigue level. We know that exercise helps with energy levels, as does good nutrition, balanced with the right amount of rest. I look at trying to optimise individual levels of energy and manage their symptoms optimally from day to day'.*

7.4.5 The altered mealtime experience

All the Hospice HCPs saw food as being important to patients. For patients whose illness had prevented them from participating in mealtimes and meal preparation, they valued the opportunity to refer to the wider healthcare team for practical help that might be of benefit.

Just as the patients and family members experienced disruption to the meal experience, one of the MDT assistants reeled off the array of issues she had witnessed in relation to being involved with Tom. She also drew on experience in managing other patients, where she perceived the wider impact of diet-related issues on the individual patient and family members adversely affecting meal preparation, the mealtime experience, inducing feelings of rejection, frustration and disrupting relationships

‘our patients might have eating and swallowing difficulties and dry mouth. Those sorts of things can affect their ability to eat and they lose their self-confidence. They might need different food consistencies to cope with their symptoms and so then it’s all about adaptation. Alongside this they may not be able to face a normal portion, that’s all hard when trying to maintain that family contact. It can become quite a difficult situation, there can then become arguments and disagreements. So, one is trying to make a nice meal for their partner and then when it is presented on the table they don't want it, they have gone off it, they can’t face the size of the meal or they can’t face the texture or don’t like the flavour or the taste so it can become quite a challenging thing to deal with’ (Tom’s MDT Assistant)

These issues all featured in the patient and carer narratives previously presented and illustrate the HCP insights into the wide-ranging impact of the issues.

Self-consciousness in only managing small portions (as experienced by Martha) were also recognised as a challenge experienced by both patient and carers alike:

Martha’s Dietitian *‘the patient can feel very self-conscious if they are not eating a normal portion or if they are struggling to cut food up to eat…there is that whole issue around not being able to eat a meal and there are lots of feelings like guilt by the patient and frustrations by the carer’*

Through an improved understanding and awareness of the cachectic process, the palliative HCPs felt passing their understanding of cachexia on to carers, alleviated the anxiety experienced by family members associated with a partner’s loss of appetite and the rejection of food that might have been ‘*lovingly prepared’*. The HCPs felt this facilitated the acceptance of a non-reversible situation in the late stages of cancer.

7.4.6 Managing tensions around eating less healthily

HCPs illustrated how they would support patients and carers in adjusting their attitude towards the role and meaning of food, to strike a balance between consuming enough energy to maintain function, whilst avoiding stresses associated with not eating a balanced diet.

George's Physiotherapist described how she felt she gave 'permission' to patients and carers to deviate from healthy eating when faced with diet-related issues– '*what you eat is a habit of a lifetime and the food you buy is too. Sometimes it boils down to giving them permission to have things which go against the healthy eating messages. If they've lost a lot of weight, I might be encouraging them to have more high-energy, high carb foods. Having little bowls of nuts and cheese and crackers and biscuits and chocolate brownies and things that the rest of us are trying to avoid to avoid weight gain'*

One dietitian described how she would explain the change in appetite when unwell to explain the need for foods that seem less healthy

'I explain how appetite is totally different if you are not well, you might not be so active, you've got a reduced appetite … patients do still find it really difficult to accept the different advice especially when we talk about 'making every mouthful count' so using things like full fat milk, using butter, using cream …obviously you have to take into account any dietary intolerances and creating means by which they may find the advice acceptable ' (David's dietitian).

One of the MDT Assistants referred to allowing treats and relaxing healthy eating messages not just for those who were underweight or losing weight but also in palliative patients who were overweight or who had diabetes *'it's a case of it being about quality-of-life, making it enjoyable and if they enjoy eating a slice of cake and with other people, as it's really sociable, then who are we to deny that'* (Tom's MDT Assistant).

7.4.7 Managing disrupted eating

Several HCPs appreciated that the impact of the patient not eating extended beyond the patient not only having an emotional impact but also deterring the carer from eating and in turn adversely affecting the carer's nutritional status and enjoyment of food and that support needed to be provided to both patients and carers.

Tom's MDT Assistant*: 'as the dietary issues escalate it can have an effect on the carer themselves, not just from an emotional point of view creating a tension between them but also 'cos the carer may then not eat as they feel guilty to sit down to a meal themselves'.*

Acknowledging this to be the case, HCPs sought to support both patients and carers by encouraging carers to attend appointments with their partners. In the hospice setting, specific courses had been established for carers or for patients and carers combined, which explored the eating difficulties common in advanced cancer including loss of weight, appetite and the physiological effects underpinning cachexia and discuss strategies for dealing with the issues. The courses created the opportunity for patients and carers to learn from experienced HCPs but also through discussions with peers on the shared experience.

7.4.8 Tailored, individualised bespoke advice

Frustration was raised by patients and carers regarding the lack of bespoke advice and in some case no advice. Patients did however comment that once under hospice care they could '*ask anything and an answer would be sought' (Tom's wife)* or at the very least an explanation given.

In the hospice setting a range of resources had been created to support all staff in delivering first line dietetic care (appendix 1, pages 165 - 167). In the narratives of patients and carers it was evident that advice was useful when the staff used the content of resources (written or from patient and carer course content) as a framework for discussion, adapting and revising key messages to tailor the advice to an individual's circumstances. Whilst the internet was seen as a source of information, its useability and reliability in finding the right information (an observation also raised by Martha's daughter) created limitations in benefit.

Tailoring advice rather than providing a formulaic approach was seen as important to meet carer needs as much as patient's needs. This was evident across all palliative care members; the MDT Assistants, specialist nurse and physiotherapist.

Tom's MDT Assistant *'I think we all realise it's (diet) so important to the patients but it's not just a case of giving some leaflets, it might be much more than that'.*

This was also echoed by Martha's nurse specialist '*there are so many skills involved, we have to think outside the norm, because everyone is different'*. Her comment resonated with David's wife's comment that '*cancers differ, patients differ and therefore advice required is likely to differ, one size does not fit all'*.

7.4.9 Supporting diet-related issues across the trajectory of care

Assessing nutritional status, symptoms and diet-related issues across the trajectory of disease was raised by all the HCPs and the changing palliative population was also acknowledged. In this excerpt from the Physiotherapist we observe a flexibility in approach to adapt care to the changing needs of the palliative population, a message that was cascaded to all as part of senior management briefings to staff in the Hospice, but captured here in a sophisticated observation:

George's Physiotherapist: *'We are not just dealing with end of life care. With increased survivorship in palliative care we may be seeing patients over a longer period of time and during that journey they often have a change in dietetic needs and change in nutritional needs and later in their disease trajectory they might end up needing more nutritional supplements because they are struggling to eat or a change in the* *consistency of their food and their drink. So, there is a change in what's happening and we need to gear up to that'.*

7.5 Diagrammatic representation of the main themes

To draw the themes together, a diagrammatic representation of the themes, inter-relationships and the process utilised to identify and manage diet-related issues is created below in figure 7.5 (main themes are indicated in bold)

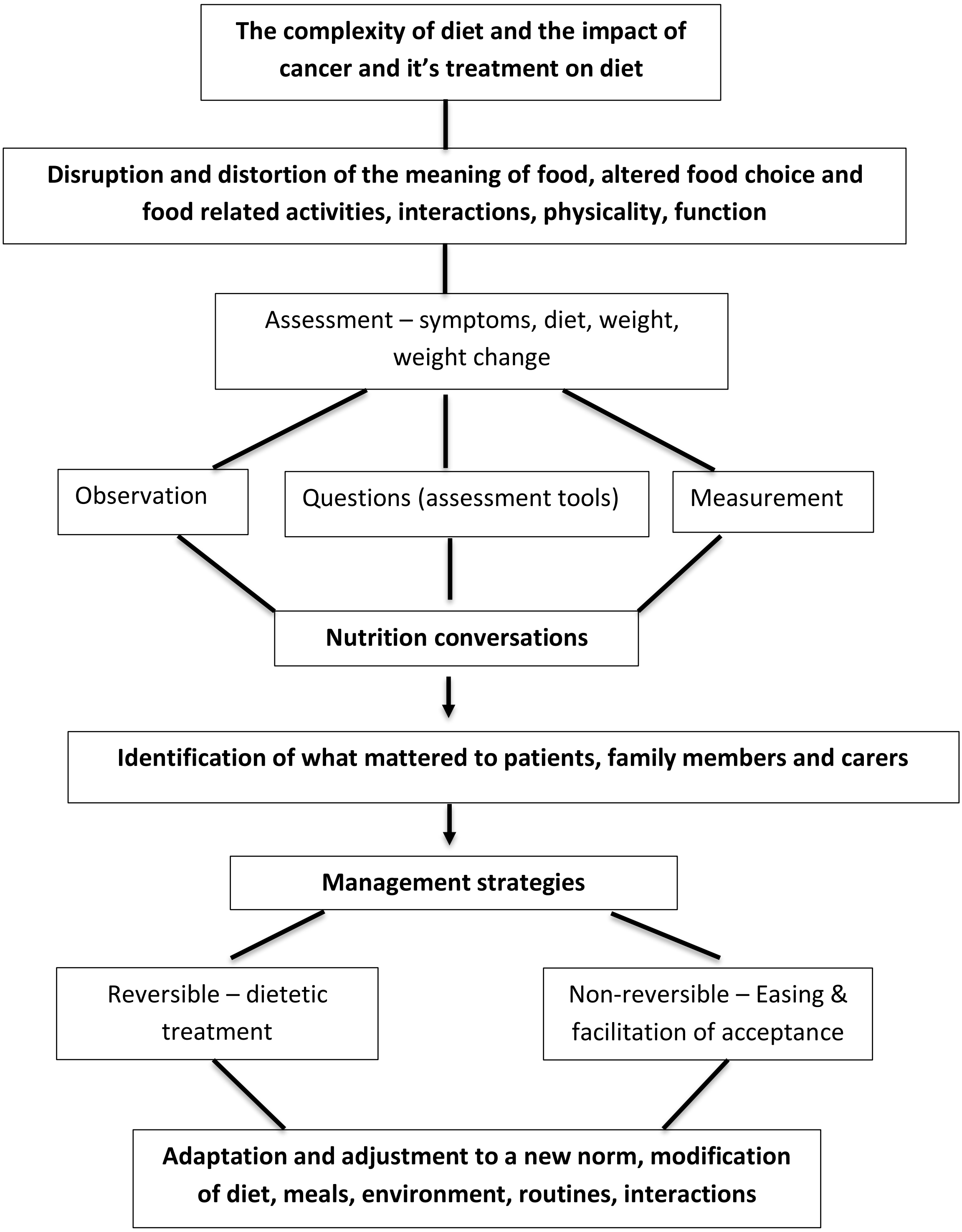


Figure 7.5 - Diagrammatic representation of the process to identify and manage diet-related issues with main themes indicated in bold.

Concluding remarks

In this chapter I have explored the perceptions of HCPs and how HCPs sought to identify the diet-related issues experienced by patients and carers. I also attempted to elucidate the strategies the HCPS drew upon and co-created with patients and carers to overcome the complex diet-related issues and help patients and carers regain a degree of control and normality in everyday life in relation to diet and nutrition.

In the next chapter I consider some of the factors that influence the identification and management of diet-related issues at an organisational level. These insights were inductively deduced from the participant’s narratives but also observations in the care setting including the policies and training in place.

Chapter 8

Facilitators of nutritional care

8.1 Introduction

In this chapter I consider the factors that facilitated nutritional care. These factors build on the findings in Chapter 7 relating to the identification of what matters and include culture, environment and the sharing of knowledge. The main influencers in facilitating nutritional care are illustrated in figure 8.1.

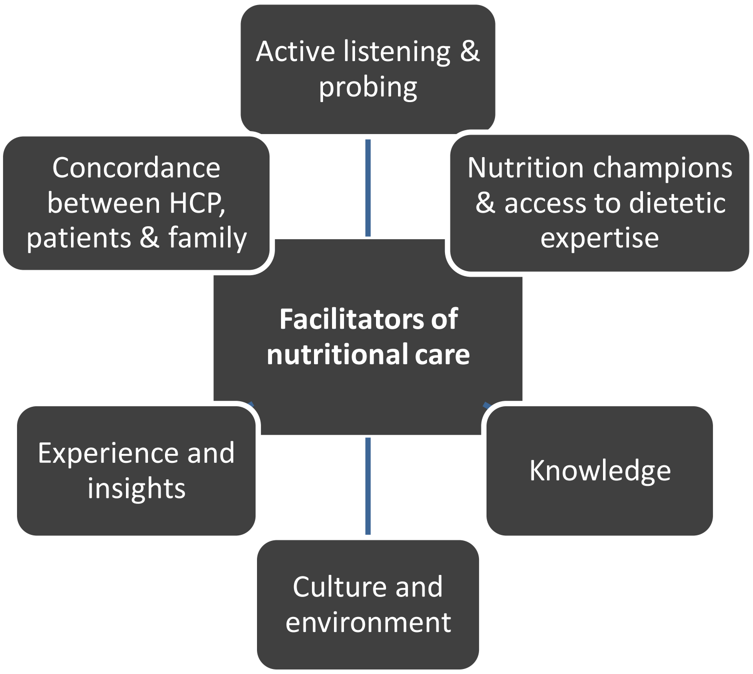


Figure 8.1 – Diagrammatic representation of key factors facilitating nutritional care

8.2. Culture and environment

One of the benefits of case study research is the ability to study the environment in which participants are operating in. Working in the Hospice one day a week meant I had insights into the culture and environment of the Hospice where the majority of HCPs participating in the study worked. As the care and experience of patients and carers was received across a number of clinical settings, it would have been beneficial in adding a further layer of understanding of attitudes to nutrition and the influence of the culture and environment in other settings. As this was not feasible for this study, I spent time evaluating the Nutrition and Hydration policies in place and insights gained from the patients and carers who received the care and the HCPs who worked there, to glean how culture and knowledge may have influenced where nutrition sat in the hierarchy of care. This is relevant as adoption of assessment tools, new ways of working and sharing of innovation can be influenced by both the environment and the culture (Baille et al., 2018, Flynn et al., 2018, Harris et al., 2019)

In the hospice, evidence existed to suggest nutrition was viewed as an integral part of care. Sources of evidence existed in the patient care records, assessments and projects involving multiple stakeholders (Souter et al., 2016). Several HCPs participating in my research referred to the enthusiasm emanating from some of the frontline staff, an enthusiasm for nutrition was also evident at board level as illustrated in correspondence with the Chief Executive of the Hospice *'Nutrition and its effective use is such an important part of the care pathway, it is integral to how we live each and every day from sustenance to companionship'.*

Amongst the palliative care professionals interviewed in the Hospice setting along with Martha's dietitian who worked in the acute hospital trust in oncology and palliative care, it was recognised that integration of nutrition into care did not happen by chance but had been achieved through a concerted effort by many players. The efforts made in the hospice were captured in the interview with one of the specialist nurses based at the hospice and who had worked there for 17 years:

'within our organisation we are well structured. Having a Dietitian as part of the team in recent years is very valuable but we've also got people in the in-patient team and outreach centres who have a particular interest in nutrition and have done some work around that and brought that information back to the teams in terms of thinking about things in a different way in terms of assessment' (Martha's nurse specialist)

The importance of individuals to champion nutrition and ensure it was on the agenda was also echoed by one of the MDT Assistants in the Hospice out-reach centre:

Tom's MDT Assistant *'There has been and are several people with an interest in nutrition. If you have somebody who is quite passionate and has an interest in nutrition, then it becomes a bigger thing. And certainly here, working in this outreach centre, the nurse specialist has been a massive driving force for nutrition'.*

In the hospice setting it was evident that nutritional care was woven into everyday care and not seen as a separate entity. Incorporating nutrition conversations into encounters in outpatient appointments, drop-in coffee clubs, patient/carer courses, appeared to be the norm for all palliative care staff. Reasons cited for this was the passion by some of the nurses for the subject which promoted awareness and relevance, thereby championing the nutrition agenda.

What was evident in the palliative care setting and for the hospital dietitian who had embedded her service in Oncology and palliative care in the acute setting, was that attempts to influence the nutrition agenda didn't just happen by chance but were orchestrated over time, through policies, teaching, case review, corridor discussions, promotion of roles.

Although I could not observe the acute setting, my research included interviews with two dietitians working in two distinct hospitals and I was given access to the Nutrition and Hydration policies in those settings. In both hospitals, nutritional screening was undertaken using 'MUST'. As was evident from the patient and carer interviews and the interviews with nurses and dietitians, the focus was on identifying the risk of malnutrition rather than diet-related issues associated with cancer and cancer treatment. For those who were identified at risk of malnutrition a modified diet and oral nutritional supplements were available to order. Referral to a dietitian could be made but both hospital dietitians were aware there were many patients who they could see who they didn't and that this meant the patients and carers might be missing out on receiving advice to cope and deal with diet-related issues.

Although in the acute settings, weight was regularly recorded as part of the malnutrition screening using 'MUST' and when attending for chemotherapy, David's dietitian felt changes in weight were not routinely acted on:

David's dietitian '*Whilst the nurses record weights at each chemotherapy session (every 3 weeks) they don't seem to register the previous weight, so the weight loss that might be occurring over the many weeks of treatment somehow gets overlooked and if a patient is not thin to begin with they may not look thin but clearly the weight loss might be considerable and affect their response to the treatment'*.

Hence the dietitian appreciated that those with a significant weight loss that could be detrimental and concerning to the patient and carer, might be overlooked as their high body mass index above normal might mask the malnutrition developing.

Both dietitians described how policies regarding the measurement of weight related to treatment; maintaining weight to avoid treatment toxicity or weight to determine dosage of chemotherapy and drugs. The relationship between weight and how a patient felt, how the weight loss might relate to distressing food-related issues or weight trends was in their view, often overlooked.

8.3 Knowledge

8.3.1. Acquisition of knowledge – a three-way process

Previous work by Hopkinson (2006) identified that patients and carers created their own solutions for managing diet-related issues but inferred this arose in the absence of support from HCPs. This was evident in this study but comparatively, the co-creation of solutions was achieved through a three-way process involving, at times, the patients, carers and HCPs.

HCPs in palliative care seemed comfortable in setting aside beliefs that you have, or are expected to have, answers to everything. This emerged in their narratives describing a consciousness of not always having the answers. This potentially facilitated their learning from their patients and carers with whom they came into contact with.

David's MDT Assistant recognised that you needed '*courage to do this as it might reveal a vulnerability when the patient thinks you should know all the answers*' and to admit this required confidence in one's ability to reaffirm to one's self that not knowing was not a failing.

Tom’s MDT Assistant spoke of embracing ideas from patients and carers:

‘patients themselves educate you because they come to the courses or coffee club and will say oh, I found this book; this is what I’ve got’

It was also evident that the peer to peer support sessions that the Hospice facilitated enabled HCPs to accrue knowledge from being a part of the patient-carer courses.

‘*You get introduced to a lot on nutrition by attending and running and being involved in our patient carer courses particularly in the session when the dietitian is involved - that gives you the basis of what nutrition is about’* (Tom’s MDT Assistant).

George’s Physiotherapist who had led on many of the coping courses for patients, spoke of the value of peer to peer support:

‘*It’s not only us as professionals giving them information, they get a lot more from the group interactions. And whilst they are having their own separate journeys and have different disease processes, they are all having similar issues whether it be around fatigue, breathlessness, diet problems, it’s about supporting them and supporting each other’* (George’s Physiotherapist)

It was evident in the interviews that advice shared at the patient-carer courses had found their way into everyday consultations. The cruciality of support for each other across the teams was seen as a key component in developing good quality care.

It was apparent that nutrition link nurses and access to a dietitian in the organisation not only gave patients and carers good access to advice and resources but also expanded the knowledge of others. *‘I learned so much from the specialist dietitian’s talks when I was in the Hospice at Home team… and learned through our nutrition link nurses too’* (David’s MDT Assistant).

In the day patient unit HCPs and volunteers assisted at lunchtime and ate in the canteen alongside the patients. The shared meals allowed direct observation of those who might be struggling. It provided a practical and illuminating experience for HCPs to witness the issues but expanding their knowledge of how patients dealt with them

‘Eating at the table alongside our patients, you find out first-hand how diet-related issues might be affecting them and what you’ve got to consider with all of that in supporting them’.

Learning from each other, recognising that we may not have all the answers at our fingertips, practicing humility and being humble and receptive to the opportunity to develop new understandings of how to deal with issues were gleaned from the patients and the carers. This in turn created new understandings of how to deal with issues.

8.3.2 Experiential knowledge

It was evident from the hospice nurses and the interviews with the dietitians, that professional knowledge was strongly influenced by experience in practice, reflecting the importance of the workplace as an environment to support learning. It perhaps highlights the potential weakness with regard to the need to ensure that knowledge can be gained early on in clinical posts to avoid lack of experience hampering best care for the patient. The dietitian's lack of experience undoubtedly contributed to David's protracted period of problems in relation to his tube feeding.

David's Dietitian: *'After David's bad experience I started thinking about my own knowledge and opinions …about why would you think one method (of feeding) is any better than another? If the patient is happy with one method, then fair enough but if they aren't then they need to know the options. Now when the patients have their views, I hope I'm listening to them…'*

If we are reliant on accrual of knowledge in clinical posts, there exists the challenge to develop knowledge without years of practice so that patient care is not compromised by lack of knowledge and lack of experience early on in careers. The importance of acquired knowledge in this study indicates a need to consider how HCPs are trained, how to undertake assessments that lead to acceptable interventions for the patient and the family and how diet, including how methods of feeding, have a wider impact on significant others.

It was evident from the interviews that case studies, mentoring, shadowing and in-house training, all played a role in enhancing knowledge. Equally though was the recognition that one can learn from the patient and carer experience and expertise. This latter source of knowledge requires recognition and acceptance that as a professional one cannot, and indeed is unlikely to, know it all. Perhaps paying more attention to, and including experiential knowledge within learning environments, a key component of healthcare education emphasised by Eraut (2000, 2004, 2007), may help to create a greater balance between scientific, clinical and technological knowledge.

8.4 Freedom to act

David's MDT Assistant, who had worked as a nurse in both the acute hospital setting and hospice setting, compared and contrasted the cultures that enabled her to freely practice as she saw fit to meet the patients' needs in palliative care. She used an example where in the acute setting 'nil by mouth' meant nothing orally whereas in palliative care, it was likely this was more easily relaxed if the patient expressed a desire to eat and the risks had been discussed with the patient:

'I think in palliative care you tend to think more about basically letting the patient do what they want to do, if they want to try that let them try it. Whereas in the acute setting they (the nurses) have so many things to think about and they are handing over

to different people all the time, they need to say maybe don't do that, do this' (David's MDT Assistant).

Whilst she recognised there was a logic explaining the difference in the environments, she felt protocols in the acute setting could be too rigid, fail to register the patient's wishes and acted more in the interests of the professional:

'sometimes, I think they (acute hospital nursing staff) take more notice of clinical staff rather than the patient themselves. Whereas I think with the Hospice we tend to listen to the patient more than anything (David's MDT Assistant)*'.*

What the MDT Assistant particularly observed and commented on was the feeling of being trusted to make decisions independent of seniority, especially if she believed her decisions directly influenced quality of life. She went on to provide a plausible explanation for the difference, outlining in the acute setting, rules abounded, that the hospital might be more risk averse than the Hospice. She was aware though that sometimes in busy acute hospitals, decisions such as 'nil by mouth' once instated were not revisited, thus imposing unnecessary restrictions on a patient's oral intake:

'I think sometimes something is recorded once and that's it, it's taken as read and no-one actually goes back to the patient again to check has it changed from last time and also is there anything we can do differently? They take it as a 'nil by mouth' that's it completely' (David's MDT Assistant).

The degree of freedom to make decisions within the Hospice perhaps reflects an underpinning philosophy and desire to place the patient at the heart of decision making, supporting the change in emphasis in care particularly in the end of life phase, when patient choice takes precedence:

'you can think a lot more for yourself here (at the Hospice), I think you're trusted more as an individual and that you're allowed to work on your own initiative, more so than in the acute setting. There's a better relationship with patients compared with the acute setting' (David's MDT Assistant).

Whist this freedom to act, placing greater emphasis on the patient's interest was seen as a privilege in working in palliative care, the MDT Assistant also recognised that clear boundaries were required in the acute setting due to the more dynamic throughput and frequent handovers which might risk harm if not adhered to making the staff more risk-averse.

8.5 Nutrition in the hierarchy of care

If nutrition is not perceived to be important by members of the healthcare team, and less crucial than chemotherapy and radiotherapy for example, then it is perhaps not surprising that discrepancies regarding concerns relating to the role and value of nutrition arise. In this research the effect of not heeding, acknowledging or ignoring the patient's and carer's diet-related concerns and their impact on patients and carers, adversely affected the healthcare professional relationship

Although I was unable to observe interactions and patient's healthcare records in the acute setting, the lack of attention to addressing nutritional care needs and dietary advice was apparent in the narratives of the palliative care team:

'I am amazed when someone comes up here and throughout all their treatments nobody has talked about nutrition' (Tom's MDT Assistant)

Tom's MDT Assistant who had worked for a number of years in older people's hospital care, did not understand why nutrition no longer appeared to be seen as part of essential basic care, an observation she gleaned in inheriting patients into the palliative care setting who had been under the acute care team. She tried to explain that the lack of attention to diet-related issues and nutritional care may be due to increased throughput and less time available for the nurses to make observations in relation to diet and nutrition:

'I don't understand why it has changed since I worked there. I don't know whether it's because it's so busy now and the staff are under so much pressure, but I would class nutrition as being basic nursing care' (Tom's MDT Assistant).

All patients in the study felt their diet related issues and concerns were either ignored or not heeded at various time points but this was particularly noticeable when under the care of acute team. Tom's MDT Assistant excused the nurses in the acute sector for not addressing nutritional issues in being *'too busy'*, but she suggested means by which the nurses could address matters such as diet, by integrating it into conversations when carrying out some of their tasks with the patients:

'can they not ask simply when hanging the chemotherapy 'how are you managing to eat and drink?' (Tom's MDT Assistant)

It is surprising that despite spending thousands of pounds on cancer treatments such as chemotherapy, nutrition may still be overlooked or not feature in routine acute care. This observation although limited by proxy, further suggests that integration of nutritional care may be cultural and relate to a low priority to nutrition. This goes against the recommendations from international opinion that suggests 'therapy to maintain normal body weight and composition, exercise capacity and the ability of a patients to benefit from anti-cancer treatment, should be considered an integral part of the package of care offered at each stage of the disease' (Aapro et al. 2013).

David's dietitian who worked solely in Oncology in the acute hospital Trust explained that she witnessed attitudes that suggested nutrition was irrelevant, or futile, once patients were deemed incurable. She felt this arose from doctors and nurses lack of understanding of the role of the dietitian and preconceived ideas on the role of nutrition in palliative care. Even amongst head and neck cancer patients, where clinically assisted nutrition and hydration via gastrostomy feeding is more routine (Belwar et al. 2016), she recounted conversations where Doctors expressed views that nutrition and proactive nutrition support had no role to play in palliative care:

‘I think a lot of people (doctors, nurses) thought if it’s palliative they shouldn't have a feeding tube and that if clinically assisted nutrition support such as tube feeding was employed the patient would have to stay in hospital which is not the case’ ..

Early in her post, David’s dietitian did not feel confident to question the doctor’s views but as she became more knowledgeable, she began to challenge them:

‘I am now more comfortable saying to a Doctor ‘well if they don't feel like eating anything, they won’t get their nutrition, so are they going to die of their cancer or of another disease before due to malnutrition?’(David’s dietitian*)*

David’s dietitian attributed these attitudes to the Doctor’s previous experience, hence if the doctors rotated from a field of medicine that was curative to managing palliative patients, even when chemotherapy or radiotherapy was being provided, they assumed tube feeding was futile:

‘I think they (the Doctors) come from say stroke care where patients are being fed and get better and so see the value but then come to Oncology and despite still treating patients with chemotherapy or radiotherapy which interferes with their eating, they believe that if someone is incurable (palliative) then feeding is irrelevant. It’s making them realise if they are going to be alive for another 6 months then we may be killing them as a result of malnutrition if we don’t feed them’ (David’s dietitian).

The observation could also occur as a result of a change in emphasis from curative medicine to supportive care, with an increased emphasis on preserving the quality of life for the period of life remaining, where the perceived risk of actions is balanced against maximising quality of life. It may also reflect the time available to talk to patients and carers in the palliative care setting to truly understand their desires and wishes.

8.6 Protraction of problems - Access to diagnostic tests

Delay or lack of access to diagnostic tests previously reported by Andreyev et al. (2011) was apparent in this research and captured in the narrative of Martha’s dietitian:

‘I*t’s difficult here where I am based because we can’t access the tests here and so the Gastroenterologists may not necessarily follow the same guidelines we should be following for the late effects of cancer treatments, this makes it very difficult’.*

She tried to work around this by taking a very thorough history:

'So, it comes back to that point about learning to do a full history and find out what is affecting the patient and what's important to them, that's really valuable' (Martha's dietitian).

This does however rely on good clinical knowledge of how cancer and the treatments might contribute to, and cause, symptoms that can managed. One can anticipate, in the absence of tests to assess gastrointestinal dysfunction, that could be treated, symptoms could persist unaddressed.

8.7 Perceived futility of nutrition

Reservations in providing nutrition support was illustrated in the specialist nurses' recall of exchanges with GPs. She described how she continued to come across GPs who felt nutritional care had no place in palliative care. This meant when oral nutritional supplements were requested to support dietary intake of food and fluid, they were denied. The nurse attributed the reluctance to prescribe nutritional supplements to the GPs belief that there was nothing to be gained:

'I suspect there will be a proportion of people including GPs, who work out there, that still have the expectation that weight loss automatically goes with cancer and therefore there is nothing you can do about it….. who wouldn't see that investing time and looking at this side of things might be beneficial to the patient but that's maybe because they don't have the experience or have seen the effect'? (Martha's specialist nurse)

Whilst the benefit of nutritional supplements in relation to survivorship may be of questionable benefit (Baldwin et al, 2012), it fails to recognise the value of nutrition support in alleviating distress. This attitude was countered by the Martha's dietitian who emphasised the role of nutritional supplements in providing supportive nutrition where providing nutrition support becomes '*an emotional goal, not a nutritional goal, easing the stress around eating'.* As Martha's specialist nurse identified, Martha's dietitian was equally conscious that her views were not always shared by GPs who were being asked to prescribe the products, and referred to many occasions where her recommendation was challenged. To defend her decision, she contacted the GPs to explain her reasoning for the product. Over time she felt this educated the GPs not only on her role within the multidisciplinary team but provided the opportunity to highlight the supportive role nutrition played in the patient's overall management.

Both dietitians working in the two acute hospital trusts spoke of struggles to get nutrition on the agenda. Although one '*chipped away'* in trying to get nutrition seen as a priority by the Oncologists and hospital specialist nurses and integrated into care, Martha and David's dietitian were both aware that nutrition remained overlooked, unaddressed and of lower priority in the acute hospital settings where they worked. She took it on board to educate the team around the role she could play:

Martha's dietitian: *'When I was new to the oncology role, the Consultant Radiologist helped me to understand that side of things, but I helped her understand what I could* *do. And even if the prognosis was just a few months, and the patient had cachexia which was not reversible, I explained there were still a few things I could do that could help improve quality of life for patients'.*

Concluding remarks

In this chapter I have considered factors beyond the individual that interplay to influence the identification and management of diet-related issues. Preedy (2011) acknowledged that some of the greatest challenges in palliative care are nutrition related. The findings in this research support this belief but illustrate that steps can be taken to facilitate acceptance, identify areas of adjustment and assist all in managing the nutrition and day-to-day issues on an individual basis. The findings contribute new understandings on how it takes time, knowledge, openness, active listening and probing to formulate and guide adjustments to alleviate diet-related issues, that are centred around the patient's wishes and desires.

In the next chapter I seek to bring all the findings together in a reflective discussion that ultimately draws this research to its final conclusion.

.

Chapter 9

Discussion

9.1 Introduction

My aim within the analysis was to utilise the considerable insights and knowledge I had gained from immersing myself in the detail of the cases, to provide the reader with an understanding of the phenomena being described. Through the descriptive passages selected in the findings I hope that I have provided insights into the experiences of patients with incurable cancer and how they, their carers and healthcare professionals dealt with the complex diet-related issues in a real-world situation. Use of quotations from the interviews is intended to give 'voice' to the participants but also enhance authenticity.

By identifying distinguishing features but drawing commonality across the cases, I hope the breadth of insight and the richness of the data has been fully utilised. My intention was to accurately represent the cases, add to our knowledge and encourage further steps to improve the management of diet-related issues through a greater understanding of what matters to our patients and their family members and carers.

The new insights gained from the research are summarised below:

I. Acknowledgement of the complexity of diet in advanced cancer that arise as a consequence of the cancer and associated treatment.
II. Disruption and distortion of the eating experience which altered the meaning of food and how this influenced a patient, and carer's drive, to take actions that focused on the preservation of the mealtime experience, routines, physical function and socialisation.
III. The value of nutrition conversations as a tool to facilitate an understanding of the diet-related issues and what mattered to patients and carers.
IV. Breadth of strategies co-created by patients, carers and HCPs to alleviate or overcome diet-related issues including adaptations, adjustment, acceptance of a new norm.
V. Factors that facilitated the provision of nutritional care including knowledge acquisition, culture and environment.

The discussion in this chapter draws on all the findings across all the case studies. It considers rival interpretations compared with previously published literature and explores the new understandings of the nuances of diet-related issues that I had not previously considered nor was evident in published literature to date.

9.2 Food - what matters?

In the palliative care setting, patients and family members and carers displayed a range of concerns related to diet and not necessarily connected to their medical problems. When these problems were not properly assessed and addressed, they became a significant source of distress, an observation previously reported in the literature (Baile at al., 2011, Amano et al., 2019). To provide care that is perceived as helpful and beneficial it is crucial in practice to accurately identify patients' concerns, only in doing so can they be adequately addressed or alleviated.

Understanding why we eat and what we eat is also essential if we are to understand the challenges patients and carers face when the pleasure of eating is removed or diminished. For all patient participants, whilst the absence of appetite (which would ordinarily act as a driver for eating), and diet-related issues played a strong part in reducing intake, the need to eat took on a new meaning in relation to survivorship, strength, physicality, function and socialisation. For healthcare professionals to deal appropriately with the diet-related issues and appetite loss, we need to understand the patient's wishes and drivers.

The patient experience in this study informs us that the historical approach in 'eating what you like' in palliative care fails to address the diet-related concerns that are prevalent amongst patients and carers in palliative care. With increased survivorship and the extended periods that patients are now being managed palliatively, the time has come to reconsider the role of diet. Patients and carers are seeking guidance to maintain social integration, continue to have the energy to work or participate in everyday activities and manage weight loss and poor appetite whilst eating what they believe comprises a healthy diet or what is 'normal' for them.

Although self and identity are complex phenomena, this study illustrated the relationship between the cancer, its symptoms, and its effect on food activities and food related identities. Eating at times was driven by necessity, devoid of pleasure and undertaken through a cognitive decision, in the absence of appetite, to preserve self (strength, physicality), survive, function and a maintain a degree of normality. Acceptance of this approach may be very individual and in a patient with late stage advanced cancer may not be possible due to the latent effects of late stage cachexia. Understanding this drive and a means of determining in practice the presence of cachexia and inflammation, may help HCPs understand and agree realistic goals for patients as well as mitigate concerns about unintentional weight loss and appetite. This is of particular relevance when we consider weight goals and what patients can expect.

9.3 Weight - what is possible, what is desirable?

Hopkinson's narrative review (2018) highlighted that patients attempts to combat weight loss resulted in disappointment as a result of gaps arising between what patients expected and what was achievable. This was intensified by poor HCP knowledge and lack of access to sound information and interventions. One of the challenges in managing weight loss in advanced and incurable cancer relates to the presence or absence cachexia. In the presence of cachexia optimal endpoints are not clear (Fearon et al, 2011). In recent years it has been acknowledged that weight loss in the early to mid-cachectic stage may be slowed, halted and in some cases may respond to nutritional interventions (Arends et al, 2017). As was evident from the weight gained by patients at various timepoints in their trajectory of care, and palliative HCPs recall of other patients, weight loss should not be automatically accepted as a natural part of the palliative care process unless the patient is cachectic, end of life or has a physical or physiologic problem that cannot be overcome. From what we learned of the patient cases in this research, a concerted effort to view weight in the eyes of the patient is needed to have meaningful conversations as to what weight might be achieved in the period of possible weight gain (pre or early cachectic phase) or what weight loss might be minimised in a cachectic phase of illness. In this study 3 of 4 patients who were palliative were able to regain weight lost when underlying contributory factors were addressed and the right dietary advice was provided.

In contrast to Hopkinson's research (2006, 2010) amongst a similar palliative care population, where staff feared raising the subject of weight and propagated a culture of avoidance for fear of not being able to do anything, in this research, palliative care professionals actively engaged in discussions with patients and families, probing to establish at a detailed level what could be tried or tested in relation to improving the diet-related experiences and the experience of weight loss. Whether this had resulted from the initial work by Hopkinson and MacMillan (2010), or the research within the setting (Souters et al, 2015) or because staff acknowledged it being important to the patient, was unclear but it was interesting to note that in the Hospice, talking about weight was not feared by staff.

The need to help HCPs to manage difficult conversations regarding weight has been raised as being a difficult topic (Amano et al. 2019). The results of this study demonstrate that weight is high on the patient's agenda and therefore HCPs need to be trained to deal with this. All HCPs in this study from the Hospice setting seemed comfortable undertaking difficult conversations about weight, weight loss and loss of appetite. This has implications for practice nationwide, as there is the opportunity to transfer the skills evident in this research with other hospices, hospitals and care settings where life-limiting, palliative conditions are being managed.

The relevance and importance of body weight was complex not least because the presence or absence of cachexia which influences weight and muscle loss is not routinely assessed in practice. Cooper et al. (2015) highlighted in their literature review that cancer cachexia was a multidimensional experience for patients and caregivers, not always recognised and managed adequately by healthcare professionals and that our understanding of cachexia in the early stages of disease is limited. Literature indicates what is possible in maintaining weight or regaining weight lost, considering the degree of cachexia. My research has shown that there is certainly a role in establishing from the patient's and carer's perspective what weight they perceive to be ideal, what goal they have in mind, what in reality is achievable and the importance of taking time to explain factors that could help achieve that goal or not. The latter could include an explanation of early versus late cachexia, this was found to be helpful and reassuring by patients and carers in this study and knowledge of cachexia gave HCPs confidence to discuss weight as a consequence.

Whilst there is considerable literature on the topic of unintentional weight loss and cancer-related loss of appetite, weight and cachexia, this study provided an opportunity to explore perceptions and experience and meaning of weight loss, in patients, carers and HCPs and how this differed at various time points according to the trajectory of the disease. It was not surprising that concordance between doctor-patient and family members over what body weight can or should be achieved and sustained was not easily achieved given the complexity of the cachectic syndrome.

Interestingly, whilst body mass index (BMI) might be a surrogate marker of function, strength and survivorship and is commonly used as a tool to set dietetic goals, it was perceived as irrelevant by patients. Instead, tying weight to function and physicality, understanding weight pre-illness as a benchmark, and establishing what the patient wished to achieve, seemed to be a more acceptable and collaborative approach in the eyes of the patient.

The rate of weight loss, changes in weight, whether it was intentional or unintentional, were factors considered by patients and family members and the relevance reflected on in relation to wellness, living, surviving. There may be gender differences in the patient's ideal of what is a normal body weight as well as what their historical weight was and hence what they considered 'normal' for them, needs to be appreciated. The concept of desires for body weight has implications for the HCPs for if we fail to grasp the relevance of weight and what patients consider normal for them, we are less able to advise and manage weight according to the patients' and families' wishes.

Whilst on the one hand a patient may want to be heavier than the HCPs want them to be, in contrast some patients may be less bothered by the weight loss in terms of weight on scales but bothered by the weakness that arises, in other words whilst not affected by readings on the scales, weight may be important in relation to self, identity and function. This highlights the importance of HCPs taking into account an individual's history and personal desires during treatment and beyond, rather than weight and BMI at a point in time.

In this study several HCPs and patients recognised the value of nutrition in supporting or maintaining physical function and activity. Functional decline or loss of function may not only impact on independence and ability but also compromise a person's sense of self and dignity. As was also evident in this research, significant wasting and weight loss can add to the fear of closeness of death. In the early to mid-palliative phase of advanced cancer it is now apparent that providing nutrition to meet nutritional requirement to preserve weight and lean tissue (muscle) is possible (Arends et al, 2017). This offers the optimism that patients seek in both preserving body mass and weight, not 'wasting away' unnecessarily and maintaining function.

In relation to function, as more patients are surviving and expect a reasonable quality of life, rehabilitation in palliative care is gaining ground (Harding et al., 2019). It is clear from the literature and some of the practitioners interviewed in this study that they see nutrition going hand in hand with function and that nutrition and physical training and conditioning influence each other and therefore a joint role should be promoted through clinic settings. With activity being encouraged as a core component of several cancer pathways, the creation of joint nutrition and activity clinics in palliative care, which are beginning to emerge, may provide a channel in which QoL can be improved or maintained through preservation of weight, self and function in those that are palliative. Future dietetic and management strategies should begin to reflect the need to combine physical therapy and conditioning programmes, alongside nutritional interventions to stimulate muscle preservation, accretion and maintain function in relation to everyday activities to be expected by the individual.

9.4 A renewed focus on diet-related issues

In the acute setting there has been national drives to detect the risk of malnutrition, however even in the absence of malnutrition, or before malnutrition arises, diet-related issues and dietary challenges warrant being identified to establish the problems and symptoms patients and carers were facing and the need for help and advice. In the palliative care setting, the risk of diet-related issues being overlooked was potentially mitigated by the use of the holistic patient led assessment for nutritional care tool (‘PLANC’ - appendix 10, pages 196 - 198) that incorporated prompts to identify likely problems but as was evident in the section on nutrition conversations, ‘PLANC’ was only the starting point. The findings indicate the need to incorporate dietary assessments into healthcare reviews not just through a simple malnutrition risk tool but though questioning and ‘nutrition conversations’ that focus on diet-related issues that are relevant and important to the patient and other family members or friendships. The questioning on nutrition and diet-related symptoms, not only facilitated the identification of issues arising but embedding it in the holistic assessment of all patients under care of the Hospice (in-patient, outpatient and out-reach) has potentially transformed the perception of nutrition within the organisation through it being a component of every day practice.

Structured questioning, as recommended by Laur (2015) could be incorporated into assessment tools but equally, as was evident amongst HCPs who dealt with the issues, probing and questioning around daily routines, food related activities and a review of symptoms that might relate to diet and nutrition, were an important part of identifying what mattered to patients and carers and where nutrition related matters sat within the patient’s and carer’s hierarchy of needs.

Barriers to screen for malnutrition and nutritional issues continue to be reported (Green et al, 2013, Harris et al, 2019). It was interesting and reassuring in this study to observe that HCPs not only took the time to question patients and carers about dietary habits, diet-related issues but that this led to actions and advice on how the patients and carers might modify diet and make small incremental changes to overcome, or at the very least manage the issues. This study also identified factors that facilitate nutritional care at an organisational level. A cultural shift away from tick box checks and a move to more engaging conversations as was observed, might facilitate the identification of issues and lead to appropriate nutritional care planning that delivers the holistic goals palliative care seeks to achieve.

As previously identified by Cocher et al, (2010) and Valentine, (1999), when life may be limited timely interventions are paramount. In this research deterioration in health brought about changes in food related activities. In turn this impacted on identity including identity related to socialising and engagement with family and friends. Patients and carers coped with this to varying degrees which in part related to the severity of disease, the issues experienced and solutions identified.

International opinion suggests '*therapy to maintain normal body weight and composition, exercise capacity and the ability of a patients to benefit from anti-cancer treatment, should be considered an integral part of the package of care offered at each stage of the disease*' (Aapro et al, 2013). Despite frequent hospital outpatient attendances and very high value treatments such as chemotherapy, the outcome of which may be adversely affected if nutrition is not addressed, pleas for advice on nutrition from patient and carers went unheeded. Engaging with the wider healthcare team including Oncologists, surgeons, radiologists and Consultants where diet-related issues in cancer types are prevalent, remain very much needed. Education on the value of nutrition, what it means to patients and carers, and impact on outcomes, including when it is ignored or undervalued, is required to gain attention to this area of medicine.

Differing perceptions on the role of diet and the meaning of food in advanced cancer and the management of symptoms were evident between patients, carers and HCPs. The indiscrepancies and varying attitudes became more apparent in the participant's interviews when they referred to their experience with the acute teams, with several struggling to obtain help to deal with diet-related issues via their Oncologist, an observation raised previously by several authors (Bozzetti 2015, Arends et al., 2017, Flynn et al., 2018)

A focus on cure, investigations and medical interventions in the acute sector as well as lack of training in nutrition, may be a reason that diet appears lower down the list in the hierarchy of care. As this research shows, its prominence in the patient-carer experience means that failing to address diet-related issues may fail to address matters that are important to patients and carers.

Although it would be difficult to achieve perfect agreement of the patient experience and what we as HCPs perceive as a problem (for example as individuals we perceive pain, symptoms differently), a clear understanding of the factors affecting patient-clinician discrepancies and lack of concordance is important to understand and overcome, not only in building and maintaining trusting relationships but also in determining patient-centred care and support for carers. In the study by Chandwani, (2017), discordance between patients reporting of severity of symptoms and clinicians were due to clinicians underestimating the degree of bothersome of symptoms. Chandwani observed that referrals to other services were based on their own judgement of symptom severity not the patients. In my research, a similar phenomenon was observed from the patient and carer narratives, particularly in relation to hospital care. If HCPs fail to heed what is important to the patient or the carer in relation to symptoms relating to diet, referral to services that may be able to help are possibly hindered. This highlights the importance of gauging the presence and relevance of diet-related issues from the patient-carer perspective by members of the healthcare team if patient-centred care is to be achieved.

Whilst it may be difficult to say that earlier dietetic advice would have made a difference, if a clinician makes referrals and recommendations to other members of the healthcare team such as dietitians, based on their own personal rating of the severity and impact of symptom, and nutrition does not resonate as a need, then patients may suffer from delays in access to specialist services. What is evident though is that when dietetic solutions were finally sought, the effect was beneficial.

Across the board, cancer affected the ability to eat in different ways. This in turn impacted on the meaning of food, function and the ability to perform tasks and engage in food-related activities. As changes occurred at varying time points, were potentially unpredictable and were affected by changes in symptoms, HCPs need to be astute to change to spot the emergence of diet-related issues. Continual assessments and vigilance are key and the results of screening for symptoms and sequential weights should be visible and accessible to HCPs. An awareness to new issues arising is essential to initiate new or different advice required and in the case of weight and pleasure around eating, may represent the need for a change in emphasis.

From an ageing population with multi-morbidities, new ways of working to manage a range of conditions requiring palliative care will require increasing knowledge for multiple disease states. Shared care, shared records and good communication including communication with patients and carers will be key for this to happen.

9.5 Socialisation and adaptation

Frustration and isolation were particularly challenging when difficulties in eating and drinking impacted on family interactions and routines. In David’s case this related to tube feeding. Rose and Howard (2014) and Brotherton et al., (2012) commented on the exclusion experienced at social occasions through tube feeding. In this research isolation and frustration was experienced by all patients when oral intake was disrupted, the impact was felt by patients and sensed by carers. In this research lack of support and detailed assessment led to avoidable and unnecessary suffering.

A variety of solutions were to hand, including those learned by patients and carers and those created by the staff’s former experience or in thinking creatively around the challenges. In this research study, patients and carers undertook a range of coping and adaptive strategies to maintain a sense of self, integration, identity, sometimes self-identified and other times supported by HCPs. Examples of successful strategies included baking for the coffee club, going out for afternoon tea or serving buffets rather than a sit-down meal, adjusting feeding regimes to encourage integration, eating just a mouthful, sham eating.

With the dynamic nature and evolution of symptoms and change, it is clear that a fluid approach to management is required if we are to better support our patients and carers in dealing with challenges. Whilst we can learn from patients, carers and each other, it is evident that solutions are based on a multiplicity of approaches which include identifying what matters to the patient, being pragmatic and realistic about what might be possible, communicating what may be possible to patients and carers and identifying what could be fixed and what could not and therefore needed to be managed.

Whilst tube feeding can be life-saving and weight preserving, the burden of tube feeding on quality of life is not to be underestimated (Brotherton et al., 2006, Blodt et al., 2018). In Brotherton's paper a series of prompts to facilitate assessment of patients on tube feeding to better manage feeding and improve quality of life was identified. Although published over 10 years ago the findings from my research show that the framework Brotherton recommended has not necessarily found its way into clinical practice. Adopting recommendations from research into practice continues to represent a challenge in delivering and improving care.

Tong et al. (2009) reported that despite a high prevalence of malnutrition and nutrition impact symptoms in medical oncology patients, only half of the group had access to a dietitian to guide nutritional interventions. The role of dietitians in palliative care and hospice care is recommended by NICE (2006). Given the emerging evidence outlining the impact of diet-related issues on quality of life and the importance of addressing diet related issues to alleviate stress and anxiety, one would anticipate that there is a call for dietitians to be working as integral members of the interdisciplinary teams in palliative care.

In care settings where a specialist dietitian was available or where there was open access to the specialist dietitian (minimal barriers to referral and appointments), participants referred to the ease with which they could access advice. The ease of access to advice was also commented on when under the Hospice care. Whilst the advice may have not always led to resolution of diet-related issues, there appears to an element of reducing the anxiety by acknowledging the problem and having an HCP to discuss it with.

The aesthetic expression of food and its central role in celebrations of life are known to become challenged when illness and disease are present. In this research the altered meaning of food, differing experiences and broad range of issues evident amongst all participants, indicated the need for tailored advice. All patient and carer participants, and some healthcare professionals, demonstrated a resilience and a remarkable ability to adapt circumstances, to recreate the environment and new ways of eating, to enable food to continue to be a social vehicle.

Many of the participants experienced dynamic changes in health as they were subjected to treatment such as radiotherapy, surgery, chemotherapy. Side effects and the treatment itself created changes in health status which further threatened the social context of food activities both in the way participants shared meals with others but also shared responsibilities in the household around food and activities. Such changes could be anticipated, and tailor-made resources may help.

HCP and carers need to identify that changes in the social context of food activities may have an important implication for maintenance and changes in identity. Support in establishing a range of activities that alleviate the distress associated with not being able to enjoy and participate in meals and eating out, need to be uniquely handled to suit the individual needs.

Hopkinson (2007) reported that eating problems encountered by patients were often coupled with low expectations of the healthcare professional's ability to achieve successful palliation in this area. Amongst the staff specialising in palliative care who were interviewed - which included a dietitian, MDT Assistants, a physiotherapist and a specialist Hospice nurse, evidence existed to demonstrate that all HCPs strived to seek solutions in conjunction with patients and carers. In the absence of advice from healthcare professionals finding solutions to the issue of weight loss, Hopkinson (2006) provided evidence that patients subsequently found their own solutions. This was true for the patients and carers in this study who sought to change their diet or adjust tube feed, to make a difference to nutritional intake and body composition. The exception was Martha, who was interviewed when closer to the end of life. At this stage it was apparent to Martha herself, and her HCPs interviewed, that little could be achieved to reverse weight loss at this late stage, considerable effort and time had however, been invested in this aspect of care earlier on in her journey.

New to this research was the resilience and endeavour to manage the issues and create solutions that was evident amongst patient and carers and HCPs with palliative care experience. Differences observed by patients and carers through their experience recounted during the earlier phases of care and the acute setting's attitude to nutrition, may reflect the focus on treatment and cure, a lower priority given to nutrition or the notion that in palliative care little can be done so why bother.

The adoption of both reactive and proactive coping strategies has the capacity to enable the patient and carer to effectively accept and, in some respects, embrace the daily realities. The palliative care team illustrated how they facilitated the development of effective coping strategies, learning from the patient and carer experience and encouraging self-management through adequate support and the provision of timely information and services. This seems paramount for an individual's sense of well-being and yet in the acute sector, with a focus on treatment, this seemed overlooked.

Associations between being able to eat and drink and survivorship and overcoming the loss of appetite associated with a feeling of deterioration are well reported in the literature (Hopkinson 2006a, 2006b).The complexity of cases and the dynamic nature of the cancer, associated treatments and symptoms on diet and nutrition presented a considerable clinical challenge to all practitioners. In this study patients and carers were confronted with multiple and simultaneously occurring diet-related problems. Patients and carers expressed a desire for timely, flexible approaches to dealing with the nutritional issues. Given the various mindsets of patients – those who have a drive to survive particularly demonstrated earlier in the trajectory of the disease and those who are approaching the last few weeks of life , HCPs need to continuously monitor and assess for diet-related issues if patients and carers are to be provided with timely advice and deal with the psychosocial and biodynamic nutritional issues that arise in populations of patients living with a diverse range of nutrition and diet-related issues.

It was evident that a patient's desire for knowledge will vary as will the extent patients and carers will seek and adopt measures to resolve the issues. HCPs therefore have to gauge how proactive to be in pursuing dietary change, for example too intense a dietetic intervention towards the end of life could be harmful through the associated distress it might cause, particularly if unrealistic expectations are set. HCPs with experience in palliative care referred to adjusting advice according to patient circumstance and the patient's desires. In some situations, patient and carer reports highlighted a near dismissive response by some HCPs to the patient experience including ignoring carer concerns with regard to diet. Better designed resources could enhance certainty about suitable actions and enhance decision-making when so much else, such as prognosis and survivorship, remain uncertain.

Evident in the patient and carer narratives was a trend that patients and carers received the most tailored advice based in the palliative care setting or under the care of members of the palliative care team. Failure by the acute care team including oncologists, to address concerns regarding diet-related issues were apparent in the patient / carer journeys. Collaboration amongst the multidisciplinary team – oncologists, dietitians, nurses, surgeons, physiotherapists, occupational therapists, speech and language therapists, catering, carers and patients remains a concern and addressing this is long overdue in an age of inter-disciplinary teams, working across care settings and where nutritional advice is clearly valued by patients and carers.

Professional boundaries and a paternalistic approach to medicine were less evident in the palliative setting where patient voice was given priority on 'what mattered to them'. Staff heeded concerns from carers as well as patients whilst retaining a focus on the patient. A determination to make a difference to the patient's experience prevailed even when faced with the uncertainty of the period of life remaining. The palliative team showed flexibility in their approach according to where they felt the patient was in their trajectory i.e. whether to encourage, coerce or relax the delivery of information and advice.

HCPs in the palliative sector and with palliative experience accepted that they did not always have solutions but by listening, learning form others, building and drawing on patients and carers they had previously been involved with, they demonstrated resourcefulness from an expanding toolkit when available.

In this research, the patient and carer experience related to tube feeding to illustrate how imperative it is for service providers to recognise the need for knowledge amongst patients and carers and adjust delivery of care and information accordingly. The recommendations by Brotherton et al (2006) on supporting patients to manage home tube feeding remain as relevant today as when published and emphasises the ongoing need for a structured framework to guide nutrition assessments for patients on home tube feeding, particularly when experience is limited and the need to integrate such frameworks into the curriculum and professional development to enhance the knowledge of practitioners managing home tube feeding. The negative experience of the participant on tube feeding in my research was put to good use as it led to several new national resources co-created with one of the participants was developed.

Food today is very much a social vehicle, bringing friends and families together. The informal patient / carer coffee clubs and group courses provided the environment in which social links were made through food. It is also a conduit where ideas were shared and new ideas generated to benefit all. A national blog of what works could be considered.

Peer support, interactions with other patients and other carers was perceived to be constructive and helpful amongst patients and participants. Expert patient programmes seek to utilise the skills and experience of patients to inform other patients. In palliative care there was no evidence of patients being used in this way perhaps because of fear of putting them in a position of responsibility when life may be limited. However, given the current duration of survival in living with a palliative condition the value of patients and carers in educating and informing others could be considerable and support the implementation of social prescribing.

9.6 Adjustment

In 2001, Brennan suggested that ‘although the term adjustment is widely used in the psychology literature and is a topic of central importance in relation to the lived experience, mechanisms have rarely been described’.

Adjustment often refers to the psychological processes that occur over time in an individual, family members and friends. Adjustment can help individuals manage, learn and adapt to the changes arising and is particularly relevant amongst patients having to deal with long-term, incurable illness and its treatment such as incurable cancer.

Adjustment can imply an element of acceptance to a deteriorating situation and this was noticed in patients and family members in this research. In my research most of the patients and carers adjusted to the situation, the extent was variable so with some the adjustment was a compromise (adjusting to tube feeding), others a degree of resignation was observed which perhaps was associated with loss such as loss of functional activity like swimming, whilst in others there was a positive gain, for example meeting the wife after work for afternoon tea. Brennan (2001) observed that adjustment may not always be for the worse with personal growth arising out of the adverse circumstances. This was true across several of the cases where both patients and family members made personal adjustments to create a more positive environment. The term adjustment is often used in cancer and health psychology to indicate a return to premorbid functioning. My own research amongst patients with palliative conditions illustrated though, that food related activities were unlikely to return to the premorbid state for some, particularly in the latter stages of disease, in some cases, this happened early on but that did not mean that the individual did not adjust. In reality adjustment resulted in acceptance of a new or at least different norm.

Understanding the degree of adjustment and, where necessary, supporting acceptance appeared of key concern for those seeking to support patients and families with diet-related issues arising from incurable cancer. Whilst for some participants the adjustment was a continuous process, for others adjustment arose from one point in time, a steady state could then be present and then later another issue arose that warranted addressing. This means that dietary advice and nutritional care cannot be delivered at a specific point in time and indicates the importance of ongoing assessment and surveillance. Time frequency for repeat nutrition assessments will be dependent on the individual and their own experience but rather than risk overlooking issues, building prompts into the care pathways and routines e.g. sequential weight mapping, questions about appetite and social routines, may go some way towards identifying issues and ensuring nutritional care is on the agenda.

9.7 Delivering patient-centred care

In my research, lack of concordance led to loss of trust and confidence. In the study by Chandwani, 2017, discordance between patients' reporting of the severity of symptoms and that of the clinicians, arose due to an underestimation of impact by the clinicians of the symptom on the patient. This has implications for those who are palliative if referrals to other services such as dietitians is based on a Clinician's own judgement of symptom severity and the clinician underestimates the impact. Given the literature identifying the low level of attention paid to nutrition by Oncologists, if a patient is having diet-related issues and raises it with the Oncologist but they underestimate the impact then a referral to dietetic services may not be made or information not provided. This might explain the lack of response, notable in the acute sector in providing dietary advice when patients or carers raised they, or their partner, was having problems.

Whilst it may be difficult to say that earlier dietetic advice would have made a difference if a clinician had acted and referred earlier, evidence in the case studies of the impact of a dietitian or palliative care professional once they got involved was evident amongst several patient and carer participants.

Although NICE guidance (2004) recommends that dietitians should be part of the MDT in palliative care the number of dietitians working in palliative care remains low (Pinto et al. 2016) and posts are not consistently present across the UK (Hospice UK survey). Access to the skills of a dietitian were considered of value in this study. Promoting the role of the dietitian through research and audit and service evaluation may result in the creation of more posts in Hospice settings and palliative care teams.

The discrepancies apparent for a patient on a texture modified diet, evident from the dietitian's interview, and the lack of belief by nursing staff of the patient's lived experience, emphasises the need for professionals to come together when either the evidence is absent, or knowledge is limited to ensure that patients and carers are not left confused and feeling not listened to.

The patient experience in this study along with commentary from the dietitian illustrated the importance of managing swallowing problems appropriately to maximise patient choice and optimise the oral eating experience. My own knowledge and observations of patients with dysphagia (swallowing difficulties) arising from a physical obstruction or mechanical issues, suggests this should be handled differently in some respects to swallowing problems that arise from a neurological issue. In this research, it was apparent that information given to the patient and carer was not only limited and confusing but did not incorporate ideas on transitional foods which could have enhanced the patient's eating experience by allowing solids that converted to a paste in the mouth on chewing and that could then be safely swallowed. The new International Descriptors for texture modified diets (IDDSI, 2016) has since been launched and if this is routinely embedded into practice, and the resources that support it reach the patients and carers, one hopes this will improve the patient experience.

Not making time to listen, nor actively listening misses cues that indicate the need for symptom resolution or the alleviation of distress symptoms or information needs amongst patients and their carers pertinent information. As this research demonstrated this can then lead to tensions and a breakdown in trust between patients, carers and HCPs.

Failure to hear what matters to patients and carers not only conveys a lack of respect, it may also result in unnecessary interventions This was evident in the patient narratives when patients expressed concerns about diet and these appeared to go unheeded, unanswered, their experience contradicted the relationship with the HCP broke down. Although I was unable to witness this first hand and only heard the patient and carers narratives, several cases reported this.

Allowing time and listening to the patient experience would enable HCPs to establish what the patients know and subsequently build on their knowledge and needs and not undermine it. By allowing the patient and carer to explain what they know and understand allows the HCP to fill the gaps and sensitively address or put into context misunderstandings and misconceptions. Where patients and carers held specific beliefs or in sharing their experience this was met with disbelief because it did not seemingly ‘fit the box’, their position was undermined. In turn this broke down the trust between the HCP, patient and carer. This observation highlights the need for HCPs to accept that patients and carers are living the experience and their views may differ from our own. Rather than prejudge such situations which risks misdirection of care, we should endeavour to understand what our patient’s belief is based upon, ascertain whether harm or benefit may be incurred (seeking advice from experts if our own knowledge is insufficient) and gently advising them otherwise if their belief or actions are thought to be potentially harmful. This research illustrated that it is not in their interest to contradict them as it may fuel the distance between ourselves and the patient and carer, and is likely to create unnecessary hierarchies, tensions and erode trust.

What was evident in the palliative care setting was that when HCPs acted with humility, respected the patient and carer experience it was more likely that all involved joined forces, built trust and broke down unhelpful barriers and hierarchies.

In an attempt to move away from paternalistic style medicine, patient choice and autonomy have gained leverage amongst healthcare circles. Patient-centred care as it has become increasingly referred to, differs from the more historical approach where the doctor ‘knows best’, in which patients were less likely to question decisions made. Patient-centred care can be open to critique for how a patient can experiencing a disease for the first time be expected to make choices on treatment in comparison to a practitioner with many years of knowledge, training and expertise. In this study all patients and all carers developed expertise to manage some if not all of the diet-related issues. What seems important from the patients and carers perspective is that it takes time to acquire knowledge and patients and carers need supporting during that time, that acquired knowledge should be respected and that knowledge from the HCP can be added to further empower patients and carers to take control if that is their desire. As was evident from patients and carers in this study, there was mixed views and experiences with patients and carers not feeling ‘heard’ nor ‘listened to’, whilst other HCPs embraced what they could learn through listening to the patient experience, showing humility in doing so. With co-partner working being promoted in healthcare all HCPs should ensure that they listen to patients and carers not only for the purpose of acknowledging the patient experience and avoiding undermining them but also striking a balance to ensure their information needs are met when they arise and are not ignored. This was true for the patient who became an expert in managing his tube feeding but this did not happen quickly, required many sessions on the journey and some negative experiences.

Family members are often integral to the lived experience of any chronic disease (Goldenberg & Goldenberg, 2007, Dunn, 2010) and due to inter-relationships between diet and social interactions, it would be inappropriate to consider the patient in isolation when considering nutrition and diet, unless it was the patient's wishes. Discussions with both patient and partners within this multiple case study approach gave insights into the family circumstances and how care could be adapted to suit the family. The carers' experience was of considerable importance and highlighted the need to ensure, with the patient's permission, that the knowledge and understanding of those caring for individuals with a palliative condition are addressed to facilitate adaptation, for example when family meals are disrupted, and dietary modifications are necessary. It was apparent that openness within the family with regard to the diagnosis and disease trajectory, and sharing issues around eating and drinking, helped patients to cope. This may of course not be applicable for all patients and families.

It is disappointing in an era of 'patient-centred' care that staff did not heed the patient experience at times and based their advice on a set of assumptions of how one might react to treatment, what foods one might or might not be able to swallow. As highlighted by several staff, patients and carers provide us with valuable insights into self-created strategies and being receptive to them provides the opportunity to learn not only about the experience but what ideas they have in relation to managing the issues.

Some patients and carers identified their own solutions but this was more in the absence of advice rather than choice. With the dynamic nature of some of the issues experienced in palliative care, it would be difficult and unrealistic to expect patients and carers to have all the answers themselves when faced with diet-related issues. If, however, we are to build trust in our relationships to manage the situation, rather than the notion of self-management and self-directed care, we should ensure that patients are engaged in the process and where possible reduce the demands on the healthcare system. Surprisingly despite the emotional challenges of being palliative, patients did demonstrate a desire to 'self-care' and 'self-direct' care, some more than others.

Creating authentic, patient-centred care has been a focus within our healthcare systems for the past decade. Best practice guidelines can be created to facilitate care and indeed I have participated and led on such initiatives to improve care. The weakness with guidance and pathways is they fail to address the complexity which may be true for diet and palliative care particularly where psychosocial issues take precedence over nutrient provision.

In undertaking this qualitative research, I felt my listening skills were enhanced which in turn assisted my development as a practitioner to deliver patient-centred care. Fuelled through my growth and confidence in working in palliative care I have become an avid promoter of the philosophy and principles of palliative care. I believe that a broad range of healthcare services could benefit from the philosophy, which relies on ‘impeccable assessment’ and engagement and hearing the patients voice to create the care that would alleviate issues that were perceived to be the most bothersome to patients and carers. Such an approach has the potential to reduce the number of episodes of care where care fails to deliver patient expectations due to our focus on what mattered to us as practitioners rather than what mattered to our patients and carers.

9.8 Skills and knowledge

Whilst enthusiasm for nutrition amongst the HCPs was evident, skills to assess and create solutions to manage diet-related issues continues to rely on adequate training and knowledge and requires resources that can be tailored to the individual. This has implications for the training of HCPs. Attempts to improve knowledge and awareness in the hospice setting were evident from the courses available which were also shared externally with other HCPs from other care settings such as care homes. Attempts to improve the profile and knowledge of nutrition in palliative care was evident across all settings including the two hospital through concerted efforts of dietitians, nurses and nutrition champions. Awareness is a pre-requisite for diet-related issues to be recognised, there is therefore good reason to embed nutrition in the curriculum of all HCPs, especially as diet-related issues are a factor in both disease prevention and disease management.

With increasing complexity of patients, knowledge and understanding was a key theme that emerged throughout all accounts by all participants. Close observation and tailoring of nutritional care to specifically take into account the individual patient and carer experience featured strongly in the hospice environment perhaps due to more time being allocated to discuss patient and carer concerns. In the acute setting perhaps as a result of time pressures, less experienced staff, a focus on routines and ‘standardisation’ of care, information and advice on nutrition was less individualised. Although the patient and carer developed expert knowledge of tube feeding, swallowing difficulties and dietary needs, their experience was at times not acknowledged and even refuted and contradicted by some staff they came into contact with. This in turn served to undermine the patient and carer-clinician relationship

Supporting those with life threatening illness and end of life care and creating a culture and environment that supports exploration of issues is not easy to achieve (Schwartz et al, ASPEN 2016). HCPs in this study illustrated their capabilities in drawing out what was important to patients and carers using advanced communication skills that could be treated through probing. What was evident from the interviews and analysis was that HCPs in palliative care, in a variety of positions, seniority, generalist and specialist, probed and questioned in a sensitive manner to drill down to what lay at the heart of the issues for patients and family members and carers. An advanced communication skills course was found to be available to all staff in the Hospice setting. HCPs listened to and acted on their reflected lack of knowledge to create new knowledge, confidence to identity and probe for nutritional issues arose.

Discussions about the options for dietary modification, adjustment of meal patterns, managing the sense of loss when not able to eat and being familiar with all tube feeding methods, with ample time for patients and family members to gain an understanding, helped the patient and family work towards decisions that ease the challenges faced and allow individuals to regain control and regain a sense of purpose in relation to meal preparation and provision.

It is evident that to successfully manage the realities of a progressive condition, one needed strike a balance between proactive and reactive coping and at times patients and carers oscillated between the two. The adoption of both reactive and proactive coping strategies has the capacity to enable the patient and carer to effectively accept and, in some respects, embrace the daily realities. The palliative care team illustrated how they facilitated the development of effective coping strategies by learning from the patient and carer experience and encouraging self-management through adequate support and the provision of timely information and services. This seems paramount for an individual's sense of well-being and yet in the acute sector, with a focus on treatment, it seemed overlooked.

Lack of interest amongst Oncologists was apparent in the patient experience in this study. De Souza et al (2015) referred to lack of nutrition in medical curriculum being a root cause. Similarly lack of nutrition in nursing curriculum has also been cited as an issue in dealing with today's healthcare issues and supporting patients to make dietary changes that benefit their situation. Moves to address this are beginning to emerge. Improving nutritional input into medical curriculums to create doctors of the future, who acknowledge the role of nutrition, and the relevance to patient care and the patient / carer experience is a key recommendation.

It was evident from the hospice nurse and the interview with the dietitian that their professional knowledge was strongly influenced by experience in practice. This reflects the importance of the workplace as an environment to support learning and highlights the need to ensure that knowledge can be gained early on in clinical posts so that lack of experience does not hamper best care for the patient. Case studies, mentoring, shadowing, in-house training, and the patient / carer experience all played a role in enhancing knowledge. Perhaps paying more attention to, and including experiential knowing within learning environments, a key component of healthcare education emphasised by Eraut (2000, 2004, 2007) may help to create a greater balance between scientific, clinical and technological knowledge.

All except one of the HCPs interviewed had worked in both the acute and primary care settings before moving into palliative care later in their careers. This might represent a natural progression as palliative patients often present with a multitude of problems which relies on experience to deal with. Experience of working in the community setting, for example district nursing, community home enteral feeding, rehabilitation, appeared to bring confidence to the role in palliative care for all professionals and all participants spoke of the positive benefit of having worked in other settings before moving to palliative care. This does question how one might gain that experience without years of training and as yet there appears limited opportunities for specialist training in palliative care including in dietetics.

In 1997, Seely and colleagues highlighted that the complex nature of palliative medicine warranted the need for specialist training. Often confronted with patients with 'multiple diseases, complex symptoms and syndromes' Seely argued that meticulous attention to the patient and treatment is required to deliver the best care and that exceptional communication skills are crucial to be able to respond to all the needs of the patient and the family; psychological, spiritual and physical.

In a similar vein, Schroeder 2018 emphasised that nurses involved in palliative care face the challenge of combining the art of caring and the science of medicine into a cohesive model that reflects compassionate, individualised care regardless of the environment. With the palliative care team now comprising a more diverse range of professionals, all HCPs involved in delivering palliative care, face similar demands. Hence it would be logical to assume that essential skills cited by Schroeder for nurses are also required by other professionals.

Currently, there is no standard education for palliative care allied healthcare professionals or nurses. Competency frameworks for a range of healthcare professionals are beginning to emerge, a recent example being the Irish competency framework https://aiihpc.org/wp-content/uploads/2015/02/Palliative-Care-Competence-Framework.pdf. To achieve quality in care provision healthcare workers need to possess appropriate competencies. The Palliative Care Competence Framework wad developed in Ireland as a valuable tool in supporting staff to achieve this goal. The competence framework aims to guide continuing professional development to identify training needs and foster competences where required, in the Hospice setting where this study took place it was introduced as a framework to guide continuous professional development amongst practitioners, as I completed this thesis.

In practice this study showed that many of the HCPs drew upon years of experience to deliver what they felt to be the best care, tailored to the individual. All of the palliative HCPs interviewed demonstrated cross-working with other disciplines both within the organisation and outside the organisation with other care provider.

In light of the broad range of issues experienced across the cases, it is likely that HCPs will continue to require a wide variety of education, training, and clinical experience. In this study, HCPs with palliative care experience illustrated that they were capable of adjusting their frame of mind from one which revolves around cure to one that focusses on patient and carer needs in whom issues and requirements oscillated over time. As diet-related issues were social, physical, psychological and influenced by cancer including treatments, the complexity was not to be underestimated. Issues were often bound up together such as diarrhoea or other symptoms, impacting on the ability to eat and inducing fear associated with eating. Advanced skills of communication were important to tease out the inter-relationship between symptoms and diet and the social experience which was not always obvious. Addressing what mattered and what could be done required motivation and a desire to explore the issues through conversations to be able to advise on solutions and potentially make a difference to the patient's and carer's experience.

With increasing numbers of patients living with and beyond cancer, including those with incurable cancer, there will be an increase in the number of requests for advice (MacMillan 2019). The need for sound, evidence-based professional knowledge and resources to assist patients in dealing with the complex issues and tailoring advice to specific needs is therefore paramount.

9.9 Self-management

In a financially stretched health service, the importance of self-management and the expert patient has gained greater momentum to facilitate meeting additional and growing demands of an ageing population with multi-morbidities. Lord Darzi has been a strong advocate for patient-centred care, self-management and cohesive partnerships within the professional team in long-term conditions (Darzi - King's Fund, 2008 and Health Care Foundation, 2015). The case studies exemplified how these elements are important in achieving a positive patient and carer experience whilst not abandoning the patient nor providing insufficient information. When time permitted, as elucidated by the patients as recipients of care in the hospice, communication and decision making for both the patient and carer improved and enabled the patient to better care for themselves or adapt to cope. It was evident when patients and carers reached a stage where enhanced knowledge, acceptance and adaptation to the realities of the condition were achieved and they could engage in everyday life to more clearly meet their expectations. What was evident with the changing nature of issues patient and carers developed, was the need to ensure HCPs possess the expertise to manage diet according to symptoms at a point in time, which requires adjustment and advice on how to adapt again when symptoms change. This has implications for the management of diet-related issues, including the information and the advice offered to support patients and carers. If we are to facilitate coping and adjustments to a new norm, this finding emphasises the need for follow up and ongoing vigilance by members of the healthcare team.

In an attempt to move away from paternalistic style medicine, patient choice and autonomy have increasingly gained leverage amongst both academic and healthcare circles. This differs from the more historical approach where the doctor knows best and patients were less likely to question decisions made by the healthcare team. This view of care though can perhaps be prone to critique, for how can a patient experiencing a disease, be expected to make choices on treatment in comparison to a practitioner with many years of knowledge, training and expertise. Rather the notion of self-management should be directed to ensure that patients are engaged in the process and where possible reduce the demands on the healthcare system. Much of this work is in the field of diabetes where the intention is for the patient to remain well but how does this approach affect the patient who is end of life, has a palliative condition and who may be imminently facing death? Surprisingly despite the emotional challenges of being 'terminal' patients did demonstrate a desire to 'self-care' and 'self-direct' care. Taking control can be perceived as a threat to the relationships with the healthcare practitioners who in some cases may wish to maintain their status in decision making (Walton, 2002). This was not observed amongst the HCPs participating in this study, if anything self-care and independence were embraced. However, patients did refer to experiences with HCPs they came into contact with who were failed to heed the request for information and advice pertaining to nutrition and at times referred to a feeling of this expressed need being dismissed.

9.10 Bespoke patient and carer resources

Confusion arising from the 'smattering of information' about diet and cancer and lack of tailored information to deal with specific problems or provide information on specific cancer types and likely problems and solutions would go a considerable way towards avoiding patients and their carers languishing with symptoms

Lack of information, lack of choice and lack of access to information or advice resulted in the development of a multitude of patient resources in the hospice setting during the period this research took place. Recognising the value of patient/carer involvement, two participants in this study (a patient and a carer) helped to co-create some of the resources. As access to information was identified as a barrier, patient -carer portals, similar to the malnutrition pathway material developed off the back of my PD Health assignment (www.malnutritionpathway.co.uk) might facilitate access in the future.

Information is reported to be a key component in developing coping strategies (Blodt et al., BMJ 2018) and hence it is crucial that if we are to support patients and carers then accurate information on managing the dietary challenges is required. Knowledge and understanding was a key theme that emerged throughout all accounts by all participants. Close observation and tailoring of nutritional care to specifically take into account the individual patient and carer experience featured strongly in the hospice environment perhaps due to more time being allocated to discuss patient and carer concerns. In the acute setting perhaps as a result of time pressures, less experienced staff, a focus on routines and 'standardisation' of care, information and advice on nutrition was less individualised. Although there were examples of patients and carers who developed expert knowledge of tube feeding, swallowing difficulties and dietary needs, their experience was at times not acknowledged and even refuted and contradicted by some staff they came into contact with. This in turn served to undermine the patient and carer-clinician relationship. With the limited number of dietetic posts in palliative care and cancer care (Pinto et al. 2016), patients are often given general information booklets that can cover many cancer types and all the nutritional issues that one can experience. This can fail to provide bespoke and individualised dietary advice necessary for a patient to best manage their condition. Reflection on the patient experience and taking note of what patients can or cannot manage or find acceptable could encourage professionals to treat patients as individuals rather than treating in a standard format specific to a specific disease group. Understanding family dynamics around work and meal patterns, shopping and cooking, would also ensure the most appropriate care is provided. What was also requested by patients was information that was cancer specific, for example information on diet-related issues that were likely to arise with head and neck cancer rather than issues across all cancer types. This was also a finding in the European cancer survey amongst patients and carers (European Nutrition and Hydration Alliance, 2018).

With increasing numbers of patients living with and beyond cancer, including those with incurable cancer, there will be an increase in the number of requests for advice. The need for sound, evidence-based professional knowledge and resources to assist patients in dealing with the complex issues and tailoring advice to specific needs is therefore paramount. The increasing numbers in a financially stretched health service further accentuate the importance of self-management and the expert patient. When time permitted, as elucidated by the patient as a recipient of care in the hospice, communication and decision making for both patients and carers improved and enabled the patient to better care for themself. It was evident that patients reached a stage where with enhanced knowledge they accepted and adapted to the realities of the condition and were then able to engage more fully in everyday life.

In recent years there has been trend in the UK, supported by government targets, funding and national drivers via organisations such as MacMillan to deliver patient education sessions on living well with cancer. This has in part been created as the number of individuals surviving and living with a cancer diagnosis has markedly increased in the last two decades. The courses incorporate a component on diet the primary focus of which is consuming a balanced diet. The relevance of the content may as such be limited in a diverse population of patients suffering from different cancer types and having undergone a range of treatments which may have impacted on the ability to consume diet and which can persist.

The adoption of both proactive and reactive coping strategies, actively seeking information and developing solutions assisted in establishing a sense of control when loss of normal function around eating and drinking was present. An effort to retain a sense of normality was evident, for example in David’s case this included the rejection of pureed foods, the success in tailoring of feeds around mealtimes and sitting at the table to enjoy even a mouthful. The indiscrepancies on texture modified dietary advice between professions highlighted in David's dietitian's interview, emphasises the need for professionals to come together to agree a consensus when multiple professionals have a part to play in delivering care. Key for the patient and carer and the hospice staff was the sharing of a realistic understanding of the condition so that care could be tailored around what was possible to maximise quality of life. Central to this was the associated integration and interactions around food and meals, maintaining some degree of normality by modifying feeding methods, sham eating, even enjoying just a few mouthfuls of 'normal' food. In the hospice setting the nurse felt she tailored care to the individual without barriers because practice was less restrictive. Perhaps in the future the principles of palliative care and its philosophy will find its way into the acute setting so that patients might benefit and feel more involved in their own care.

9.11 Reframing food and the eating experience

Even in the presence of multiple diet-related issues including abolished appetite and a distorted food experience, participants showed a determination to eat to maintain weight, function and survive. In all cases carers helped support this seeking new foods or new ways of eating to maintain socialisation, integration, weight and function. This conscious control of eating has previously been cited in the work by Shragge et al. (2007) and has also formed the basis of a new approach to managing nutrition in head and cancer patients (Britton and McCarter, 2015).

Up until the last decade the focus in palliative care has been on the importance of eating for pleasure with less emphasis on eating to preserve nutritional status. There has also been limited information on the role of dietary modifications and its impact on symptom management. Considerable progress has been made in the last 10 years on managing gastrointestinal related issues associated with cancer treatments albeit, as commented on by Andreyev et al. (2011) they may persist unnecessarily as no HCP is responsible to look for the side-effects which go unnoticed and underdiagnosed. Actions to try and change this have been raised by MacMillan to ensure care of those living with cancer have access to follow up with named GPs who know the history and might consider whether new symptoms are due to cancer, recurrence, secondaries or adverse effects of former treatments.

Despite a former emphasis on food being tied in with pleasure, family routines, social interactions and enjoyment, food took on a new meaning for some. Faced with difficulties being unable to eat anything with ease and not having to worry about unintentional weight gain in health, several patients in this study demonstrated that food and nutrition was not confined to comfort but that they would go to considerable measures to improve their intake to maintain physicality and function. Food therefore became a source of nutrients, a means of keeping them connected with the outside and normal world through maintenance of strength. This introduces the concept of eating for survivorship even when the patients accepted their condition was palliative. For many participants – patients, carers and HCPs - there was a strong desire to acquire knowledge on nutrients required and how to achieve an optimum intake when faced with diet-related issues. For many a greater understanding of nutrition and nutrients and relationship with symptoms, could empower individuals to adjust food, including tube feeds, to manage bowels, weight, co-existing conditions such as diabetes, thereby creating greater control and management by the individual if that is their wish.

Concluding remarks

Overall, food oscillated from providing nutrition purely for survival, to a vehicle for enjoyment. What was evident from this research is that diet in palliative care is complex, as are the needs of patients and carers. Diet-related issues are rarely singular in nature and far from static, they vary considerably and change over time. For HCPs to deal with them effectively requires a range of skills, one of which is a desire and motivation to understand and be receptive of the changed meaning of food. In understanding this we can begin to work with patients and carers to help them deal with the challenging dietary situations associated with incurable cancer and work with them to achieve the adjustments necessary for them to live life to the full.

This discussion is intended to capture my personal insights into some of the key elements that arose from the analysis and interpretation of the cases. In the next chapter I draw my thesis to conclusion.

Chapter 10

Concluding chapter

In this final chapter I draw my conclusions, present the limitations of the study, discuss the implications of this study for clinical practice and make suggestions for further research.

10.1 Conclusion and summary of thesis

This research and all the associated work during my years of studying for a professional doctorate, has identified the impact of diet-related issues in palliative care, identified a range of strategies from my own knowledge and experience, the knowledge and experience of practitioners and the knowledge and lived experience of the patients and carers with whom I have worked with and who participated in this study. The findings ultimately demonstrate that resilience, coping, adaptation, adjustment are used in combination to maintain identity and life experiences and support change when needed.

I believe the multiple case study approach illustrated the challenges in delivering multimodality treatments and supportive care to optimise nutritional care in the palliative phase of illness, supporting both patients and carers and family members.

In the textbook ‘Palliative Care’, Geoffrey Dunn, Chapter 4 ‘Diet and palliative care’ page 49 stated ‘the greatest clinical challenge for all practitioners are almost always related to nutrition’. Although challenging, this research has demonstrated that steps can be taken to facilitate acceptance, identify areas of adjustment and assist all involved in managing the nutrition and diet-related issues on a day-to-day basis. It is evident though, that this takes time, knowledge, an openness and most of all active listening so that solutions are geared to guide adjustments that are centred around the patient’s wishes and desires.

In palliative care, the importance of listening to the patient experience, not dismissing history and experience, and moving towards achieving realistic and collaborative goals, can generate a mutually beneficial affiliation in which patient and family members and healthcare professionals can freely communicate. The importance of understanding and gaining insight into routines at home, what is important to patients and family members, not making assumptions on behalf of the patient regarding preferences, developing a care plan that is truly patient-centred, embracing patient involvement and helping patients and carers with decision making by anticipating the impact of decisions on life-style and burden of care, are all crucial factors in determining the lived experience for both the patient and family

The complexity of patient and carer needs is only beginning to be recognised (Greenhalgh and Papoutsi, 2018). Thus research illustrated the complex nature of nutrition in palliative care and how dietary issues can be fluid, dynamic and influenced by a multitude of factors that may be precipitated by the disease and the treatment at varying points during cancer treatment and into the palliative phase of care when the cancer is not curable. As the patients experienced the nutrition and diet-related issues across the trajectory of care it is important to initiate care in a timely manner to optimise food-related activities and manage symptoms and weight accordingly. This research shows that diet-related issues including weight loss, rarely arise in an instant in time but can appear, resolve or become worse across the trajectory of palliative journey. This means that HCPs need to remain vigilant through the patient’s journey if we are to assess and treat, or manage the issues, and support patients and carers in a timely manner across the continuum of care.

With gaps identified in addressing issues including overlooking the inter-relationship between symptoms and dietary intake and the importance of diet to patients and carers, greater collaboration amongst surgeons, oncologists, nursing teams, allied healthcare professionals and patients and carers is indicated. The Forsyth report (2007) highlighted the complexity of obesity, its development and management. This research and previous research by others are beginning to map the complexity of nutrition and diet-related challenges with different cancer types. One size cannot fit all. A more bespoke approach to nutrition, involving access to those with expert knowledge will be key to improving the nutrition and diet-related experience of palliative patients in the future.

The adoption of both proactive and reactive coping strategies, actively seeking information and developing solutions, assisted in establishing a sense of control when loss of normal function around eating and drinking was present. In these situations, the value of information and an enhanced understanding of the underlying reasons for the issues, seemed to assist patients and carers in accepting the issues. Similar to a study by Blodt et al (2018) this suggests that information itself can help to provide a feeling of control and ease anxiety. As information needs differed over the course of disease and patients and carers expressed a wish for tailored, individualised advice, this means the information on diet-related issues, is best provided around the time it occurs and not in a generic booklet to cover all.

An effort to retain a sense of normality was evident. Key for patients and carers and the hospice staff was the sharing of a realistic understanding of the condition so that care could be tailored care around what was possible to maximise quality of life. This often centred on integration around food and meals and associated interactions, maintaining some degree of normality by modifying feeding methods, sham eating, enjoying a few mouthfuls of food, the rejection of pureed foods, the tailoring of feeds around meal-times, sitting at the table to enjoy even a mouthful, afternoon tea, buffets etc (adjust) . In the hospice setting the HCPs tailored care to the individual without barriers, practice was less restrictive.

Perhaps in the future the principles of palliative care and its philosophy will find its way into the acute setting so that patients might benefit and feel more involved in their own care. Considerations as to how this might be achieved through integrating palliative care into the training und undergraduate curriculum warrants attention. It is reassuring to observe that actions to achieve this is beginning to emerge in some localities for some professions (personal experience and information from the Chartered Society of Physiotherapists).

HCPs should aim to facilitate the development of knowledge with any patient or carer who wishes to expand their understanding of the diet and nutrition challenges they face and how they might best deal with them. Similarly, the duality of knowledge between patient and carer should be respected and the desire for individualised information must never be assumed nor overlooked. Overall there was evidence gleaned from the patient and carer experience, that at times practical solutions to deal with diet-related issues that impact on day to day life were overlooked. This has implications for training and enhancement of knowledge for HCP specialists and generalists. As it was evident that patients and carers learn much from their experience, opportunities exist for patients and carers to be more involved in developing the learning and future information that could improve care and indeed as a result of this research I have since involved patients and carers in many resources I seek to develop.

Case studies, mentoring, patient interactions, the quest for lifelong learning, open ward-based discussions and reflection on practice, access to dietetic expertise and those with nutrition knowledge, could help facilitate the likelihood of offering the right advice.

To optimise nutritional care the holistic assessment of the patients following diagnosis should incorporate ongoing assessment of nutrition and dietary issues. Whilst treatment is often centred in the acute setting, community support and services are vital for continuity and useful in gaining a window into the world of patients and carers. Indeed, delivering care in settings closer to the patient’s home would realise the ambition and vision in the NHS England Ten Year Plan (NHS 2019)

The pace of life in a hospice out-patient setting and the time allocated to supporting patients, including patient to patient contact, were of merit. It would be interesting to test if elements of hospice care could be mirrored in an acute setting or other community care settings.

Decisions regarding dietary advice in advanced cancer patients are clearly dependent on a host of issues. This research suggests that effective identification requires an in-depth assessment which may be best undertaken through nutrition conversations, rather than a brief screening tool. Such conversations may not only identify the issues but also facilitate an understanding by HCPs of the impact and severity of issues on everyday living as experienced by the patients, carers and family members.

On a personal level, I learned much from the cases which enabled me to enhance the dietetic care I provide. I have also sought to transfer this knowledge to others not just from the pages of writing within this thesis but in new courses we have created to train others; HCPs, carers and patients in palliative care and in the review of cases in team meetings.

The views of patients, carers and HCPs, on the management of the issues, successes, barriers, what worked what didn't, have provided an additional understanding and added meaning to our knowledge.

Capturing the experiences of the participants that they experienced over months and in some cases years, through qualitative interviews provided the opportunity to understand all the significant actors, what advice might be effective and where the gaps in our service provision currently exist.

Data from the patients and carers reflected the unique aspects of individual's drive which in turn initiated their own actions including acceptance and adaptation. Patient and carers employed cognitive adaptation through a greater understanding and acquisition of knowledge to develop strategies and adjustments to recreate the meal experience and enable social situations to be maintained, or create new approaches to maintain activities with the outside world.

Previous literature has indicated that clinicians tend to focus on the disease and its treatment and management. In contrast patients focus on the effect of the cancer on their everyday living (Dwamena, 2012). Although this rang true for the participants in this study, they equally demonstrated concerns about the effect of the treatment and response to treatment such as tumour size.

Managing tensions between feeling torn about the need to eat healthy because of cancer and the inability to do so have previously been raised (Bernhardson et al, 2012, Hopkinson et al 2006, 2010, 2019). In my own research, patients and carers rationally weighed up the diet considered to be of greatest benefit at various timepoints according to the issues faced.

Diet-related issues in palliative care are complex and for HCPs to deal with them effectively a range of skills are required including a desire and motivation to understand and be receptive to the patient's desires and the carer's frustrations.

Understanding the changed meaning of food but also the desire to maintain a degree of normality around eating and drinking should underpin our approaches. In doing this we can begin to work with patients and carers to help them deal with the challenging dietary situations associated with incurable cancer and work with them to achieve the adjustments necessary for them to live life to the full.

The impact of this research has already found its way into practice through the following channels:

(i) a revised programme for training and education in palliative care at the Hospice (offered to internal and external HCPs

(ii) new national resources for patients on aspects of tube feeding (https://www.peng.org.uk/pdfs/hcp-resources/enteral-tube-feeding-your-questions-answered.pdf and https://www.peng.org.uk/pdfs/hcp-resources/having-an-enteral-feeding-tube-faqs.pdf)

(iii) a new chapter in the updated version of the Royal College of Physicians guide (2020) 'Oral feeding difficulties and dilemmas at the end of life' (in press)

(iv) presentations and posters delivered at conferences and clinical meetings.

A summary of the outputs, including publications and presentations associated with this thesis, is included in the appendices (appendix 12, pages 202 - 203)

10.2 Limitations of the study

The multiple case study approach was chosen to provide the depth of understanding and insights into the phenomena to answer the research questions ensuring all involved were represented – patient, carers, HCPs. I had intended through using thematic analysis to create succinct themes. However, as the issues identified were so broad ranging I am aware that the data does not fit neatly into a small number of themed categories and potentially overlap. I hope through the assemblance and presentation of the data the key categories and areas of interest are identifiable and understandable.

I am conscious that all the participants were Caucasian and whilst this reflects the local population where the study took place, it is not representative of the UK. Diverse cultural aspects that we know influence diet were therefore not addressed.

I am also aware that cancer has traditionally received more attention from specialist palliative care services. Hospices are however changing their remit and non-cancer patients now make up a considerable component of their client base. Whilst this study only included cancer patients and introducing other conditions would have lost the focus, many of the findings may be transferable to other life-limiting conditions where similar diet-related issues exist. In addition, one could argue that listening skills, nutrition conversations and education on nutrition are generalisable to other areas of healthcare and relevant to both acute and community settings

Overall, I felt the research process itself enriched my practice as a clinician. The qualitative interviews taught me to be patient, to listen and observe, to not interject, to not interrupt and to be guided by the participant. The process enhanced my skills in listening carefully to the concerns of patients and carers to what was important to them in the palliative care phase. This skill has transformed my approach in the clinical setting since but also the approach of others through training others in clinical skills and listening skills. To share this experience with others I went on to publish a short summary of the role of qualitative research in enhancing clinical practice (Holdoway, 2017, appendix 13, page 204).

10.3 Next steps: Developing a national framework to guide assessment of diet-related issues and plan nutritional care

The next steps planned are to utilise the findings and build on the locally developed tool ‘PLANC’, to create an assessment tool and framework to identify issues, guide decision-making and support dietetic care of palliative patients. Initial mapping for this is included in the appendices (appendix 14, pages 205 - 207). This could be further developed in conjunction with other experts in the field using a Delphi technique to shape and agree content and test in practice.

Once tested through a pilot study, this could be rolled out nationally to other Hospices and palliative services to help HCPs identify diet-related issues pertinent to patient and carers and plan care. The framework would aim to capture the intricate nature of diet in relation to symptoms, dietary needs, the cancer type, whether issues are reversible or have to be managed, set realistic goals for weight, take into account the disease trajectory and further refine the work undertaken in the hospice in this field. The framework could also be supported by an educational element which at current is provided by face to face training but could be provided in other formats.

In addition, the following three papers will be pursued to disseminate and share the unique contribution of this doctorate research:

I. The complexity of diet-related issues as experienced by patients with incurable cancer and their families receiving palliative care
II. The importance of nutrition conversations in identifying what nutrition and diet-related issues matter to patients and carers
III. Strategies adopted to alleviate or manage diet-related issues in palliative care

10.4 Future research

Research is never complete and this thesis has inspired ideas for future research which could focus on the following aspects of nutrition in palliative care:

1. evaluating knowledge and competencies of healthcare professionals following training and education on the role of nutrition and dietary advice in palliative and end of life care
2. a study to assess patient / carer knowledge and quality of life in care settings where the framework has been adopted
3. evaluating service provision in various regions, identifying similar models of care and contrasting care to measure differences in outcomes in respect to the patient and carer experiences.

References:

Aapro, M., Arends, J., Bozzetti, F., Fearon, K. et al. (2014) Early recognition of malnutrition and cachexia in the cancer patients: a position paper of a European School of Oncology Task Force. Annals of Oncology **25**, 1492-1499

Academy of Nutrition and Dietetics Oncology Expert Work Group (2013): Nutrition and the Adult Oncology Patient. Chicago, Ill: Academy of Nutrition and Dietetics Evidence Analysis Library.

Acreman, S. (2009) Nutrition in Pall Care Br J Community Nursing

Ahmad, AS., Ormiston-Smith, N. & Sasieni PD. (2015). Trends in the lifetime risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960., British Journal of Cancer **112**: 943–947

Al-Shahri, MZ., Eldali, AM., Al-Zahrani, O. (2012) Prevalence and severity of suffering among patients with advanced cancer. Support Care Cancer; **20** (12), 3137–3140

Amano, K., Baracos. V. and Hopkinson, J. (2019). Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. Critical Reviews in Oncology/Hematology 143: 117-123. (10.1016/j.critrevonc.2019.08.006)

American Association for Physician Leadership (2017) Improving the patient – physician relationship and healthcare itself through communication. A collaboration of the American Association for Physician Leadership® and The Beryl Institute https://cdn2.hubspot.net/hubfs/2735001/Whitepapers/WHITE%20PAPER%20—%20FINAL%20CRX.pdf Last accessed 10.02.2020

Andreyev, HJN., Davidson, SE. et al. (2011) Practice Guidance on the management of acute and gastrointestinal problems arising as a result of treatment for cancer GUT doi:10.1136/gutjnl-20111-300563

Arends, J., Bachmann, P., Baracos, V. et al. (2017) ESPEN guidelines on nutrition in cancer patients. Clin Nutr **36**, 11– 48

Argiles, JM., Busquets, S., Garcia-Martinez, M., Lopez-Soriano, FJ. (2005) Mediators involved in the cancer anorexia-cachexia syndrome: past, present and future. Nutrition **21** (9), 977-985

Aston, T. (2006) Nutrition in palliative care: effective or ineffective? Journal of Community Nursing. **20** (10), 41-44.

August, DA., Huhmann, M. (2014): Nutrition support of the cancer patient. In: Ross AC, Caballero B, Cousins RJ, et al., eds.: Modern Nutrition in Health and Disease. 11th ed. Philadelphia, Pa: Wolters Kluwer Health/Lippincott Williams & Wilkins, pp 1194-1213

Baguley BJ, Skinner TL, Leveritt MD, Wright ORL. Nutrition therapy with high intensity interval training to improve prostate cancer-related fatigue in men on androgen deprivation therapy: a study protocol BMC Cancer (2017) **17** (1) DOI 10.1186/s12885-016-3022-6 (accessed 24th February 2020)

Baile, WF., Palmer, JL., Bruera, E., et al. (2011) Assessment of palliative care cancer patients' most important concerns. Support Care Cancer. **19** (4), 475–481.

Baldwin, C., Weekes, E. (2009) Dietary advice for illness related malnutrition in adults. Cochrane database of Systematic Reviews Update 2011 http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD002008.pub4/pdf

Baldwin, C., Spiro, A., Ahern, R. et al. (2012).: Oral nutritional interventions in malnourished patients with cancer: a systematic review and meta-analysis. J Natl Cancer Inst **104** (5), 371-85

Bazzan, AJ., Newberg, AB., Cho, WC., Monti, DA. (2013) Diet and nutrition in cancer survivorship and palliative care. Evid Based Complement Alternative Medicine

Bernhardson, BM., Olson, K., Baracos, VE., Wismer, WV. (2012) Reframing eating during chemotherapy in cancer patients with chemosensory alterations European Journal of Oncology Nursing, **16** (5), 483-490

Blödt, S., Kaiser, M., Adam, Y., Adami, S et al. (2018) Understanding the role of health information in patients' experiences: secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany. BMJ Open 2018; 8: e019576. doi:10.1136/bmjopen-2017-019576

Boyatzis, RE. (1998). Transforming qualitative information: thematic analysis and code development. Sage.

Bozzetti, F. (2009) Screening the nutritional status in oncology: a preliminary report on 1,000 outpatients. Support Care Cancer **17**, 279–284

Bozzetti, F. (2015) The oncologist as coordinator of the nutritional approach Nutrition **31** 619-620

Bove, CF., Sobal, J., Rauschenbach, JS. (2003) Food choices among newly married couples: convergence, conflict, individualism, and projects Appetite **40** (1), 25-41

Bowling, A. (2002) Research methods in health; investigating health and health services Open University Press: Buckingham, UK

Braun, V & Clarke, V. (2006), Using thematic analysis in psychology. Qualitative Research in Psychology, **3**, 77-101.

Britton, B., McCarter, K., Baker, A., Wolfenden, L et al. (2015). Eating as Treatment (EAT) study protocol: a stepped-wedge, randomised controlled trial of a health behaviour change intervention provided by dietitians to improve nutrition in patients with head and neck cancer undergoing radiotherapy. BMJ open, **5** (7) https://doi.org/10.1136/bmjopen-2015-008921

Burnham D et al. (2010) Oral feeding difficulties and dilemmas in end of life care A working party report behalf of the Royal College of Physicians https://www.rcplondon.ac.uk/projects/outputs/oral-feeding-difficulties-and-dilemmas last accessed 24.02.2020

Bryman (2008) Social Research Methods (3rd edition) Oxford University Press

Brotherton, A., Abbott, J., Aggett, P. (2006) The impact of percutaneous gastrostomy feeding upon daily life in adults . Journal of human nutrition and dietetics **19** (5), 355-367

Brown. Oncol Nursing Forum (2002) **29**: 5 517-532

Butler, J., Chapman, S., Kendall, M., Martin, J., Murtagh, EM., Tate, T., Wee B. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives (2012) http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf Last accessed 4.12.2014

Bury, M (1982) Chronic illness as biographical disruption. Sociology of Health and Illness **4** (2), 167 - 182

Cameron, L and Levanthal, H. (2003) The self-regulation of health and illness behaviour. New York NY, Routledge

Cancer research UK (2020) https://www.cancerresearchuk.org/health-professional/cancer-statistics/cancer-stats-explained

Capra, S., Ferguson, M., Ried, K. (2001) Cancer: impact of nutrition intervention outcome—nutrition issues for patients. Nutrition, **17** (9), 769-772,

Caro, MM., Laviano, A. and Pichard, C. (2007) Impact of nutrition and quality of life during cancer. Curr Opinions Nutr Metab **10** (4), 480 -487

Cassel, EJ. (1982) The nature of suffering and the goals of medicine N Engl J Med 18; **306** (11), 639-45.

Chasen, MR. and Dippenaar, AP. (2008) Cancer nutrition and rehabilitation – its time has come! Current Oncology **15** (3), 117- 122

Charmas, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. Sociology of Health and Illness. **5** (2), 168-195

Coates, V. (2004) Qualitative research: a source of evidence to inform nursing practice? Journal of Diabetes Nursing, **8** (9), 329-334

Cooper, C., Burden, S., Cheng, H. and Molassiotis (2015) Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research J Cachexia Sarcopenia Muscle. **6** (1), 99–111.

Corben, JM. and Strauss, A. (1992) A nursing model for chronic illness management based upon the trajectory framework. In the Chronic Illness Trajectory Framework (Woog P. ed) Springer, New York, 9-28

Crotty, M. (2004) The Foundations of Social Research, Meanings and Perspective in the Research Process. Sage publications: London. Chapter 3, pp 42 - 65

Czerwinska, A., Holdoway, A., Renzie-Brett, H. (2013) Nurses attitudes towards 'MUST' and Nutrition screening in palliative care. BAPEN Annual Conference proceedings

Darzi, Lord in the King's Fund (2008) Background to the Next Stage Review https://www.kingsfund.org.uk/sites/default/files/background-lord-darzi-nhs-next-stage-review-kings-fund-june-2008_0.pdf Last accessed 16.2.2018

Dean, RA., McClement, SE. (2002) Palliative Care Research: methodological and ethical challenges. International Journal of Palliative Care Nursing **8** (8), 376-380

Dearnley, C. (2005) A reflection on the use of semi structured interviews Nurse Researcher **13** (1) 19-28

Dewey, A. and Dean, T. (2007) Assessment and monitoring of nutritional status in patients with advanced care: part 1 International Journal of Palliative Nursing **13** (6), 258-265

Deshayes, E., de Forges, HC., Fraisse, J., Eberle, MC. et al. (2018) Artificial nutrition in patients with cancer has no impact on tumour glucose metabolism: Results of the PETANC Study. Clinical Nutrition 1-6

Deshields, TL., Potter, P., Olsen, S., Jungxia, L. (2014) The persistence of symptom burden: symptom experience and quality of life of cancer patients across one year. Supportive Care in Cancer **22** (4) 1089- 96.

Dunn, G. (2010) Dealing with the difficult family: Lessons from palliative care. Bulletin of the American College of Students **95**, 16-19

Dyer, WG. and Wilkins, AL.(1991) Better stories, not better constructs, to generate better theory: a rejoinder to Eisenhardt. Academy of Management Review **16**: 613–619.

Ehrsson, YT., Sundberg, K., Laurell, G. & Langius-Eklöf, A. (2015). Head and neck cancer patients' perceptions of quality of life and how it is affected by the disease and enteral tube feeding during treatment. Upsala journal of medical sciences, 120 (4), 280–289

Elia, M. (2003) Screening for malnutrition: a multidisciplinary responsibility. Development and use of the “Malnutrition Universal Screening Tool” (‘MUST’) for adults. Redditch: BAPEN.

Eliot, JA. and Olver, IN. (2009) Hope, life and death – qualitative analysis of dying cancer patients’ talk. Soc Science and Med. **64** 138-149

Elliott, V. (2018) Thinking about the coding process in qualitative data analysis The Qualitiative Report **23**, 11 How to Article 5, 2850-2861

Eraut, M. (2000) Non-formal learning and tacit knowledge in professional work. British Journal of Educational Psychology, **70**, 113–136

Eraut, M. (2004) Informal learning in the workplace. Studies in Continuing Education, **26** (2), 247-273

Eraut, M. and Hirsh, W. (2007) The significance of workplace learning for individuals, groups and organisations. Economic and Social Research Council, Centre on Skills, Knowledge and Organisational Performance. www.skope.ox.ac.uk/sites/default/files/Monogrpah%209.pdf. Accessed

Etherington, K. (2004) Becoming a Reflexive Researcher. London and Philadelphia, Jessica Kingsley publishers

Evans, R (2003) Patient centred medicine: Reason, emotion and human spirit? Some philosophical reflections on being with patients. Journal of Medical Ethics, **29**, 8-15

Fearon, K., Strasser, F., Anker SD. et al. (2011) Definition and classification of cancer cachexia: an international consensus. Lancet Oncol **12**, 489– 495.

Flynn, B., Barrett, M., Sui, J., Halpin, C. et al. (2018) Nutritional status and interventions in hospice: physician assessment of cancer patients. J Hum Nutr Diet. **31**, 781–784

Fereday, J., & Muir-Cochrane, E. (2006) Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. International Journal of Qualitative Methods, **5,** 1-11.

Goldenberg and Goldenberg (2007) Family Therapy: An Overview 7th Edition Minnesota MN: Brooks and Cole

Grace, EM., Shaw, C., Lalji, A., Mohammed K., Andreyev, HJN., Whelan, KJ. (2018) Nutritional status, the development and persistence of malnutrition and dietary intake in oesophagogastric cancer: a longitudinal cohort study J Hum Nutr Diet **31**, 785-792

Grant, M. and Kravits, K. (2000) Symptoms and their impact on nutrition. Seminars in Onocology Nursing **16**, (2) 113-121

Greenhalgh, T. and Taylor, R. (1997) Papers that go beyond numbers (qualitative research) BMJ. 315, 740–3

Greenhalgh, T. and Papoutsi, C. (2018) Studying complexity in health services research: desperately seeking an overdue paradigm shift. BMC Med 16, 95 https://doi.org/10.1186/s12916-018-1089-4 Last accessed 12th Sept 2020

Gullett, NP., Mazurak, VC., Hebbar, G., Ziegler, TR. (2011) Nutritional Interventions for Cancer-Induced Cachexia Current Problems in Cancer, **35** (2), 58-90

Hami, F., Bryan, T., Quigley, C. (2003) Symptoms in 400 patients referred to palliative care services: prevalence and patterns. Medicine 17: 310-314

Hancock, K., Clayton, JM., Parker, SM., Walder, S., Butow, PN., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., Tattersall, MH. (2007) Discrepant perceptions about end-of-life communication: a systematic review. J Pain Symptom Manage **34**:190–200

Harding, Z., Hall, C. and Lloyd, A. (2019) Rehabilitation in palliative care: a qualitative study of team professionals BMJ Supportive & Palliative Care doi: 10.1136/bmjspcare-2019-002008

Harris, P.S., Payne, L., Morrison, L. et al. (2019). Barriers and facilitators to screening and treating malnutrition in older adults living in the community: a mixed-methods synthesis. BMC Fam Pract **20**, 100

Hawkins, C. (2000) Anorexia Journal of Human Nutrition & Dietetics **13**:113-117

Health Foundation (2015) A practical guide to self-management support – key components for successful implementation http://www.health.org.uk/publication/practical-guide-self-management-support Last accessed 16.2.2018

Hébuterne, X., Lemarié, E., Michallet, M., et al. (2014).: Prevalence of malnutrition and current use of nutrition support in patients with cancer. JPEN J Parenter Enteral Nutr **38** (2): 196-204

Higginson, IJ., Evans, CJ. (2010) What is the evidence that palliative care teams improve outcomes for cancer patients and their families? The Cancer Journal **16** (5): 243-435

Homsi, J., Walsh, D., Rivera, N. et al. (2006) Symptom evaluation in palliative medicine: patient report vs systematic assessment. Support Care Cancer **14**: 444– 453.

Hopkinson, J., Wright, D., McDonald, J. and Corner, J. (2006) Prevalence of concern about weight loss and change in eating habits in people with advance cancer. Journal of Pain and Symptom Management **32** (4), 322-331

Hopkinson, J., Wright, D. and Corner, J. (2006a) Exploring the experience of weight loss of people with advanced cancer. Journal of Advanced nursing **54** (3) 304 -312

Hopkinson, J. & Corner, J. (2006b) Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. Journal of Pain and Symptom Management. **31**, 293-305

Hopkinson, J., Wright, D., Foster, DN. et al. (2010) The emotional aspects of cancer anorexia. Current Opinion in Supportive & Palliative Care. **4** (4), 4254-4258.

Hopkinson, J., Fenlon, DR., Foster, CL. (2013) Outcomes of a nurse delivered psychosocial intervention for weight eating related distress in family carers of patients with advanced cancer. Intnl Journal of Palliative Nursing **19**, 3.

Hopkinson, J. (2018). Psychosocial support in cancer cachexia syndrome: the evidence for supported self-management of eating problems during radiotherapy or chemotherapy treatment. Asia-Pacific Journal of Oncology Nursing **5** (4), 358-368.

Huhmann, M. (2018): Nutrition management of the surgical oncology patient. In: Leser M, Ledesma N, Bergerson S, et al., eds.: Oncology Nutrition for Clinical Practice. Chicago, Ill: Oncology Nutrition Dietetic Practice Group, pp 135-42.

International Dysphagia Diet Standardisation Initiative (IDDSI)
IDDSI Framework (2016) Available on line at: https://iddsi.org/framework/

Joffe, H. (2012) In Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners. Edited by David Harper and Andrew Thompson Chichester: Wiley-Blackwell, pp. 209-223.

Johnston, B., Rogerson, E., Macijauskiene, J., Blaževičienė, A. et al. (2014) An exploration of self-management support in the context of palliative nursing: a modified concept analysis. BMC. Nursing **13**:21

Krauss, SE. (2005). Research paradigms and Meaning Maker: A primer. The Qualitative Report, **10**, 758-770.

Kutner, JS., Steiner, JF., Corbett, KK., Jahnigen, DW., Barton, PL. (1999) Information needs in terminal illness. Soc Sci Med **48**, 1341– 1352

Laur, C., McCullough, J., Davidson, B., Keller, H. (2015) Becoming Food Aware in Hospital: A Narrative Review to Advance the Culture of Nutrition Care in Hospitals. Healthcare, **3,** 393-407

MacDonald, N. (2005) Modern palliative care: An exercise in prevention and partnership. Seminars in Oncology Nursing **21**, 69-73

MacMillan Learning Zone (MAWE) Last accessed April 2016. Content now removed.

Mann, K., Gordon, J., MacLeod, A. (2009) Reflection and reflective practice in health professions education: A systematic review. Advances in Health Sciences Education, **14**, 595-621

Macasa, ED., Jarrett, PM. (2016) The impact of weight loss on patients with cancer. Nursing Times; **112** (11), 20-22.

McClement, SE., Degner, LF., Harlos, MS. (2003) Family beliefs regarding the nutritional care of a terminally ill relative: a qualitative study. J Palliativ Med 6 (5) 737-748

Meares, CJ. (2000) Nutritional issues in palliative care. Seminars in Oncology Nursing 1**6** (2), 135-145

Miles, MB., Huberman, AM., Saldana, J. (2014) Qualitative data analysis: A methods sourcebook (3rd ed.) London, UK: SAGE

Morris, NP. (2014) The neglect of nutrition in medical education - A firsthand look. JAMA Internal Medicine; **174** (6), 841-842 National Cancer Institute USA https://www.cancer.gov/publications/dictionaries/cancer-terms/def/advanced-cancer?redirect=true Last accessed 05.02.2020

National Council for Palliative Care (NCPC) (2009) Palliative care explained. www.ncpc.org.uk/palliative_care.html. Accessed 16.2.2018

National Council for Hospice and Specialist Palliative Care Services. Definitions of Supportive and Palliative Care. Briefing paper 11. London: NCHSPCS. September 2002.

NHS England (2014) The Five Year Forward View https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf Last accessed 16.2.2020

NICE (2004) Improving supportive and palliative care for adults with cancer. https://www.nice.org.uk/guidance/csgsp/evidence/supportive-and-palliative-care-the-manual-2 Last accessed 4.12.2019

NICE (2006) Nutrition support in adults Clinical Guideline 32 http://pathways.nice.org.uk/pathways/nutrition-support-in-adults Last accessed on 4.12.2019

NICE (2012) Support for commissioners and others using the quality standard on nutrition support in adults http://www.nice.org.uk/nicemedia/live/13977/61747/61747.pdf (accessed 20.11.2019)

Nipp, RD., El-Jawahri, A., Fishbein, JN., Eusebio, J. et al. (2016) The Relationship Between Coping Strategies, Quality of Life, and Mood in Patients with Incurable Cancer. Cancer; **122** (13), 2110–2116

Nolan, MT. and Mock, V. (2004) A conceptual framework for end-of-life care: a reconsideration of factors influencing the integrity of the human person. Jo Prof Nurs **20** (6) 351-360

Nugent, B., Lewis, S., & O'Sullivan, JM. (2013). Enteral feeding methods for nutritional management in patients with head and neck cancers being treated with radiotherapy and/or chemotherapy. The Cochrane database of systematic reviews. https://doi.org/10.1002/14651858.CD007904.pub3

Ovesen, L., Allingstrup, L., Hannibal, J. et al (1993) Effect of dietary counselling on food intake, body weight, response rate survival and quality of life in cancer patients undergoing chemotherapy: a prospective, randomised study Journal of Clinical Oncology **11** (10), 2043-2049

Ovesen, L. (1993) The interrelationship of weight loss, dietary intake and quality of life in ambulatory patients with cancer of the lung, breast and ovary. Nutrition and Cancer **19**, 159-167

Pinto IF, Pereira JL, Campos CJ, Thompson JL (2016) The Dietitian's Role in Palliative Care: A Qualitative Study Exploring the Scope and Emerging Competencies for Dietitians in Palliative Care. J Palliat Care Med **6** (2), 253.

Planas, M., Alvarez-Hernandez, J., Leon-Sanz, M., Celaya-Perez, S. et al. (2016) Prevalence of hospital malnutrition in cancer patients: a sub-analysis of the PREDyCES study. Support Care Cancer **24** (1):429 - 435

Posthauer, ME. (2007) The role of nutritional therapy in palliative care. Advanced Skin Wound Care **20** (1) 32-33

Preedy, VR. (2011) Diet and nutrition in palliative care 1st edition CRC Press

Pressoir, M., Desne, S., Berchery, D., Rossignol, G., Poiree, B., Meslier, M. et al. (2010) Prevalence, risk factors and clinical implications of malnutrition in French Comprehensive Cancer Centres. Br J Cancer **102** (6), 966 - 971.

Prevost, V. & Grach, MC. (2012) Nutritional support and quality of life in cancer patients undergoing palliative care. Eur J Cancer Care (Engl) **21**, 581– 590.

Ravasco, P., Monteiro-Grillo, I., Vidal, PM. et al. (2004) Cancer: disease and nutrition are key determinants of patients' quality of life. Support Care Cancer **12**, 246–252

Ravasco, P., Monteiro GI., Maria, C. (2007) Cancer wasting and Quality of Life react to individualised nutritional counselling Clinical Nutrition 26 (1) 7-15

Ravasco, P. (2019) Nutrition in cancer patients J Clin Med Aug: **8** (8), 1211

Richards, L. (2015) Handling Qualitative Data A Practical Guide 3rd edition SAGE

Ridder, HG. (2017) The theory contribution of case study research designs Business Research **10**, 281–305

Rowley, J. (2002) Using case studies in research management research news Management Research News **25** (1)

Royal College Physicians Feeding difficulties and dilemmas at the end of life (2014)

Sarna, Oncol Nursing Forum (1993); **201** (3), 481-489

Schroeder, K. and Lenz, K. (2018) Nursing and the future of palliative care Asia-Pacific Journal of Oncology Nursing **5** (1), 4-8

Seely, JG., Scott, JF., Mount BM. (1997) The need for specialized training programs in palliative medicine Can Med Assoc J **157**:1395-7

Sepúlveda, C., Marlin, A., Tokuo, MH., Yoshida, MD. and Ullrich, A. (2002) WHO Palliative Care: The World Health Organization's Global Perspective J Pain and Symptom Management **24** (2), 91-97

Sesterhenn, AM., Szalay, A., Zimmermann, AP., Werner, JA., Barth, PJ., Wiegand, S. (2012) Significance of autopsy in patients with head and neck cancer. Laryngorhinotologie; **91** (6), 375-380.

Shaw, C. and Eldridge, L. (2015) Nutritional considerations for the palliative care patient. Intnl Journal Palliative Care **21** (1), 7-8

Shaw, C (2011) Nutrition and Palliative Care Chapter 10. In Nutrition and Cancer. Wiley Blackwell

Shragge, JE., Wismer, WV., Olson, KL. et al. (2007) Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer Palliative Medicine **21** (3) 227-233

Silverman, D. (2005) Doing qualitative research .2nd edition. Age: London

Simons, H. (2009) Case study research in practice. London. SAGE publications ltd

Sivell, S., Prout, H., Hopewell-Kelly, N., et al. (2015) Consideration and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper BMJ Supportive & Palliative Care, 0:1–7. doi:10.1136/bmjspcare-2015-000892 (accessed 28th July 2019)

Sobotka L. editor. (2012) Basics in clinical nutrition. 4th ed. Galen.

Souter, J. (2005) Loss of appetite: a poetic exploration of cancer patients and their carers' experiences Journal of Palliative Nursing 11 (10)

Souter, J., Czerwinska, A., Cooley, S. (2016) A holistic approach to nutrition in palliative care FONS study https://www.fons.org/Resources/Documents/Project%20Reports/A-

Holistic-Approach-to-Nutrition-and-Diet-in-Palliative-Care.pdf (accessed 12th Sept 2020)

Souter, J., Czerwinska, A., Cooley, S., Holdoway, A. (2016). A holistic approach to nutrition and diet in palliative care
https://spcare.bmj.com/content/bmjspcare/6/Suppl_1/A51.2.full.pdf

Sowerbutts, AM., Lal, S., Sremanakova, J., Clamp, A., et al. (2018) Home parenteral nutrition for people with inoperable malignant bowel obstruction. Cochrane Database of Systematic Reviews. Issue 8. Art. No.: CD012812. DOI: 10.1002/14651858.CD012812.pub2.

Spencer, L., Ritchie, J., Ormston, R., O'Connor and Barnard, M. (2014) Analysis Principles and Processes in Qualitative Research Practice A guide for social science students and researchers 2nd edition Centre for Soc Research Chapter 10, 269-293

Spencer, L., Ritchie, J., O'Connor, W., Morrell, G. et al. (2014) Analysis in Practice in Qualitative Research Practice A guide for social science students and researchers 2nd edition Centre for Soc Research Chapter 11, 295-346

Spiro, A., Baldwin, C., Patterson, A. et al. (2006) The views and practice of oncologists towards nutritional support in patients receiving chemotherapy. Br J Cancer **95**, 431– 434.

Stake, RE. (2003) Case Studies. In Strategies of Qualitative Inquiry. 2nd edition Editors: Denzin NK and Lincoln YS Sage Publications. Chapter 5, 134-164

Stake, RE. (2005) Qualitative case studies In The SAGE handbook of qualitative research 3rd edition. Ed. Denzin N K and Lincoln Y S 443-466 London, Thousand Oaks: Sage publications

Strasser, F., Binswanger, J., Cerny, T., Kesselring, A. (2007) Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. Palliative Medicine. **21** (2), 129-137

Taylor, D. and Bury, M. (2007) Chronic illness, expert patients and care transition. Sociology of Health & Illness Vol. **29** (1), 27–45

Teunissen, SCC., Wesker, W., Kruitwagen, C. et al. (2007) Symptom prevalence in patients with incurable cancer : A systematic review. Jo Pain and Symptom management **34** (1), 94-104

Thorne, SE. and Robinson, CA. (1988) Healthcare relationships: the chronic illness perspective. Research in Nursing and Health, **11**, 293-300

Tong, H., Isenring, E., Yates, P. (2009) The prevalence of nutrition impact symptoms and their relationship to quality of life and clinical outcomes in medical oncology patients. Support Care Cancer. **17** (1), 83-90.

Van Cutsem, E., Arends, J. (2005) The causes and consequences of cancer-associated malnutrition. Eur J Oncol Nurs; 9 Suppl 2:S51-63

Van-Manen, M. (1990) Researching lived experiences Human Science for an Action Sensitive Pedagogy The Althouse Press: The State university of New York: London, Chapeter 4 pp. 87-90

Vaughn (1992) Theory elaboration. The heuristics of case analysis. In C.C.Ragin and H S Becher (Eds) What is a case exploring – the foundations of Social enquiry 173-292 Cambridge Unit Press

Wainwright, D., Donovan, JL., Kavadas, V. et al. (2007) Remapping the body: learning to eat again after surgery for esophageal cancer Qual Health Res. Jul; **17** (6):759-71.

Walton, M. (2002) Patient autonomy: does Doctor know best? Medicine Today. **3** (6), 107 - 109

Wie, GA., Cho, YA., Kim, SY., Kim, SM., Bae, JM., Joung, H. (2010) Prevalence and risk factors of malnutrition among cancer patients according to tumor location and stage in the National Cancer Center in Korea. Nutrition; **26** (3):263-268.

World Cancer Research Fund (WRCF) Diet, Nutrition, Physical Activity and Cancer: a Global Perspective - The Third Expert Report https://www.wcrf.org/dietandcancer Last accessed 24.02.2020

World Health Organisation (2002). National Cancer Control Programmes: policies and guidelines. Geneva: WHO.

Yin, RK. (2014). Case study research. Design and methods, 5th ed. London, Thousand Oaks: Sage

Appendices

APPENDIX 1

Hospice Nutrition and Hydration Policy (updated version 2018)

NUTRITION AND HYDRATION POLICY

Policy Number:	63
Version Number:	2
Policy Applicable to:	All Clinical Staff, Volunteers and Staff Caring for Patients
Responsible Department:	Patient & Family Services Directorate
Author:	Nutrition Steering Group
Approved by:	Patient & Family Services Directorate
Effective Date:	September 2017
Revision Date:	September 2020

RESPONSIBILITY (ACCOUNTABILITY)

Ultimate responsibility held by: Chief Executive
First line responsibility held by: Executive Clinical Lead Inpatient Services (ECLIPS)

The Chief Executive will ensure that:

- This policy is operationally implemented.
- There are sufficient resources available to enable the management and implementation of the policy by Clinical Team Managers for in-patient settings and Specialist Nurses and team leaders in the community setting; thereby promoting the relationship between diet, health and well-being so that all staff, patients and public can make informed choices regarding nutrition and hydration.
- There is close collaboration with local authorities and other service providers to enable the provision of equitable screening and other services.
- A nutritious standard of food is provided throughout the organisation and that a safe catering service is delivered in line with national core standards (Department of Health 2007).

The Clinical Teams Managers will ensure that:

- The implementation of this policy is monitored as part of the Clinical Governance Strategy.
- The Nutritional Steering Group remains operable and includes relevant representatives from across the organisation.

Nurse Specialist and Clinical Team Managers will ensure that:

- Systems are in place to ensure that all appropriate patients are nutritionally screened and their dietary / nutritional needs are addressed.
- All staff involved in caring for patients will have the skills and competencies needed to ensure that the patients' nutritional needs are met. Staff must be able to access relevant training on nutritional screening and nutritional management.
- Systems are in place and procedures followed to enable patients to make informed choices to meet their nutritional requirements.
- Adequate training on basic nutrition issues is provided to all staff.
- Link persons from each department will be identified, as well as specialist nurses, to be trained to act as nutritional links for information and training to be cascaded to their team members for each group to access.
- At operational level all aspects of the provision of food and fluids, including meal services, quality, staffing and training standards, will be monitored.
- Suitable equipment for measuring weight, height, will be available and accessible for staff.

The Catering Service's Manager's responsibility will ensure that:

- Menus provided for patients will comply with national and organisational standards.
- Menus will provide sufficient choice to cater for personal preference, healthier eating, therapeutic diets and provision will be made to meet religious and ethnic requirements.
- All DH menus for patients will be approved by the organisation's Registered Dietitian prior to them being adopted.
- Food quality and safety monitoring will be undertaken and patients' satisfaction will be regularly measured. Patients will have the opportunity to comment via questionnaires on their individual menus and a sample will be interviewed by catering staff. A yearly survey will be circulated and audited by Catering Services.

All staff involved in caring for patients will:

- Follow the procedures to ensure that patients receive good nutritional care and undertake training on current food and health issues.
- Report non-compliance with any of the procedures.

Staff identified as nutritional links will cascade information to their team members and partake in any working groups.

1. POLICY

1.1 Introduction– Nutrition in Palliative Care – Over-arching Principles Quality Standards

The Care Quality Commission (Care Quality Commission 2009) signalled their commitment to nutrition and hydration by giving greater priority to issues around dignity and assistance with eating in their inspections, as reflected in Outcome 5 'Meeting Nutritional Needs'. The CQC standards including the CQC Key Lines of Enquiry for assessment, build on the guidance available on the subject of nutrition and hydration now available in multiple sources (NICE, 2006, NICE, 2012, NHS England 2015). CQC standards state that that all people who use services should be supported to have adequate nutrition and hydration. The content of this policy draws on the content of the guidance available and aims to fulfil CQC standards whilst placing the standards in context for the clients under the specialist care of the Dorothy House Hospice.

Nutrition in palliative and end-of-life care

The very nature of the patients under the care of Dorothy House Hospice i.e. those with life-limiting conditions such as cancer, COPD, neurological diseases, means that eating and drinking may be adversely affected, predisposing an individual to the risk of malnutrition (undernutrition) and cachexia (the wasting associated with diseases such as cancer). As malnutrition has adverse consequences on immunity, muscle strength, fatigue, wound healing, fluid balance and psycho-social function, the recognition and treatment of malnutrition and the provision of good quality nutritional care is essential (NICE QS24 2014). In palliative and end of life care it is paramount however, to recognise the phase of illness to determine and plan the most appropriate nutritional care. For example, in the early to mid palliative phase cachexia can be slowed whereas in the late stages of disease it may not be possible or feasible to reverse the effects of under-nutrition and cachexia (Arends 2016). Indeed, for some patients the goal to provide nutrition to meet estimated nutritional requirements may in itself create stress and anxiety, adversely affect the patient experience and outcome and thus go against the governing principals of palliative care to optimise quality of life. Dorothy House Hospice therefore looks to provide nutritional care that is appropriate for the patient taking into account their trajectory of disease, symptoms and the gains to be made through achieving nutritional requirements. In cases where it is not possible nor feasible to reverse the malnutrition every attempt will be made to optimise nutritional intake if this is considered in the patient's interest.

Food – more than nutrients

Food not only provides nutrients to meet physiological requirements, but goes beyond this because it has psychological, spiritual, social and cultural benefits for patients and care-givers (Acreman, 2009). Dorothy House Hospice believes there is a positive role of nutrition to be gained in relation to the psychological benefit of eating, gaining relief in overcoming or alleviating feeding difficulties, managing expectations and manipulating diet to relieve other associated symptoms. Meeting these aims are achieved through the empowerment and education of staff, the provision of diet resources and the tailoring of advice, to address the reversible causes of poor intake and manage nutritional problems as is practical and feasible.

The Patient Led Assessment tool (PLANC) at Dorothy House and education aims to encourage all those involved in delivering care to recognise that when making decisions about nutrition support/dietary interventions, one must carefully consider current status, likely prognosis, anticipated pathway and progression of disease/diseases, potential treatments and, possible side effects, patient comfort, social support, family support, peer support, socioeconomic status, religious status, ethical and legal issues (Hopkinson, 2006a, Bazzan et al 2013).

Nutrition and hydration at the end-of-life

The aims of nutritional care at the end-of-life (here intended to mean the last few weeks or days of life) should focus on minimising food-related discomfort and maximising food enjoyment (GMC, 2010). Identification of any nutritional problems need to be discussed with the patient and their families and reviewed regularly as conditions change. In addition, ethical questions will be raised concerning the provision of food and fluids to a person nearing the end of their life and should be discussed by those qualified to do so.

Living Well with a Life-Limiting Condition

As the concept of palliative care has evolved to include aspects of survivorship and living with a life-limiting condition, not just ‘end of life’, Dorothy House Hospice has embraced this approach and look to optimise diet and address problems as part of their holistic approach to treatment utilising skills and a range of resources to meet an individual’s needs. Dorothy House Hospice has therefore embedded nutritional care and advice in the range of services that it provides for example Carers Courses, Palliative Rehabilitation programmes and more recently teaching cooking skills to increase client’s confidence and independence.

The principal aim of this policy is to ensure the safe delivery of timely and appropriate nutrition and hydration to patients under the care of Dorothy House (DH) staff and premises, in line with current guidance including the latest recommendations from NHS England ‘Commissioning Excellent Nutrition and Hydration’ (2015).

2. PURPOSE AND SCOPE

To standardise the procedures and approaches used to assess, guide and develop nutritional care for DH patients ensuring that the nutrition and hydration requirements of all patient groups are **appropriately** met.

To provide safe, high quality food, fluid and nutrition and ensure that patients on the in-patient Unit (IPU) and attending the Day Patient Unit (DPU) will receive food that is nutritionally adequate, be able to make informed choices, and receive assistance with feeding, if needed, in an environment that is conducive to eating.

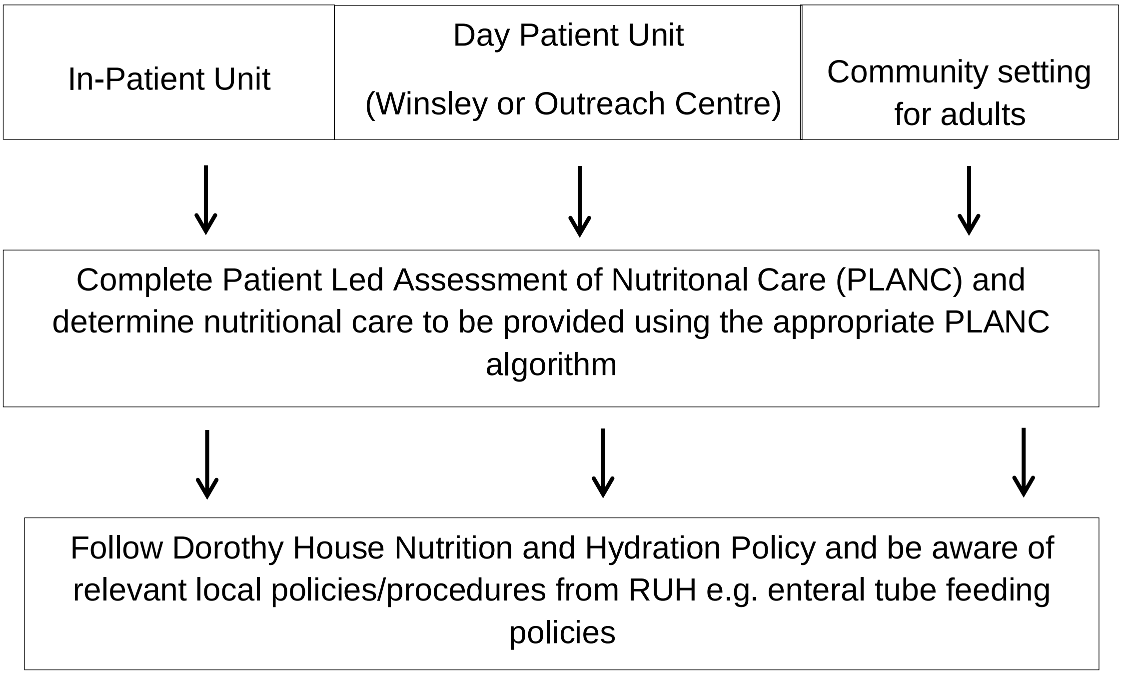
To recognise the organisation's responsibility to inform, educate and advise the community it serves on the benefits of appropriate nutrition and hydration, within the constraints that palliative conditions bring, to optimise well-being and QoL and manage symptoms at various stages in the patient journey.

This policy relates to nutritional care of patients seen by Dorothy House Staff at the Hospice itself in Winsley, Outreach Centres and within the community. The policy provides guidance for staff on the processes they must follow with regard to:

- Nutritional assessment
- Nutritional care planning
- Protected mealtimes

Where patients are on the current caseload of multiple services, professionals should discuss who the relevant person to undertake the nutritional assessment If a non-clinical service is solely involved, it should refer on to an appropriate clinical service.

3. APPLICATION – FLOW CHART



In-Patient Unit

Day Patient Unit

(Winsley or Outreach Centre)

Community setting for adults

Complete Patient Led Assessment of Nutritonal Care (PLANC) and determine nutritional care to be provided using the appropriate PLANC algorithm

Follow Dorothy House Nutrition and Hydration Policy and be aware of relevant local policies/procedures from RUH e.g. enteral tube feeding policies

4. KEY PRINCIPLES

The aim of this policy is to guide nutritional care that is appropriate for patients to meet their individual nutritional and hydration needs taking into account their trajectory of disease and life expectancy. All patients will have their nutritional needs considered and assessed using PLANC and clinical judgement and will be fully involved in all aspects of decision making.

5. NUTRITION ON THE IPU

i. On admission, the nutritional status and dietary needs of patients admitted for respite care or symptom control, will be assessed by a nurse within 24 hours using the 'Patient Led Assessment for Nutritional Care' tool (PLANC) and the appropriate nutritional care determined using the appropriate PLANC algorithms for which there are 2 – an algorithm for early – mid palliative phase, an algorithm for end of life phase.

ii. Nutritional issues and their management will be incorporated into the care plans and be part of the handover of patient care. These will be regularly reviewed and staff will support patients to meet their eating and drinking needs with sensitivity and respect for their dignity and ability. There may be occasions when professional judgement may conflict with the patient's wishes; these will be addressed sensitively and as best as possible by Dorothy House staff.

iii. Patients who have experienced rapid weight loss / or had minimal intake for > 5 days and in whom an increase in food intake is likely or achievable will be at risk of 'refeeding syndrome'. Reintroduction of food and nutritious fluids including oral nutritional supplements (ONS), needs to be undertaken cautiously as rapid increases in nutrient intake may induce 're-feeding syndrome'. Baseline bloods for magnesium, phosphate, potassium should be checked and abnormalities corrected. For further advice on supplementation, restrictions, rates of tube feeding and avoidance of 're-feeding syndrome' please consult the Dietitian or refer to NICE re-feeding guidance (NICE 2006).

iv. Patients on IPU will be offered a choice of meals, snacks and beverages that aim to best meet their nutritional requirements, taking into account medical condition, ethnic, cultural and religious requirements

v. The catering department will be notified of the need for any special therapeutic diet required e.g. gluten free, diabetic, modified texture to ensure an appropriate meal choice is available.

vi. Where required, referral to other members of the Multi-disciplinary Team according to issues identified using local referral protocols, e.g. Physios for breathlessness management, Occupational Therapists for specialist cutlery or equipment, speech and language therapy for swallowing problems and texture modification and advice.

vii. Nutritional issues and their management will be part of the handover of patient care. These will be regularly reviewed and staff will support patients to meet their eating and drinking needs with sensitivity and respect for their dignity and ability.

viii. Patients requiring advice to manage nutritional challenges or a therapeutic diet will be provided with resources and information, and if further advice is required, referral to the Dietitian will be made or advice sought.

5.1 The Patient during Their Hospice Stay

i. With consent, patients will have their nutritional status and issues assessed on a weekly basis.
ii. The IPU will apply the principles of 'Protected Mealtimes' i.e. provide an environment conducive to patients enjoying and being able to eat their food with no (or minimal) interruptions. Family members and carers will be encouraged to be present to assist and encourage eating/drinking at meal times. Where a patient's meal is missed, catering will provide a meal as close to the meal service as possible.
iii. The Senior Ward Nurse is responsible for ensuring that the ward area provides an environment conducive to eating before the meals are served and actions taken to ensure that patients' dignity is respected. Where possible, patients are encouraged to eat socially with others away from the bedside when appropriate.
iv. The Senior Ward Nurse on duty is responsible for ensuring that patients are offered assistance, when needed, in choosing from the menus.
v. Patients with physical or mental impairment, who may experience difficulty in eating, will be offered assistance to be placed in a safe and comfortable eating position and offered assistance to eat. Hand wipes will be offered if unable to wash hands before eating.
vi. For patients in whom nutritional / dietary problems exist. intake will be observed and recorded, advice provided, referred to the Dietitian and progress against care aims monitored.
vii. It will be the responsibility of nursing staff to liaise with the Dietitian, catering and in some cases pharmacy of any specific dietary requirements including allergies or texture modified diets and fluids
viii. Special feeding equipment as recommended by Occupational Therapists will be provided to patients having difficulty using standard equipment.
ix. Patients who are unable to achieve sufficient nutrition via the normal menu and snacks will be prescribed and offered nourishing drinks or oral nutrition supplements (ONS) as per flow chart. Samples of ONS for the patient to trial to establish individual preferences and optimise intake, taking into account any allergies or intolerances, are available from the Dietitian.
x. Where appropriate, patients who are unable to manage adequate oral intake due to swallowing difficulties may be offered artificial nutritional support and appropriate enteral feeding procedures followed (refer to Royal United Hospital Enteral Feeding Procedures and Care Plans). For patients admitted on an enteral feeding every effort should be made to obtain information form patient, carer, home enteral feeding team to ensure the correct feeding regimen is available and followed including care of the enteral feeding tubes. If the regimen is deemed unsuitable due to changing patient needs or the regimen is considered unsuitable du to changing clinical circumstances a referral to the Dietetic Assistant / Dietitian should be made to enable early

intervention and management during the in-patient stay and prepare for discharge.

- xi. Patients who are fed artificially will have their oral hygiene needs attended to.
- xii. Information for patients about diet and food service will be available in various formats to include availability of catering for ethnic, cultural or religious dietary requirements.
- xiii. Visitors and relatives should be actively encouraged to participate in mealtimes.

5.2 Hospice Menus and Meal Service

- i. All food will be of good quality, with a range of choices each day.
- ii. DH will follow their Food Safety Codes of practice, which incorporate current statutory regulation as per 'The Food Hygiene Regulations 2006' and any subsequent amendments to ensure that all food and beverages provided by DH will be safe and served at appropriate temperatures. All staff involved in food service will be appropriately trained.
- iii. The menu will provide a choice of hot and cold dishes at each meal, including vegetarian and lighter options.
- iv. Patients with ethnic, cultural or religious dietary requirements will be catered for upon request.
- v. Meals, together with snacks and beverages, will be sufficient to meet the Estimated Average Requirement (EAR) for energy and the Reference Nutrient Intake (RNI) for protein, vitamins and minerals (DH 1991).
- vi. Patients will be able to choose their portion size (small, medium or large) and will be offered at least seven beverages each day.
- vii. Patients with dysphagia (swallowing difficulties) are likely to require a modified texture diet and modified fluids. The Hospice will provide meals and fluids that adhere to the IDDSI framework (see online resource) as clinically indicated, following Speech and Language Therapist recommendations where available. All staff involved in the preparation and provision of texture modified diets will be required to complete the IDDSI mandatory training.
- viii. Patients who have special dietary needs will be catered for and, where possible, offered a range of choices comparable to the normal menu.
- ix. An 'accessible menu pack' will be available on the IPU/DPU giving information on textures and pictorial images of foods and dishes available on the menu to support patients ability to make appropriate menu choices.
- x. A 24-hour meal service will be available for those patients who have missed a meal because of treatment or tests, or have been admitted and not had the opportunity of a meal.
- xi. A 24-hour ward service will be available to provide hot and cold beverages, toast, biscuits, cereal and texture modified meals.

5.3 Provision of Meals for Staff and Visitors on Hospice Premises

- i. The Catering Department will ensure that staff have the opportunity to receive a well-balanced diet, with both hot and cold food choices available.

ii. Staff who work night shifts will have facilities made available to them to enable them to heat food.
iii. Visitors to the hospice will have access to the Dining Room with beverages available.
iv. Food for staff and visitors will be of the same standard of quality and safety as that provided for the patients.
v. When staff or visitors have food brought into the Hospice, the Hospice will not accept any responsibility for food safety. Staff will not be permitted to store food in refrigerators designated for patient food.

5.4 Nutritional Assessment on the DPU

i. As part of the holistic assessment, nutritional status and any dietary issues will be identified using the PLANC resources. Any nutritional problems identified will be documented in the patients' record, a nutritional care plan will be discussed and developed in conjunction with the patient recorded in patient's notes and acted upon.
ii. Patients will receive advice and support to overcome or manage dietary issues utilising clinical knowledge and expertise and the Dorothy House resources available and referred to the Dietitian if required.
iii. All patients will be offered a menu, including snacks and beverages appropriate to their cultural, religion requirements and dietary requirements.
iv. The catering department will be notified of the need for any special therapeutic diet required e.g. gluten free, diabetic, modified texture (IDDSI framework), to ensure an appropriate meal choice is available.
v. As for IPU, referral to other members of the Multi-disciplinary Team will be made according to local referral protocols, e.g. Physiotherapy, Occupational Therapy.
vi. Nutritional issues and their management will be incorporated into the care plans and be part of the handover of patient care. These will be regularly reviewed and staff will support patients to meet their eating and drinking needs with sensitivity and respect for their dignity and ability. There may be occasions when professional judgement may conflict with the patient's wishes; these will be addressed sensitively and as best as possible by Dorothy House staff.
vii. The DPU will provide hot and cold beverages throughout the time spent on the unit. The Unit will also provide a meal during the lunch period.

5.5 The Patient on Discharge from IPU and DPU

i. Any special dietary requirements or nutritional risks identified and their subsequent management should be included in the discharge summary in order to inform relevant healthcare professionals in the community of on-going needs and, where appropriate.
ii. As nutritional issues and challenges can affect the carers of the patient, carers should be involved and informed of the appropriate nutritional care at the earliest opportunity and as a minimum on discharge.

iii. When patients are discharged on ONS, staff will follow the locally agreed procedure for prescribing guidance and inform the patient's GP/Dietitian.
iv. When patients are discharged home on artificial enteral nutrition (tube feeding), staff will follow locally agreed procedures (refer to Royal United Hospital *(RUH)* Enteral Feeding Procedures and Care Plans) and their care transferred back to the home enteral feeding team (Sirona, Virgin, Somerset, Bristol HMS, Nutricia Homeward Enteral Feeding Services) to ensure the transition from hospital to home is managed efficiently and effectively and updates are provided. Seek advice from the Dorothy House Dietitian.

6. NUTRITION IN THE COMMUNITY

6.1 Nutrition Screening and Assessment in the Community

iv. DH Nurse Specialists/Health Professionals will screen and assess patients to identify nutritional risk problems using PLANC', within the first 3 visits. The problems identified, planned care and anticipated outcome will depend on the phase of illness. Care and advice given should be documented in the patients' notes and expected goals agreed and discussed with patient and carer. Including expectations.
v. Nutritional assessment must be carried out by healthcare professionals with appropriate skills and training.
vi. Patients will be monitored according to their nutritional risk and issues identified and an appropriate nutritional care plan discussed, agreed and completed.
vii. Community based nurses will be trained to an appropriate level to best support their patients. Referral to the Dietitian can be made if further support / advice is required.
viii. Resources provided to support the patient and/or carer(s) e.g. diet sheets, will be documented in the patient's records.

6.2 Nutritional Support including appropriate use of oral nutritional supplements (ONS)

i. If patients are unable to manage sufficient oral intake through normal food and drinks, advice can be offered about how they might improve their nutritional intake using clinical knowledge and the resources available from the Diet and Nutrition Resources folders. Note: all resources are available in the Dorothy House public folders P drive > Nutrition > diet resources for patients and carers. Advice should be tailored to individual need taking into account, and treating where possible, the underlying reasons for poor dietary intake.
ii. Oral nutritional supplements should be considered if:
    - the patient is at 'high risk' of malnutrition, losing weight / low body mass index
    - appetite is poor
    - it is anticipated or observed that little improvement in nutritional intake will be achieved through a food-based approach (food-first approach)

- or where improved intake could help manage clinical condition e.g. heal pressure ulcers, prevent recurrent infections, preserve muscle and function

Samples of ONS are available at all Dorothy House settings and should be selected according to the deficit in dietary intake, individual choice and preference. Seek further advice from the dietitian. Once tolerance and acceptability is established arrangements can then be made for a prescription according to the ONS guidance for prescribing ONS, available in DH Nutrition resources or as described in the following link http://malnutritionpathway.co.uk/ons-pathway (website endorsed by RCGP, BDA, RCN and other health professional organisations).

iii. All patients taking ONS must be reviewed regularly and the prescription discontinued if it is no longer appropriate / required / patient dislikes or is unable to take the ONS.

iv. If standard ONS are not effective and 'disease specific' or 'macronutrient' only (modular carbohydrate or fat e.g. Calogen, Procal) supplements are indicated please seek advice from the Dietitian.

6.3 Artificial Nutrition Support

i. Patients who are unable to manage oral intake due to swallowing difficulties/malabsorption/loss of gut function/physical issues, may be considered for enteral nutrition support (tube feeding) if appropriate and enteral feeding procedures followed. A Dietitian should be involved in discussions from an early stage.

ii. Any patient requiring artificial nutrition support will be referred to the Dietitian at the earliest stage possible. Information regarding type of feeding and other issues will be discussed with the patient and/or carers and other health professionals involved in care.

iii. Patients requiring a gastrostomy will need to be referred to the appropriate Diagnostics Centre (to include Nutrition Nurse) and appropriate care plans followed. Follow the gastrostomy procedures identified by the discharging hospitals (available from the Dietetic Departments), e.g. RUH, Salisbury District Hospital and Great Western Hospital (GWH).

iv. Patients on home artificial nutrition support are managed by the Home Enteral Tube Feeding Dietitians from Great Western NHS Foundation Trust for patients in North and West Wiltshire, Home Management Services in BANES and Somerset Community Health Service in Mendip. The relevant team should be notified of any change in clinical condition, feeding tolerance, issues with feeding equipment / devices. The Dorothy House Dietitian may also be consulted.

For all patients communication of nutritional care needs is crucial to ensure continuity of care across care settings.

7. STAFF TRAINING REQUIREMENTS

An up-to-date training programme will be delivered and monitored by the DH Education Department.

8. RESOURCES

- The Patient Led Assessment for Nutrition in Palliative Care (PLANC) including algorithms for care planning and management, is available in the DH public folders. A template for completion on initial assessment and in subsequent assessments is incorporated into the electronic patient record on SystmOne.
- Advice on nutrition screening and assessment, patient / carer information booklets (including handy hints and tips), on a range of nutritional problems commonly experienced by DH client groups and carers, is available and kept up to date according to demand and clinical need by the Specialist Dietitian. Content is reviewed annually.
- Each department and DH site will have a Master copy of dietetic resources available for use by patients and carers.
- All resources are available for clinical staff to download and print via the DH Public folders (see DH Public folder > Nutrition> Diet resources for patients and carers).

9. MONITORING AND EVALUATION

An annual audit programme will be developed by Dorothy House Nutrition Steering Group to ensure compliance with standards and will include:

- Nutrition assessment, care planning – inpatients and community.
- Nutritional analysis of DH food provision by the Dietitian in conjunction with Catering.
- Annual patient and service users satisfaction surveys.
- Quarterly monitoring of complaints and untoward incidents relating to nutrition and hydration by DH Nutrition Steering Gro

Goals to consider (document in notes)

Goals are not limited to but can include:

- ✓ Preventing further weight loss
- ✓ Maintaining or increasing weight
- ✓ Improving strength (including grip strength)
- ✓ Increasing nutritional intake
- ✓ Improving the individual’s ability to undertake activities of daily living
- ✓ Improving the individual’s quality of life
- ✓ Alleviating anxiety amongst patient and carer
- ✓ Improving immunity / preventing opportunistic infections / preventing pressure ulcers.

Further advice and information

For further information on dietary advice, oral nutritional supplements (ONS) and managing malnutrition and diet problems see Dorothy House Nutrition and Diet resources (available in hard copy at each Dorothy House Hospice site or online: DH Public folder > Nutrition> Diet sheets) or visit: www.malnutritionpathway.co.uk

For more information on 'MUST' please visit: www.bapen.org.uk

RESOURCES AVAILABLE

Available as hard copy in patient areas and outreach centres and also in electronic format – see DH Public Folders>Nutrition >Diet resources for patients& carers

Nutrition Screening	
Managing Adult Malnutrition in the Community	1 Booklet
PLANC	4 Sheets

Dealing with a Poor Appetite	
Coping with a Small Appetite	1 Booklet
Food First – Advice for Improving Nutrition	1 Booklet
Hints & Tips – Coping with a Small Appetite	1 Sheet
Your Guide to Making the Most of Your Food	1 Sheet
Nutrition Dinks (ONS) Advice for Patients and Carers	2 Sheets
Ideas for Snacks/Nibbles and Finger Foods	2 Sheets
Calorie Boosters	1 Sheet
Hidden Calories (Use of Maxijul Power energy supplement)	2 Sheets
Managing Malnutrition with Oral Nutrition Supplements (ONS) Advice for Health Professionals:	
Pathway for Using ONS – When to Start and Stop and Setting Goals	1 Sheet
Nutrition Drinks (range available on prescription)	2 Sheets
Carer Information on Nutrition in Disease (Carer's UK Booklets):	
The Role of Good Nutrition When Caring For Someone	1 Booklet
Understanding the Nutrition Gap	1 Booklet

Swallowing Problems and Texture Modified Diets (IDDSI)	
Easier Swallowing – Hints and Tips	2 Sheets
Swallowing Difficulties – Advice for Thickening Fluids	2 Sheets
IDDSI resources	
Level 0 Thin fluids	1 Page

Level 1 – Slightly thick fluid	1 Page
Level 2 Mildly thick fluid	1 page
Level 3 Liquidised	1 page
Level 3 Moderatley thick fluid	1 page
Level 4 Extremely thick	1 page
Level 4 Pureed	1 page
Level 5 Minced & Moist	3 pages
Level 6 Soft & Bite-Sized	3 pages
Level 7 Regular Easy to Chew	4 pages
Level 7	1 page
Transitional	1 page

Diabetes	
Eating Well with Diabetes	1 Leaflet
Diabetes and Being Unwell	2 Sheets
The Very Best HYPO Treatment	1 Sheet
Hints and TPIS – Coping with a Small Appetite and Diabetes	2 Sheets
Carbohydrate Counting	1 Leaflet

Oral Feeding	
Feeling Sick (A Helping Hand)	1 Sheet
Dry or Sore Mouth (A Helping Hand)	1 Sheet
Dry or Sore Mouth During Radiotherapy (A Helping Hand)	1 Sheet
Taste Changes	2 Sheets
Nausea and Vomiting	1 Booklet
Eating with Sore Dry Mouth and Throat	1 Booklet

Special Diets and Intolerances	
Lactose Intolerance	Review Article and Content Table

COPD	
Respiratory Health Professionals – Guidelines	1 Sheet
Eating Well for Your Lungs (Green)	1 Sheet
Improving Your Nutrition (Amber)	1 Sheet
Nutritional Support (Red)	1 Sheet

Bowel Function	
Normal Bowel Function	1 Booklet
Explaining How to Take Loperamide (Imodium)	1 Booklet
Dietary Advice for People with a High Stoma Output	1 Booklet

Constipation (A Helping Hand)	1 Sheet

Weight Management	
Ten Top Tips for Weight Loss	
Tips for Successful Weight Management	
Food Diaries Double Weight Loss Success	
Tips to Keep Weight Loss Going	
Tips to Keep Weight Loss Saboteurs	
Tips to Keep Moving to Help Weight Management	
Cancer Prevention	
Eating Well and Keeping Active After Cancer Treatment	1 Booklet
Eat Well for Life	1 Booklet
Know Your Risk	1 Booklet

9. REFERENCES

- Acreman, S (2009) Nutrition in Pall Care Br J Community Nursing
- Age Concern. Hungry to be Heard (2006). Am J Nurs 100 (4): 45-51.
- Arends et al (2016) ESPEN Gudielines Nutriton in Cancer patients http://www.espen.info/wp/wordpress/wp-content/uploads/2016/11/ESPEN-cancer-guidelines-2016-final-published.pdf last accessed 12.3.2019
- Bazzan AJ, Newberg AB, Cho WC, Monti DA (2013) Diet and nutrition in cancer survivorship and palliative care. Evid Based Complement Alternative Medicine
- British Association for Parenteral and Enteral Nutrition (201p) Malnutrition Matters – A toolkit for commissioners an providers in England http://www.bapen.org.uk/pdfs/toolkit-for-commissioners.pdf
- British Association for Parenteral and Enteral Nutrition. (2007) Nutrition Screening Survey and Audit of Adults on Admission to Hospitals, Care Homes and Mental Health Units in the UK.
- British Association for Parenteral and Enteral Nutrition. (2003) Malnutrition Universal Screening Tool ('MUST'). http://www.bapen.org.uk/pdfs/must/must-full.pdf
- British Dietetic Association 'The Nutrition and Hydration Digest: Improving Outcomes through Food and Beverage Services' (2012) https://www.bda.uk.com/publications/professional/NutritionHydrationDigest.pdf (last accessed 22nd January 2016)
- Brown JK. A Systematic Review of the Evidence on Symptom Management of Cancer-related Anorexia and Cachexia. *Oncol Nurs Forum* 2002; 29, 517-532.
- Care Quality Commission – Essential Standards of Quality and Safety. (2009).
- Department of Health. (1991) Dietary Reference Values for Food Energy and Nutrients for the UK.
- Department of Health (2000).The NHS Plan: a Plan for Investment, a Plan for Reform.
- Department of Health. (2007) Improving Nutritional Care: A Joint Action Plan from the Department of Health and Nutrition Summit stakeholders.
- Dewey and Dean (2007)NICE (2004) Guidance on cancer services: Improving Supportive and Palliative Care for Adults with Cancer. NICE London available at www.nice.org.uk last accessed 23rd April 2014
- Elia M *et al*. Enteral (oral or tube administration) Nutritional Support and Eicosapentaenoic Acid in Patients with Cancer: a Systematic Review. *Int J Oncol* 2006; 28, 5–23.
- Essence of care. Patient Focused Benchmarks for Clinical Governance. Department of Health. (2001).
- A Holistic Approach to Nutrition in Palliative Care (2016) https://www.dorothyhouse.org.uk/wp/wp-content/uploads/2016/11/FONs-report-A-Holistic-Approach-to-Nutrition-and-Diet-in-Palliative-Care.pdf last accessed 6.3.2019
- General Medical Council (2010) Treatment and Care Towards the End of Life http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life___English_0414.pdf_48902105.pdf
- Hopkinson J, Wright D and Corner J (2006) Exploring the experience of weight loss of people with advanced cancer Journal of Advanced nursing 54 (3) 304 -312
- Hopkinson, J. & Corner, J. (2006) Helping patients with advance cancer live with concerns about eating: a challenge for palliative care professionals. Journal of Pain and Symptom Management. Vol.31.pp 293-305
- Hospital Catering Association (2006) Good Practice Guide to Healthcare Food and Beverages Service Standards: A Guide to Ward Level Services
- Laviano, A. & Meguid, MM. (1996) Nutritional Issues in Cancer Management. Nutrition 12 (5): 358-71.
- Malnutrition Matters – Meeting Quality Standards in Nutritional Care: A Toolkit for Commissioners and Providers in England. BAPEN (2010).

- MacDonald, N. (2005) Modern palliative care: An exercise in prevention and partnership. Seminars in Oncology Nursing 21, 69-73
- Maltoni, M. & Amadori, D. (2001) Palliative medicine oncology. Annals of Oncology 12, 443-450
- National Patient safety Agency. (2008) Council of Europe Ten Key Characteristics of Good Nutritional Care in Hospitals.
- National Institute for Health and Clinical Excellence. (2006). Nutrition Support for Adults. Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition. Guideline 32. Accessed on 11.07.2010 at www.nice.org.uk
- National Institute for Health and Clinical Excellence Quality Standards in Nutrition Support QS24 http://www.malnutritiontaskforce.org.uk/wp-content/uploads/2014/07/COM-Quality_standard_for_nutrition_support_in_adults_qs24.pdf
- National Institute for Health and Clinical Excellence (2012) Nutriton Support in adults Quality Standards QS24 https://www.nice.org.uk/guidance/QS24 last accessed 6.9.2017
- National Collaborating Centre for Acute Care (2006)
- NHS England Guidance - Commissioning Excellent Nutrition and Hydration 2015-2018
- https://www.england.nhs.uk/wp-content/uploads/2015/10/nut-hyd-guid.pdf accessed 6.9.2017
- NHS Institute for Innovation and Improvement (2009) High Impact Actions for Nursing and Midwifery
- National Institute for Health and Clinical Excellence (NICE) (2006) Quality Standard for Nutrition Support in Adults QS24. http://publications.nice.org.uk/quality-standard-for-nutrition-support-in-adults-qs24
- Posthauer ME (2007) The role of nutritional therapy in palliative care. Advanced Skin Wound Care 20 (1) 32-33
- Preedy (2011) Diet and nutrition in palliative care 1st edition CRC Press
- Royal College Speech and Language Therapists and the British Dietetic Association. (2002) National Descriptors for Texture Modification in Adults. http://www.bda.uk.com/publications/statements/NationalDescriptorsTextureModificationAdults.pdf
- Ravasco P. Monteriro GI, Maria C (2007) Cancer wasting and Quality of Life to individualised nitrioal counselling Clinical Nutrition 26 (1) 7 – 15
- Shaw, C (2011) Nutrition in Palliative Care. Chapter 10. Nutrition and Cancer. Wiley Blackwell
- Wilkes, G. (2000) Nutrition: The Forgotten Ingredient in Cancer Care.
- Multiprofessional Consensus on Managing Adult Malnutrition in the Community www.malnutritionpathway.co.uk

---

EXECUTIVE TEAM FINAL APPROVAL

APPENDIX 2

Interview Guides

Patient interview Guide

Title of project: The role of diet in palliative care as perceived by patients, carers and healthcare professionals

First may I thank you for agreeing to take part in this study and for taking the time to talk to me. As you know we are interested in understanding your experience and views since your illness was diagnosed. I have a range of topics which might be useful to discuss but most importantly I would like to hear about your experience and so would not wish the questions to restrict what you would like to share on the subject.

I am going to record the interview so that I can listen to what you have said at a later date. Note that your name will not be mentioned in any reports arising from this study. If you want to stop the interview or the recording at any time, please say so. All the information you provide will be strictly confidential.

1. Section One – Your general health and your previous diet (before cancer).

1.1.Would you like to tell me about your general health before your diagnosis of cancer?

1.2 What was your diet like?

1.3 What were your views about diet and health?

1.4 Can you describe a typical day – describe what you ate and when?

1.5. Who did the cooking and shopping?

(Aim: to gain insights into whether any special diets in the past for any reason and how diet was viewed in relation to health and well-being).

Prompts if needed –

When you were 'well' what did you eat, how and when?

What did diet mean to you? Prompt – health, well-being, enjoyment, pleasure, ‘eat to live’ or ‘live to eat’? Who usually does the cooking? Would you normally eat out (before being unwell)?

2. Section Two – Your diagnosis of cancer and treatments (supported by review of medical records).

2.1. So we can understand your experience with cancer can you tell me a little about what has happened so far?

Prompt: for example how long is it since you were diagnosed, how and where and what treatment (if any) have you had or are you receiving at the moment?

3. Section Three - How has your condition affected your ability to eat and drink?

4. Section Four: Diet and Symptoms

4.1 In relation to your symptoms experienced, did you feel diet played a role?

4.2 Do you think that diet has a part to play in your condition?

4.3 Could you tell me what advice was given in relation to diet to help with the symptoms or eating certain foods (the ‘right foods’), who gave it and when.

4.3 Was advice helpful, useful, easy to adopt, difficult to put in practice – what worked, what didn't?

5. Section Five – Food and your relationship with others

5.1 Have there been any changes in your relationship with your family and friends particularly around food and the social aspects of food?

5.2 How have you managed this?

6. Section Six – Current and future concerns

6.1. How are you managing your diet at the moment?

6.2 Do you (and do you feel those around you) have any current or future concerns about your diet?

6.4 How do you feel you are coping at the moment?

6.4 How do you feel others are coping?

Do you feel you need further information? If yes, can you outline what type of information might be helpful and in what format – written, electronic, individualised advice for you/for others?

Finally do you have anything you would like to add that would help us to understand your experience so far in relation to diet and the type of support that you have found helpful, what may be missing and what you believe others might find helpful?

Thank you for your participation in this study

Carer Interview Guide

Title of project: The role of diet in palliative care as perceived by patients, carers and healthcare professionals

First may I thank you for agreeing to take part in this study and for taking the time to talk to me. As you know we are interested in understanding <u>your</u> experience and views since the person you know was diagnosed with cancer. I have a range of topics which might be useful to discuss but most importantly I would like to hear about your experience and so would not wish the questions to restrict what you would like to share on the subject.

I am going to record the interview so that I can listen to what you have said at a later date. Note that your name will not be mentioned in any reports arising from this study. If you want to stop the interview or the recording at any time, please say so. All the information you provide will be strictly confidential.

1. Section One – General health and previous diet (before cancer).

1.1.How would you describe the health of xxxx before the diagnosis of cancer?

1.2 What was their diet like?

1.3 What are your views about diet and health?

1.4 Can you describe a typical day – describe what they ate and when?

1.5 Who did the cooking and the shopping?

(Aim: to gain insights into whether any special diets were required in the past for any reason and how diet was viewed in relation to health and well-being).

Prompts if needed –

When they were 'well' what did you and they eat, how and when?

What did diet mean to you? Prompt – health, well-being, enjoyment, pleasure, ‘eat to live’ or ‘live to eat’? Who usually does the cooking? Would you normally eat out (before they were unwell)?

2. Section Two – Diagnosis of cancer and treatments (supported by review of medical records).

2.1 So we can understand your experience as a carer for someone with cancer can you tell me a little about what has happened so far from your perspective (experience)?

Prompts (if needed) : for example how long since they were diagnosed, how life changed, and where and what treatment (if any) they had or are receiving at the moment?

3. Section Three - How has their condition affected their ability to eat and drink?

4. Section Four: Diet and Symptoms

4.1 In relation to symptoms experienced by the person you care for, did you feel diet played a role?

4.2 Do you think that diet has a part to play in their condition?

4.3. Could you tell me what advice was given in relation to diet to help with the symptoms or eating certain foods (the ‘right foods’), who gave it and when?

4.3 Was advice helpful, useful, easy to adopt, difficult to put in practice – what worked, what didn't?

5. Section Five – Food and the relationship with the person you care for and others

5.1 Have there been any changes in your relationship particularly around food and the social aspects of food?

5.2 How have you managed this?

5.3 Have changes in your diet resulted in a change in their body shape and necessitated a change in clothes? If yes, what was the impact and how did you cope or deal with this?

6. Section Six – Current and future concerns

6.1. How are you managing their diet at the moment?

6.2 Do you (and do you feel the person you care for) have any current or future concerns about diet?

6.3 How do you feel you are coping at the moment?

6.4 How do you feel the person you care for and others are coping

Finally, do you have anything you would like to add that would help us to understand your experience so far in relation to dealing and caring for someone with cancer and the role of diet? What type of support have you found helpful, what may be missing and what do you believe others might find helpful?

Thank you for your participation in this study

Healthcare Professional Interview Guide

Title of project: The role of diet in palliative care as perceived by patients, carers and healthcare professionals

First may I thank you for agreeing to take part in this study and for taking the time to talk to me. As you know we are interested in understanding your experience and views on the role of diet in patients with cancer considered to be palliative.

I have a range of topics, which might be useful to discuss, but most importantly I would like to hear about your views and experience and so would not wish the questions to restrict what you would like to share on the subject.

I am going to record the interview so that I can listen to what you have said at a later date. Note that your name will not be mentioned in any reports arising from this study. If you want to stop the interview or the recording at any time, please say so. All the information you provide will be strictly confidential.

1. Section One – General health and diet (before cancer).

1.1.What are your views of the role of diet in health?

1.2. Do those views differ for patients who are unwell?

1.3. What are our views regarding the role of diet when advising patients and their carers

(Aim: to gain insights into the HCPs views of diet in health and diet in disease. Their perception of diet in relation to health and well-being).

2. Section Two – Diagnosis of cancer and treatments

2.1. So we can understand your experience as a healthcare professional caring for patients with cancer and their carers can you tell me a little about what has happened so far from your perspective in relation to patient XXX and their carer (experience)?

2.2 How have you been involved?

3. Section Three - How has the patient's condition affected their ability to eat and drink?

It is known that cancer and its treatments can affect one's ability to eat and drink. Can you recall some of the problems you may have observed in the person you care for in relation to eating and drinking, perhaps during certain treatments such as chemotherapy or maybe because of surgery (modify according to patient medical records). If easier we can make a note of the issues that you would like to discuss and then explore them in further detail.

4. Section Four: Diet and Symptoms

4.1 In relation to symptoms experienced by the person you provide care for, do you feel diet has a role to play?

4.2 Do you think that diet has a part to play in their condition/prognosis/quality of life?

4.3. Could you tell me what advice you have given in relation to diet to help with the symptoms? Can you recall when you gave the advice and what promoted you to do so?

4.4. Have you given any advice on eating certain foods (the 'right foods'). How did you give this advice (verbal, written leaflet, tailored to the individual based on diet history).

4.5 Do you think the patient of their carer found the advice helpful, useful, easy to adopt, difficult to put in practice?

4.6 Can you recall what worked, what didn't?

4.7 Are you aware of any other advice the patient and / or carer was given? If so can you describe the advice given and by whom and whether it was acted upon?

- Did you feel enough information was given about diet and nutrition in general e.g. getting the right balance? Were there any unmet concerns?
- Has your view on the role of diet changed as a result of the care you provided to this patient and / or their carer – if yes can you describe how your view has changed?

5. Section Five – Food and relationship with others

5.1 Have you noted any changes in the patient and their carer / key relationships particularly around food and the social aspects of food?

5.2 Have you observed any strategies that the patient and / or carer undertook to manage this?

5.3 Did you give any specific advice to the patient and / or carer as to how they might deal with this?

5.4 If yes to 5.3 was the advice acted on? Do you think the patient/carer found it helpful?

6. Section Six – Current and future concerns

6.1. How is the patient / carer managing their diet at the moment?

6.2 Do you (and do you feel other HCPs around you) have any current or future concerns about their diet (from the patient's perspective/from the carer's perspective)?

6.3 How do you feel the patient / carer is coping with any dietary challenges at the moment?

6.4 How do you feel the person you care for and others are coping in genera

Finally, do you have anything you would like to add that would help us to understand your experience so far in relation to dealing and caring for someone with a palliative condition such as cancer and the role of diet? What type of support have you found helpful, what may be missing and what do you believe others might find helpful.

Thank you for your participation in this study.

APPENDIX 3

Rationale for questions for semi-structured interviews:

Diet in general health	to gain insights into the value placed on diet, how dietary habits might have formed or been influenced e.g. by other conditions, by partnerships, by family members
Diet-related issues encountered	The clinical literature highlights numerous problems associated with cancer treatment and the consequences of cancer Clinical experience has highlighted the difficulties encountered by patients in the palliative care phase with needs being unmet in the acute sector,
Impact on daily life and relationships	Food is central to many social occasions and the routines of our daily life. This was considered an important part of the interview as it had the potential to unveil how difficulties in eating or ability arose and explored how participants dealt with them. This was explored on a physical basis as well as the impact on others and relationships within a family setting.
	Diet and nutrition could also affect interactions with others, role reversal when patients might be in a position where they can no longer cook and prepare meals which in turn influence choice and meal types
Support from healthcare professionals	This question was included to seek the patient and carer views regarding the provision of healthcare professional

	support in various settings where patient and carers were cared for. Questions were phrased to capture the patient / carer experiences both in the acute and community settings
Feelings	The patients and carers feelings towards diet and nutrition were considered to be of particular importance as feelings can impact on experience and perceptions
Service improvements/addressing unmet needs	Patients, carers and healthcare professionals were asked if they could think of any means, or any specific support, that could be provided to have a positive impact on patients carers and the experience of health care professionals in the future.
Invitation to provide other comments on the participant's experience	Although it was hoped that the questions within the semi-structured interview would cover the key issues and concerns that all participants were comfortable to discuss, participants were asked if there were any additional comments, they wished to add to enhance my insight into the information provided and experience of those involved to enhance my insights into the experience and perceptions of those involved.

APPENDIX 4

Ethics approval documentation

Health Research Authority
South West - Central Bristol Research Ethics Committee
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol BS1 2NT
Email: nrescommittee.southwest-bristol@nhs.net

26 October 2015

Mrs Anne Holdoway
Specialist Dietitian
Dorothy House Hospice
Winsley
Bradford on Avon
BA15 2LE

Dear Mrs Holdoway

Study title: **The Role of Diet in Palliative Cancer Care - Perceptions of Patients, Carers and Healthcare Professionals (HCPs)**
REC reference: **15/SW/0276**
Protocol number: **N/A**
IRAS project ID: **182190**

Thank you for your letter of 21st October 2015 , 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Naazneen Nathoo at nrescommittee.southwest-bristol@nhs.net.

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.

Conditions of the favourable opinion

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 organisations 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 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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC, but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration, they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the 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).

Ethical review of research sites

NHS 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).

Approved documents

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

Document	*Version*	*Date*
Covering letter on headed paper [AH_ResponsetoSouthWest-CentralBristolREC_20thOct2015]	v1	21 October 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Dorothy_House_Hospice_-EL_PL_Certs_(1)]	1	25 September 2015
GP/consultant information sheets or letters [GP_letter_15thSept2015_v2]	v2	15 September 2015
Interview schedules or topic guides for participants [Interview_Schedule_Patient_v2]	v2	15 September 2015
Interview schedules or topic guides for participants [Interview_Schedule_Carer_version2]	v2	15 September 2015
Interview schedules or topic guides for participants [Interview_Schedule_HCP_version2]	v2	15 September 2015
IRAS Checklist XML [Checklist_20082015]		20 August 2015
IRAS Checklist XML [Checklist_20082015]		20 August 2015
IRAS Checklist XML [Checklist_16092015]		16 September 2015
IRAS Checklist XML [Checklist_25092015]		25 September 2015
IRAS Checklist XML [Checklist_21102015]		21 October 2015
Letter from sponsor [Sponsor's declaration14thAugust2015]	Final version	14 August 2015
Other [Letter from 1st REC]		02 September 2015
Participant consent form [Patient_ConsentForm_v3]	v3	21 October 2015
Participant consent form [Carer_ConsentForm_v1]	v1	21 October 2015
Participant consent form [HCP_ConsentForm_v1]	v1	21 October 2015
Participant information sheet (PIS) [Participant_Information_Sheet_Carer_v3]	v3	21 October 2015
Participant information sheet (PIS) [Participant_Information_Sheet_patient_v3]	v3	21 October 2015
Participant information sheet (PIS) [Participant_Information_sheet_HCP_v3]	v3	21 October 2015
REC Application Form [REC_Form_20082015]		20 August 2015
Research protocol or project proposal [Researchprotocol_v3]	v3	21 October 2015

Summary CV for Chief Investigator (CI) [CV Ethics July2015]	Final version	30 July 2015

Statement of compliance

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

After ethical review

Reporting requirements

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

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

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/SW/0276 Please quote this number on all correspondence

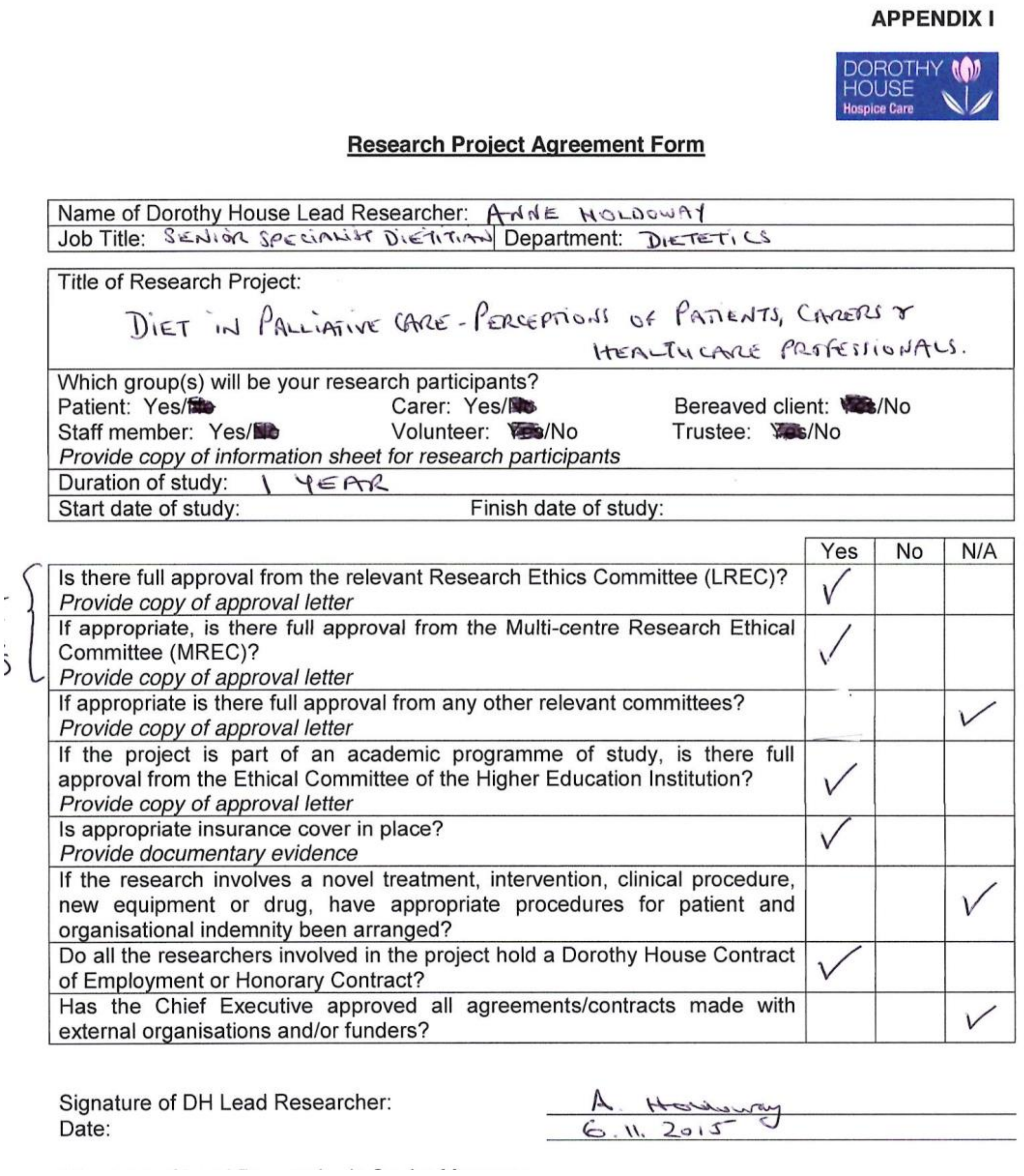
With the Committee's best wishes for the success of this project.

Yours sincerely

Pp Pam Cairns Chair

Enclosures: “After ethical review – guidance for researchers” *[SL-AR2]*

Copy to: *Mrs Helen De Renzie Brett, Dorothy House Hospice*



APPENDIX I

DOROTHY HOUSE
Hospice Care

Research Project Agreement Form

Name of Dorothy House Lead Researcher: ANNE HOLDOWAY
Job Title: SENIOR SPECIALIST DIETITIAN Department: DIETETICS

Title of Research Project:
DIET IN PALLIATIVE CARE - PERCEPTIONS OF PATIENTS, CARERS & HEALTHCARE PROFESSIONALS.

Which group(s) will be your research participants?
Patient: Yes/[redacted] Carer: Yes/[redacted] Bereaved client: [redacted]/No
Staff member: Yes/[redacted] Volunteer: [redacted]/No Trustee: [redacted]/No
Provide copy of information sheet for research participants

Duration of study: 1 YEAR
Start date of study: Finish date of study:

	Yes	No	N/A
Is there full approval from the relevant Research Ethics Committee (LREC)? *Provide copy of approval letter*	✓		
If appropriate, is there full approval from the Multi-centre Research Ethical Committee (MREC)? *Provide copy of approval letter*	✓		
If appropriate is there full approval from any other relevant committees? *Provide copy of approval letter*			✓
If the project is part of an academic programme of study, is there full approval from the Ethical Committee of the Higher Education Institution? *Provide copy of approval letter*	✓		
Is appropriate insurance cover in place? *Provide documentary evidence*	✓		
If the research involves a novel treatment, intervention, clinical procedure, new equipment or drug, have appropriate procedures for patient and organisational indemnity been arranged?			✓
Do all the researchers involved in the project hold a Dorothy House Contract of Employment or Honorary Contract?	✓		
Has the Chief Executive approved all agreements/contracts made with external organisations and/or funders?			✓

Signature of DH Lead Researcher: A. Holdoway
Date: 6.11.2015

APPENDIX 5

Letter to inform GP of patient participation

Dear Dr

Re: xxxxxxxxxxxx Dob: xxxxxxxxx

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Research Study - The role of diet in palliative cancer care – perceptions of patients, carers and healthcare professionals.

I am writing to inform you that the patient detailed above and a nominated carer xxxx and two healthcare professionals involved in their care, have consented to take part in a qualitative study to explore the role of diet in palliative cancer care from the patient’s, carer’s and healthcare professionals perspective. I have included information in this letter that outlines the rationale of the study and what is expected of participants.

Study Rationale and Background

Amongst patients with a palliative condition related to cancer, there are sound clinical rationale for attempting to improve nutritional intake, maintain weight and alleviate some of the metabolic and physical effects of the disease process and treatments. Symptoms in palliative care can impact on dietary intake; equally diet can be modified to alleviate symptoms including nausea, anorexia, early satiety, and bowel obstruction. Diet can also influence immune function and skin integrity. The management of unintentional weight loss and nutritional problems often centres on increasing dietary intake with the use of energy and nutrient rich foods. Advice is based on a logical approach and when feasible involves a skilled Dietitian to provide individualised counselling. Despite recommendations to offer advice and enhance dietary intake there is currently a lack of information on how patients and carers perceive or act upon the advice given. This study aims to gain insights into the experiences of patients, their carers and healthcare professionals, to help understand their views regarding the perceived role of diet and acceptability of advice given in a palliative condition related to cancer.

Study design:

Using a multiple case study approach, this study aims to explore through semi-structured interviews, the experience of patients and carers/family members and healthcare professionals, in managing diet related issues in palliative care including:

i. *how patients, carers and healthcare professionals currently perceive the role of diet in palliative conditions*

ii. how dietary issues and symptoms have been identified
iii. what advice was given, by whom and when
iv. what advice was adopted, was acceptable/practical, what worked, what didn't work and what facilitated / prevented uptake of advice and ideas.

A maximum of 8 patients, 8 matched family members/carers and 2 healthcare professionals for each patient who has been involved in the patient's care will be interviewed. Interviews will be recorded transcribed and analysed thematically.

How will the results be used and be of benefit:

Whilst 'nutrition' may influence immune function, skin integrity, bowel habit, physical symptoms, including nausea, anorexia, early satiety, bowel obstruction, food and eating experiences are deeply entwined with culture and the ability to eat has psychosocial ramifications. The Chief Investigator is an experienced dietitian currently working at Dorothy House Hospice as part of the specialist palliative care team and supports patients, carers and healthcare staff. It is evident from the literature, clinical network and clinical experience, that exploratory work is required in the UK to understand whether current approaches are acceptable to the patient and carer and the professionals involved to ensure that advice given is helpful rather than adding to the burden of disease.

The findings from the case studies will help expand our understanding of the identification of everyday challenges in managing dietary issues in life-limiting conditions, including but not restricted to identifying coping strategies, barriers to adoption of advice, success and impact of dietary interventions. Subsequently it is hoped this will assist Dietitians and healthcare professionals (at a National level) to develop educational materials, resources and deliver care that are tailored to the patients and carers' needs to optimise nutritional status, manage symptoms, functional status and enhance quality of life (QoL) in those with life-limiting conditions such as cancer undergoing palliative care.

The findings may also facilitate and enhance service development to meet the needs of palliative care patients and carers from which the participants may benefit.

I have enclosed a copy of the patient information sheet for your information, which gives more details of what is required of your patient.

If you have any questions or concerns relating to your patient or their nominated carer who have consented to taking part in this study, please do not hesitate to contact me on the number below.

With kind regards,

Anne Holdoway BSc RD MBDA

Chief Investigator Telephone xxxxxxxxxxxx

APPENDIX 6

PARTICIPANT INFORMATION SHEETS

A study to investigate the role of diet in palliative care as perceived by patients, family members /carers and healthcare professionals

Information sheet for patients

What is the study about?

Many people who have an incurable condition, such as cancer, experience symptoms and problems that can affect choice of food, appetite and ability to eat and drink. The pleasure around eating is often affected by both the treatments to manage the condition and the cancer itself. This study aims to find out first-hand, from individuals with incurable cancer, and a close family member or carer and healthcare professionals, views on the perceived role of diet.

What will you be asked to do?

We will ask you to have an interview with the investigator to gain an understanding of your experience of managing diet-related problems. We would first ask about your view on the role of diet in health and your diet before your illness. We will then ask you to describe any diet related problems you have had, outline any advice you were given, by whom and when, what was helpful, what was not and what is important. The overall aim of the study is to see if there are ways in which information and services for people should be changed and improved, thereby helping others to benefit in the future.

Who is involved in this project?

Anne who is leading the study is a healthcare professional at Dorothy House Hospice. Anne is undertaking the study as part of her doctorate studies at the University of Bath. As a patient under the care of Dorothy House Hospice, Anne’s colleagues have suggested that you might wish to participate. This information sheet is intended to provide more detail on your involvement and what is required to help you decide if you would like to take part and help in this study.

What is involved if I do take part?

You will be asked to take part in a one to one, face-to-face interview. The interview is likely to last up to an hour; you may be asked if you are happy to be contacted a second time to discuss the meaning of some of what you said in your interview. The second interview if needed is expected to be shorter and could take place face to face of over the phone the format will depend on how much needs to be discussed and what you are comfortable with.

The interview will have some structure. During the interview a series of prompts may be used to guide the discussion. The prompts act as a guide only and what is discussed will very much depend on what you wish to share. The more open you can be the more we can understand your experience.

We will try to make you feel comfortable throughout the interview so that you can talk openly about your experience. We will listen carefully to your answers. We will also record the interview to have an accurate record of your comments and experience. After the interview we will type up all you have said to then spend more time at a later date understanding what issues you have highlighted and compare your experience with the experience of others. None of the information will be attributable to you, that is it is anonymised. We may ask if we can revisit after interviewing other participants to clarify or go over some of your comments.

The role of others in the study.

We will also ask if you are happy to put forward the name of someone who is a close family member or friend who is involved in your care to share their experiences as a carer.

In addition you will also be asked to name two healthcare professionals (Nurses, Physiotherapist, Doctor, etc) who are involved in your care so that we can explore their experiences too to shape an overall picture how both you and those around you view the role of diet in palliative care.

Do I have to take part?

Taking part in the project is entirely optional. If you choose not to be part of the study your on-going care and support will not be affected.

Are there any potential drawbacks for you?

It is recognised that talking about food and diet may be an emotive topic, potentially stirring up certain feelings particularly if you have faced some real difficulties in eating and experienced for example unintentional weight loss, loss of enjoyment in eating.

Should you find it too distressing you can stop the interview or withdraw from the interview at any time. Equally talking about your experience can also be helpful, even if you are distressed. Although Anne will be visiting you as a researcher, if necessary, she will use her professional experience as a Dorothy House specialist to support you and, with your permission, she will let your nurse specialist know of any particular concerns that you express.

If you decide to participate in this study, we want you to feel that no additional demands are placed upon you. It is important that you do not feel under any pressure to take part and that you only participate if you feel you want to. If you have agreed to take part and then feel that being interviewed is too much for you to take on, you can withdraw and cancel the appointment at any time. Or you may wish to change the appointment. You can contact Anne at Dorothy House on Telephone number xxxxxxxxxxxx or email Anne at email xxxxxxxxxx.

What happens to the information?

All information you give remains entirely confidential. The voice recordings are ‘transcribed’ (typed up) into written words. All the comments are analysed together to create a picture of your experiences, and other patients like you. All the tapes and documents are kept in a locked cupboard and only the team analysing the data can see the information. At the end of the project all original material will be destroyed. When the research report is written your name will be replaced with a pseudonym and it will not include information that could identify you.

Disclosing information to others

There are rare circumstances, in which a researcher has a duty to disclose information gained during the research with the healthcare team. Should a situation like this arise, we would inform you and would seek professional advice, before disclosing any relevant information.

What if I want more information?

Please feel free to contact Anne for more information.

Anne can be contacted on Mobile _______________________
or email: xxxxxxxxxxxxxxxx

If Anne is unavailable on the phone, please leave a message as Anne will phone you back at the earliest opportunity.

What if I wish to make a complaint?

If you have any concerns or problems, please raise them initially with Anne if you feel able to. If you would prefer to speak to someone else please contact Helen de Renzie-Brett, Head of Education and Research or Ruth Gretton, Acting Director of Out Patients Services at Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE. Tel: xxxxx xxxxxx

---

A study to investigate the role of diet in palliative care as perceived by patients, family members /carers and healthcare professionals

Information sheet for family member / carer

What is the study about?

Many people who have an incurable condition, such as cancer, who are described as being in a palliative phase of care, experience symptoms and problems that can affect choice of food, appetite, ability to eat and drink. The pleasure associated with eating may also be affected by the treatments to manage the condition and the cancer. Whilst issues relating to diet have an impact on the person with the condition, they also may affect those around them. This study aims to find out first-hand, from individuals with incurable cancer and their carers, family members and healthcare professionals what diet-related issues have arisen and the perceived role of diet. As a family member/friend /carer (delete as applicable), we are looking to seek your views in being close to someone with a palliative condition. The study hopes to capture your experience of dealing with diet-related problems that have arisen, how you dealt with issues, what advice you were given by whom and when, what advice was helpful, what was not, what you feel is important to you and why. The overall aim is to see if needs are being met and whether there are ways in which information and services for people should be changed and improved, thereby helping others to benefit in the future.

Who is involved in this project?

Anne who is leading the study is a healthcare professional at Dorothy House Hospice. Anne is undertaking the study as part of her doctorate studies at the University of Bath. Xxxxxxxxx is currently a patient under the care of Dorothy House Hospice. xxxxxxxxxx who is taking part in the study has suggested you might agree to participate to share your experience as a family member / friend / carer. This information sheet is intended to provide more detail on your involvement and what is required to help you decide if you would like to take part and help in this study.

What is involved if I do take part?

You will be asked to take part in a one to one, face-to-face interview with Anne on 2 separate occasions. The first interview is likely to last up to an hour; the second interview if needed is expected to be shorter. This interview is scheduled to take place after we have interviewed xxxxxx. There will be some structure to the interview to guide the discussion but this is only a guide and what is discussed will very much depend on what you wish to share as an individual based on your experience in helping someone with an incurable disease manage dietary issues and your views on the role of diet. The more open you can be the more we can understand your experience.

Anne will try to make you feel comfortable throughout the interview so that you can talk openly about your experience. Anne will listen carefully to your answers but will also record the interview, in order to make an accurate record of your comments and experience. After the interview Anne will type up all you have said to then spend more time at a later date understanding what issues you have highlighted and compare your experience with the experience of others. None of the information will be attributable to you, that is, it is anonymised.

Anne may ask if she can revisit after interviewing other participants to clarify or go over some of your comments.

Do I have to take part?

The patient xxxxxx thought you would be happy to participate, however taking part in the study is entirely optional. If you choose not to be part of the study, on-going support will not be affected.

Are there any potential drawbacks for you?

It is recognised that talking about food and diet may be an emotive topic and stir up certain feelings particularly if the person you care for has faced some real difficulties in eating and experienced for example unintentional weight loss, loss of enjoyment in eating.

Should you find it too distressing you can stop the interview or withdraw from the interview at any time. Equally talking about your experience can also be helpful, even if you are distressed. Although Anne will be visiting you as a researcher, if necessary she will use her professional experience as a Dorothy House specialist to support you and, with your permission, she will let the nurse specialist know of any particular concerns that you express.

In participating in this study Anne does not wish to add to the demands on you. It is important that you do not feel under any pressure to take part and that you only participate if you feel you want to. If you feel that being interviewed is too much for you to take on, you can withdraw and cancel the appointment at any time. Or you may wish to change the appointment. You can contact Anne at Dorothy House on Telephone xxxxx xxxxxx or email Anne at xxxxxxxx

What happens to the information?

All information you give remains entirely confidential. The voice recordings are ‘transcribed’ (typed up) into written words. All the comments are analysed together to create a picture of your experiences, and others like you. All the tapes and documents are kept in a locked cupboard and only the team analysing the data can see the information. At the end of the project all original material will be destroyed. When the research report is written your name will be replaced with a pseudonym and it will not include information that could identify you. There are rare circumstances, in which a researcher has a duty to disclose information gained during the research with the healthcare team. Should a situation like this arise, Anne would inform you and would seek professional advice, before disclosing any relevant information.

What if I want more information?

Please feel free to contact Anne for more information.

Anne can be contacted on Mobile ________________________
Or email xxxxxxxxx

If Anne is unavailable please leave a message and Anne will then phone you back at the earliest opportunity.

What if I want to complain?

If you have any concerns or problems, please raise them initially with Anne if you feel able to. If you would prefer to speak to someone else please contact Helen de Renzie-Brett, Head of Education and Research or Ruth Gretton, Acting Director of Out Patient Services at Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE. Tel: xxxxx

A study to investigate the role of diet in palliative care as perceived by patients, family members /carers and healthcare professionals

Information sheet for healthcare professional

What is the study about?

Many people who have an incurable condition, such as cancer, who are described as being in a palliative phase of care, experience symptoms and problems that can affect choice of food, appetite, ability to eat and drink. The pleasure around eating is often affected by both the treatments to manage the condition and the cancer itself. This study aims to find out first-hand, from individuals with incurable cancer and their careers, family members and healthcare professionals the perceived role of diet in palliative care. Interviews with healthcare professionals will explore what diet related problems arose amongst the person whose care you have been involved with, how you identified problems, how you believe diet may influence symptoms, whether you feel dietary problems or issues were treatable or reversible, what advice you gave, other advice that you know was given when and by whom, what you feel was helpful to the patient / carer, what was not. The overall aim is to see if there are ways in which information and services for people with palliative conditions and their carers and healthcare teams could be changed and improved, thereby helping others to benefit in the future.

Who is involved in this project?

Anne who is leading the study is a healthcare professional at Dorothy House Hospice. Anne is undertaking the study as part of her doctorate studies at the University of Bath. XXXXXXXX is currently a patient under the care of Dorothy House Hospice. XXXXXXXX who is taking part in the study has recommended you as a healthcare professional who is involved in their care to participate.
This information sheet is intended to provide more detail on your involvement and what is required to help you decide if you are happy to take part in this study.

What is involved if I do take part?

You will be asked to take part in a one to one, face-to-face interview with Anne on 2 separate occasions. The first interview is likely to last up to an hour, the second interview will be shorter (and may not be required). The interview is scheduled to take place after we have interviewed the patient xxxxxx. There will be some structure to the interview to guide the discussion but this is only a guide and what is discussed will very much depend on what you wish to share as an individual based on your experience in helping someone with an incurable disease manage dietary issues. The more open you can be the more we can understand your experience. The interview is not being used to 'test' your knowledge or assess your level of skill.

Anne will aim to make you feel comfortable throughout the interview so that you can talk openly about your experience and will listen carefully to your answers.

Anne will record the interview in order to make an accurate record of your comments and experience. After the interview Anne will type up all you have said to then spend more time understanding what issues you have highlighted and compare your experience with the experience of others. None of the information will be attributable to you, that is, it is anonymised.

Anne may ask if she can revisit after interviewing other participants (patients, carers, family members, other healthcare professionals) to clarify or go over some of your comments.

Do I have to take part?

The patient xxxxxx and carer xxxxxx have volunteered to participate and thought you would be happy to participate; however taking part in the study is entirely optional.

Are there any potential drawbacks for you?

Should you find the interview distressing in any way you can stop the interview or withdraw from the interview at any time. Although Anne will be interviewing you as a researcher, she will, if necessary, use her professional experience as a Dorothy House specialist.

In participating in this study Anne does not wish to add to the demands on you. It is important you do not feel under any pressure to take part and that you only participate if you feel you want to. You can withdraw and cancel the appointment at any time. Or you may wish to change the appointment, if this is the case please contact Anne at Dorothy House on Telephone xxxxxx or email Anne at xxxxxxxxx

What happens to the information?

All information you give remains entirely confidential. The voice recordings are ‘transcribed’ (typed up) into written words. All the comments are analysed together to create a picture of your experience, and others in a similar role. All the tapes and documents are kept in a locked cupboard and only the team analysing the data can see the information. At the end of the project all original material will be destroyed. When the research report is written your name will be replaced with a pseudonym and it will not include information that could identify you. There are rare circumstances, in which a researcher has a duty to disclose information gained. Should a situation like this arise, Anne would inform you and would seek professional advice, before disclosing any relevant information.

What if I want more information?

Please feel free to contact Anne for more information.

Anne can be contacted on Mobile ________________________
Or email: xxxxxxxx

If Anne is unavailable please leave a message, as Anne will then phone you back at the earliest opportunity.

What if I want to complain?

If you have any concerns or problems please raise them initially with Anne if you feel able to. If you would prefer to speak to someone else please contact Helen de Renzie-Brett, Head of Education and Research or xxxxxxx, Acting Director of Out Patient Services, Dorothy House Hospice, Winsley, Bradford on Avon, BA15 2LE. Tel: xxxxxxx

APPENDIX 7

Consent Form

A study investigating the role of diet in palliative care as perceived by patients, family/carers and healthcare professionals.

Lead researcher: Anne Holdoway

Please initial each box to confirm consent:

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

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my care or that of the person I care for or my legal rights being affected. ☐

I agree to take part in an interview in relation to this study. ☐

I understand that the information collected will be used to support other research the future and may be shared anonymously with other researchers ☐

I agree to my General Practitioner (GP) being informed of my participation in this study ☐

The study has been approved by the University of Bath Research Committee and NHS research and ethics.

Name of participant ____________________ Date __________ Signature ____________________

Name of interviewer ____________________ Date __________ Signature ____________________

1 copy for participant

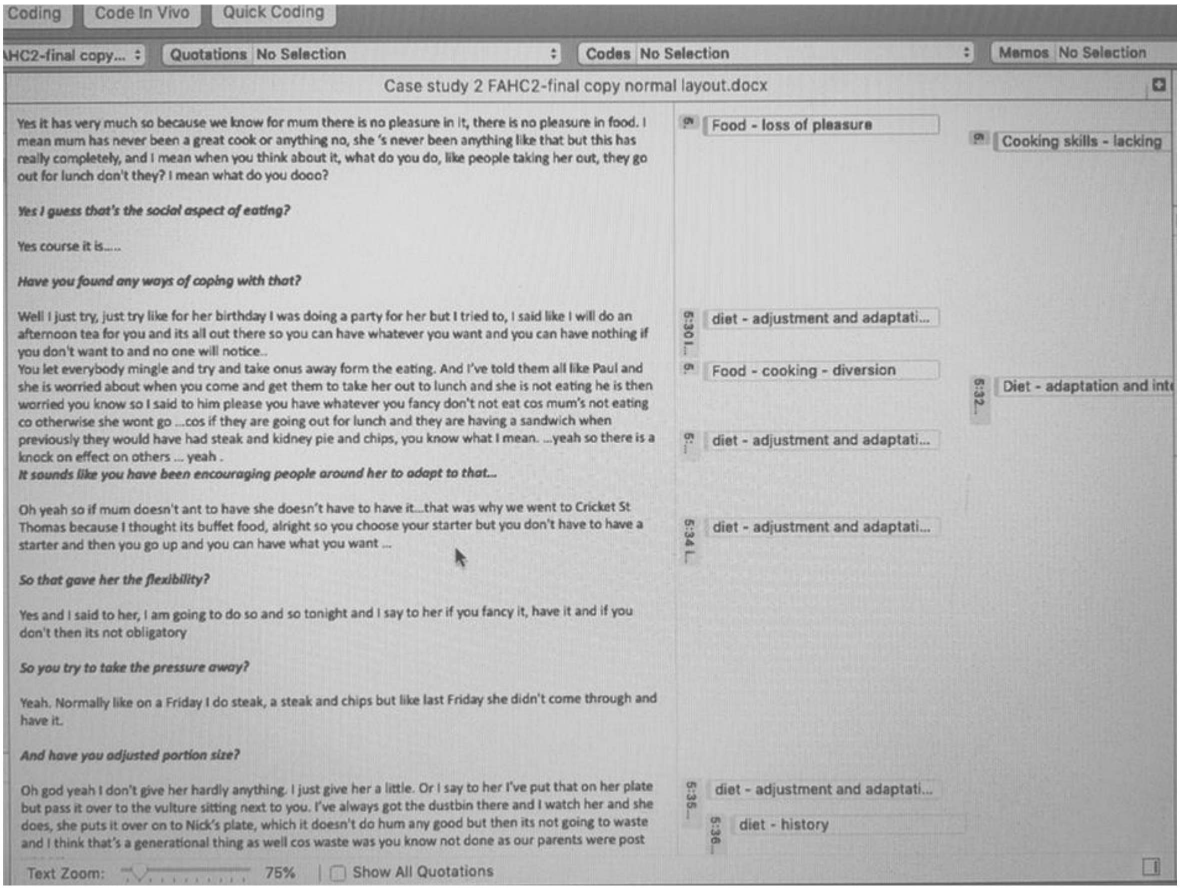
1 copy for interviewer

1 copy for medical record

APPENDIX 8

Coded transcripts and codes created

Example of coded transcript and codes created in first stage familiarisation



Yes it has very much so because we know for mum there is no pleasure in it, there is no pleasure in food. I mean mum has never been a great cook or anything no, she 's never been anything like that but this has really completely, and I mean when you think about it, what do you do, like people taking her out, they go out for lunch don't they? I mean what do you dooo?

Yes I guess that's the social aspect of eating?

Yes course it is.....

Have you found any ways of coping with that?

Well I just try, just try like for her birthday I was doing a party for her but I tried to, I said like I will do an afternoon tea for you and its all out there so you can have whatever you want and you can have nothing if you don't want to and no one will notice..
You let everybody mingle and try and take onus away form the eating. And I've told them all like Paul and she is worried about when you come and get them to take her out to lunch and she is not eating he is then worried you know so I said to him please you have whatever you fancy don't not eat cos mum's not eating co otherwise she wont go ...cos if they are going out for lunch and they are having a sandwich when previously they would have had steak and kidney pie and chips, you know what I mean. ...yeah so there is a knock on effect on others ... yeah .
It sounds like you have been encouraging people around her to adapt to that...

Oh yeah so if mum doesn't ant to have she doesn't have to have it...that was why we went to Cricket St Thomas because I thought its buffet food, alright so you choose your starter but you don't have to have a starter and then you go up and you can have what you want ...

So that gave her the flexibility?

Yes and I said to her, I am going to do so and so tonight and I say to her if you fancy it, have it and if you don't then its not obligatory

So you try to take the pressure away?

Yeah. Normally like on a Friday I do steak, a steak and chips but like last Friday she didn't come through and have it.

And have you adjusted portion size?

Oh god yeah I don't give her hardly anything. I just give her a little. Or I say to her I've put that on her plate but pass it over to the vulture sitting next to you. I've always got the dustbin there and I watch her and she does, she puts it over on to Nick's plate, which it doesn't do hum any good but then its not going to waste and I think that's a generational thing as well cos waste was you know not done as our parents were post

CODES (LABELS) AND CATEGORIES

CATEGORIES:

- Dietary issues when living with non-curative cancer - Impact of cancer and treatments to social life, food choice, interactions, job, status, identity, weight, function
- How dietary issues were identified or not – questioning, probing, where, when.
- Dietary advice offered – acceptability, usefulness, understanding, self-determined,
- Knowledge – standardised, individualised, experience (novice vs expert, junior vs senior), incidental, accidental (serendipity), experimenting, logic, influence of others, previous life experiences
- Success in dealing with issues – nutrition as a priority, realism, previous experiences, openness to see patients and carers as source of information and heeding their lived experience, seeing nutrition as a modifiable factor in managing symptoms/function /QoL, adaptation, acceptance of a 'new norm'

APPENDIX 9

Initial coding in first round of familiarisation

Background	Participant Social situation Medical history Diagnosis Treatment -journey
Diet before cancer	Attitudes towards diet & health Healthy eating Weight management Psychosocial elements Determinants/influence Role of food and meals
Diet when living with non-curative cancer - Impact of cancer and treatments to social life, food choice, interactions, job	Challenges Changes e.g. taste Dependency on artificial nutrition support Need for dietary modification Treatment effects e.g. side effects of treatment producing symptoms interfering with ability to eat and drink Appetite, satiety, hunger Symptoms impacting on food choice/diet and QoL Nutrient intake and function - functional loss, weight, activities of daily living. Identity

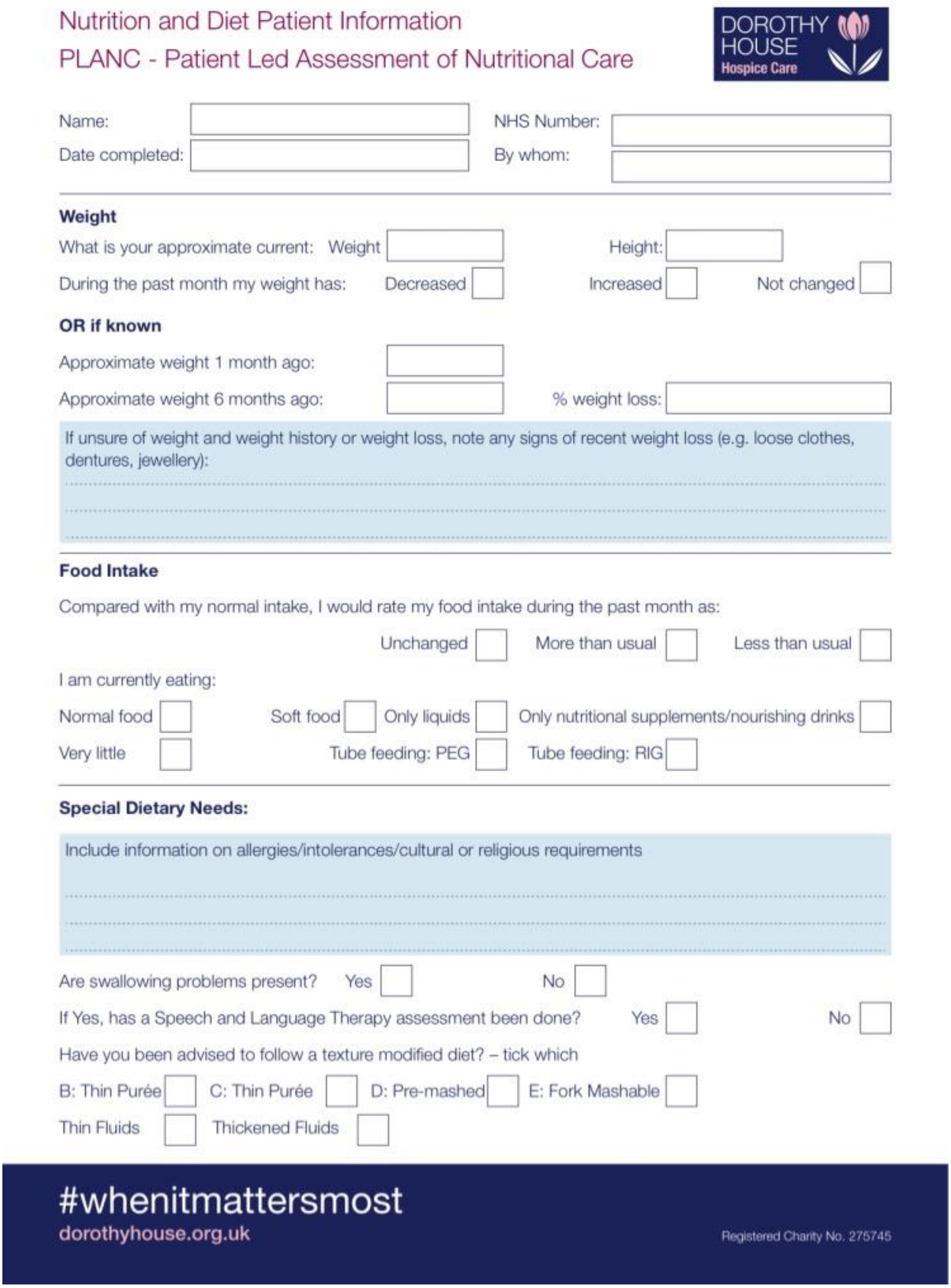
	Symptoms affecting or affected by diet. Losses Persistence and drivers to eat Social life, family life, routines
Dietary advice offered	Practical, useful, able to act / implement, timeliness, not available, conflicting, unhelpful
Knowledge and understanding and expectations	Professional knowledge / acquired knowledge to advise on diet, symptoms and how the two may be connected Patient / carer knowledge – previous experiences, structured or by accident 'serendipidty' Knowledge to empower the patient and carer to cope, become self-managing, adjust anticipating projection or likely symptoms and progression of disease. Conflicting and contradictory advice Hearing the patient / carer voice and heeding their lived experience and adjusting
Coping with a progressive condition	Acceptance of a 'new norm' by the patient and by the family and the need to change with time Experience of the HCP in anticipating issues and anticipating change and supporting the patients and carers
Adaptation	Dealing with loss e.g. eating out Adjusting to what was possible – finding new ways, family interactions, meals, shopping, texture, tube feeding.
Barriers	Patient / carer and HCP knowledge

	Resources Time in consultations. Loss of time by not knowing or not being sorted. Conflicting advice and not ‘fitting the norm’. Not heeding the patient voice/experience
Facilitators	Experience in clinical practice accrued from patients (Seeing it before / drawing from other cases, purposively using experience). Probing – beneath the surface – not the obvious. The patient’s /carer’s own experience and joint desire to seeking solutions Viewing the role of nutrition and diet as important (survivorship, function, outcomes, well-being) Being able to access an ‘expert’, willingness to learn and seek advice from expert. Being proactive Remaining upbeat, focussing on what was possible, accepting loss or change.

APPENDIX 10

Hospice Nutrition Assessment Tool

Patient Led Assessment for Nutritional Care (PLANC)



Nutrition and Diet Patient Information
PLANC - Patient Led Assessment of Nutritional Care

DOROTHY HOUSE
Hospice Care

Name:
NHS Number:
Date completed:
By whom:

Weight

What is your approximate current: Weight ☐ Height: ☐

During the past month my weight has: Decreased ☐ Increased ☐ Not changed ☐

OR if known

Approximate weight 1 month ago: ☐

Approximate weight 6 months ago: ☐ % weight loss: ☐

If unsure of weight and weight history or weight loss, note any signs of recent weight loss (e.g. loose clothes, dentures, jewellery):

....

....

....

Food Intake

Compared with my normal intake, I would rate my food intake during the past month as:

Unchanged ☐ More than usual ☐ Less than usual ☐

I am currently eating:

Normal food ☐ Soft food ☐ Only liquids ☐ Only nutritional supplements/nourishing drinks ☐

Very little ☐ Tube feeding: PEG ☐ Tube feeding: RIG ☐

Special Dietary Needs:

Include information on allergies/intolerances/cultural or religious requirements

....

....

....

Are swallowing problems present? Yes ☐ No ☐

If Yes, has a Speech and Language Therapy assessment been done? Yes ☐ No ☐

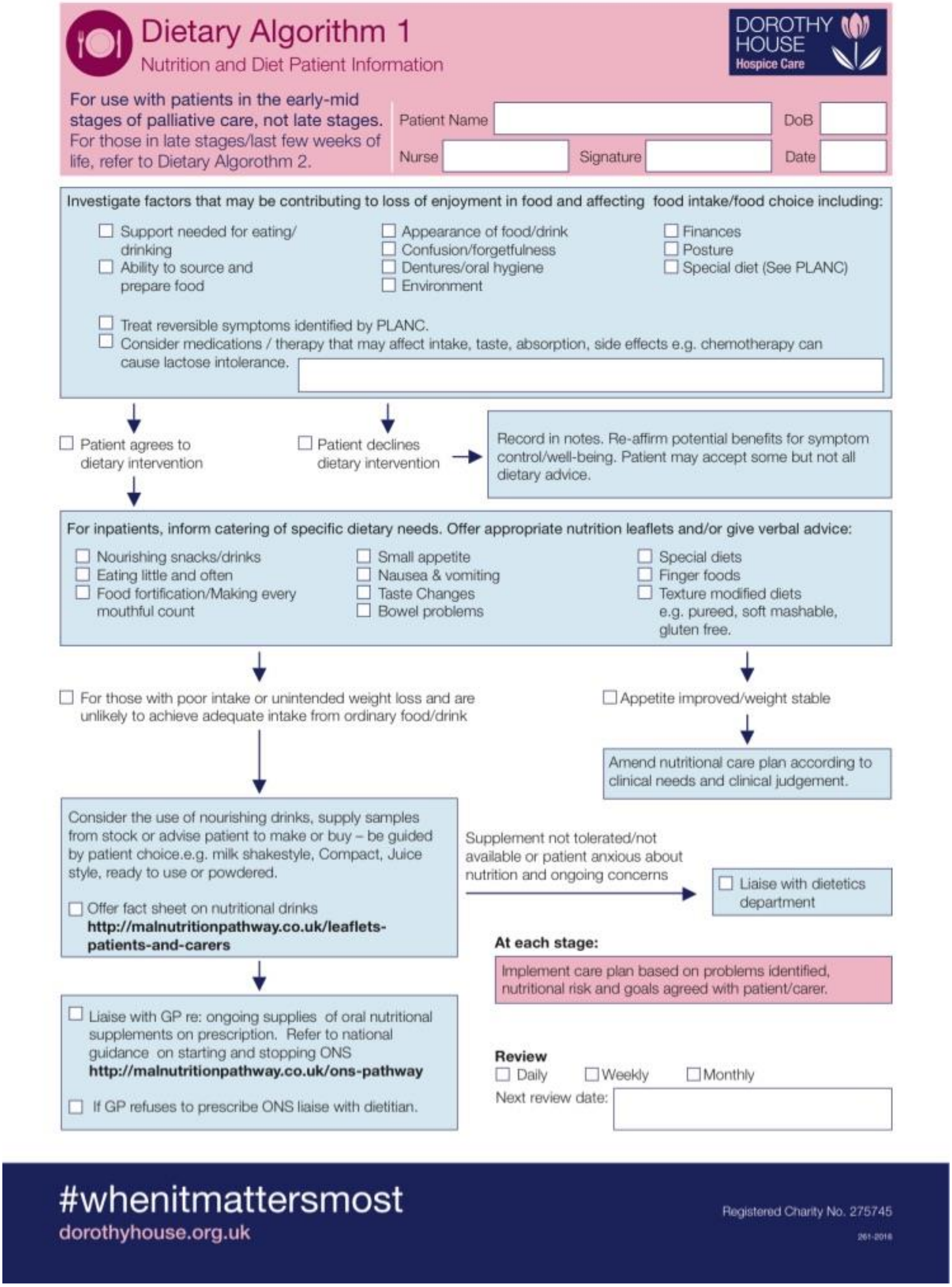
Have you been advised to follow a texture modified diet? – tick which

B: Thin Purée ☐ C: Thin Purée ☐ D: Pre-mashed ☐ E: Fork Mashable ☐

Thin Fluids ☐ Thickened Fluids ☐

#whenitmattersmost
dorothyhouse.org.uk

Registered Charity No. 275745



Dietary Algorithm 1

Nutrition and Diet Patient Information

DOROTHY HOUSE
Hospice Care

For use with patients in the early-mid stages of palliative care, not late stages. For those in late stages/last few weeks of life, refer to Dietary Algorothm 2.

Patient Name ________ DoB ________
Nurse ________ Signature ________ Date ________

Investigate factors that may be contributing to loss of enjoyment in food and affecting food intake/food choice including:

- ☐ Support needed for eating/ drinking
- ☐ Ability to source and prepare food
- ☐ Appearance of food/drink
- ☐ Confusion/forgetfulness
- ☐ Dentures/oral hygiene
- ☐ Environment
- ☐ Finances
- ☐ Posture
- ☐ Special diet (See PLANC)

- ☐ Treat reversible symptoms identified by PLANC.
- ☐ Consider medications / therapy that may affect intake, taste, absorption, side effects e.g. chemotherapy can cause lactose intolerance.

☐ Patient agrees to dietary intervention

☐ Patient declines dietary intervention → Record in notes. Re-affirm potential benefits for symptom control/well-being. Patient may accept some but not all dietary advice.

For inpatients, inform catering of specific dietary needs. Offer appropriate nutrition leaflets and/or give verbal advice:

- ☐ Nourishing snacks/drinks
- ☐ Eating little and often
- ☐ Food fortification/Making every mouthful count
- ☐ Small appetite
- ☐ Nausea & vomiting
- ☐ Taste Changes
- ☐ Bowel problems
- ☐ Special diets
- ☐ Finger foods
- ☐ Texture modified diets e.g. pureed, soft mashable, gluten free.

☐ For those with poor intake or unintended weight loss and are unlikely to achieve adequate intake from ordinary food/drink

Consider the use of nourishing drinks, supply samples from stock or advise patient to make or buy – be guided by patient choice.e.g. milk shakestyle, Compact, Juice style, ready to use or powdered.

☐ Offer fact sheet on nutritional drinks **http://malnutritionpathway.co.uk/leaflets-patients-and-carers**

☐ Liaise with GP re: ongoing supplies of oral nutritional supplements on prescription. Refer to national guidance on starting and stopping ONS **http://malnutritionpathway.co.uk/ons-pathway**

☐ If GP refuses to prescribe ONS liaise with dietitian.

☐ Appetite improved/weight stable

Amend nutritional care plan according to clinical needs and clinical judgement.

Supplement not tolerated/not available or patient anxious about nutrition and ongoing concerns → ☐ Liaise with dietetics department

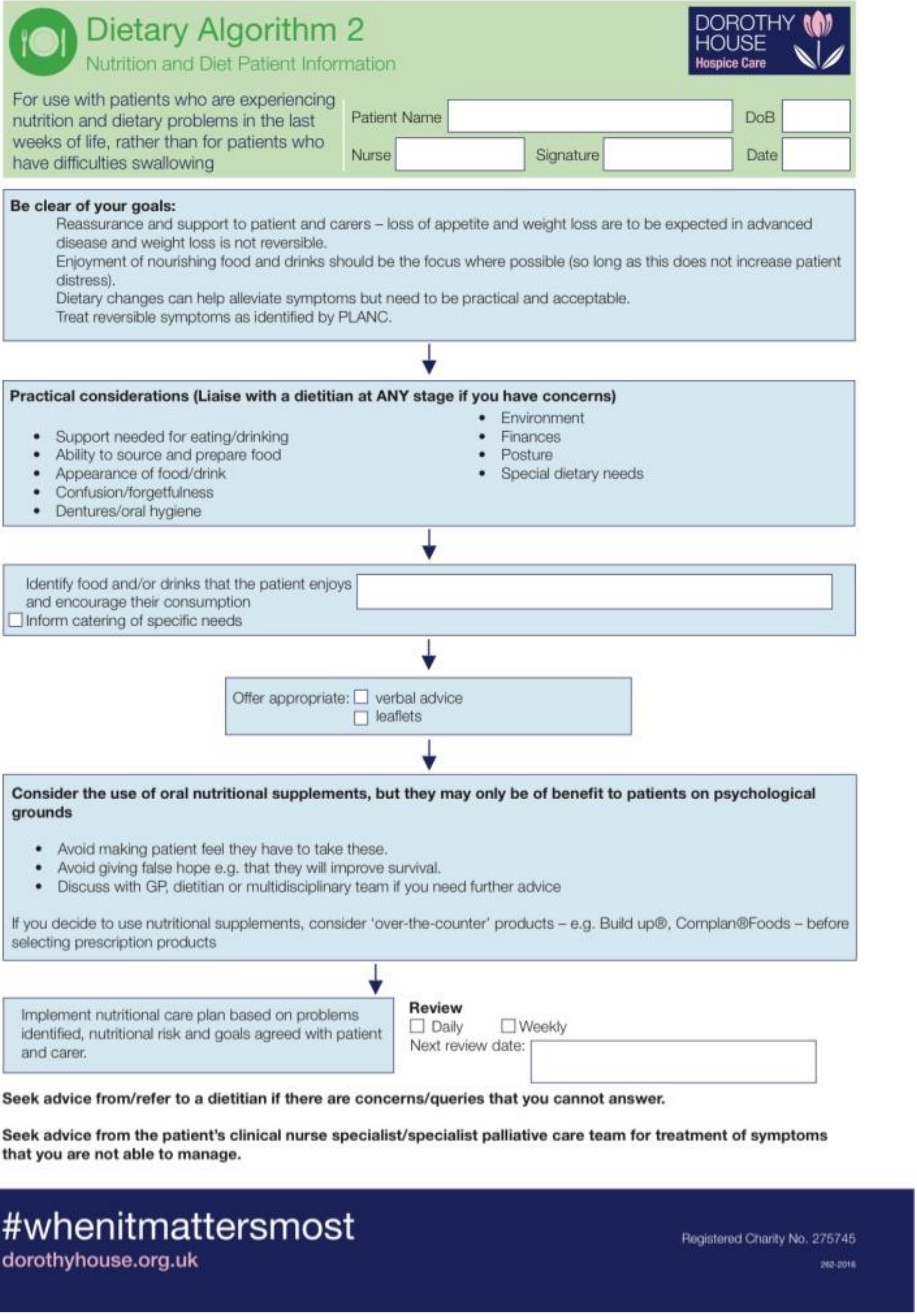
At each stage:

Implement care plan based on problems identified, nutritional risk and goals agreed with patient/carer.

Review
☐ Daily ☐ Weekly ☐ Monthly
Next review date: ________

#whenitmattersmost
dorothyhouse.org.uk

Registered Charity No. 275745
261-2016



Dietary Algorithm 2

Nutrition and Diet Patient Information

DOROTHY HOUSE
Hospice Care

For use with patients who are experiencing nutrition and dietary problems in the last weeks of life, rather than for patients who have difficulties swallowing

Patient Name
DoB
Nurse
Signature
Date

Be clear of your goals:

Reassurance and support to patient and carers – loss of appetite and weight loss are to be expected in advanced disease and weight loss is not reversible.

Enjoyment of nourishing food and drinks should be the focus where possible (so long as this does not increase patient distress).

Dietary changes can help alleviate symptoms but need to be practical and acceptable.

Treat reversible symptoms as identified by PLANC.

Practical considerations (Liaise with a dietitian at ANY stage if you have concerns)

- Support needed for eating/drinking
- Ability to source and prepare food
- Appearance of food/drink
- Confusion/forgetfulness
- Dentures/oral hygiene
- Environment
- Finances
- Posture
- Special dietary needs

Identify food and/or drinks that the patient enjoys and encourage their consumption

☐ Inform catering of specific needs

Offer appropriate: ☐ verbal advice
☐ leaflets

Consider the use of oral nutritional supplements, but they may only be of benefit to patients on psychological grounds

- Avoid making patient feel they have to take these.
- Avoid giving false hope e.g. that they will improve survival.
- Discuss with GP, dietitian or multidisciplinary team if you need further advice

If you decide to use nutritional supplements, consider 'over-the-counter' products – e.g. Build up®, Complan®Foods – before selecting prescription products

Implement nutritional care plan based on problems identified, nutritional risk and goals agreed with patient and carer.

Review
☐ Daily ☐ Weekly
Next review date:

Seek advice from/refer to a dietitian if there are concerns/queries that you cannot answer.

Seek advice from the patient's clinical nurse specialist/specialist palliative care team for treatment of symptoms that you are not able to manage.

#whenitmattersmost
dorothyhouse.org.uk

Registered Charity No. 275745
262-2016

APPENDIX 11

Hospice training course on nutrition ‘A Holistic Approach to Nutrition in Palliative and End of Life Care’

Outline / facilitator notes

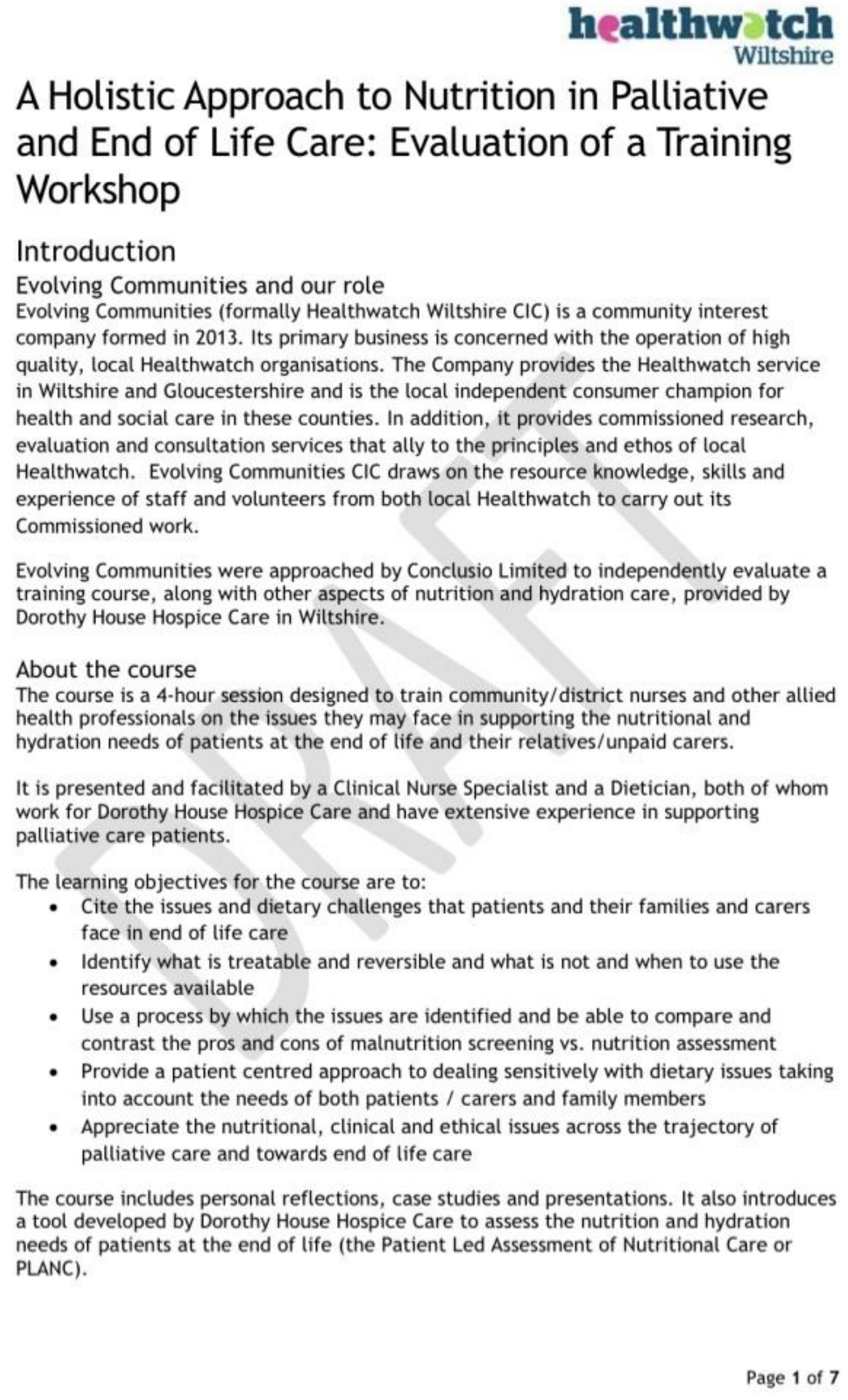
Learning outcomes

- Cite the issues and dietary challenges that patients and their families and carers face in end of life care
- Identify what is treatable and reversible and what is not and when to use the resources available
- Use a process by which the issues are identified and be able to compare and contrast the pros and cons of malnutrition screening vs. nutrition assessment
- Provide a patient-centred approach to dealing sensitively with dietary issues, considering the needs of both patients / carers and family members
- Appreciate the nutritional, clinical and ethical issues across the trajectory of palliative care and towards end of life care

Facilitators: xxxxxxxx (Specialist Dietitian) & xxxxxx (Palliative Nurse Specialist)

Activity	Resources	Facilitator
Registration and refreshments		
Welcome and Introductions • Ground rules • Housekeeping and Health Warning • Learning outcomes	**Flipchart**	
Nutrition and End of Life Care Introductions for afternoon session Overview and expectations **Participant’s experience of nutritional issues in end of life care.** **In groups (x mins):** • What is your experience of caring for people with dietary issues in end of life care? • What kind of diet related issues have you experienced which are challenging at the end of life? **Feedback:** Draw out; the issues they have witnessed, how they identify the issues, tensions between patients and family members, expectations, physical issues such as swallowing, appetite and portions, dietary habits and the	**Flipchart**	

challenge of change and acceptance. How have they dealt with them? Support from other healthcare professional including accessing dietetic services?		
Nutritional problems in palliative and end of life care • Underlying causes • Patient and carer perspectives • Misconceptions, myths and beliefs around nutrition	**PPT slides** **Participants / flip chart**	
Issues in nutrition **What is treatable/fixable** and what's not and the importance of timely advice across the palliative care trajectory	**PPT slides**	
Tea/Coffee		
Assessment – PLANC, identifying issues • Screening vs. assessment – what's the difference? • Nurse led study (FONs) and the development of tools and resources to assess and provide a holistic approach to nutrition in palliative and end of life care	**Copies of the tools**	
Ethics and nutrition • When diet becomes a burden not a benefit. • Is it acceptable to not offer nutrition? • Supporting the family with ethical decisions.	**National guidance,** **PPT slides and discussion**	
Care Planning – application of knowledge to practice Case studies - group work (15 mins): each group (6 – 8) Discuss a case study, identify the issues and discuss how you might deal with them. Feedback to all participants (20 mins).	**Group work - Case studies and discussion.** **AH/JS and others to facilitate**	
Summary, signposting, evaluation and close		



A Holistic Approach to Nutrition in Palliative and End of Life Care: Evaluation of a Training Workshop

Introduction

Evolving Communities and our role

Evolving Communities (formally Healthwatch Wiltshire CIC) is a community interest company formed in 2013. Its primary business is concerned with the operation of high quality, local Healthwatch organisations. The Company provides the Healthwatch service in Wiltshire and Gloucestershire and is the local independent consumer champion for health and social care in these counties. In addition, it provides commissioned research, evaluation and consultation services that ally to the principles and ethos of local Healthwatch. Evolving Communities CIC draws on the resource knowledge, skills and experience of staff and volunteers from both local Healthwatch to carry out its Commissioned work.

Evolving Communities were approached by Conclusio Limited to independently evaluate a training course, along with other aspects of nutrition and hydration care, provided by Dorothy House Hospice Care in Wiltshire.

About the course

The course is a 4-hour session designed to train community/district nurses and other allied health professionals on the issues they may face in supporting the nutritional and hydration needs of patients at the end of life and their relatives/unpaid carers.

It is presented and facilitated by a Clinical Nurse Specialist and a Dietician, both of whom work for Dorothy House Hospice Care and have extensive experience in supporting palliative care patients.

The learning objectives for the course are to:

- Cite the issues and dietary challenges that patients and their families and carers face in end of life care
- Identify what is treatable and reversible and what is not and when to use the resources available
- Use a process by which the issues are identified and be able to compare and contrast the pros and cons of malnutrition screening vs. nutrition assessment
- Provide a patient centred approach to dealing sensitively with dietary issues taking into account the needs of both patients / carers and family members
- Appreciate the nutritional, clinical and ethical issues across the trajectory of palliative care and towards end of life care

The course includes personal reflections, case studies and presentations. It also introduces a tool developed by Dorothy House Hospice Care to assess the nutrition and hydration needs of patients at the end of life (the Patient Led Assessment of Nutritional Care or PLANC).

APPENDIX 12

Outputs associated with the thesis

List of resources created as a result of the research ‘Perceptions of diet in palliative cancer as perceived by patients, carers and healthcare professionals

- Dietetic resource folder – includes 30 advice sheets and tips for managing diet-related issues in palliative and end of life care. For use by the palliative care MDT
- Having an enteral feeding tube – further questions to ask https://www.peng.org.uk/pdfs/hcp-resources/having-an-enteral-feeding-tube-faqs.pdf
- Enteral tube feeding – Your questions answered https://www.peng.org.uk/pdfs/hcp-resources/enteral-tube-feeding-your-questions-answered.pdf
- Integration of carer questions and development and validation of a patient centred nutrition assessment tool http://www.ehospice.com/ArticleView/tabid/10697/ArticleId/21504/View.aspx
- A guide to bolus tube feeding for healthcare professionals: https://www.nutriciahcp.com/uploadedFiles/Main/Sub_sites/ONS_Site/ons/Studies/BolusFeedingInAdultsAPracticalGuide.pdf
- Holdoway A, Smith, Harp K on behalf of the Royal College of Physicians (2020) ‘Feeding Difficulties and Dilemmas towards the End of Life’ Chapter 2 (in press)
- Co-author of paper submitted to the All Party Parliamentary Group in Westminster on Nutrition in End of Life care
- Conference presentations on the role of nutrition in palliative care
- Creation of a nurse and dietetic led training programme ‘A holistic approach to nutrition in palliative and end of life care’. See appendix Xx for course outline and content
- Healthwatch survey to evaluate change in knowledge following attendance at training programme ‘A holistic approach to nutrition in palliative and end of life care’ . See evaluation report appendix XXXXX
- Presentations at educational forums to help shape future care and guidance on diet and nutrtion in palliative care – Southwest Oncology Dietitians, Hospice Annual Conference 2016
- 2 x poster presentations at Hospice UK Annual meeting 2016, abstracts published in BMJ:
  P-113 Holdoway, A, King K, Gretton R Service innovation to meet the increasing demand for dietetics in palliative care
  P-114 Souter J, Jill Souter, Czerwinska A, Cooley S, Holdoway A. A holistic approach to nutrition and diet in palliative care
  https://spcare.bmj.com/content/bmjspcare/6/Suppl_1/A51.2.full.pdf

Abstract accepted for poster presentation at BAPEN annual conference 2018

Title: A holistic approach to nutrition and diet in palliative care. By: A Holdoway, J Souter, A Czerwinska and S Cooley, *Dorothy House Hospice, Winsley, England BA15 2LE*

Background: In response to the Care Quality Commission[1] and NHS contract requirements, a validated screening tool; the Malnutrition Universal Screening Tool 'MUST'[2] was introduced into our hospice setting in 2012. Subsequent research amongst nursing staff[3] confirmed lack of suitability of 'MUST' in identifying and guiding decisions for appropriate nutritional care in our patient population. A project team was established to investigate how we might assess, plan and deliver appropriate nutritional care, taking into account the changing and complex needs of patients and carers in the hospice setting. Funding was awarded from the Foundation of Nursing Studies to assist project costs.

Aims: To identify nutritional issues experienced and develop a nutrition assessment tool to sensitively determine and deliver nutritional care to meet the needs of patients and carers.

Methods: A practice development approach[4] was utilised, engaging all stakeholders. The approach included:

- questionnaires to staff
- discussion forums involving members of the multidisciplinary healthcare team, patients, carers, volunteers and catering.
- qualitative interviews with patients/carers.

Findings were used to initiate change and refine and validate a nutrition assessment tool.

Results: Results from the questionnaires and forums identified issues affecting the delivery of optimal nutritional care. Solutions were identified and tested - patient and carer participation was a key component. A new nutrition assessment tool – the 'Patient Led Assessment for Nutritional Care' (PLANC) was developed based on the MacMillan Durham Cachexia tool. PLANC was then tested in practice, refined and validated, to ensure that it could identify nutritional issues and determine care taking into account the stage of disease. The tool and nutrition and hydration were integrated into the dashboard of the shared patient record for use by all members of the healthcare teams. New training courses, pathways and resources were created to address common nutritional problems with triggers for escalation management to a specialist dietitian when required. The philosophy of the organisation has changed to acknowledge that whilst all patients are not at risk of malnutrition, all are likely to have nutrition and dietary issues that require recognition and support.

Conclusion: The practice development process for change fitted well with the ethos of the organisation and resulted in practice improvements to enhance nutritional care. The 'PLANC' tool and algorithms[5] for nutrition assessment and planning of nutritional care have since been integrated into all settings including out-patients, the in-patient unit and the community.

1. Care Quality Commission [2010] Guidance about Compliance: Essential Standards of Safety and Quality. London: Care Quality Commission. http://www.cqc.org.uk/db/documents/Essential standards of quality and safety March 2010 FINAL.pdf.
2. Elia, M. (Ed.) [2003] The 'MUST' Report. Nutritional Screening for Adults: A Multidisciplinary Responsibility. Development and use of the 'Malnutrition Universal Screening Tool' ('MUST') for adults. A report by the Malnutrition Advisory Group of the British Association for Parenteral and Enteral Nutrition. Redditch, Worcs: BAPEN.
3. BAPEN Conference (2013) Nutrition Screening in Palliative Care – An evaluation of Nurses' Attitudes to 'MUST'. Czerwinska, A, Holdoway A, de Renzie-Brett H.
4. McCormack, B., Manley, K. and Tinchen, A. (Eds.) [2013] Practice Development in Nursing and Healthcare. (2nd Edition). Oxford: Wiley-Blackwell.
5. Czerwinska A, Souter, J and Cooley, S (2016) A holistic approach to nutrition in palliative care https://www.fons.org/library/report-details/70527

APPENDIX 13

Reflective article on qualitative research

Delivering Patient-centred Care

How skills learned through qualitative research can underpin and enhance clinical proficiency to deliver patient-centred care

Anne Holdoway, BSc RD FBDA,
Consultant Dietitian – @AnneHoldoway

There is no doubt that medicine continues to progress, with patients benefitting from greater scientific knowledge and the application of that knowledge. Clinical care and medicine however are not purely science. In recent years there has been considerable emphasis on 'patient-centred care' and, indeed, in previous dietetic comments I have focused on this topic. Two recent but unrelated experiences, in which close family members required hospital care, inspired me to re-visit the topic of patient-centred care and what makes a good practitioner. I hope this commentary, based on a 30-year career and my own experiences including that involving qualitative research, will encourage you to reflect on your ability to listen to what is important to your clients and in turn deliver care that is truly patient-centred.

How many of you have heard friends and family members specifically single out good clinicians as a result of their great bedside manner. Such practitioners not only know their subject inside out but perhaps set themselves apart because of their interactions with patients and clients. It is likely that they sat down, appeared relaxed and listened to the patient's story. They no doubt expressed concern about the patient's problems and contextualised them. In contrast, if we fail to establish or listen to our patient's concerns during a consultation it can hardly be classed as consultative. Whilst we could claim we 'treated' them, the recipient may not view the treatment as successful, or satisfactory, if we failed to address their concerns.

So how might we as practitioners improve our skills? From a personal perspective undertaking qualitative research enhanced my skills in a manner that has been extremely valuable in clinical practice. Qualitative interviewing for clinical research purposes forces one to question openly, review content and uncover themes which are then contextualised. I believe similar skills lie at the heart of effective clinical interviewing (history taking). Including open ended questions, allowing patients to express themselves and their experience from their perspective, and carefully listening, can in my opinion enhance decisions about care and is particularly pertinent in solving complex cases.

In addition, skills learned in undertaking qualitative research such as being conscious of our own biases, beliefs and being non-judgmental in our approach, can benefit the partnership with our patients, helping us see the patient's issues as experienced by them rather than basing decisions on our own experience and values. Such an approach can reinforce the partnership working that lies at the heart of patient-centred care.

Learning to ask open-ended questions, as opposed to leading questions with only yes/no options, can take time and it is a technique that is at risk of being lost in standard pathways, care protocols and checklists.

Interestingly, studies by Beckman and Marvel in the 80s and 90s documented how physicians interrupted patient histories within 18 seconds, suggesting that clinicians have historically been quick to control the conversation. This may arise from time pressures in clinic but failing to engage and appreciate the patient perspective is likely to perpetuate client dissatisfaction and fuels the revolving door situation where clients continually bounce back into the system as we fail to treat them effectively.

Increasingly, clinical trials are utilising both quantitative and qualitative research techniques. Going forward effective healthcare is likely to rely on outcomes using both quantitative research from controlled trials to provide the hard data (the truths) on the impact of a treatment and qualitative research data to understand the patient experience and determine if the treatment is acceptable.

For me, undertaking qualitative research allowed me to gain a new perspective on the importance of objectivity and empathy; skills which I believe are particularly in supporting clients with life-limiting conditions and in palliative care where dietetics is increasingly playing an important role in symptom control, quality of life and achieving optimum nutrition. Understanding the patient's reality from their perspective though is arguably important to any field of healthcare – preventative, curative and supportive.

I would urge anyone who has the opportunity to be involved in qualitative research to seize the opportunity. The skills gained from collecting and interpreting rich data, and not imposing our values and prejudices, are highly transferable into practice and would serve to enhance clinical proficiency.

Returning to my recent experiences where family members were on the receiving end of healthcare, I witnessed stark contrasts in the care provided and patient engagement. In one setting my family member was managed at arm's length, observations were performed without a word being exchanged between professional and patient, neither the care plan nor investigations were communicated, nor was the potential working diagnosis discussed, and my family member was discharged with medications for which the purpose was not explained. In contrast, in another setting where another family member was cared for, they felt in a safe, trusted and caring environment and fully informed of the tests and outcome. Although the clinical outcome for either setting might be similar, I would argue the patient experience would differ. I know which organisation I would wish to be associated with and feel proud to be a part of – would you?

Anne Holdoway BSc RD MBDA e: anne@hph.ltd.uk

APPENDIX 14

INITIAL MAPPING OF FRAMEWORK TO ASSESS AND MANAGE DIET-RELATED ISSUES IN PALLIATIVE CARE INCLUDING PHYSIOLOGICAL AND PSYCHOSOCIAL FACTORS, BARRIERS AND FACILITATORS

PHYSIOLOGICAL	**PSYCHOSOCIAL FACTORS**
Small appetite and early satiety	Disruption to routines and social interactions
Swallowing problems	Loss of social integration
Gastrointestinal issues - Mucositis, sore mouth, dry mouth, taste changes, obstruction, diarrhoea, constipation	Anxiety and depression including that associated with life-limiting condition
Weight loss – physical function	Acceptance of new normal
Cachexia (early, mid, late)	Reframing the meaning of food – survivorship vs healthy eating
Treatment effects secondary to radiotherapy or chemotherapy – immediate and latent	Altered identity
Access to diagnostic tests	
Fatigue	
Cooking skills and access to shops	
Support for those who are dependent on others	

BARRIERS	**FACILITATORS**
Nutrition not seen as important or relevant e.g. focus on cure with treatments Concerns regarding inability to address the psychosocial aspects of eating and drinking – lack of knowledge or futility	Sensing whether diet was important for the patient and carer to gauge the need to address issues or let them rest Drive to seek solutions to 'make things better' including diversional activities, sham eating, feeding methods, family support, alternative social events Valuing role of diet in creating social interactions Supporting a new meaning and relationship with food
Not recording sequential weights, seeing one or two weights in isolation so not aware of trends over weeks and months	Gaining insights into what weight the patient considers normal, unintentional

Not acknowledging patient's ideal weight / physicality	weight changes, assessing weight over time
Failing to put into context the impact of the cancer and its treatments on the ability to eat, drink, maintain nutritional status	Explaining the physiology / mechanisms of cancer cachexia to facilitate acceptance of weight loss/poor appetite and agree realistic goals
Lack of conversation or questioning on ability to eat, problems	Conversations probing for diet-related issues and concerns
Lack of time to question nutrition	Building conversations about appetite and eating into other tasks
Ignoring patient requests for information. Failing to acknowledge or observe diet-related or nutrition related problems	Access to resources custom made for client population
Scepticism as to whether nutrition made a difference, served a purpose, belief unable to effect weight Dietary modification viewed as unhealthy	Linking nutrition to functional ability, strength, fatigue management Alleviating tensions around eating and food Balancing desires to achieve healthy diet with the need to get Calories in Promoting the supportive role of nutrition Putting 'health messages' into context e.g. explain they are population driven and unsuitable for those poor appetite
Limited knowledge to deal with issues	Access to nutrition champions, dietitians, training and education Providing resources, signposting, creating new resources where gaps identified Suggesting adaptations in food choice, preparation, frequency, eating patterns Encouraging peer to peer support and shared experience to facilitate coping - rebuilding confidence
Weight viewed as taboo topic, HCP fear of not having answers solutions, not being possible to gai weight or eradicate symptom	Sensing the loss and looking to fill or replace it Supporting a new meaning and relationship with food – afternoon tea as opposed to large meal
Too tired to prepare, cook or shop	Gaining help from family members – using food and meal preparation as a

	means of leveraging help e.g. in the home, when needed
Not being aware of range of symptoms	Questioning for nutrition impact symptoms using prompts.
Persistence of symptoms	Seeking help as to whether underlying cause could be tested for, relieved or addressed by the MDT
Lack of concordance in healthcare team	Agreement, reiteration and reinforcement of potential benefit of nutrition amongst the healthcare team, case study discussions to enhance knowledge
Lack of concordance between HCP and patients and carers	Active listening to gain an understanding of patients and carers beliefs. Dealing empathically and with compassion