A mixed methods study exploring fatigue in advanced cancer care

This thesis is submitted in partial fulfilment of the requirements of the award

of

Doctor of Philosophy

By

John Patrick Curtin

Faculty of Health and Life Sciences

Oxford Brookes University

January 2019

Abstract

Background: Many people are living for longer with advanced cancer because of improvements in cancer treatments. Fatigue is the most prevalent and burdensome symptom in this cohort of patients. Thus, many could benefit from any improvements in the assessment and management of fatigue in advanced cancer care. This PhD explored how fatigue was talked about in advanced cancer care, how oncologists approached it and how patients dealt with it.

Methods: A mixed methods design combining video-recordings, questionnaires and interviews was used. The study was divided into three parts: Part A, video-recorded observations of palliative oncology visits; Part B, interviews with patients with fatigue; and Part C, interviews with oncologists. Data from observations were analysed using content analysis and some of the concepts and tools of conversation analysis. Data from semi-structured interviews were analysed using thematic analysis. The data were integrated, with the CA findings the primary component of this study and a summary of findings was produced.

Results: In Part A, 60 visits were recorded, and 37 patient participants reported clinically relevant fatigue. Talk connected with fatigue occurred in 82% of consultations and was often sequentially linked with discussions around goals of care and end of life issues. Resistance to treatment recommendations and advice giving for fatigue was recurrently observed. In Part B, 22 patients with fatigue were interviewed. The overarching theme ‘interconnectedness’ demonstrated how participants coped with fatigue through an array of interrelated strategies and influences. In Part C, nine oncologists were interviewed. The overarching theme ‘fatigue is perceived as different’ described how fatigue was challenging to assess and challenged the role of the cancer doctor.

Conclusions: The findings showed how fatigue is a complex phenomenon in advanced cancer care and how it can be integral to the decision-making surrounding palliative cancer treatments. For patients, fatigue is seen as an acceptable trade-off for the prolongation of life, and this was acutely observed when resistance to proposals to reduce or withdraw cancer treatments occurred. Cancer clinicians may need to consistently reassure patients that alterations to palliative cancer treatments to lessen the burden of fatigue would not reduce survival.

Acknowledgements

First, I would like to thank the participants who very kindly allowed me to record their consultations and shared their experiences with me. I am privileged to have been able to observe and listen to you.

I would also like to thank my supervisors, Dr Helen Walthall, Prof Eila Watson and Prof Bee Wee, who showed great courage in allowing me to shape this PhD and persevered with my efforts to complete it. I am very grateful for your continued support, guidance and endless patience throughout the whole PhD process. I am lucky to have had you as my supervisors.

I would also like to extend my appreciation to Prof Paul Drew, my academic advisor, who was incredibly generous with his time, supportive and good humoured, and an inspiring teacher – I am indebted to you.

A special thanks to my PhD friends and colleagues, Dr Carolina Casañas i Comabella and Dr Marta Wanat who helped this novice researcher enormously along this long and tortuous PhD journey.

A special mention also to my amazing friend Shane, who helped me over the line.

Finally, I would to thank my wife Mairead and four children, Cora, Darragh, Orla & Úna. Life, naturally, doesn't stand still during a PhD and I am enormously appreciative for the way things worked out. I would not have been able to complete this thesis without the incredible support and patience from Mairead; I owe you everything.

I gratefully acknowledge the support of the Strategic Health Authority and Oxford Brookes University who funded my studentship.

Contents

Chapter 1: General introduction and thesis overview

Chapter 2: Fatigue in advanced cancer

Chapter 3: Methodology and Methods

Chapter 4: Examining fatigue-talk in advanced cancer care

Chapter 5: Patient interview findings

Chapter 6: Clinician interview findings

Chapter 7: Discussion and conclusion

Appendices

Tables

Figures

Abbreviations and acronyms

AXIS	Appraisal tool for cross-sectional studies
CA	Conversation Analysis
COREQ	Consolidated criteria for reporting qualitative research
EAPC	European Association of Palliative Care
ECOG PS	Eastern Cooperative Oncology Group Performance Status
FACIT-F	Fatigue Subscale of Functional Assessment of Chronic Illness Therapy
FREC	Faculty Research Ethics Committee
HCPs	Health care professionals
NCCN	National Comprehensive Cancer Network
NHS	National Health Service
NRS	Numerical Rating Scale
PIS	Patient information sheet
PROMs	Patient reported outcome measures
RCT	Randomised control trial
VAS	Visual Analogue Scale
WHO	World Health Organisation

Chapter 1: General introduction and thesis overview

1.1 Introduction

This introductory chapter provides a brief summary of the background information and rationale for conducting this PhD project. The first section will outline how many people are living with advanced cancer; this number will likely increase over time because of developments in cancer treatments and patient care. After that, fatigue will be presented as an important symptom to assess and manage in those living with advanced cancer in order to preserve quality of life. The research questions guiding this PhD will be stated and a brief overview of the structure of this thesis is provided.

1.2 Living with advanced cancer

Every year, many people are diagnosed with advanced cancer and less than half undergo palliative chemotherapy with the aim of controlling the disease. In 2015, there were nearly 360,000 new cases of cancer in the UK and the incidence is projected to increase by 2% between 2015 and 2035 (CRUK, 2018). Nearly three-quarters of all new cancer cases in England and Northern Ireland are staged at diagnosis and of those staged, about 45% are diagnosed with late-stage cancer or advanced cancer (NCIN, 2016; NCIR, 2016). Advanced cancer is a term used to describe cancer that is unlikely to be cured. It mostly refers to stage 4 cancer, when cancer has spread to distant organs but also refers to stage 3 cancer in certain cancer types. In England, between the years 2013 and 2014, nearly half of those with stage 3 (46%) and stage 4 (39%) received palliative chemotherapy as part of the primary treatment for cancer (NCRAS, 2017a). Hence, there is a large population of people living with advanced cancer and many receive palliative chemotherapy, with this number likely to increase in years to come.

In general, people diagnosed with advanced cancer are living longer because of improvements in cancer treatments and patient care. Over the last 40 years within the UK, cancer survival has doubled and now, on average, 50% of those diagnosed with cancer will be alive after 10 years (Quaresma et al., 2015). However, cancer survival data usually reflects those who are cured of cancer and does not differentiate between those with cancer recurrence or advanced cancer. Until recently, there has been little information on the number of people living with advanced cancer in the UK. A national cancer register in England has confirmed that 17,000 people survived more than two years after being diagnosed with stage 4 cancer (NCRAS, 2017b). Nonetheless, this was likely an underestimate as the stage of the disease at diagnosis was omitted from many records on the register. A further 43,000 were alive after being diagnosed two to four years previously and it was possible that many of these individuals had advanced cancer (NCRAS, 2017b). Moreover, the figure for those with stage 3 cancer and where the disease could not be cured was unknown. Thus, there will be an increasing number of people living with advanced cancer for over a year or more as cancer treatments continue to improve.

In advanced cancer care, it is widely accepted that the aim of palliative cancer treatments is to improve or maintain quality of life, with the possibility of extending life. Thus, it is important that people living with advanced cancer maintain a good quality of life for as long as possible whilst receiving palliative cancer treatments and in the gaps of time between these treatments. Although policy for improving cancer care has tended to concentrate on cancer survivorship, through considerable investment on measures concerned with cancer prevention and the earlier detection of cancer, there has also been an emphasis on enhancing the quality of life of those living with cancer and patient experience (NHS England, 2016). Hence, policy-makers should develop strategies that are directed towards patients maintaining their quality of life whilst receiving palliative cancer treatments as well as measures to improve quality of life once treatments have been completed.

1.3 Managing fatigue in advanced cancer care

Fatigue is the most prevalent and burdensome symptom in patients living with advanced cancer. Nearly three-quarters of patients living with advanced cancer experience fatigue and the prevalence of fatigue increases as the disease progresses and end of life approaches (Teunissen et al., 2007). Patients frequently feel fatigue as an enduring symptom, disproportionate to physical activity and it is not relieved by rest or sleep (Glaus et al., 1996). Fatigue has been described as a complex multidimensional symptom with the potential to impinge significantly on quality of life (Radbruch et al., 2008). Patients often report fatigue as one of the most important and distressing symptoms related to cancer treatments and the disease itself (Stone et al., 2000). Moreover, fatigue has the potential to be a strong and independent predictor of decreased patient satisfaction and quality of life (Lis et al., 2009).

Thus, policy should focus on improving fatigue in patients with advanced cancer to better patient experience and quality of life.

A strategy aimed at reducing fatigue in advanced cancer care would first be dependent on it being adequately assessed by clinicians and then once identified, appropriately managed. Hence, this requires effective communication between patients and clinicians about fatigue. An example of effective communication could relate to the problem or concern of the patient, in this case fatigue, being appropriately or sufficiently addressed by the clinician in oncology care consultations. Shared decision-making includes the sharing of information that concerns the balancing of benefits of treatments against the risks and costs, and also avoiding harm (Charles et al., 1997; Stiggelbout et al., 2012). Policy regards shared decision-making as good communication and advocates for all healthcare professionals (HCPs) to practice in this way (Coulter & Collins, 2011). Thus, an example of good communication might be the doctor proposing to the patient with fatigue about the need to balance the burdens of palliative cancer treatments (i.e. worsening fatigue) on quality of life against any potential benefit of treatments (i.e. prolonging survival). However, the views held by patients and doctors regarding fatigue in advanced cancer might also have an influence on how they behave towards this symptom.

The patient's perspective on fatigue in advanced cancer might be important as it is suggested that some frequently do not report fatigue to the doctor despite the effect it may have on everyday living (Donovan et al., 2005; Spichiger et al., 2012; Stone et al., 2000). Research has hinted at why this might occur and some possible reasons include: an acceptance of fatigue as an inevitable side effect of cancer treatments; believing fatigue must be endured for the benefits of cancer treatments; not wanting to complain to the doctor; and not being aware of any treatments for fatigue (Passik et al., 2002; Pertl et al., 2014; Spichiger et al., 2012; Stone et al., 2000). Moreover, some patients perceive barriers to the dialogue of fatigue with clinicians because: fatigue was difficult to explain unless one has experienced it; others confused fatigue with usual tiredness, and; a busy outpatient clinic environment limited the time for discussion (Poulson, 2001; Pertl et al., 2014; Spichiger et al., 2012). Hence, research that provides more understanding on how patients with advanced cancer approach fatigue and how they communicate this symptom could potentially help in the development of strategies to improve the understanding, assessment and management of fatigue in advanced cancer care.

Little is known about the perspectives of doctors in relation to fatigue in advanced cancer care and this could be important to investigate as they have an important role in the assessment and management of fatigue. Some research suggested that most oncologists believe fatigue was overlooked and undertreated (Vogelzang et al., 1997). However, patients have reported that although they were usually informed about fatigue before initiating cancer treatments, doctors often do not offer any treatments for fatigue (James et al., 2015; Passik et al., 2002; Pertl et al., 2014; Spichiger et al., 2012; Stone et al., 2000). This reported behaviour regarding doctors from patients raises some interesting questions about why this might occur. Research that explored how doctors referred to patient-reported outcome measures (PROMs) in oncology consultations, revealed that doctors offered treatments more often to reported problems other than fatigue (Greenhalgh et al., 2013). In addition, this conversation analytic study suggested that doctors closed down the dialogue of fatigue by: changing the subject; minimising fatigue; and presenting fatigue as an inevitable consequence of chemotherapy (Greenhalgh et al., 2013). However, standard or usual clinical practice in advanced cancer care may not routinely use PROMs in every day palliative oncology clinics. Hence, research that provides more understanding of how doctors approach fatigue in advanced cancer care and how they communicate this symptom could potentially help in the development of strategies to improve the assessment and management of fatigue in advanced cancer care.

To summarise, fatigue in advanced cancer care is an important area to research in order to ensure that quality of life can be maintained for those patients receiving palliative cancer treatments and for those patients being monitored in the oncology clinic. Patients are living longer with advanced cancer and this is likely to continue to improve with the developments in new cancer therapies. Thus, many people could benefit from any improvements in the assessment and management of fatigue in advanced cancer care. Healthcare communication research has the potential to assess the effectiveness of current care, make recommendations for future practices and improve patient outcomes (Barnes et al., 2005; Jenkins et al., 2015; Street et al., 2009). Hence, research examining the communication of fatigue in advanced cancer care could potentially identify communication practices that could improve the assessment and management of this symptom.

1.3 Aims and research questions

The overall aims of this study are to explore how patients and doctors approach fatigue in advanced cancer, and how they communicate this symptom in oncology care.

The overarching research questions were:

- What talk connected with fatigue occurs in palliative oncology visits and how do participants talk about it?
- How do patients with advanced cancer deal with fatigue?
- How do oncologists approach fatigue in those with advanced cancer?

1.4. Thesis overview

This section provides a brief overview of the thesis and summarises the main features of each chapter.

Chapter 1: General introduction and thesis overview

This chapter has sketched the rationale for this doctorate and the overall aims of this thesis.

Chapter 2: Fatigue in advanced cancer

Chapter two will outline a definition of fatigue in cancer care and present the results from a review of the literature examining fatigue in advanced cancer.

Chapter 3: Methodology and methods

The methodological approach of this PhD and the rationale for the use of mixed methods will be discussed. Then, the methods of data collection and the methods of data analysis will be outlined in detail. The last section will describe each of the three parts of this study separately: Part A, observations of oncology consultations; Part B, interviews with patients with fatigue; and Part C, interviews with oncologists.

Chapter 4: Fatigue-talk in palliative oncology visits

This chapter will present and analyse the findings from the observations of naturally occurring palliative oncology visits. The structural organisation of oncology interactions and an overview of talk connected with fatigue is presented. Next, the chapter will examine the main finding from the micro-analysis of talk: misalignments between oncologists and patients with clinically relevant fatigue. These misalignments in relation to fatigue are concerned with the goals of palliative cancer treatments and advice giving.

Chapter 5: Findings from the patient interviews

Chapter five will analyse the findings from the qualitative interviews conducted with patients who reported clinically relevant fatigue. Participants' approaches to fatigue and how they managed this symptom will be examined. The chapter will present the most relevant findings from the patient interview study through the overarching theme: the interconnectedness of fatigue.

Chapter 6: Findings from the clinician interviews

This chapter will examine the findings from the qualitative interviews conducted with oncologists. Participants' approaches to fatigue and how they routinely managed this symptom in clinical practice will be revealed. The chapter will present the overarching theme: fatigue is perceived as different.

Chapter 7: Discussion and conclusions

The final chapter of this PhD thesis will discuss the findings of the study, integrating the three separate datasets in order to provide a multifaceted and nuanced understanding of fatigue in advanced cancer care. The limitations of each part of this study will also be discussed. This will be followed by the policy and practice implications, and recommendations for future research.

Chapter 2: Fatigue in advanced cancer

2.1 Introduction to chapter

This PhD thesis is concerned with how patients and doctors approach fatigue in advanced cancer. The present chapter is comprised of five parts. The first section provides a definition of fatigue and outlines the methods for the literature review. The second section provides a broad overview of fatigue in advanced cancer and presents: the experience and impact of fatigue; the prevalence, associations and course of fatigue; the causes of fatigue; and the management of fatigue. The third section presents the patient's perspectives on the management of fatigue in advanced cancer. The fourth section outlines the perspectives and behaviours of doctors to fatigue in advanced cancer. Finally, the fifth section proposes how oncologists and patients with advanced cancer make decisions about palliative chemotherapy and how these might be relevant to fatigue.

2.1 Fatigue

2.2.1 Definition of fatigue in cancer

This doctorate seeks to explore fatigue in cancer care and specifically fatigue that occurs in patients with advanced cancer. Fatigue has been defined by international consensus groups that provide care to patients with advanced cancer (NCCN, 2014; Radbruch et al., 2008). The National Comprehensive Cancer Network (NCCN) in the United States uses the term cancer-related fatigue. This relates to four different groups of cancer patients: survivors, cured from cancer but living with side effects of treatments; receiving cancer treatments with curative intent or potentially curable from cancer; receiving treatment with palliative intent or living with advanced cancer; and those near the end of life (NCCN, 2014). Cancer-related fatigue has been defined as *'a distressing persistent sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning'* (NCCN, 2014 p. 4).

The populations explored in this PhD concerned those who are receiving cancer treatments with palliative intent or living with advanced cancer, and who attend oncology outpatient clinic. Palliative care is an '*approach that improves the quality of life of patients and their* *families facing the problems 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'* (Sepúlveda et al., 2002 p.94). It is also applicable early in the diagnosis of incurable cancer, *'in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy'* (Sepúlveda et al., 2002 p.94). The European Association for Palliative Care (EAPC) defined fatigue as "*a subjective feeling of tiredness, weakness or lack of energy"* (Radbruch et al., 2008 p.14). As the EAPC provided a broader definition of fatigue in comparison to the NCCN, I chose this definition for fatigue in this thesis.

2.2.2 Fatigue in illnesses other than cancer

Fatigue also occurs in many advanced progressive illnesses other than cancer. In the last year of life, fatigue is highly prevalent in those with chronic obstructive pulmonary disease, heart failure and neurodegenerative diseases such as multiple sclerosis (Bakshi, 2003; Elkington et al., 2005; Goodlin, 2005). It is likely that there are some similarities in the experience of fatigue across advanced progressive illnesses. Therefore, some of the findings of this literature review and thesis may resonate with the fatigue experienced in other advanced illnesses. For example, how people define and articulate their experience of fatigue and the language they use, could be comparable across various conditions. However, there are also likely to be some important differences in how fatigue is experienced and perceived in cancer care. Fatigue is closely associated with cancer treatments which have the aim of controlling the disease and prolonging life. Thus, fatigue may have a temporal relationship to cancer treatments and this association could likely have an influence on the coping mechanisms used by patients for fatigue in cancer care. In summary, the findings of this literature and thesis primarily relate to cancer care but there may be some relevance to other advanced progressive illnesses.

2.3 Literature review methods

This review aimed to present an overview of a diverse body of scientific literature on fatigue in cancer care, specifically in advanced cancer care. The review included a broad range of study designs and methodologies. Hence, a scoping review was performed, and the methods are outlined below (Pham et al., 2014).

Several research questions guided this review:

- What is the patient experience of fatigue in advanced cancer?
- How prevalent is fatigue in advanced cancer?
- What causes fatigue in advanced cancer and how best can it be treated?
- What are the views of patients with advanced cancer to fatigue?
- What are the views of oncologists to fatigue in advanced cancer?
- How is fatigue managed by patients and oncologists in advanced cancer?
- How is fatigue communicated in patient-doctor interactions in cancer care?

Data sources and search strategy

Peer-reviewed journals were searched on the following databases: Medline, Cochrane Library and the Applied Social Sciences Index and Abstracts (ASSIA). ASSIA yielded reviews but this, in turn, led to original research. There were no date restrictions on the search strategy, but it was limited to the English language. The primary search terms used were 'fatigue' and 'cancer'. The search strategy used a broad scope initially, which was narrowed down as parameters became more defined. Several other search terms were used in combination with the primary search terms to focus on the relevant sections of the literature review. These terms included 'advanced cancer', 'palliative', 'qualitative', 'qualitative analysis', 'quality of life', 'health-related quality of life', 'HRQoL', 'self-care', 'oncologists', 'doctors', 'communication' and 'interactions'.

Eligibility criteria

Publications were included in this review if they:

- Reported results from primary research exploring fatigue in cancer;
- Reported findings from samples composed of people receiving treatment with palliative intent, and those potentially receiving palliative care through oncology care;
- Reported findings from samples composed of specialist doctors providing oncology care or oncologists; and
- Publications that had study designs including: randomised controlled trials, observational studies and qualitative studies.

The exclusion criteria for this review were:

- Publications that focused solely on fatigue in cancer survivors;
- Publications that focused solely on fatigue in those receiving cancer treatments with curative intent;
- Publications that focused solely on fatigue in people with blood cancers;
- Publications that focused solely on fatigue in brain cancers;
- Publications that contained samples composed of HCPs other than specialist doctors providing oncology care or oncologists; and
- Publications that were research protocols or conference abstracts.

Title and abstract relevance screening

For the first level of screening, only the title and abstract of citations were reviewed. This researcher was the sole reviewer throughout the screening process. All citations deemed relevant after title and abstract screening were obtained for subsequent review by full-text article.

Results from the literature review

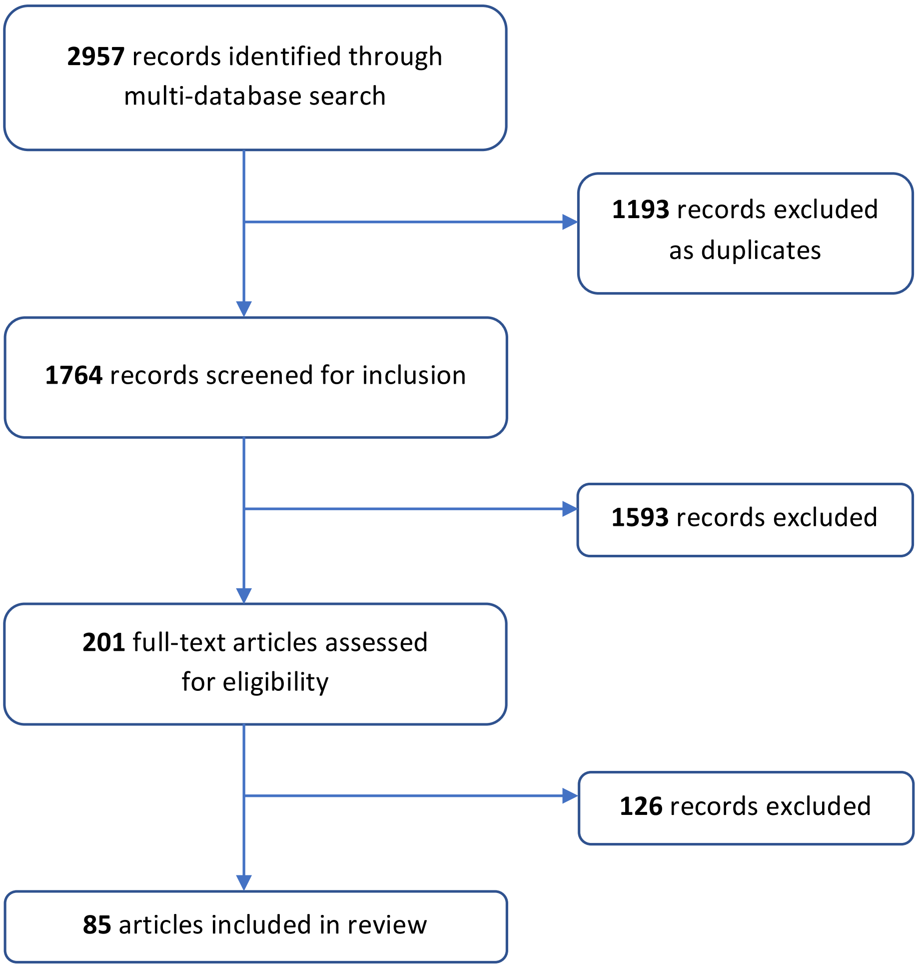
The flow of articles through identification to final inclusion is represented in Figure 2.1.

Quality appraisal tools

A critical appraisal was performed on publications that met the inclusion criteria to assess the quality of the primary research. The critical appraisal of each included study was integrated with the description of the study's findings in the literature review. Several quality appraisal tools were used, and these included:

- The consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist for, views and focus groups (Tong et al., 2007);
- Critical Appraisal of a Survey, as used by Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre and BMJ editor's checklists (Crombie & Harvey, 1997); and
- The Appraisal tool for Cross-Sectional Studies (AXIS tool) was used for cross-sectional studies (Downes et al., 2016).

Figure 2.1. – PRISMA flowchart of study the selection process.



Presenting the findings from the literature review

The findings from the literature review were divided and grouped together by relevance. The research questions guiding the review also provided for some structure and stratification to the findings. Three broad and distinct categories emerged which best synthesised the literature and hence guided the presentation of the findings. These three categories or headings included: fatigue in advanced cancer; the perspectives of patients to fatigue in advanced cancer; and the perspectives of doctors to fatigue in advanced cancer.

2.4 Fatigue in advanced cancer

This section provides an overview of fatigue in advanced cancer. The findings presented are relevant to or suggested to have an influence on the perspectives of patients and doctors to fatigue in advanced cancer. The following sub-headings are described in this section:

- the experience and impact of fatigue in advanced cancer;
- the prevalence, associations and course of fatigue in advanced cancer;
- the causes of fatigue in advanced cancer; and
- the management of fatigue in advanced cancer.

2.4.1 The experience and impact of fatigue in advanced cancer

The experience of fatigue in cancer care has been explored in many published qualitative studies and various studies have suggested that fatigue is a different experience to tiredness (Adamsen et al., 2004; Glaus et al., 1996; Magnusson et al., 1999; Richardson & Ream, 1996; Wu & McSweeney, 2007). A qualitative interview study by Glaus et al. (1996) compared the experiences of fatigue of 20 healthy individuals with 20 cancer patients. The patient sample included 14 different cancer diagnoses, three-quarters had incurable disease, 85% were undergoing cancer treatment and less than half could fully self-care. Grounded theory was used as a theoretical framework and an inductive approach to analysis yielded 16-20 themes in participant groups which were counted and conjoined to make three identical categories (Glaus et al., 1996). The authors noted differences in the categories between groups and the data identified qualitative differences in the experiences of tiredness or fatigue. Healthy individuals often viewed tiredness as a rhythmic normality that occurred after a day's work or a pleasant phenomenon experienced after exercise. However, cancer patients frequently saw fatigue as an overwhelming sense of tiredness which was more intense than previously experienced and an abnormal experience of tiredness associated with weakness and an unusual need to rest (Glaus et al., 1996).

These findings by Glaus et al. (1996) were further supported by a systematic review and meta-synthesis of published qualitative studies to examine the effects of fatigue on patients with cancer (Scott et al., 2011). In total, 26 articles from the published literature that contained direct patient quotes about fatigue were identified by Scott et al. (2011). A coding scheme was developed based on the literature and the analysis used the constant comparison process to describe the meaning of fatigue. Breast cancer patients receiving chemotherapy treatment accounted for the largest patient sample in that review and many studies included a mix of patients treated with curative and palliative intent. The authors coded and counted the descriptors of fatigue (words or phrases) that were used by patients. There were 667 words or phrases coded for fatigue, represented by with frequency: tired 37%, fatigue 16%, references to energy 9% and being weak 3% or exhausted 3% (Scott et al., 2011). In addition, a wide range of synonyms for fatigue was used by patients and these could be based on colloquial expressions. For instance, 'just deathly hung over' (Messias et al., 1997, p.45). Many studies reported that patients frequently used metaphors or imagery to describe and convey the experience of fatigue (Barsevick et al., 2001; Messias et al., 1997; Porock et al., 2004).

Scott and colleagues (2011) identified three sensitising concepts through verbatim quotations, which included sensations of fatigue, the impact of fatigue, and coping strategies. In addition to the intense and abnormal sensations of fatigue described earlier (Glaus et al., 1996), temporal descriptions of fatigue were identified in 15 studies. Fatigue was described by patients as constant and following certain patterns, particularly coinciding with cancer treatments or worse at specific times of the day (Barsevick et al., 2001; Messias et al., 1997; Porock et al., 2004). In 11 studies, patients described the experience of fatigue as not being relieved by rest and this also distinguished it from exertion induced or sleep-deprivation related tiredness or fatigue (Glaus et al., 1996; Messias et al., 1997). The concept 'impact of fatigue' had cognitive, emotional, physical and social components (Scott et al., 2011). The cognitive effects of fatigue (n=13) most often related to a patient's inability to think and concentrate, which could be severely limiting (Barsevick et al., 2001; Glaus et al., 1996; Messias et al., 1997; Porock et al., 2004). The emotional impact of fatigue related to feelings of anger, frustration, sadness or loss because of the limitations placed on the patient by fatigue (Barsevick et al., 2001; Glaus et al., 1996; Messias et al., 1997; Porock et al., 2004). The physical component related to physical sensations associated with fatigue and the functional limitations fatigue caused (Barsevick et al., 2001; Glaus et al., 1996; Messias et al., 1997; Porock et al., 2004). Fatigue also had an on impact patients' social and family life leading to feelings of isolation due to restrictions in their socials lives and maintaining relationships (Barsevick et al., 2001; Glaus et al., 1996; Messias et al., 1997; Porock et al., 2004).

In relation to this PhD study, there were several limitations with the meta-synthesis by Scott et al. (2011). First, the findings may not fully translate to the experience of fatigue in advanced cancer as some studies included cancer survivors, those receiving treatment with curative intent and non-cancer diagnoses. It was also not possible in many studies to differentiate and compare the patient quotations from those with advanced cancer and those with curable disease or cancer survivors. Only three studies solely included samples of patients with incurable or advanced cancer: one was a mixed sample receiving active treatment or palliative approach to care (Krishnasamy, 2000) and the other two studies included patients who had completed chemotherapy or radiotherapy treatments and were receiving palliative care in a hospice setting (Olson et al., 2007; Potter, 2004). Second, eight of the 26 studies contained ten or fewer direct patient quotations, possibly as a result of word limitations in cancer care journals, which may have limited the contribution of these data. Furthermore, some studies had very brief quotations and therefore, the experience of fatigue could be under-represented by these abbreviated quotations. Third, the meta-synthesis did not include a quality assessment of included studies such as that recommended by the 32-item COREQ checklist for interviews (Tong et al., 2007). A thorough quality appraisal of included studies could have helped to describe the range of quality found (Atkins et al., 2008). Fourth, the method of pre-coding in this meta-synthesis may have lent itself more towards a deductive approach and perhaps had an influence on the identification of sensitising concepts. The overall design of the qualitative synthesis and hence the analytic approach resulted in concepts rather than any higher level of interpretative analysis, which could occur in a meta-ethnography (Atkins et al., 2008; Britten et al., 2002).

Two further qualitative studies that explored the experience of fatigue in patients with advanced cancer were identified (Charalambous & Kouta, 2016; Kirshbaum et al., 2012). Charalambous & Kouta (2016) aimed to explore the experience of fatigue in patients with advanced prostate cancer undergoing chemotherapy treatment. The study design utilised a mixed-methods approach, with a cross-sectional survey followed by qualitative interviews. Fifteen patient interviews were analysed using an inductive approach and thematic content analysis. Three main themes that reflected the impact of fatigue were described: dependency on others; loss of power over decision making; and daily living disruption (Charalambous & Kouta, 2016). However, when the interview stage of the study was analysed with the COREQ checklist (Tong et al., 2007) several deficits and limitations in the reporting and quality were identified. Little if any information was provided on the personal characteristics of the researchers and the relationship with participants. The selection of participants for the interview study was vague and information on the setting of data collection and description of the sample was absent. Information on the interview guide was sparse and no information on field notes or duration of interviews was provided. Data saturation was discussed but it appeared the authors also used this to justify an advanced decision to recruit 15 patients. No information on data coders, description of the coding tree, derivation of themes or software used was provided. Quotations were presented but were not identifiable and some did not accurately illustrate the themes. Overall the qualitative arm of this mixed-methods study appeared to be of poor quality and therefore any relevance should be viewed with caution.

Kirshbaum et al. (2012) explored the perception and experiences of fatigue reported by patients attending a hospice in England. An ethnoscience design was utilised and nine individuals with advanced illness took part, eight with metastatic cancer and one with a neurodegenerative disease. Nine were interviewed once and eight of them had a second interview. Seven participants rated fatigue as moderate or worse on a visual analogue scale. The findings described a taxonomy of fatigue, a continuum ranging from tiredness to exhaustion as a progressive decline in physical function (Kirshbaum et al., 2012). Two concepts derived from the taxonomy: the mental challenge and the physical challenge. The core components of the mental challenge were represented by emotional effects (worry, frustration, annoyance and fear), cognitive realisation of decline, and mental tenacity (conveying a sense of perseverance). The core components of the physical challenge were represented by: limitations of leisure activities; limitations of functional roles; and re-patterning of daily routines (adapting) (Kirshbaum et al., 2012).

A COREQ checklist appraisal (Tong et al., 2007) performed on this study revealed some deficits in the reporting concerned with the research team and reflexivity. The small sample size may have been a significant limitation, although the narrow scope of the study and quality of data could lessen the need for large interview samples (Morse, 2000). The small sample might be explained by the population studied as two participants died very soon after taking part, and recruitment lasted eight to nine months. However, it was uncertain whether participants were inpatients or day patients in the hospice and no information was provided on oncology care. Overall this study provided some insights into the experiences of fatigue in a palliative care patient population.

In summary, the literature review of the experience of fatigue in advanced cancer suggests that it is perceived as an abnormal experience, an altogether different experience to tiredness, associated with physical weakness, an unusual need to rest and, as it worsens, physical decline. Fatigue appears to have multidimensional constructs and components, with an effect or influence on the individual's cognitive, emotional, physical and social domains. The varied language used to describe fatigue and the common use of metaphors to articulate the experience may indicate the uniqueness and complexity to fatigue.

2.4.2 Prevalence, associations and course of fatigue in advanced cancer

In this section, a review of the literature outlines the prevalence of fatigue in advanced cancer and in care settings that are relevant to the study population in this thesis. The degree and severity of fatigue that might be important to patients and relevant to clinicians will be introduced. The common associations of fatigue with other cancer symptoms and will be described. Finally, the trajectories and course of fatigue are suggested in those with incurable cancer receiving cancer treatments in palliative oncology clinics.

A systematic review of 17 studies including 6,727 patients with incurable cancer revealed a pooled symptom prevalence of 74% for fatigue (Teunissen et al., 2007). However, it should be noted there was significant heterogeneity within the patient populations of the studies included and this contributed to large 95% confidence intervals (63%-83%). The authors excluded studies if they focused on only one specific symptom without prevalence on other symptoms and only gave data on symptom intensity. The inclusion criteria for the literature review of this PhD was broader than the systematic review by Teunissen et al. (2007) and hence some important studies were excluded. Furthermore, the calculated symptom prevalence in many of the included studies only accounted for the occurrence of some degree of fatigue which could mean anywhere from very mild to very severe disabling fatigue. Therefore, this calculated prevalence contains patients who may perceive fatigue not to be bothersome or something that does not necessarily need medical or nursing attention (Teunissen et al., 2007).

In some clinical and research settings, the symptoms of patients with cancer are routinely screened with instruments that measure the intensity of symptoms, including fatigue, on a 0-10 numerical rating scale (NRS), in which 0 means no fatigue and 10 the worst possible fatigue (Bruera et al., 1991; Cleeland et al., 2000). Clinically relevant or significant fatigue has been defined in ambulatory cancer patients receiving chemotherapy or radiotherapy and palliative outpatients as moderate fatigue or worse (Butt et al., 2008; NCCN, 2014; Selby et al., 2010). A systematic review has identified the cut-off point for moderate fatigue as 4 and the cut-off point for severe fatigue as 7 or 8 (Oldenmenger et al., 2013). Therefore, it may also be helpful to examine the prevalence of clinically relevant or meaningful fatigue in patients with advanced cancer receiving oncology and palliative care.

Storey et al. (2007) performed a cross-sectional survey of consecutive patients attending cancer outpatients in a single UK cancer centre. All patients attending follow-up appointments were invited to complete a fatigue subscale on a touch screen computer. The response rates were high, although slightly lower in the disease present group (85% versus 82%) which suggested that the questionnaire design was not overly burdensome for patients with fatigue. In 974 patients with disease present, defined as local or metastatic, 43% had clinically relevant fatigue. In contrast, 1892 patients (27%) in the disease-free group had clinically relevant fatigue. The overall findings of the study suggested that clinically relevant fatigue was independently associated with the primary cancer site, the stage of the disease, the type of cancer treatment and emotional distress (defined by Hospital Anxiety Depression Scale (HADS) score ≥15) (Storey et al., 2007).

The Appraisal tool for Cross-Sectional Studies (AXIS tool) was performed on this study to assess for quality (Downes et al., 2016). The strengths of this study were in the design as it prospectively collected patient-reported data in a real-life hospital clinic environment and there were fewer potential barriers to patient enrolment because written consent was not required. A limitation was that the disease-present group also included an unknown number of patients treated with curative intent, and this should be considered in the estimation for prevalence in advanced cancer. Moreover, some cancer diagnoses such as upper gastrointestinal, head and neck, pancreatobiliary and lung could be expected to have a higher prevalence of fatigue because of anorexia-cachexia syndrome and these only accounted for <4% of the total cancer diagnoses in the patient sample (Stone et al., 2000). Nonetheless, other research supports the findings that clinically relevant fatigue in patients receiving oncology care appears to be associated with the cancer diagnosis, the stage of disease and cancer treatment (Walling et al., 2015; Wu et al., 2014).

The prevalence of clinically relevant fatigue increases with advancing disease, and research suggests that the severity of fatigue is associated with a decline in functional ability (Ghoshal et al., 2017; Yennu et al., 2008; Yennu et al., 2012; Zeng et al., 2012). Yennu et al. (2012) retrospectively reviewed the records of 2071 consecutive patients with advanced cancer attending an outpatient palliative care clinic in a single US tertiary referral cancer centre. A total of 1,778 patients who prospectively completed a symptom screening assessment tool at an initial visit and subsequent follow-up visit were included. The prevalence of clinically relevant fatigue was 84%, with moderate fatigue (4-6) present in 51% and severe (7-10) present in 33%. Eight other cancer symptoms were screened for and the severity of fatigue correlated with all eight symptoms, with pain and appetite having the strongest associations. The study reported that fatigue was not associated with age, gender, type of cancer or anaemia (Yennu et al., 2012). In addition, the severity levels of pain, depression, appetite, nausea, drowsiness, feeling of well-being and shortness of breath were predictive of the severity of fatigue. The strengths of this study are in the relatively large patient sample size and the routine collection of prospective patient-reported data in a specialist outpatient clinic over a period of 5 years. However, these findings all originated from a single institution in a US healthcare setting so may not be generalisable to similar patient populations and care settings in other countries.

The research presented thus far on the prevalence of fatigue in advanced cancer only provides a cross-sectional view of a broad group of individuals along different trajectories of their cancer illness and cancer treatments. A longitudinal perspective of the course of fatigue with patients receiving cancer treatments could provide further insights for patients, clinicians and researchers. With the development of newer treatment options, some patients with incurable cancer live for many years with advanced disease and this could potentially have implications for people living with chronic fatigue or a pattern of relapse and remitting fatigue on treatments (Italiano et al., 2008).

A longitudinal observational study by Peters et al. (2014, 2016) provided some findings on the course of fatigue in a broad cohort of incurable cancer patients receiving or about to start on cancer treatments. A total of 137 patients were well enough to complete five brief questionnaires, including a fatigue questionnaire at baseline, and were then asked to complete a fatigue questionnaire monthly until study completion at 6 months. The majority of study participants received chemotherapy, oral or chemo-targeted therapies and, most received first-line treatment (67%). The prevalence of clinically relevant or severe fatigue at baseline was 47% (64/137) and 44% on study completion (39/89). The attrition rate was 35% (48/137), with death accounting for nearly half (20/48). In this drop out group, mean scores for fatigue were higher at baseline and at measured time points (Peters et al., 2016). For those completing the study, with percentages calculated from the total sample: 27% never experienced severe fatigue; 19% experienced severe fatigue at all measured time points; 9% became severely fatigued; and fatigue decreased in 9%, changing from severely to not severely (Peters et al., 2016).

This study was examined with the AXIS tool (Downes et al., 2016). There were several limitations in this study which preclude it from generalising its findings as participants were not at the same point in their disease trajectory or treatment schedule and the validated multidimensional fatigue scale, the Checklist Individual Strength, has seldom been used in cancer care studies which makes comparisons difficult. Although the very high attrition rate raised some questions about the study design, it is noted that higher attrition rates are a feature in palliative oncology trials with higher levels of fatigue at baseline and longer study duration (Hui at al., 2012). Nonetheless, this study provided useful insights into the course of fatigue in a broad cohort of patients with advanced cancer receiving oncology care.

To summarise, fatigue is highly prevalent in patients with advanced cancer receiving active treatment and even more prevalent in patients who are entering the terminal phase of their illness. Studies showed that the severity of fatigue was associated with cancer treatments, progressive disease, deterioration in functional ability and other common cancer symptoms. The Eastern Cooperative Oncology Group Performance Status (ECOG PS) is a scale used by oncologists to determine the functional ability of patients with advanced cancer and predicts how palliative cancer treatments might be tolerated (Bachelot et al., 2000; Oken et al., 1982). Thus, increasing levels of fatigue associated with deteriorating functional ability mean patients are less able to tolerate cancer treatments. Fatigue could, therefore, be important in cancer treatment decision-making and this is discussed later in the chapter. It was suggested that most but not all patients with advanced cancer receiving active treatment experience clinically relevant fatigue and some experience chronic fatigue lasting many months which has implications for quality of life. Overall, these findings suggest fatigue is a symptom faced by many who regularly attend palliative oncology clinics. Thus, understanding of how fatigue is routinely managed in this setting and how patients with advanced learn to cope with fatigue would be important to explore for both patients and clinicians.

2.4.3 Causes of fatigue in advanced cancer

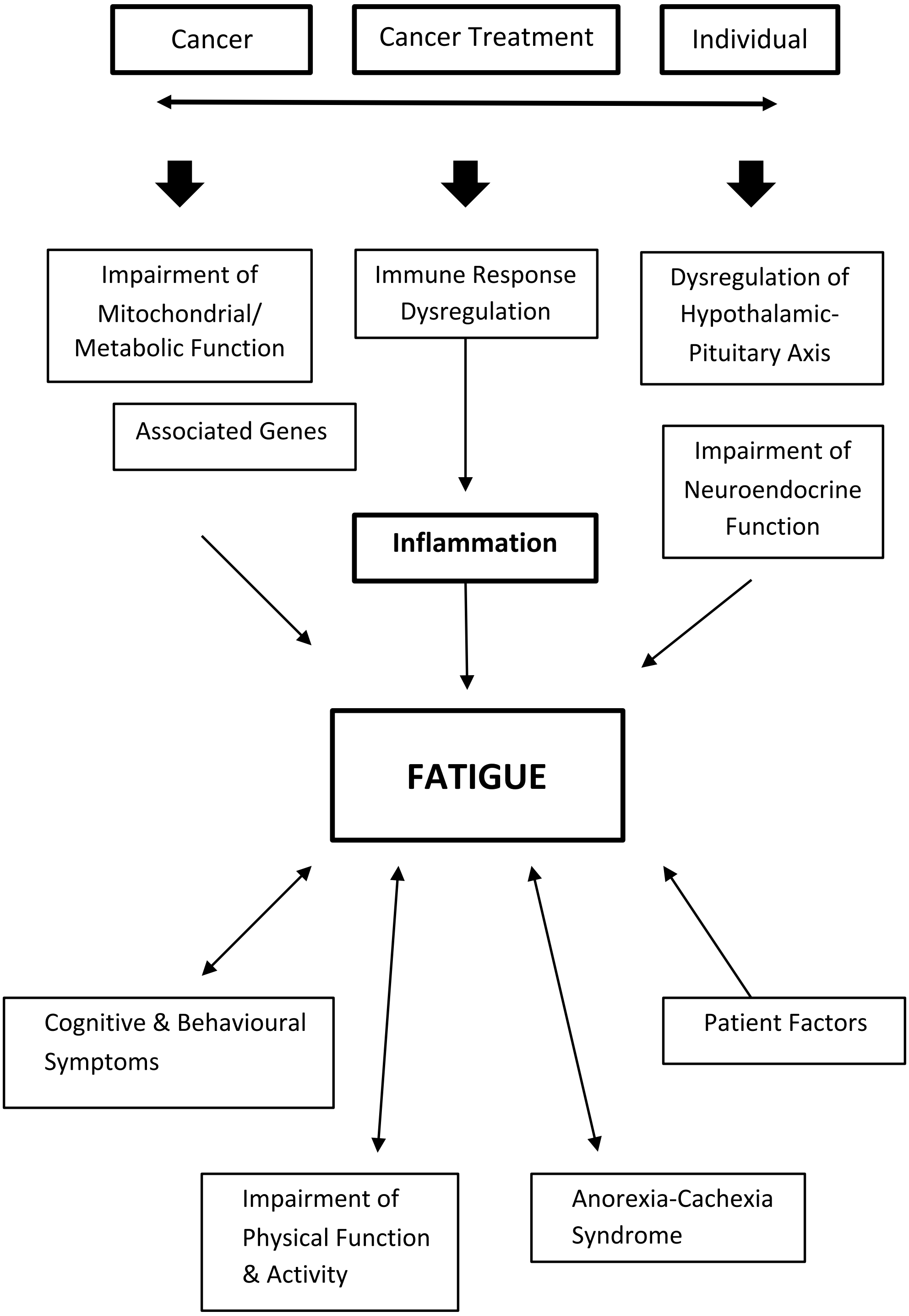
In the following paragraphs, the biological and contributory causes of fatigue in advanced cancer will be summarised, with several proposed hypotheses and mechanisms outlined. The underlying biological processes are poorly understood and the potential contributory causes of fatigue in the individual are considerable. Therefore, this could raise challenges for the oncologist in determining the causes of fatigue in the individual patient with advanced cancer.

Currently there is no conclusive pathophysiological evidence to explain whether a sequence of interrelated mechanisms or a centrally mediated abnormal process causes fatigue in cancer care (Bower & Lamkin, 2013; Saligan et al., 2015). Emerging evidence has suggested that there is an association between inflammation and fatigue in cancer (Saligan et al., 2012; Saligan et al., 2015). The inflammation hypothesis proposes that cancer and the treatments used to eradicate the disease can activate the proinflammatory cytokine network, leading to fatigue through effects on the nervous system (Bower & Lamkin, 2013; Cleeland et al., 2003).

A systematic review of 34 studies examining the association between immune/inflammatory markers and levels of fatigue in cancer care revealed mixed findings (Saligan et al., 2012). Longitudinal studies, which mostly included women with early-stage breast cancer receiving cancer treatments, provided some consistent findings to link immune/inflammatory markers and elevated fatigue symptoms (Saligan et al., 2012; Saligan et al., 2015). However, these associations were less consistent in the cross-sectional studies included (Saligan et al., 2012). More recent cross-sectional studies have explored links between inflammation with advanced cancer, but the findings have been inconclusive (Kwak et al., 2012; de Raaf et al., 2012; Rodrigues et al., 2016). The mixed results in these cross-sectional studies with advanced cancer patients could be explained by several factors: small sample sizes, heterogenous patient populations; the use of different fatigue instruments to define/measure fatigue and the variable immune/inflammatory markers utilised in these studies (Saligan et al., 2015).

It is possible that proinflammatory cytokines act independently to generate fatigue or influence or work synergistically with other mechanisms that act either directly or indirectly on the central nervous system (Bower & Lamkin, 2013). Although research in recent years has concentrated on examining the relationships between immune/inflammatory biomarkers and fatigue in cancer, other biological processes have also been suggested to cause fatigue. These mechanisms include the dysregulation of the hypothalamic-pituitary axis, impairment of neuroendocrine function, serotonin dysregulation, vagal afferent nerve activation and circadian rhythm modulation (Ryan et al., 2007; Saligan et al., 2015). Genetic factors may also play a part with some abnormal genes identified that encode inflammatory cytokines related to fatigue and other genes which interfere with metabolism (Saligan et al., 2015). A further hypothesis proposed for a peripheral cause of fatigue: that cancer and/or cancer treatments lead to a defect in the mechanism for regenerating skeletal muscle and comprise the capacity or ability of the muscle to function (Ryan et al., 2007). Overall, it is likely that fatigue in the individual with advanced cancer, is a result of multiple biological processes, some perhaps working independently of each other and others interconnected through similar or different mechanisms of action (see Figure 1).

Figure 2.2 – Causes of fatigue in advanced cancer. Adapted from (Saligan et al., 2015).



Researchers postulating the immune/inflammation hypothesis as a cause for fatigue in cancer observed potential similarities in patients with cancer and those with cytokine induced sickness behaviour, with a clustering of symptoms: fatigue, pain, disturbed sleep, drowsiness and poor appetite (Cleeland et al., 2003). Several studies have explored for symptom clusters in patients with advanced cancer receiving palliative care and these have suggested associations between fatigue, anorexia and weight loss (Walsh et al., 2006; Jiménez et al., 2011). Cancer cachexia has been postulated as a cause of fatigue in advanced cancer and inflammatory cytokines may contribute as one of many biologic pathways that disrupt metabolism and reduce food intake (Ryan et al., 2007; Fearon et al., 2011). However, a cross-sectional study of 720 patients with advanced cancer, of whom nearly half were receiving chemotherapy, found no association between clinically relevant or severe fatigue and primary cachexia (Minton et al., 2012).

The study by Minton et al. (2012) was assessed for quality with the AXIS tool (Downes et al., 2016). The strengths were identified: the large sample size, originating from an international multicentre study, with an unselected mixed group of patients receiving oncology and/or palliative care; 44% having clinically relevant or severe fatigue; and; 25% having primary cachexia as measured on a triad of measures recommended by an international consensus group. The limitations included: the cross-sectional design and the inability to assess variables over time; the primary aim of the study being to investigate pain, and fatigue assessment was a secondary outcome; the fatigue subscale of the validated assessment tool was not comprehensive; and uncertainty about the accuracy of the local investigator measuring primary cachexia as defined by the variables.

Some studies have reported that fatigue in cancer is strongly correlated with cognitive and behavioural symptoms, including anxiety, depression and sleep disorders (Brown & Kroenke, 2009; Roscoe et al., 2007). In a large sample of patients with advanced cancer, clinically relevant or severe fatigue was significantly associated with depression (Minton et al., 2012). However, correlation indicated a relationship between fatigue and depression but was not affirming causation, nor does it conclude that they both originate from the same underlying process, such as inflammation. Some studies provided evidence that suggests fatigue and depression are distinct entities. Two randomised controlled trials (RCTs) involved breast cancer patients with fatigue receiving chemotherapy being randomised to 20mg paroxetine or placebo (Morrow et al., 2003; Roscoe et al., 2005). They found no improvement in fatigue scores between groups but differences in depressive scores. However, this should be treated with caution because of shortcomings: the sample sizes were moderate and follow up of eight weeks was short (Morrow et al., 2003; Roscoe et al., 2005). In studies with advanced cancer patients receiving oncology or palliative care, poor sleep or insomnia are routinely an independent predictive of fatigue severity (George et al., 2016; Minton et al., 2012). Cancer symptoms (e.g. pain, anxiety) are also prevalent in these patient samples and are independently associated with fatigue severity (Minton et al., 2012; Yennu et al., 2012).

In summary, the biological processes that cause fatigue in cancer are complex and remain poorly understood. It has been suggested that these biological processes are likely mediated through multiple mechanisms and pathways. Over recent years, considerable knowledge has been gained through research examining the relationship between biomarkers and fatigue in cancer, with 33 studies alone published between 2010 and 2013 (Saligan et al., 2015). This search to identify biomarkers could help increase understanding of the aetiology of fatigue and guide on the potential development of therapeutic targets, which are currently lacking. It is possible that mechanism-driven symptom intervention could prevent or treat underlying fatigue, particularly in cancer survivors. However, it seems likely that individual patients with advanced cancer may have a complicated array of similar and dissimilar mechanisms or contributory causes for fatigue. Patients living with advanced cancer may receive several cancer treatments, all of which cause transient or lasting fatigue. The complexity and ambiguity that surrounds fatigue could raise some difficulties for the oncologist attempting to define fatigue and convey this uncertainty to patients. For patients with fatigue, this lack of understanding around fatigue could also be challenging in their attempts to deal with it.

2.4.4 Management of fatigue in advanced cancer

This section will provide a broad overview of the management of fatigue in advanced cancer. First, research that concerns the pharmacological management of fatigue will be described. Secondly, literature concerned with non-pharmacological interventions for fatigue, including exercise and multimodal interventions will be explored. Finally, it will be suggested that the lack of evidence-based treatments to manage fatigue in advanced cancer may leave oncologists feeling that nothing can be done for fatigue.

A Cochrane review performed by Minton et al. (2010) assessed the efficacy of drugs for the management of cancer-related fatigue. Therefore, included studies contained samples of cancer patients: those receiving cancer treatments with curative intent and palliative intent, those receiving palliative care and those cured of cancer but living with side effects of treatments, and cancer survivors. Methylphenidate, a psychostimulant, was the only recommended drug treatment for cancer-related fatigue and the five studies included showed a small but significant improvement in fatigue over placebo ($Z = 2.83$; $P = 0.005$). Of the five RCTs included, only one study solely included patients with solid tumour cancers and advanced disease (Auret et al., 2009). This was a small sample of 50 patients receiving palliative care and there was no improvement in fatigue on study completion (Auret et al., 2009). Two further Cochrane reviews assessed the efficacy of drugs on fatigue in palliative care, including patients with advanced cancer and advanced chronic progressive illnesses. (Peuckmann-Post et al., 2010; Mücke et al., 2015). The authors could not recommend a specific drug treatment for fatigue in palliative care patients. However, one RCT showed dexamethasone was significantly superior to placebo with respects to FACIT-F subscale, a multidimensional fatigue assessment tool but not with numerical rated fatigue intensity scores on study completion at 15 days (Yennurajalingam et al., 2013).

Several RCTs which assessed the efficacy of drugs for fatigue in a patient with advanced cancer have noted clinically significant placebo effects (Bruera et al., 2006; Bruera et al., 2007; Spathis et al., 2014, Yennurajalingam et al., 2013). It was postulated by some researchers that the regular contact with nurses and attention provided to fatigue during the trial in the placebo arm might have contributed to this placebo effect (Bruera & Yennurajalingam, 2010). Subsequently, an RCT was designed comparing the effects of methylphenidate and/or a nursing telephone intervention with placebo (Bruera et al., 2013). A total of 190 participants were stratified into four groups and were randomly assigned to a nursing telephone intervention (NTI) or control telephone intervention (CTI). The NTI group were contacted by a research nurse with training in palliative care for a total of four to six sessions over the two weeks study period. The CTI group were telephoned by a person who was not a healthcare professional and was contacted a similar number of sessions with also controlled time. Methylphenidate and NTI alone or combined were not superior to placebo. However, a placebo effect was possibly observed with clinically relevant improvements in fatigue intensity scores in all four groups. This raised interesting questions about the possible effect of participation in a clinical trial, with attention on fatigue provided by the healthcare and research team, potentially providing some clinical benefit.

A Cochrane review assessing the effect of exercise on cancer-related fatigue both during and after cancer treatment concluded that aerobic exercise can be beneficial (Cramp & Byron-Daniel, 2012). However, many included studies contained samples of cancer survivors or those treated with curative intent. Fewer studies have solely focused on patients with advanced cancer and the review of subsequent studies have been mixed (Cheville et al., 2013; Dhillon et al., 2017; Pyszora et al., 2017). Dhillon et al. designed an RCT comparing an exercise intervention with usual care in patients with advanced lung cancer (2017). The exercise intervention consisted of a physical activity programme, including eight weekly sessions with an exercise provider and general health educational materials. Usual care consisted of health education materials only. Patients were eligible for inclusion if they had a prognosis greater than six months and performance status ≤ 2. A total of 111 patients took part, completing outcome measures for fatigue (FACT-F) every two months until study completion at six months. Seventy-two participants completed the study with a 35% attrition rate, larger in the usual care group and death being the commonest reason (21%). The findings revealed that the intervention provided no benefit to fatigue or physical or functional status at all time points (Dhillon et al., 2017). The study was powered to allow a 30% attrition rate, but this was exceeded. The high attrition rate may be reflected by the patient population studied, the longitudinal study design and the difficulty in estimating prognosis. Although the intervention appeared burdensome, adherence was good but the response was insignificant.

In contrast, a separate study with a similar design but with a less burdensome intervention and shorter follow up, appeared to show some benefit for exercise for fatigue (Cheville et al., 2013). Cheville et al. (2013) conducted an RCT comparing a home-based exercise intervention with usual care in patients with stage IV lung and colorectal cancer. The intervention consisted of a single face-to-face instructional session on an exercise programme, subsequently exercising four days per week with bimonthly telephone calls from the therapists. Secondary outcomes measured fatigue (FACT-F). A total of 66 participants took part and 56 completed the study at 2 months. The findings suggested some benefit in mobility and fatigue at study completion (Cheville et al., 2013). However, the mean difference in FACT-F was 4.46 which may not be clinically significant. Overall, these studies suggest that the benefits of exercise in advanced cancer are uncertain.

A Cochrane review assessed the effects of psychosocial interventions for fatigue in patients with incurable cancer receiving treatment with palliative intent (Poort et al., 2017). Fourteen studies were included in the review and most contained mixed samples of patients. The authors were unable to extrapolate the samples of participants with incurable cancer and perform a meta-analysis. The findings suggested little evidence or very low-quality evidence for the benefit of psychosocial interventions provided to reduce fatigue in this patient population (Poort et al., 2017). Sharpe et al. (2014) designed a multicentre RCT comparing a complex psychosocial intervention for patients with major depression and cancer with usual care; 500 participants took part and data were collected for up to 48 weeks. Fatigue measurement was a secondary outcome measure and participants in the intervention group had a reduction in fatigue scores at all time points which were statistically significant and clinically relevant. There were several strengths to the design of this study including the large sample size, randomisation, blinding of outcomes and relatively low attrition rate. However, only 13% of the sample had incurable disease so these findings cannot be straight forwardly transferable to patients with advanced cancer.

In summary, there are few drug or supportive interventions which provide a clear benefit for fatigue in advanced cancer. It is conceivable that this could contribute to oncologists feeling that nothing can be done for fatigue in advanced cancer care. Moreover, oncologists may believe fatigue contrasts with other cancer symptoms because more effective drug treatment options could exist for nausea/vomiting and pain. If oncologists routinely feel nothing can be done for fatigue, this could create a barrier to the assessment and management of fatigue in the palliative oncology clinics. These hypotheses could be examined by observing the behaviour of oncologists in palliative oncology clinics and by interviewing oncologists to explore how they approach fatigue in advanced cancer care.

2.5 The perspectives of patients to the management of fatigue

This section outlines findings that provide some insights into the views of patients that relate to fatigue in cancer care. The perspectives of patients on how healthcare professionals (HCPs) and oncologists address fatigue are relevant. Research that suggests patients commonly use self-care or self-management behaviours to cope with fatigue will be explored. In addition, it is proposed that some patients who experience fatigue may have unmet needs and could welcome more support to manage fatigue.

The findings of two large surveys of cancer patients have suggested that even though fatigue was perceived to have an impact on daily life, most respondents believed that fatigue was something to be endured and many did not report fatigue to their oncologist (Stone et al., 2000; Vogelzang et al., 1997). Stone et al. (2000) performed a cross-sectional survey in three UK cancer sites and invited consecutive patients attending the oncology outpatient clinic or chemotherapy day unit to participate. A total of 576 patients participated (response rate = 44%) and a quarter were receiving chemotherapy. The majority (93%) experienced some degree of fatigue over the previous month and 52% (n=285) had never raised the issue with their doctor (Stone et al., 2000). The main reasons given by patients included: believing fatigue was inevitable; fatigue was not important enough; believing nothing could be done; and the doctor never raised it as an issue. Half of all patients who experienced some fatigue felt it was just something they had to live with and only 22% felt it could be relieved or controlled. These findings could lead to questions about how patients accept fatigue and cope with it by themselves if they do not seek support. It could also raise questions about whether there were barriers to the communication of fatigue, either from the patient or the oncologist, with perhaps either believing nothing could be done for fatigue.

There were several important limitations to consider when the AXIS tool was used (Downes et al., 2016). The fatigue data presented made it difficult to interpret clinically meaningful fatigue in the sample. The validated instrument Functional Assessment of Cancer Therapy-Fatigue (FACT-F) was used but the scoring system was described incorrectly in the methods and the timescale was changed from one week to one month (Yellen et al., 1997). If the FACT-F median score of 18 was accurate, this suggested about half of the sample had severe fatigue (Hwang et al., 2002). Mild fatigue was suggested in at least 35% and if it was not bothersome to some patients perhaps this could explain why many never raised fatigue with their doctor. The response rate was low, and this could lead to responder bias. The sample was overpopulated with breast cancer patients (44%) which could make the findings less transferable because of selection bias. Non-responder data was not collected for reasons related to anonymity. It is conceivable that the task of completing a long questionnaire and posting it might have been too burdensome for some fatigued patients. Strengths in the design included the pretesting of the questionnaire with patients to improve validity and the consecutive invitation to all patients. Lastly, the sample contained no information about the stage of disease or whether cancer survivors were included which meant the findings were difficult to transfer to patients with advanced cancer.

A US telephone survey was performed by Vogelzang et al. (1997) on cancer patients who had received cancer treatments within 2 years; 419 participated (response rate 77%) and 78% reported or recalled fatigue during treatment (Vogelzang et al., 1997). Most believed fatigue (74%) was something to be endured. Over a quarter of participants (27%) reported that their oncologists suggested or prescribed treatments for fatigue (Vogelzang et al., 1997). A critical appraisal of this survey was performed with a standardised tool and the study was deemed of moderate to poor quality (Crombie & Harvey, 1997). Insufficient information was provided about the sample related to the stage of the disease and there was missing data. It is likely the sample contained significant numbers of cancer survivors as 50% of the sample had cancer treatments between one and two years previously. Although randomisation was used, selection bias was possible. Recall bias was also possible as the sample included participants who had chemotherapy up to two years previously. As a result, these survey findings may not be transferable to patients with advanced cancer who experience clinically meaningful fatigue. Nevertheless, they provided some suggestive findings which could be better examined further by interviewing patients.

A Swiss qualitative study explored the perspectives of patients regarding fatigue, focusing on communication with HCPs and self-care activities (Spichiger et al., 2012). Nineteen patients were interviewed immediately after receiving their third cycle of chemotherapy in the outpatient clinic. Eleven were receiving treatment with curative intent and eight were receiving palliative treatment. Five patients had a diagnosis of lymphoma and the rest derived from solid tumours (Spichiger et al., 2012). The median Functional Assessment of Chronic Illness Therapy (FACIT-F score) (Cella et al., 2002) for fatigue was 26 (range 10 – 51) which may have suggested that about half of the sample had clinically meaningful fatigue (Hwang et al., 2002). Most participants felt adequately informed about fatigue by HCPs and were aware that fatigue was an expected side effect of chemotherapy. Patients experienced fatigue with varying degrees of intensity ranging from almost none to extreme, with various patterns over time and mainly physical signs. All patients were willing to endure fatigue, regardless of the severity, as a trade-off or price for successful treatment (Spichiger et al., 2012). This was equally true for patients receiving curative and palliative treatment. Patients receiving palliative chemotherapy knew their cancer was incurable and they had lower expectations regarding the effects of chemotherapy but they remained hopeful. This was illustrated clearly from a quotation in the study.

'Let's just hope that this suffering was somewhat effective. I believe it is.'

(68 years old woman with lymphoma; palliative)

(Spichiger et al., 2012)

Even though all patients were prepared to accept fatigue as an inevitable side effect of chemotherapy, how they coped with fatigue and managed the effects of it varied. Some modified their daily family activities to match their levels of fatigue, but some were unable to carry on with their usual activities. Some could easily accept support and others found it more difficult (Spichiger et al., 2012). It was noted that support from family and friends was important both in practical and psychological terms when it was available or accepted by patients. The authors reported self-care as patients reacting intuitively to the effects of fatigue and being guided by how their bodies were feeling. Resting was the preferred strategy used by patients and a few used exercise.

A COREQ checklist was performed on this study and revealed some limitations (Tong et al., 2007). Two research assistants conducted the interviews and were experienced oncology nurses, yet there was no reference to reflexivity to minimise potential bias or assumptions. However, it was uncertain if the research assistants were part of the analytic process and no background information was supplied on the authors. A modified grounded theory approach was reported as the theoretical framework but the analytic approach more resembled qualitative content analysis. There was no development of a theory and the authors reported this was never their intention. Participants were recruited through another study but the selection process for patients with fatigue was vague. Data saturation was not reached, and the authors reported that this was planned for. An inductive approach to analysis was suggested which resulted in descriptive rather than interpretative data. It was not clear whether the findings were presented as categories or as themes. In summary, this research was of moderate quality and despite the limitations the findings give some insights into how some patients receiving chemotherapy approach fatigue. Further, the findings may not be transferable to a patient population with advanced disease and clinically meaningful fatigue.

Researchers have surveyed the self-care or self-management behaviours used by patients receiving chemotherapy to cope with fatigue (Chan et al., 2016; O'Regan & Hegarty, 2017; Richardson & Ream, 1997). Richardson and Ream described the self-care strategies used by 109 patients as noted in daily diaries over a period of 3-4 weeks (1997). Over half had metastatic cancer and treatment was generally given with palliative intent. The majority experienced some fatigue, but mild fatigue was prevalent in several cancer groups. The data on missing diary entries were not described but was associated with increasing fatigue intensity. Self-care actions were classified in categories and the most commonly used were: modification or alteration in activity and rest pattern (83.6%); psychological strategies (24.7%); and social interventions (17.8%) (Richardson & Ream, 1997). Self-care activities were reported to provide at least some relief on nearly 90% of occasions and the majority were reported as self-learned with very little apparent input from HCPs.

Chan et al. (2016) developed a fatigue self-management instrument based on the literature and longitudinally surveyed the self-management behaviours of 152 patients with advanced cancer experiencing clinically meaningful fatigue. The behaviours were organised in domains: activities; complementary or alternative therapies; cognitive; psychological; and nutrition. Breast (40%) and lung (29%) cancer were the most common diagnoses and over 80% were receiving some cancer treatment. The most effective behaviours for relieving fatigue were: pacing activities; taking a short sleep during the day; planning activities to make the most of energy levels throughout the day; doing things that distract from fatigue; and doing things to improve sleep at night (Chan et al., 2016). However, the effectiveness of these self-care strategies appeared to lessen at study completion at eight weeks.

These surveys provided some insights into the self-care strategies used by patients and their perceived effectiveness. However, it is possible that these pre-defined surveys, based on the literature, have omitted some other important self-care strategies that patients have found useful. Moreover, the effectiveness or appropriateness of each strategy may vary depending on the intensity or pattern of fatigue experienced over time. Talking with patients in-depth about how they manage fatigue might help to understand how and when these strategies might be useful. As these strategies often appear to be self-learned there may be other patients who could benefit from learning about them through the support from HCPs.

Some authors have suggested that some patients who experience fatigue have unmet needs after not receiving any support from HCPs on how to manage it. A large Danish cross-sectional survey of patients with advanced cancer reported that some patients with clinically meaningful fatigue had unmet needs and wanted help to support and manage it (Johnsen et al.,2009; Madsen et al., 2015). A total of 1,447 patients (response rate 61%) participated in a mail survey and 827 (60%) experienced some fatigue. Nearly two-thirds had advanced cancer related to solid tumour cancers and the rest derived from blood cancers. Of the 827 respondents who experienced some fatigue, over half reported receiving no help and/or treatments for fatigue from HCPs even though most would have been interested in receiving help if it was available (Madsen et al., 2015). An unmet need for fatigue was defined as the patient had not received help for fatigue but wanted it, had received help which was inadequate or had received help which was partly adequate. An unmet need was present in 474 (57%) of those experiencing some fatigue and more than half had clinically meaningful fatigue. There were some limitations with this survey which could affect the generalisability of its findings: the potential of sample and recall bias, and heterogeneity of the sample, where only 33% received oncology care. Nevertheless, the findings suggested that a significant proportion of patients living with advanced disease did not receive any help or treatments for fatigue despite being interested in receiving it.

Other cross-sectional surveys of cancer patients receiving oncology care have suggested that fatigue was frequently not assessed or managed by cancer clinicians (Passik et al., 2002; Stone et al., 2000; Vogelzang et al., 1997). Findings from a small survey of cancer patients (n=108) who received oncology care from a single cancer centre may suggest improvements in this pattern in recent years (James et al., 2015). Two-thirds of respondents reported that fatigue was assessed by cancer specialists during treatment, and over half were offered advice which most found helpful. However, a third reported they were not offered any advice for fatigue and some of this group reported they would have welcomed this, meaning they had unmet needs (James et al., 2015). Therefore, it could be possible that some patients with fatigue have unmet needs and may benefit from learning about how others have coped with fatigue.

In conclusion, studies have suggested that some patients receiving treatment with curative and palliative intent may share similar views on the acceptability of fatigue as a side effect of treatment. The reported acceptance of fatigue may contribute to a sense that it needs to be endured to receive the potential benefits of treatment. However, this needs to be fully explored by talking with patients who have advanced disease and clinically meaningful fatigue. Self-care strategies or self-managed behaviours appear to be intuitively learned and used by patients for fatigue but the research that investigates this is lacking. These strategies could be individually-based or some could be more effective with different patterns or trajectories of fatigue. Talking with patients about how they coped with different patterns of fatigue and the impact it had on their lives could benefit others.

It is suggested that patients with fatigue have unmet needs and perhaps this could be improved if fatigue was better assessed and managed in healthcare interactions. Observing and examining naturally occurring interactions could reveal practices that perhaps might better support and improve the communication of fatigue in oncology care. There are some suggested barriers to the communication of fatigue and perhaps this could be explored by observing and talking with patients and doctors.

2.6 The perspectives of doctors on fatigue in advanced cancer

Following on from the patient perspectives on the management of fatigue, it is important to understand what doctors think about fatigue in the palliative setting and how they approach it in their clinical practice. The findings from published literature on the perceptions of oncologists is described. The literature is limited but some insights are explored. The micro-analysis of talk between patients and oncologists could help to understand how fatigue is approached by oncologists and one such study is highlighted.

There is limited published research on the perceptions and attitudes of oncologists towards fatigue in cancer care. Four cross-sectional surveys of oncologists were identified, based on similar study design and aims, comparing the perceptions of patients and oncologists on the prevalence and effects of fatigue (Dillon & Kelly, 2003; Stone et al., 2003; Vogelzang et al., 1997; Williams et al. 2016). However, three studies were deemed of poor quality and the findings are not reported in this thesis (Dillon & Kelly, 2003; Stone et al., 2003; Vogelzang et al., 1997).
A US mail survey of oncologists was performed by Williams et al. (2016) and 400 participated (response rate 75%). The eligibility criteria for oncologists was defined to those in clinical practice (75% work time) and this mostly devoted to caring for patients with solid

tumours receiving chemotherapy. The majority (98%) of the 550 patient participants reported experiencing fatigue but 72% of oncologists thought this was the case (Williams et al. 2016). Over half (58%) of patients receiving cancer treatments perceived fatigue impacting on daily lives more than pain and this contrasted with 29% of oncologists (Williams et al. 2016). A critical appraisal of this study identified some strengths and weaknesses (Crombie & Harvey, 1997). The strengths included the response rate and the selection of oncologists providing direct patient care. Measures were also taken by the authors to minimise bias in the study design and a pretest feedback survey was performed to improve validity. The questionnaire suggested other data from oncologists was collected but this was not reported, and this may be a limitation. Overall, the findings from this study were of moderate to good quality. The findings suggest that oncologists may underestimate the prevalence of fatigue in oncology clinics and the effect of fatigue has on patient's daily lives when compared to pain. Perhaps this may be a factor in the suggestion that patients with fatigue have unmet needs.

There is very limited data in the literature that explores the attitudes and experiences of oncologists to fatigue in patients with advanced cancer. However, some interesting insights that relate to fatigue were revealed in a Swedish qualitative study that explored the opinions and experiences of oncologists with a focus on the effect of palliative chemotherapy on cancer symptoms, especially in those receiving third-line or more treatment (Strang & Bergqvist, 2017). Thirty-five doctors were interviewed, the majority senior clinicians and 94% were oncologists. All participants revealed the main goal of palliative chemotherapy was to improve symptom burden, even in late stages of treatment, aside from the limited chance to prolong of life. Some felt there was a realistic chance that fatigue caused by cancer could improve but this was mostly seen in the first- or second-best cancer treatment options and only in cancer diagnoses that were considered to respond to treatment. All stated that fatigue in late stages seldom improved, with an expectation that it would worsen with a deterioration in ECOG PS because of burdensome treatments. Most felt it was difficult to evaluate the contributory causes of fatigue and differentiate between the effects of treatment and disease. In contrast, the evaluation of fatigue in the curative setting was more straightforward because fatigue was solely caused by cancer treatments rather than the disease.

A COREQ checklist performed on this study revealed some limitations: no reference to reflexivity was described; no method of approach of participants was provided; and data saturation was not discussed. However, the strengths included maximum variation sampling of oncologists, the large sample, the analytic rigour described, and the findings presented. This study raises some curious findings which warrant further investigation. Firstly, how oncologists evaluate fatigue in advanced cancer as this could perhaps be different compared to the curative setting. Secondly, how oncologists manage fatigue in patients with advanced cancer as the side effects of cancer treatments become more burdensome, with less chance of improving symptoms and prolonging life.

There are very few interactional studies observing naturally-occurring patient-doctor clinical encounters, in the literature that examine how oncologists assess and manage of fatigue in cancer care. Secondary qualitative analysis was performed on audio-recorded consultations between oncologists and patients that were originally collected as part of a single RCT evaluating the effect of patient-reported outcome measures (PROMs) in oncology care (Greenhalgh et al., 2013; Takeuchi et al., 2011; Velikova et al., 2004). Greenhalgh et al. selected 22 recordings for analysis, first from those in which oncologists received a patient's PROMs data on the first occurrence (n=108) and then sub-selected from those where PROMs data were explicitly referred to (n=37). The authors used a combination of content and conversation analysis to examine how the health-related quality of life issues were opened-up or closed-down within the consultation and how they were managed. The findings suggested that oncologists closed-down discussions about fatigue in several different ways. These included: a candidate cause for tiredness of chemotherapy was provided; the subject was changed to explore other symptoms; minimising the severity, duration or impact of fatigue; and presenting fatigue as an inevitable consequence of chemotherapy or normalising fatigue (Greenhalgh et al., 2013). The authors also suggested that more treatments were offered for other symptoms compared to fatigue when the entire data set was coded (Takeuchi et al., 2011).

The strengths of the study were in the methods for analysis which provided a micro-analysis of talk and resulted in an in-depth understanding of how fatigue was approached by oncologists in cancer care. However, the ethnographic account that relates to the interactional data should be fully considered. It is uncertain whether the data relates to patients with advanced cancer as 22% of the full corpus of data possibly included patients treated with curative intent (Takeuchi et al., 2011). This could be important as oncologists may have approached the assessment and management of fatigue differently in the adjuvant setting compared to the palliative setting, as previously documented (Strang & Bergqvist, 2017). The authors reported that PROMs data may have encouraged patients/relatives to report symptoms compared to consultations without PROMs data available to the oncologist (Takeuchi et al., 2011). It is also possible that PROMs data could have influenced the actions of doctors if, for example, the patient had reported mild fatigue. Although the study was performed in a UK cancer centre, this was a trial setting and PROMs are not routinely used in oncology care settings within the UK. Therefore, the examination of interaction data without PROMs could be worthwhile.

In conclusion, the current understanding of how oncologists perceive and communicate about fatigue in advanced cancer is restricted to several surveys of poor quality and one qualitative interview study of good quality where the primary study aim was broad. Perhaps oncologists routinely expect patients with advanced cancer receiving chemotherapy to experience fatigue as a side effect of treatment, eventually worsening with a decline in function and ECOG PS. However, as fatigue worsens, it might be difficult for the oncologist to decipher whether the treatment or the disease contributes more to fatigue and maintain the goals of palliative treatment. The expectation of fatigue occurring with cancer treatments could, perhaps, explain the normalising behaviour observed in interactional data. The lack of available treatments for fatigue might also explain how fatigue conversations were closed-down and other symptoms more amenable to treatments were explored.

Interviewing oncologists to explore their views on fatigue in advanced cancer could develop knowledge in this area. And exploring their perspectives matters because during their patient-facing encounters, oncologists have a crucial role in addressing the potential concerns of patients with fatigue and helping to manage this symptom. Observing and analysing naturally-occurring clinically encounters could advance the understanding of how oncologists and patients approach fatigue in advanced cancer.

2.7 Palliative cancer treatments and decision making

This section will outline some of the understanding in relation to the decision-making surrounding palliative cancer treatments in advanced cancer care. First, it will propose that oncologists usually make decisions about palliative cancer treatments by measuring the fitness of the patient for treatment which can be associated with fatigue levels. Second, it will suggest patients with advanced cancer often make decisions about palliative cancer treatments by remaining optimistic about the benefits of treatment and this perhaps facilitates an acceptance and tolerance to fatigue over time. Third it will highlight problems with the delay in withdrawing palliative chemotherapy near the end of life, with conceivable detrimental outcomes to quality of life and end of life care. Finally, this section will suggest how fatigue could be relevant to cancer treatment decision making in palliative oncology clinics.

2.7.1 Oncologist's decision-making regarding palliative cancer treatments

In palliative oncology clinics, as part of the assessment of the patient, the oncologist determines whether to offer or continue with palliative cancer treatments by measuring fitness for treatment. Fitness for palliative chemotherapy is generally determined by the universal marker ECOG PS which essentially defines functional status (Bachelot et al., 2000; Oken at al., 1982; Simon et al., 2004). In addition, the ECOG PS is an important predictor of prognosis and in identifying the terminal phase of illness (Glare et al., 2008). There are six scales to the ECOG PS with Grades 1 to 4 the most relevant to mention and are defined as follows: Grade 1, restricted in activity but ambulatory and able to carry out work of a light or sedentary nature; Grade 2, ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours; Grade 3, capable of only limited self-care, confined to bed or chair more than 50% of waking hours; Grade 4, completely disabled and cannot carry on any self-care, totally confined to bed or chair (Oken at al., 1982). Accordingly, severe disabling fatigue could correspond to Grade 3/4 ECOG PS and this impedes on fitness for palliative chemotherapy as research has shown that offering or continuing with chemotherapy leads to more treatment toxicity and poor survival outcomes (Bachelot et al., 2000; Swetz & Smith, 2010). Thus, in guidance, palliative chemotherapy could be offered and continued by oncologists, until the level of fatigue was deemed to impede on fitness for treatment.

The determination of ECOG PS may not be straightforward and an overestimation of functional ability could lead to problems for patients who experience fatigue. Research suggests there may not be uniformity amongst healthcare professionals in relation to the grading of ECOG PS and this could contribute to patients experiencing severe disabling fatigue on palliative cancer treatments. Kim et al. (2015) reported on the grading of ECOG PS of 278 patients with advanced cancer who had met a medical oncologist and palliative care specialist within one week. Over three-quarters of the patients had clinically relevant fatigue and 82% received palliative chemotherapy (Kim et al., 2015). Assuming ECOG PS ≤2 equates to fitness for treatment, a third of patients (n=93) deemed fit by oncologists were deemed unfit by a palliative care specialist (Kim et al., 2015). This raises two significant considerations. First, it was conceivable that some unfit patients could have received palliative chemotherapy which further worsened disabling fatigue and limited their survival (Bachelot et al., 2000; Glare et al., 2008; Swetz & Smith, 2010). Second, the role of the oncologist is to provide cancer treatment with the aim of controlling the disease and perhaps this could sometimes contribute to an underestimation of ECOG PS in palliative oncology clinics.

The decision by oncologists to offer palliative cancer treatments could further depend on the expected response of a specific cancer to treatment. Broadly, different cancer types could be expected to respond to cancer treatments to varying degrees with clinical trial data providing a guide to average treatment response and median overall survival (Cassidy et al., 2008; Conroy et al., 2011; Cunningham et al., 2008; Slamon et al., 2001). In general, pancreatic and oesophageal cancers are less responsive to cancer treatments, resulting in a poorer prognosis when compared to breast and colorectal cancers (Cassidy et al., 2008; Conroy et al., 2011; Cunningham et al., 2008; Slamon et al., 2001). Therefore, oncologists who care for patients with pancreatic cancer may have fewer treatment options to offer and may be less optimistic about the benefits of cancer treatments in comparison to oncologists who care for patients with breast cancer. Because the survival benefit from palliative cancer treatments for pancreatic cancer is much less than breast cancer, perhaps this has an influence on how oncologists approach patients with severe disabling fatigue in these patient groups.

To summarise, oncologists usually measure the ECOG PS to decide whether the patient with advanced cancer is fit enough for palliative cancer treatments. The functional impact of fatigue can be associated with the grading of ECOG PS and severe disabling fatigue impedes on fitness for treatment. There may not be uniformity amongst oncologists and related healthcare professionals in the grading of ECOG PS and this perhaps could unintentionally lead to worsening clinically relevant fatigue that may have been avoidable. The oncologist's decision-making surrounding palliative cancer treatments could also be influenced by the expected responsiveness of the cancer type to cancer treatments. All these factors appear to be important in how oncologists make decisions about offering or continuing palliative chemotherapy. This also suggests fatigue may inform part of the decision-making process for oncologists. The potential relevance of fatigue in palliative cancer treatment decision-making will be explored by observing and talking with cancer clinicians.

2.7.2 Patient's decision-making regarding palliative cancer treatments

Patients with advanced cancer often take up the offer and continue receiving palliative cancer treatments in order to control the disease and prolong life. Research suggests some patients receiving palliative cancer treatments are optimistic about treatment prolonging life and this may help them deal with fatigue. Bergqvist and Strang (2017) investigated the motives of 20 patients with metastatic breast cancer for continuing with their second to eighth lines of palliative chemotherapy treatment (i.e. line of treatment refers to a trial of a cancer treatment regimen, usually over months). They found participants continued with treatment to postpone death, this meant having treatment equated with living and not having treatment equated to dying so there was no choice but to carry on (Bergqvist & Strang, 2017). It was also described how fatigue was easier to cope with when attributable to treatment rather than cancer which was sometimes associated with a fear of imminent death (Bergqvist & Strang, 2017). Some participants were reported to have said they would eventually stop cancer treatment when completely out of energy (Bergqvist & Strang, 2017). Thus, patients with advanced cancer remain hopeful that cancer treatments prolong life and this could likely offset the experience of fatigue. However, it is possible that maintaining hope with cancer treatments could lead to acceptability of fatigue that had a detrimental impact on quality of life.

A continued optimism for the perceived benefits of palliative cancer treatments can make fatigue more tolerable over time. This means that some patients with advanced cancer can readjust their perception and tolerance of fatigue during treatment cycles because the prolongation of life is more important. Westerman et al. (2007) performed a longitudinal study containing 23 participants, mostly with incurable lung cancer, and identified a recalibration response shift in patients who reported fatigue. For most participants, the impact of fatigue on quality of life and functional status was reported to have worsened as the cycles of treatment progressed. However, some participants were shown to have altered their perception of fatigue as their reference point to fatigue severity changed over time (Westerman et al., 2007). This meant some patients perceived the impact of fatigue on quality of life and functional status was tolerable when hitherto this level of fatigue would not have been bearable or acceptable. Therefore, it was suggested that some patients can adapt to the changing impact of fatigue on daily living while perceiving a benefit from palliative cancer treatments. Thus, it is possible that some patients can shift their limits of tolerability of fatigue over time and recalibrate their perception of fatigue when they remain optimistic that palliative cancer treatments control cancer and prolong life.

If patients were to be overly optimistic about the benefits of palliative chemotherapy this could conceivably lead to patients experiencing and accepting fatigue with a detrimental impact on quality of life perhaps unnecessarily. Research suggests that the optimism patients have for palliative cancer treatments may mismatch with the oncologist and this can sometimes be misplaced. Gramling et al. (2016) independently assessed the survival expectations of patients with advanced cancer and their oncologists along with comparing their ratings of 2-year survival probability. The authors found 66% (155/236) of patients with advanced cancer were more optimistic than their oncologist about the survival benefit (Gramling et al., 2016). Therefore, this cross-sectional study suggests there may commonly be a mismatch between the perceptions of patients and their oncologist about the benefit of survival from palliative chemotherapy. A separate US study by Weeks et al. (2012) asked 1193 patients recently diagnosed with advanced cancer and receiving palliative chemotherapy about their expectations that treatment might be curative. The study found about 50% of lung and 65% of colorectal patients reported it was ‘very likely’ or ‘somewhat likely’ treatment was curative (Weeks at al., 2012). Thus, many patients with advanced cancer may believe the intent of treatment is to cure and this may have consequences in how they rationalise the trade-off of fatigue on cancer treatment. It could lead to patients willingly accepting levels of fatigue which have a negative impact on quality of life and functional status even when the benefit to survival might be limited.

To recap, patients with advanced cancer remain optimistic about the benefits of palliative cancer treatments controlling the disease and this informs their decision making. This optimism can facilitate the acceptance of fatigue on treatment as it becomes a trade-off for prolonged survival. However, patients with advanced cancer might be overly optimistic about the survival benefit of palliative chemotherapy and this could lead to problems in how they cope with the effects of fatigue. It is possible that unrealistic expectations about the benefits of palliative cancer treatments could lead to patients accepting levels of fatigue that have a detrimental impact on quality of life. In addition, for patients with advanced cancer near the end of life, unrealistic expectations could lead to poorer quality of life and increased healthcare costs. This could be explored further by observing how patients approach fatigue in palliative cancer treatment decision discussions and asking them how they deal with fatigue.

2.7.3 Decision-making to withdraw palliative chemotherapy near the end of life

The decision to withdraw palliative chemotherapy treatments near the end of life can be difficult but a delay could worsen levels of fatigue. Research has suggested it can be hard for both patients and oncologists to recognise the right time to stop such treatments. A systematic review by Clarke et al. (2015) on the decision-making concerning the withdrawal of anticancer drugs towards the end of life within clinical practice included 42 studies. The authors reported clinicians found it was difficult to judge the appropriate time to stop, especially when a patient remained fit enough for treatment and the benefits of such treatments were uncertain (Clarke et al., 2015). Patients with advanced cancer were also reported to have found it difficult to anticipate the right time to make decisions to withdraw from all cancer treatments (Clarke et al., 2015). A previously mentioned study reported patients describing the cessation of cancer treatments as a life or death decision with little option but to continue (Bergqvist & Strang, 2017). These studies suggest both parties in the decision-making process can find it hard to know when to withdraw cancer treatments in the latter stages of the disease. This has relevance for patients experiencing fatigue because a delay in the withdrawal of futile cancer treatments could risk fatigue having a greater impact on the individual’s daily life and hasten the onset of severe disabling fatigue.

A difficulty in not knowing when to withdraw from palliative cancer treatments could result in unforeseen and unintended consequences for the patient and their family. Research has suggested there may be costs in terms of how and where people die. Wright et al. (2014) examined the outcomes of a cohort of 386 patients with advanced cancer who died during a larger study. Study participants were eligible if they had already progressed through at least one chemotherapy treatment and an oncologist estimated prognosis at less than 6 months. 56% (216/386) of participants were receiving palliative chemotherapy on study enrolment and the median time to death was 4 months (Wright et al., 2014). In comparison to the group not receiving palliative chemotherapy, those who received chemotherapy were significantly more likely to have had cardiopulmonary resuscitation and/or mechanical ventilation, to have died in an intensive care unit and not to have died in their preferred place of care (Wright et al., 2014). This study suggests that an active approach to disease management near the end of life may lead to a poorer quality of life and death for patients and their families. It also suggests a delay in the withdrawal of palliative chemotherapy could be associated with a higher burden of healthcare costs through intensive medical treatments as well as the added costs of futile chemotherapy treatments. Thus, apart from the risk of worsening fatigue, a delay in withdrawing palliative cancer treatments near the end of life may have additional costs to the patient, their families and healthcare providers.

In palliative oncology visits concerning patients with clinically relevant fatigue, it is uncertain how cancer treatment decisions occur and whether talk connected with fatigue forms part of the discussion. It is possible that oncologists could introduce fatigue as a marker of quality of life, because not having the energy to do family activities or engagements may provide enjoyment to patients. Oncologists and patients could agree or disagree about the impact of fatigue on quality of life and fitness for treatment depending on how patients prioritise survival over quality of life. Because patients may feel the cessation of cancer treatments is a life and death decision, they may seek to continue with treatment regardless of the effects of fatigue on their daily lives. Understanding how patients and oncologists approach fatigue in palliative oncology visits and how they manage any potential discordance could be important for other cancer clinicians to be aware of. Recording and analysing patient-doctor interactions from palliative oncology clinics could examine whether talk connected with fatigue plays a role in palliative cancer treatment decision making and if so, how it is approached by participants.

2.8 Summary

This chapter has examined the topic of fatigue in advanced cancer from different perspectives. First, definitions of fatigue in cancer and the literature review methods were presented. The second section provided a broad overview of fatigue in advanced cancer and included: the experience and impact of fatigue; the prevalence, associations and course of fatigue; the causes of fatigue; and the management of fatigue. The third section described some evidence to support how patients perceive fatigue in advanced cancer. The fourth section suggested some perspectives and behaviours of doctors to fatigue in advanced cancer. Finally, the fifth section proposed how decision-making might occur in palliative oncology clinics and how this could be relevant to fatigue.

Fatigue is perceived by patients as an abnormal experience, altogether different to tiredness and is associated with physical decline with increasing severity. Fatigue has multidimensional components which can contribute to a significant impact on quality of life. The uniqueness and complexity of fatigue are highlighted by the diverse language used by people to describe it. Fatigue is highly prevalent in those with advanced cancer receiving active treatment, and increases in severity with the accumulation of cancer treatments and progressive disease. People are living longer with advanced cancer and therefore living longer with the side effects of cancer treatments, with chronic fatigue potentially having a huge impact on quality of life. However, the biological causes of fatigue remain complex and poorly understood which means targeted treatments for fatigue are currently lacking.

In regard to the perspectives of patients with advanced cancer on the management of fatigue, this chapter has explored the limited literature covering this area. It is suggested they may find fatigue an acceptable consequence of palliative cancer treatments and might be willing to endure it for the perceived benefits of treatment. Some evidence might support the intuitive learning of self-management behaviours for fatigue in patients receiving oncology care but in general, there appear to be unmet needs for those experiencing fatigue in advanced cancer.

The chapter also examined the limited evidence that outlines the perspectives of oncologists to fatigue in cancer care and in advanced disease. It seems that oncologists generally expect fatigue to occur in patients receiving active treatment in the palliative setting and for fatigue to eventually worsen, accompanied by a deterioration in performance status and cessation of cancer treatments. Some oncologists perceive limited benefits of palliative cancer treatments with respects to fatigue, especially when the disease progresses on palliative cancer treatments and there are fewer treatment options available. Interactional studies have suggested oncologists normalise fatigue in cancer care and might offer more attention to other cancer symptoms compared to fatigue.

The fifth section of this chapter suggested fatigue may have a role in cancer treatment decision-making in palliative oncology clinics. Oncologists routinely assess fitness for treatment and fatigue may be associated with this. Patients may tolerate fatigue on palliative cancer treatments for the potential benefit of survival and this tolerance may shift over time through the coping measures that patients use. Patients with clinically relevant fatigue might be overly optimistic about the benefits of palliative cancer treatments and perhaps this could mean some tolerate fatigue that even interferes with fitness for treatment. Lastly, oncologists and patients might have difficulty identifying the appropriate time to withdraw palliative chemotherapy and this may have relevance to patients who experience worsening fatigue on treatment with uncertain benefits for survival.

This chapter has shown how fatigue in advanced cancer is a complex phenomenon that has received insufficient attention from researchers. Little is known about how patients cope with fatigue while receiving oncology care in the palliative setting and some in this population have unmet needs. Very little is known about how doctors assess and manage fatigue in the patients they care for. A number of questions remain unanswered and include: how do patients come to terms or not, with the worsening fatigue on cancer treatments and advanced disease; what strategies might be helpful with different patterns of fatigue observed; how do doctors approach fatigue, while expecting it to worsen with cancer treatments and progressive disease; how do doctors manage fatigue when there are few pharmacotherapeutic options; how do doctors and patients communicate about fatigue in clinical encounters and might there be communication practices which support the assessment and management of fatigue; what is the relevance of fatigue in cancer treatment decision-making in palliative oncology clinics is; and how doctors might manage patients who disagree with them that fatigue levels are detrimental to quality of life and/or interfere with fitness for treatment.

This doctorate will aim to address these gaps in research by exploring in-depth how patients and doctors approach and talk about fatigue in advanced cancer. Interviewing participants and observing naturally occurring interactions may help to add knowledge in this area.

Importantly, this research will collect and examine palliative cancer treatment decision discussions in patients with clinically relevant fatigue.

Chapter 3: Methodology and methods

3.1. Introduction to chapter

This chapter provides the rationale for the research methodology chosen and describes the research methods used in this PhD study. First, the study design adopted, mixed methods, will be described and the research paradigm that forms the basis of this study will be provided. Then, the methods of data collection will be outlined; and this will be followed by a detailed explanation of the methods of data analysis. Several important ethical considerations were relevant, relating to the population studied and the research methods used, and these will be comprehensively addressed. Finally, the last section will explain the three parts of the study: Part A, observations of oncology consultations; Part B, interviews with patients with fatigue; and Part C, interviews with oncologists. Each part will be covered and addressed separately for ease of presentation. Furthermore, each part will include a description of how participants were selected, how the methods were used and how analysis was undertaken.

As mentioned in Chapter 1, this study aimed to explore how fatigue was approached and managed by patients with advanced cancer, and to explore how oncologists approached and addressed this symptom in their clinical practice.

The overarching research questions were:

1. What talk connected with fatigue occurs in advanced cancer care consultations and how do participants talk about it?
2. How do patients with advanced cancer deal with fatigue?
3. How do oncologists approach fatigue in those with advanced cancer?

3.2. Study design

In this PhD study, the research questions and objectives guided the choice of study design and methods. These research questions were complex and could be answered by using mixed methods.

Examining how fatigue was talked about and managed in advanced cancer care was suited to the observation of palliative oncology outpatient visits and the measurement of fatigue. Understanding how patients dealt with fatigue and how oncologists approached fatigue in advanced cancer was appropriately explored through in-depth qualitative interviews. Hence, a qualitative approach to mixed methods were utilised in this study, to investigate a set of complex research questions, while providing detailed and multifaceted explanations. This study was a concurrent mixed methods design that was qualitatively driven with a quantitative element embedded in the primary component.

This section will outline the theoretical underpinnings of mixed method research, explain why mixed methods were appropriate to address the research questions in this PhD and outline how mixed methods were used.

3.2.1. Mixed methods research

Mixed methods research is a research paradigm and consists of the combination of both qualitative and quantitative research methods aiming to provide a complete and precise understanding of the phenomenon studied. Mixed methods emerged as a research approach in the late seventies and it has been reported that the quantitative component has usually dominated over the qualitative component in most study designs (Bryman, 2006; Cresswell, 2009). However, mixed methods design which are primarily qualitative can offer a range of insights and new understandings as they tend to be exploratory and theory generating (Hesse-Biber, 2010). Mixed methods research has become increasingly common in health services research and the main reasons reported by researchers for using this approach were that several research questions or the overall research question could be addressed comprehensively (O'Cathain et al, 2007). The research questions in this PhD were interrelated and therefore the approach of mixed methods research was an appealing feature to enable different dimensions of the complex phenomenon, fatigue in advanced cancer, to be examined.

Johnson et al. (2007) provided a summary definition of mixed methods research after consulting several leaders in the field (p.123).

> *Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis,*

> *inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.*

Other researchers take the view that mixed methods design may be applied to the use of two methods within the same paradigm; for example, using two qualitative research methods within a qualitatively driven mixed methods study (Hennink et al., 2010; Morse, 2010; Silverman, 2013). Morse and Niehaus (2009) defined mixed methods design as consisting of a 'complete method' or 'core component', plus one or more 'incomplete methods' or 'supplementary components' (p.9).

Qualitatively driven mixed methods study

An example of a qualitatively driven mixed methods study was this PhD and a description follows. The core component consisted of observational research methods that focused on the interactional practices that participants used and relied upon in producing their own behaviour and interpreting and dealing with the behaviour of others (Murphy et al., 1998). These practices related to the communication, reporting, assessment and management of a complex phenomenon which in this case was fatigue in advanced cancer. Supplementary components consisted of qualitative interviews to help understand what was being observed so that the raw data was more accessible for analysis (Murphy et al., 1998). In addition, interviews explored the views of participants in relation to the complex phenomenon being studied and attempted to understand how they perceived and managed it (Murphy et al., 1998). In this study, exploring the views of patients related to how they understood and dealt with fatigue in their daily lives. Moreover, exploring the views of doctors related to how they understood and approached fatigue in advanced cancer care. Thus, there were merits to doing a qualitatively driven mixed methods design that used two qualitative research methods to understand more about a complex phenomenon.

Distinct differences between the qualitative research methods used in a qualitatively driven mixed methods study can influence the chosen core study method. The data obtained from qualitative interviewing is reported through the distorted lenses of respondents and what is said could also be misunderstood by the interviewer (Murphy et al., 1998). During the analytic process, the researcher interprets the meaning from the interview data to produce findings that are interpreted (Murphy et al., 1998). Moreover, anything less than a precise application of the qualitative data analysis chosen by the researcher may produce findings that are under-analysed and less meaningful (Antaki et al., 2003; Potter & Hepburn 2004).

Conversely, the data obtained from the audio-visual recordings of social interaction provides raw data which can be scrutinised repeatedly and subjected to forensic analysis by researchers (Murphy et al., 1998). Conversation analysis (CA) involves identifying and explicating what is observable in the data which means the findings are anchored in the raw data. Hence, CA findings are observed and not interpreted. Moreover, other researchers can evaluate the strength and quality of the analysis (Murphy et al., 1998). This was an important difference when these qualitative data analytic methods were combined in a qualitatively driven mixed methods study. Therefore, the interpreted findings from the interviews may not be used to warrant claims that have not been grounded in the findings from interaction data (Murphy et al., 1998). In sum, in a qualitatively driven mixed methods study, the CA research is the core component and the qualitative interviews are supplementary components.

Mixed methods design

There are many different approaches or types of mixed methods research and some important features that influence the design have been discussed (Cresswell, 2009; Hesse-Biber, 2010; Johnson et al., 2007; Morse, 2010):

1. The timing of the methods used for data collection, whether it will be in phases (sequentially) or collected at the same time (concurrent). In concurrent nested designs, both qualitative and quantitative data are collected at the same stage, although one form of data is given more weight over the other. For example, a fatigue questionnaire nested within the recording of palliative oncology visits provides an added description of participants that is relevant.

2. The weight or priority of the methods used, in some studies the weight might be equal between methods but in others, it might emphasise one or the other. For example, a qualitatively driven mixed methods design may prioritise one qualitative method over another qualitative method.

3. The mixing, combining or integration of data from different methods used, specifically when and how it occurs. The integration of these data could occur during data collection, the data analysis, interpretation or at all three stages. For example, a concurrent embedded approach could have a primary qualitative method such as the coding of interaction data and a secondary nested quantitative

> method such as questionnaires gathered at the same time. The integration of these data could occur in the data analysis and in the interpretation.

This PhD study collected data from the observations of palliative oncology visits and qualitative interviews at the same time. The complex phenomenon studied, fatigue, was measured using quantitative tools to understand fatigue's wider relevance within the clinical setting. Hence, this study was a concurrent mixed methods design that was qualitatively driven with a quantitative element nested within the primary component. Mixed methods research aims to understand more about the phenomenon studied by bringing together the findings from the data generated by two or more methods (Moran-Ellis et al., 2006).The use of qualitative interviews complemented the observational findings and the micro-analysis of talk. These methods provided different insights and overall contributed to a better understanding of fatigue in advanced cancer care.

3.2.2. Rationale for using mixed methods

There were several reasons for deciding to use mixed methods in this study. Using qualitative and quantitative methods provided an opportunity to answer the research questions from different angles and contributed to making the findings more relevant to clinical practice. For example, the measurement of the phenomenon studied, fatigue in advanced cancer, using validated tools helped to describe the clinical relevance of fatigue in the patient sample. The combination of the qualitative and quantitative methods used to gather and analyse data facilitated a richer understanding of fatigue in advanced cancer from the perspectives of patients and doctors. Thus, the complementary approach of mixed methods research meant the observable findings from CA and the interpretable findings from the analysis of qualitative interviews were enhanced and more clinically relevant.

The primary focus of this study was how participants talked about, assessed and managed fatigue in palliative oncology visits. Hence, the methodology of CA was the core component of this study as guided by the research questions. CA is a data-driven methodology which seeks to ground analytical claims in the observed conduct of participants in the data (Murphy et al., 1998). Importantly, CA does not interpret what lies behind the conduct of participants and speculate on their motivations or perceptions (Heritage & Maynard, 2006). The is the opposite from the interpretive analysis of data from qualitative interviews which aims to interpret the experiences, understanding and perceptions of participants (Murphy et al., 1998). Therefore, the use of these two methods in a single study could be viewed as controversial by some CA researchers (Murphy et al., 1998; Potter & Hepburn, 2004). However, there were merits to conducting qualitative interview in this study as it helped to understand the complex patterns of interaction and the organisation of activities in palliative oncology visits (Murphy et al., 1998). Potentially, problems could have arisen if the analysis of the qualitative interviews led this researcher to make claims that were not observable in the raw data or contributed to a misunderstanding of the principles of CA. In this study, CA was conducted and completed before the analysis of the qualitative interviews and so this risk was avoided.

A pragmatic approach was helpful in conducting a study that used separate qualitative research methods which yielded observable and interpretable findings. Pragmatism or a pragmatic approach has been most commonly associated with mixed methods research and offers an alternative paradigm or worldview to those of constructivism and positivism (Feilzer, 2010; Johnson & Onwuegbuzie, 2004). It aims to find a middle ground between these philosophical paradigms and seeks a practical workable solution to the problems identified by researchers through their shared experiences (Morgan, 2007; Walker, 2009). A pragmatic approach also relies on a systematic inquiry as a basis of research and these empirical qualities have been postulated by some researchers to create a dialogue with the methodology of conversation analysis (CA) which was the core component in this study (Emirbayer & Maynard, 2011). This approach to research relies on a version of abductive reasoning or abduction that oscillates between induction and deduction (Morgan, 2007). This abduction was necessary for the methods used in this qualitatively driven mixed methods study.

In this PhD, a mixed methods design was chosen to address the complex phenomenon of fatigue in advanced cancer and this provided a nuanced appreciation of how fatigue is communicated and approached by patients and oncologists in advanced cancer care. This approach provided richer understandings of this multi-faceted and complex phenomenon.

3.2.3. How mixed methods were used in this study

This study was a concurrent mixed methods design that was qualitatively driven with a quantitative element nested within the primary component. The study was comprised of three components or parts: Part A was the primary component; Part B and Part C were supplementary components (Morse, 2010). In Part A, a questionnaire measuring fatigue was embedded in the gathering of data from the observations of palliative oncology consultations. This quantitative element had an important function in the overall study design as it measured the reported fatigue in the patient population studied and identified those with clinically relevant fatigue (i.e. NRS ≥4). The measurements of self-reported fatigue were linked with the interaction data and talk connected with fatigue. Finally, the fatigue measurements identified patients with clinically relevant fatigue and potential participants for Part B: interviews with patients with fatigue. Part C related to interviews with oncologists.

The study design (see Figure 3.1) followed several steps as advised by key authors on mixed methods design (Creswell & Creswell, 2017; Morse 2010).

1. Data gathering from the observations (Part A) and interviews (Part B & Part C) occurred concurrently and prior to the analysis of the data from each component.

2. In Part A, the researcher separately analysed the data using the methods. Later sections in this chapter will detail the analysis process. The findings from the quantitative and qualitative data were integrated and are presented in Chapter 4.

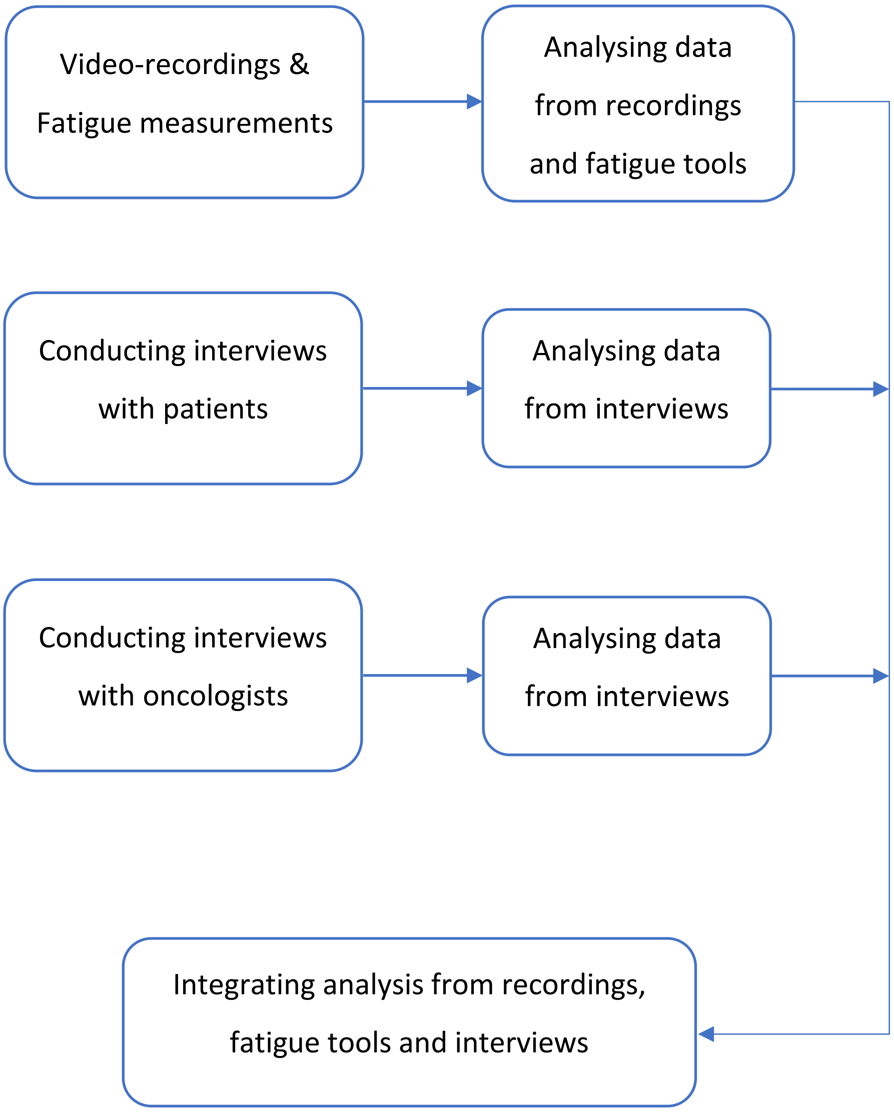
3. In Part B, the researcher separately analysed the patient interview data and the findings are presented in Chapter 5. The analysis of the patient interview data occurred after the analysis of the interaction data.

4. In Part C, the researcher separately analysed the clinician interview data and the findings are presented in Chapter 6. The analysis of the clinician interview data occurred after the analysis of the interaction data and the patient interview data.

5. The findings from all three datasets (Parts A, B & C) were integrated and are presented in Chapter 7. The integrated findings focused on how they complemented each other. The primary component (Part A) was given the most weight in this thesis due to the methodologies used which provided observable findings. However, the other components provided important insights that helped to explore the

perspectives of participants and suggested reasons for the behaviour observed. The integration of methods is discussed further in section 3.9 at the end of this Chapter.

Figure 3.1 How a qualitatively driven mixed methods design was used in this PhD



3.3. Methods of data collection

This section will explain the methods used to obtain data in this study. Video-recordings and fatigue measurement questionnaires were used to gather observational data and semi-structured interviews were used to generate qualitative data.

3.3.1 Video-recording of consultations

Using video-recordings to carefully examine how patients and clinicians communicate in real-life consultations can lead to important insights about practice (Drew et al., 2001; Robinson & Heritage, 2014; Parry, 2010). The video-recording of healthcare communication is superior to audio-recording as nonverbal communication behaviour forms an important part of the analytic process (Heath et al., 2010). Gaze, gesture, facial expressions, touch and body positions can be very important in how people interact with one another and share meaning and understanding together (Parry, 2010). Video-based research has increased considerably over the last decade and the findings from this research can improve healthcare communication. For example, this research has contributed to the development of communication interventions to aid in the diagnosis of epilepsy (Jenkins et al., 2015). Moreover, this research has developed practice implications for the discussion of end of life issues including prognosis (Pino et al., 2016; Pino & Parry, 2018). The acceptability and ethical concerns of using this method in health research and how these were addressed in this study, will be covered in a later section of this chapter.

3.3.2. Fatigue measurement questionnaires

Two separate fatigue measurements tools were used in this study to describe the patient population in Part A, the observational study and select those who reported clinically relevant fatigue for an invitation to Part B, the patient interview study.

3.3.2.1. Fatigue Visual Analogue Scale (VAS)

The Fatigue VAS was a line of 100mm in length with a scale for rating fatigue intensity from 0-10 and included word descriptors for severity: none, mild, moderate, severe and very severe (see Appendix 3.8). Visual analogue scales have been validated for use in symptoms and have been widely used to assess fatigue in cancer and palliative care (Bruera et al., 1991; Oldenmenger et al., 2013; Price et al., 1983). The Fatigue VAS was chosen as it was simple to use for patients and it facilitated the easy identification of those potentially eligible for the interview study, defined as participants with fatigue ≥4.

3.3.2.2. Fatigue subscale of Functional Assessment of Chronic Illness Therapy (FACIT-F)

The Fatigue subscale of FACIT-F consists of 13-items specifically related to fatigue (Cella, 1997). The FACIT-F was originally developed in the 1990s by Cella et al. (1993) and is a collection of quality of life questionnaires targeted to the management of chronic illness. The Fatigue subscale is the most widely used cancer-related fatigue outcome measure and probably the best validated (Minton & Stone, 2008). It has also demonstrated convergent validity with other fatigue measurement tools (Yellen et al., 1997).

Each item can be answered on a 5-point scale with responses varying from ‘not at all’ to ‘very much’. Scores can range from 0 and 52 with lower scores representing more fatigue and worse quality of life (see Appendix 3.9).

The reasons for the inclusion of this instrument were:

- It has been validated and extensively used in cancer care;
- It provided data on the status of fatigue and quality of life in this population; and
- The brevity of the instrument for patients with fatigue.

3.3.3. Semi-structured interviews

Qualitative interviews are a frequently used method in health research and have been suggested as an ideal method to explore the views of patients and clinicians (Britten, 2006). The approach to research interviews can be placed along a spectrum, ranging from structured to unstructured interviews. Structured interviews consist of predetermined questions arranged in a schedule that the researcher is obliged to follow with little scope to deviate from. Conversely, unstructured interviews have no obvious organisation or structure and do not reflect any preconceived theories or ideas (Silverman, 2001). In the middle of this spectrum lie semi-structured interviews, as they have some predetermined questions and order, but there is flexibility in the way issues are addressed by the participant. Moreover, semi-structured interviews are broadly designed around a ‘loose structure’ and consist of open-ended questions that relate to the area to be explored or prompts to guide the researcher (Britten, 2006; Rapley, 2012).

Qualitative interviews were used in this study to explore the approach of participants to fatigue in advanced cancer and complement the findings from the observational study. The use of semi-structured interviews provided a deeper understanding of the phenomena explored (Silverman, 2001). This study was addressing a gap in knowledge - how clinician participants approached and managed fatigue in advanced cancer - and this was best examined with semi-structured interviews. Furthermore, using semi-structured facilitated the investigation of detailed insights, such as how patient participants with advanced cancer coped with fatigue.

Strengths and limitations of using semi-structured interviews

The use of semi-structured interviews can present with some limitations. Participants for interviews can be self-selected, as in this study, they were free decide to whether they wanted to be interviewed after partaking in Part A. Therefore, those who declined to take part may have different characteristics from those who were interviewed. Participants could also be inclined to portray themselves as to how they were expected to be viewed by the researcher and hence, this could influence the validity of the data collected (Murphy et al. 1998). Interviews should therefore not be treated as accurate reports of external realities but rather displays of the participant's perspectives (Murphy et al. 1998). The strengths of using semi-structured interviews were that specific questions such as how participants learned to cope with fatigue could be explored with some structure and consistency by a topic guide that was prepared in advance. Hence, the use of a topic guide helped to elicit data in this study. The flexibility in semi-structured interviews also allowed for participants to influence the content and facilitated discussions about issues that may have otherwise not occurred.

3.4. Methods of data analysis

This research used three qualitative approaches to analyse and synthesise the data, and these included: content analysis, CA and thematic analysis. This section outlines each approach separately and the rationale for their use in this study.

3.4.1. Content analysis

Content analysis was used to analyse the interaction data from the video-recorded consultations. This is a qualitative research method that can be used to analyse the data from observed healthcare interactions and provided a means to transform qualitative data into quantitative data (Jackson, 2008). Content analysis is a flexible research technique with several recognised approaches that depend on the phenomenon studied as well as the researcher identifying which approach best answers the research questions (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004).

Hsieh and Shannon (2005) outlined three distinct approaches to using content analysis: conventional, directed, or summative. Conventional content analysis follows an inductive approach and is best used when an existing theory or research literature on a phenomenon is limited. Researchers avoid using preconceived categories and instead allow the categories to develop following immersion in the data. Directed content analysis follows a deductive approach and might be used to validate a theory or further describe a phenomenon when the literature is incomplete. Existing theory and prior research provide the basis for initial coding strategies and the researcher begins coding immediately with predetermined codes. Summative content analysis quantifies certain words or content in the text to explore the usage of these terms. However, this approach goes beyond mere word counts to include latent content analysis, which interprets the words or content and aims to discover their underlying meanings (Graneheim & Lundman, 2004).

Rationale for using summative and directed content analysis

The strength of using content analysis on the interaction data was that it allowed documentation of what communication about fatigue took place (Jackson, 2008). The flexibility of this method allowed for a specific coding scheme to be developed by the researcher and for this to be based on the specific research questions in this study (Downe-Wamboldt, 1992). The researcher's background medical training in oncology care helped to identify any conversation relevant to fatigue in the data and enhanced the validity of these methods (Downe-Wamboldt, 1992; Jackson, 2008).

Content analysis provided a broad overview or macro-analysis of the interaction data and identified segments of data that required more detailed and nuanced analysis or micro-analysis. However, content analysis did not help to understand how fatigue was approached and addressed by participants in the data or why some conversations might have followed certain trajectories. These were important research questions in this study and were addressed by combining analytic methods: CA and content analysis. When used together, these methods added a greater understanding of the talk connected with fatigue in the data (Heritage & Maynard, 2006).

3.4.2. Conversation analysis

Interactions in which fatigue was discussed were selected and these data were analyzed using some of the concepts and tools of CA. This qualitative methodology is a detailed and systematic method for studying talk and real-life interaction among humans, which can be applied to health communication research (Barnes, 2005; Peräkylä, 1997). The aim of CA research is to examine and discover the socially organised practices through which participants make themselves understood, and through which they manage the activities in talk (Drew et al., 2001).

CA emerged as a qualitative research method in the 1960s from pioneering research by Harvey Sacks among others, and initially focused on ordinary conversations between relatives, friends and acquaintances (Heritage & Maynard, 2006). These sociologists then moved on to study institutional interactions, such as medical interactions, using the same forensic analytic approach (Maynard & Heritage, 2005). There are important differences between ordinary conversation and institutional interaction which concerns the tasks and identities that shape the speaker's contributions (Heritage & Clayman, 2010). These authors identified three basic elements of institutional talk (Heritage & Clayman, 2010, page 34):

1. Participants are involved in specific goal orientations tied to their 'institutional-relevant identities' (i.e. doctor and patient);
2. There are special constraints on the interaction related to what will be treated as 'allowable contributions to the business at hand'; and
3. The interaction contains 'inferential frameworks and procedures' specific to a medical context.

In relation to medical interactions and this study, several important features of this analytic approach are mentioned here.

1. **Turn-taking** – refers to the organisation of how turns are constructed and allocated by speakers (Heritage & Maynard, 2006). Turns are built out of turn construction units (TCUs) and after a TCU is produced, a possible turn transitional place (TRP) is created for the next speaker to begin their turn of talk. The organised rules of interaction confirm that if there is a delayed response after a TRP this can signal an upcoming dispreferred turn, such as a disagreement or resistance of advice (Schegloff, 2007).

2. **Social action** - all utterances are considered to perform social actions of various kinds, which are generally part of broader activities within the consultation (Drew, 2001). Examples of actions in medical consultations include: history taking, treatment recommendations and advice giving.

3. **Sequence organisation** – utterances and actions are not produced in isolation but are connected in sequences of actions which is dependent on a dynamic process between participants (Heritage & Maynard, 2006). For example, diagnosis is a precursor to treatment recommendation.

4. **Turn design** – Sequences are made up of turns and the concept of turn design aims to describe this. Turn designs appear to have stable patterns, for example, how participants speak can be shown to have predictable consequences for how the other responds (Drew et al., 2001).

5. **Overall structural organisation** – this refers to the phase-structure of the interaction such as how the conversation was opened and closed. In medical interactions this usually includes the presenting complaint, examination, diagnosis and treatment (Heritage & Maynard, 2006).

6. **Epistemological asymmetry** – doctors have acquired scientific knowledge and specific skills through medical training and clinical practice experience. Therefore, doctors have medical authority in relation to the process of diagnosis and treatment recommendations (Heritage & Clayman, 2010). On the other hand, patients have acquired knowledge of fatigue because they have lived through the experience.

> Hence, patients have epistemic authority over doctors in relation to the experience of fatigue.

In general, CA focuses on sequential interaction rather than on individual's talk, and views what happens in these interactions as co-constructed (Barnes, 2005). Therefore, CA's methodology is concerned with sequential patterns and the practices through which these patterns are generated. Three steps are connected in the analytic process: 1) the identification of a possible phenomenon; 2) the making of a collection of episodes in which the phenomenon occurs; and 3) determining the sequential pattern associated with the phenomenon (Drew, 2007).

Rationale for using CA

CA was the most appropriate interaction research method to explore and understand how participants talked about fatigue in palliative oncology visits. It focuses not only on what was said but *how* it was said (the exact words used, emphasis, hesitations or interruptions) and, also examines human behaviour (Drew et al., 2001). Moreover, the systematic approach and empirically grounded nature of CA mean the findings are transparent to other CA researchers. In sum, CA findings are observed in the data and not interpreted. Other CA researchers can evaluate the accuracy of the analytic findings by examining the raw data and this provides an important constraint on the influence of personal preconceptions and analytic bias (Murphy et al., 1998). Hence, the research method negates the influence of bias within the researcher on the analytic findings (Heritage & Maynard, 2006).

Other interaction research methods, such as Roter Interaction Analysis System (RIAS), are commonly used in healthcare communication studies (Roter & Larson, 2002). RIAS uses pre-defined codes to implement an exhaustive classification of the interaction and categorises the data with a three-function model (e.g. gathering data, developing rapport and, education and motivation) (Roter & Larson, 2002). However, there are consequences of the coding process as some of the content, context and meaning of the interaction is sacrificed (Heritage & Maynard, 2006). Furthermore, RIAS is unable to explore how one participant's communicative behaviour might influence the conduct of the other because utterances are coded individually and removed from their initial context (Schegloff, 2007). In contrast, sequential analysis in CA can reveal, for example, how treatment recommendations for fatigue were mutually agreed and negotiated in the building of sequences.

CA research has been described as a pragmatic methodology in health settings and has several applications that could benefit healthcare communication (Drew et al., 2001). These potential benefits include:

1. The identification of behaviours or communication practices and their consequences that may allow clinicians to consciously reconsider in their communication with patients. This could, therefore, have training implications for clinicians.
2. The identification of communication strategies that facilitate patient participation in the decisions and discussions about healthcare.
3. The exploration of the association between certain phenomena and outcomes, such as between accepting or resisting treatment recommendations or advice giving for fatigue.

CA research in palliative oncology settings has identified some potential practical implications and one such study is mentioned here to further explain the rationale for using this method (Singh et al., 2017). Singh et al. reported on the analysis of 33 audio palliative oncology visits wherein patients with incurable lung cancer and their oncologist discussed scan results (Singh et al., 2017). In consultations where disease progression was evident, oncologists often quickly steered the conversation towards cancer treatment related talk. This limited the opportunity to talk about prognosis, which may have denied patients important information in making decisions about cancer treatments (Singh et al., 2017). Hence, the authors proposed communication practices which could better promote shared decision making by giving patients an opportunity to reflect and understand the prognostic implications of the scan results (Singh et al., 2017).

3.4.3. Thematic analysis

Thematic analysis is a qualitative approach that can be used to analyse and interpret qualitative interview data. It can be defined as a method for identifying, analysing and reporting patterns or themes within data (Braun & Clarke, 2006). Themes from the data capture something that is important in relation to the research question and these themes represent some form of patterned meaning within the data set, and become the categories for analysis (Fereday & Muir-Cochrane, 2006).

Thematic analysis can be applied across a range of theoretical and epistemological approaches because of it being independent of theory and epistemology (Braun & Clarke, 2006). Flexibility is a term that describes the theoretical freedom of thematic analysis, which can be an advantage for this approach to be used as a research tool. Owing to this flexibility, this method can, therefore, be applied in several ways such as an inductive versus deductive or theory-driven approach to data coding and analysis (Braun et al., 2014). The form of thematic analysis chosen is dependent on a set of assumptions that relate to the topic area being studied and decided on by the researcher (Braun et al., 2014).

Braun and Clarke proposed a systematic and practical approach to thematic analysis, and described a process entailing six phases (See Figure 3.2) (Braun & Clarke, 2006). The first phase, common to all forms of qualitative analysis, is familiarisation with the data where the researcher reads and re-reads or listens again to the interviews. This is followed by generating initial codes that capture something meaningful in the data, line by line, and the collation of all the data relevant to each code. The next phase searching for themes identifies a patterned meaning across the dataset where similarity and overlap between codes are identified. Themes are generated and a set of candidate themes develops. This is followed by reviewing potential themes where the themes are checked in relation to the coded data and the whole dataset to produce a final set of themes. The next phase, defining and naming themes reflects the interpretative analysis of the themes and their relationship to each other. The last phase, producing the report, is an integral part of the analytic process and is the final opportunity to refine the analysis.

Figure 3.2 The phases of thematic analysis (Braun & Clarke, 2006)

1	Familiarisation with data
2	Generating initial codes
3	Searching for themes
4	Reviewing themes
5	Defining and naming themes
6	Producing the report

Rationale for using thematic analysis

This study aimed to explore how patients dealt with the experience of fatigue and how doctors approached this symptom in advanced cancer care. Thematic analysis was a suitable qualitative approach that sought to understand these phenomena from the perspective of the participants.

Thematic analysis, interpretative phenomenological analysis (IPA) and grounded theory all share some similar features in their approach to understanding people's experiences, but there are some important differences (Rivas, 2011). IPA is bound to a phenomenological epistemology and therefore this limits the flexibility of this method which was required for this mixed method research (Smith & Osborn, 2007). Grounded theory involves the construction and development of theories but this was not the aim of this study (Glaus et al., 1996; Greenhalgh et al., 2013; Holloway & Todres, 2003).

Pragmatism underpinned the epistemological stance taken in this mixed methods study and the flexibility of thematic analysis meant that it was compatible with this philosophical approach and study design. An inductive approach to analysis was possible and the findings could be matched to the goals of the study in which three separate datasets were integrated (Braun & Clarke, 2006; Holloway & Todres, 2003). This qualitative data analysis method is commonly used in health research which may help this research to be more accessible and reachable to the target audience (Vaismoradi et al., 2013). Furthermore, thematic analysis may be viewed as 'more accessible' to those with limited qualitative research experience as the approach is systematic and clearly defined (Braun & Clarke, 2006).

The flexibility of thematic analysis may lead to concerns about inconsistency and a lack of coherence (Holloway & Todres, 2003). By researchers making their epistemological position and assumptions explicit, this may enhance the coherence of their empirical claims (Holloway & Todres, 2003). It is also important that researchers apply a method to data analysis and reveal how this was undertaken so the research can be evaluated against the consistency previously outlined (Braun & Clarke, 2006). Full transparency in the methods undertaken by researchers and a rigorous approach to the analytical process could potentially allow for the transferability of the findings in the data to other clinical settings (Holloway & Todres, 2003). Moreover, without rigor and full transparency, the study may be open to the ‘anything goes’ critiques of qualitative research and this would impact on the credibility or validity of the findings (Antaki et al., 2003; Morse et al., 2002). The methods used by this researcher to analyse the qualitative interview data and the rigorous approach to analysis are outlined in a later section in this Chapter (3.7.3 p. 84).

3.5 Ethics and research governance

3.5.1. Ethical considerations

There were a number of important ethical issues to consider in the planning of this research, particularly in relation to: the patient population studied; the potential harm to the therapeutic relationship through the video-recording of oncology consultations; and finally, the potential burden on all participants. Each ethical issue is introduced separately, with a discussion on how it was addressed in this study. It should be noted that in the design stage, contact was made with several experienced researchers who had used similar methods, in order to design this study with the best possible ethical standards (Robinson et al., 2006; Seale et al., 2007; Toerien et al., 2013).

3.5.1.1. Palliative care population

The patient participants in this study had an advanced progressive incurable illness and it was conceivable that they could die within the next 12 months. Therefore, by definition, these patient participants could be recognised as a palliative care population (Sepulveda et al., 2002). Some authors take the view that patients with a terminal illness are frail and vulnerable (de Rave 1994; Raudonis 1992). They may question whether it was appropriate to invite them to participate in research and argue that they do not have the ability to consent.

Others take a different stance and contend that this patient population was not inherently vulnerable (Addington-Hall 2007). The literature for conducting research within this specific group was carefully examined and some evidence to support the decisions for this study is outlined.

An important Australian study sought the views of 22 hospice inpatients about participating in research (Terry et al., 2006). Participants were aged from 28 to 93 years, most had advanced cancer and over half of the participants died within 48 hours of being interviewed. Despite these patients being near the end of their lives, all of them wished to participate in research and the majority viewed it as a means of benefiting others. As one participant explained: 'It would be a way to give something back now before I die, I would have done something good for the future' (Terry et al., 2006:408). Participants were asked if they could say no to partaking in research and many gave responses suggesting that their autonomy remained. As one participant remarked: "We can just say what we think, there is nothing to lose" (Terry et al., 2006:410).

Terry and colleagues (2006) study gives an insight and vital perspective of those near the end of their lives, suggesting these individuals value their contribution to research and wish to be given the opportunity to do so. Furthermore, a systematic review by White and Hardy (2010), revealed similar themes and findings. This review examined the views of palliative care patients and their relatives towards participation in research and identified eight such studies. This researcher took the position that it was ethical and indeed imperative to respect the autonomy of palliative care patients and to not exclude them from being offered the opportunity to participate in research.

3.5.1.2. Potential to harm the therapeutic relationship

In view of the nature of the patient population in this study, it was recognised that recorded oncology consultations may contain the disclosure of bad news from recent scan results, sensitive discussions relating to prognosis and possibly the exploration of end of life issues. The careful development and maintenance of the therapeutic relationship was an important factor in exploring such sensitive topics and enabling patients to discuss their feelings, expectations and care preferences at the end of life (Curtisa et al., 1999; Parker et al., 2007). It was conceivable that the recording equipment could have a negative impact on the therapeutic relationship, impeding on participants' ability to communicate naturally and effectively, with the end result that it could ultimately be detrimental to their care.

Video-based research in healthcare has been shown to be acceptable to participants in a variety of clinical settings, including primary care, hospital and hospice consultations (Hargreaves & Peppiatt, 2001; Herzmark, 1985; Penner et al., 2007; Rushmer et al., 2011). Pino et al. interviewed hospice patients, carers and members of the care team about the acceptability of video-recording consultations in the hospice environment and their views were incorporated into the design of their study protocol (Pino et al., 2016).
Some evidence from video-based research in oncology clinics, has suggested that participants adjust to the presence of the camera equipment relatively quickly and the equipment does not interfere with the interaction (Penner et al., 2007). Hargreaves and Peppiatt (2001) interviewed hospice day-care patients after the recorded consultation and most reported that they forgot about the camera. All 30 participants reported that the camera did not make them less willing to talk or nervous, which suggested this method had a limited or minimal effect on the therapeutic relationship (Hargreaves & Peppiatt, 2001).

In this study, a number of steps were taken to make the video-recording process as unobtrusive as possible and ensure that participants could withdraw at any time. In order to lessen the sense of intrusion on privacy for patients, the researcher was not present during the video-recording of the consultation. One compact camcorder was discreetly attached to a clinical trolley, with the camera lens in a fixed position. All participants were aware that physical examination would not be recorded and a screen could be placed over the lens should this be necessary. A remote control for the camcorder was placed on the consulting room table so that any participant could stop the recording at any time, for any reason or should they change their mind during the consultation.

3.5.1.3. Burdens on participants and withdrawal from the study

As this research aimed to explore how fatigue was talked about in the outpatient clinic, it was an important ethical consideration that participants experiencing fatigue were not burdened unnecessarily. The study was carefully designed to reflect the needs of this potentially frail patient group by involving patient and carer representatives early in the research process and by limiting questionnaire administration to a single brief study questionnaire (Daveson et al., 2015; Preston NJ et al., 2013). Additional time spent in the clinic to take part in the study was curtailed to a minimum in order to limit the physical and financial burdens on potential participants. Moreover, patient interviews were conducted on a separate day, in a setting of their choosing and were suitably paced to accommodate the individual’s needs.

Participants could have given consent for their video-recorded consultation to be viewed by the research team, other researchers and used for teaching and training purposes. However, it was recognised that they may not have anticipated sensitive discussions occurring and then may have regretted taking part in the study. Therefore, it was ethically paramount that participants were made aware that they could change their minds and withdraw from the study at any time. Immediately after the recording of the consultation, consent was verbally rechecked with participants to ensure that they were happy for their recording to be used for research purposes.

3.5.2. Ethics and Research Governance approval

Prior to the start of data collection, ethics approval was sought and obtained from appropriate sources:

- Oxford Brookes University’s Faculty Research Ethics Committee (FREC) (letter of approval shown in Appendix 3.1)
- NHS Research Ethics Service (NRES) (letter of approval shown in Appendix 3.2)

As the research took place in two separate NHS Trusts, approval from the relevant Research and Development (R&D) departments were necessary and granted.

3.6. Part A – Observational study in oncology clinics

3.6.1. Research Setting and Negotiating Access

The research was conducted within three cancer centres of two separate NHS Trusts that were located within the same Cancer Strategic Clinical Network. The research sites consisted of one large tertiary referral cancer centre where the majority of research took place and two smaller satellite cancer centres. Access to these hospitals was obtained by seeking the support of the Clinical Director of the Cancer Research Strategic Clinical Network and the Cancer Lead Clinicians of these hospitals. Support was also gained following a meeting with the nurse manager of the outpatient department of the large cancer centre. The nature and purpose of the study were explained in detail and questions were encouraged and answered.

During the design phase of the research process, similar preparatory meetings took place with several consultant oncologists and clinical nurse specialists. These clinicians influenced how the research design was finalised and consequently they became an integral part of this study. New case consultations were not selected for the following reasons: it would have been difficult for clinic co-ordinators to correctly identify potential patient participants; the turnaround of urgent oncology outpatient appointments was usually within two weeks and this was likely to be too short to meet the requirements of Good Clinical Practice for giving participants time to consider to taking part; and finally, new case consultations might be more concerned with breaking bad news or cancer treatment decisions rather than communication about fatigue, which was the focus of this research.

Consultants preferred to approach and select potential patient participants in their outpatient clinic rather than send invitation letters by post in advance of outpatient appointments. Their cancer clinics consisted of patients who were treated with either curative or palliative intent, and therefore it was easier to correctly identify potential participants at the outpatient clinic. Standard oncological treatment trials usually have similar recruitment procedures (Kerr et al., 2016; Weaver et al., 2014) and Consultants felt this created some consistency for their patients and staff in the outpatient clinics.

3.6.2. Sample

The objectives of this study included examining how fatigue was communicated and approached by participants in advanced cancer care consultations. Therefore, the target population for this study were those attending routine palliative oncology clinics. A broad definition for fatigue was chosen in this PhD and this meant fatigue was likely to be commonly prevalent in patients attending palliative oncology clinics.

Sampling decisions were made about the specific patient groups with advanced cancer to be studied during the study design. For example, patients with haematological malignancies were not included in this study because of the assumed frequent occurrence of anaemia in this group and how fatigue could be solely attributed to anaemia (Siegel et al., 2012). Hence, patients with solid tumours and those with incurable disease became the target population. Further sampling decisions were made about the setting to be studied during the design phase of the study. The participant observation of palliative oncology clinics identified certain clinics which were difficult to include in a small PhD study. For example, the head and neck cancer clinic was sometimes a series of consultations with several clinicians in the same consultation room and this was practically difficult to video-record with one camera.

Study participants

Potential participants were invited to the study and consisted of three potential groups:

1. Patient participants had a diagnosis of advanced cancer and were attending an oncology outpatient clinic in the hospital.
2. Patient companions (e.g. partners, family members or carers) were any persons attending the consultation with the patient.
3. Clinician participants were specialist doctors in oncology working within the regional area: this included consultants oncologists and junior doctors undergoing specialist training to become consultant oncologists.

Inclusion criteria:

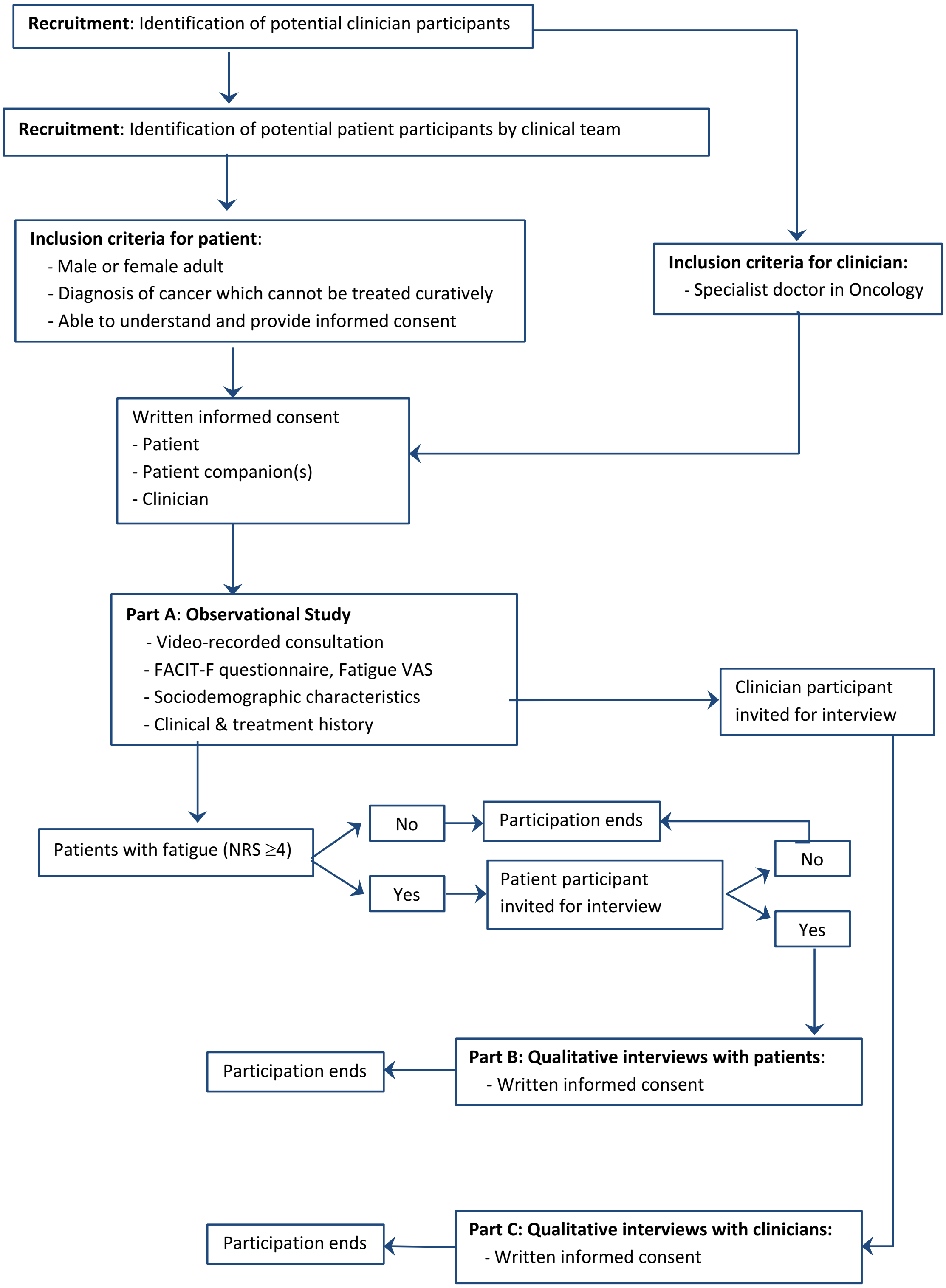
- Over 18 years of age
- Participant was willing and able to give informed consent to take part in the study; and
- Patient participant had a diagnosis of cancer which could not be treated curatively

Exclusion criteria:

- Unable to read or speak English fluently
- Patient participant had a primary diagnosis of a haematological cancer

The study flowchart (see Figure 3.3) outlines the stages of the study for participants and the inclusion criteria for patients.

Figure 3.3. Study Flowchart



3.6.3. Selection and recruitment of doctors

Consultant Oncologists were selected to participate in the study if they regularly managed the care of patients diagnosed with advanced incurable cancers and led cancer site specific outpatient clinics, that suited the aims and objectives of the study. Consultant Oncologists were asked if they would like to take part in the study and to give permission for their patients to be involved. They were sent an invitation letter and a clinician Participant Information Sheet (PIS) by email and for those that responded with an interest in taking part, a face-to-face meeting was arranged to discuss the study further and to address their questions (Clinician PIS is shown in Appendix 3.3).

Snowball sampling

The selection and recruitment of oncologists relied mostly on snowball sampling. Once a clinician was recruited, they helped the researcher to recruit other clinicians in the outpatient clinic. In the tertiary referral cancer centre, there were often several cancer site specific clinics run concurrently where several consultant oncologists might be consulting with the same cohort of patients, for example, patients diagnosed with colorectal cancer. In each site-specific cancer clinic, the consultant oncologists would usually manage their own patient list but sometimes the patient's care would be shared by several Consultants who might be working in tandem. If one Consultant agreed to participate, this provided the researcher with the opportunity to have face-to-face introductions with other Consultants at the clinic and invite them to take part. If they were interested, clinician PIS was provided at the clinic and all their questions were answered.

Participating Consultants usually supervised and worked alongside Specialty Registrars (StRs) and Clinical Research Training Fellows (CRTFs) in their outpatient clinics. StRs are doctors who work as part of a specialty training programme (oncology) and CRTFs are clinically active doctors who are undertaking a higher research degree (MD or PhD). In this study, StRs and CRTFs selected were training to become consultant oncologists and might work independently in the clinic. StRs usually rotated every 6 months between disease-specific groups, for CRTFs this was more variable. Typically, after a few weeks of recruiting the StRs and CRTFs were invited to take part in the study but it was made clear that there was no obligation to take part.

3.6.4. Selection and recruitment of patients

Clinicians selected and introduced the study to potential patient participants in the outpatient clinic who had a future return appointment. If they wished to hear more about the study, they were then offered the opportunity to speak with the researcher in the waiting area of the clinic. Potential patient participants were asked if they would like to take part in the study and to give permission for their future consultation to be video-recorded and for their oncological history to be accessed. A detailed explanation of the study was provided with a period of time to answer any questions and a PIS was handed over for review at home (Patient PIS is shown in Appendix 3.4). They were directed to confirm their interest and the date of their future appointment by sending a reply slip with a stamped addressed envelope or by making telephone or email contact.

Consecutive sampling

The selection and recruitment of patients relied on consecutive sampling. Clinicians introduced the study to every potential participant as they progressed through the outpatient clinic list. In some participating clinics, prompts about the study were left by the researcher in front of the patient clinic notes. The presence of the researcher in the clinic environment was also a prompt to clinicians.

Modifying the recruitment strategy

It was necessary to modify the recruitment strategy in the early stages of recruitment because some potential participants reported that the reply slip was an unnecessary barrier to taking part. Frequently they forgot to send a reply slip or make contact because their lives were so busy. Hence, the recruitment process was altered to ask potential participants how they wished to let the researcher know whether they were interested in taking part. Most potential participants directed the researcher to meet them in the waiting area of the clinic, just before their future appointment, suggesting that they would decide on the day whether to participate. The FREC officer within the University was consulted and confirmed that as potential participants were directing the researcher to their wishes and preferences, the recruitment process remained within the ethical approval for the study and no further action was required (Correspondence from FREC officer shown in Appendix 3.5).

Patient companions were participants

Patients often attended the outpatient clinic with a relevant other or others, such as family, friend or carer. It was observed from participant observation of oncology clinics during the design phase of the study, that patient companions frequently had an active role within the consultation. Patient companions were therefore considered participants in the study and were also invited to participate during the recruitment process (Patient Companion PIS shown in Appendix 3.6). If a person accompanying the patient to the consultation did not wish to take part, then the patient was not included in the study.

Finally, with permission, patients and their companions were met in the waiting area of the outpatient clinic, just before their future appointment. They were asked if they would like to hear more about the study and if they agreed, they were directed to a separate private room when this was available. Patients and their companions were reminded of the study details in full as often, several weeks had passed since the initial conversation. All of their questions were answered prior to discussing the consent process.

3.6.5. Issues of consent

Written informed consent was obtained from doctors prior to their first recorded consultation and lasted for the duration of the study. Doctors were reminded that taking part in the study was completely voluntary and that it was possible to withdraw at any time.

Written informed consent was obtained from patient and patient companion participants before the recording of the consultation. To ensure that participants were capable of giving informed consent, they had to be able to speak English and capable of making their own decisions. Participants were reminded that there was no obligation to take part in the study and that their decision to partake or decline, would not affect their clinical care in any way. They were told that they could withdraw from the study at any time and that no one would be adversely affected should they accept and then later withdraw consent. No participant asked to be withdrawn from the study.

The consent process required participants to opt in rather than opt out. Some items on the consent form were optional for taking part in the study. For example, participants were asked to give permission for their video-recordings to be used for training and teaching purposes but were free to take part without agreeing to this (consent is shown in Appendix 3.7). Finally, after the recording of the consultation, consent was verbally rechecked with all participants to give them an opportunity to change their minds.

3.6.6. Video-recording of consultations

It was important to ensure that good quality video and audio data was obtained so that it could be analysed sufficiently to meet the aims of this research. In addition, the recording equipment had to be discreet and have the facility to be easily stopped by all participants when necessary (Parry et al., 2016; Rushmer et al., 2011). Hence, considerable research and planning went into the procurement of suitable and reliable recording equipment (Heath et al., 2010; Parry, 2010). Researchers who had used similar methods in their healthcare communication studies were consulted about the equipment that they had used and would recommend (Toerien et al., 2013, Pino et al., 2016).

Consultations were recorded at three separate research sites and each outpatient clinic had consulting rooms of various designs, which necessitated some planning in advance. A pilot study was therefore performed in each research site with the aim of establishing how best to set up the recording equipment to capture video data and how to minimise the burden on a busy outpatient clinic. The pilot testing took place in the evenings when the clinics were closed for patients with the permission of the nurse manager in charge of the Outpatient Department. For ease of set-up, the recording equipment was attached to a clinical trolley so that it could be quickly wheeled in and out of the consulting rooms. Before each video-recorded consultation, all participants were shown the on and off button of the camcorder remote control.

In most cases, the researcher set up the recording equipment in the consulting room while the doctor was preparing for their next consultation. This process usually took less than 2 minutes to complete and therefore any delay to the appointment schedule in the clinic was kept to a minimum. One camcorder with a wide camera lens was orientated to ensure the faces of all participants were included in the camera field. The camcorder remote control and back up audio recorder were placed on the consulting room table in between the doctor and the patient. The recording was commenced when the doctor was ready to call the patient in and then the researcher immediately left the consulting room. Doctors often checked that everyone was happy to proceed with the recording when they greeted the patient. The researcher waited near the consulting room door and was invited inside to turn off the recording equipment, once the consultation had ended. Patients and their companions were then guided to a private room in the clinic if it was available or the waiting area in the clinic, while the recording equipment was removed from the consulting room.

3.6.7. Measuring fatigue

After the recorded consultation and usually in a private room in the oncology outpatient clinic, patients were asked to describe their level of tiredness or fatigue by indicating this on the Fatigue VAS. After this, patients were asked to complete the Fatigue subscale of FACIT-F (see Appendix 3.8 & 3.9). This 13-item scale was often completed by the patient independently of their companion and any queries related to the item questions were answered immediately. The researcher was present while all the questionnaires were completed.

In the design of the study, it was proposed that the fatigue scales would be completed after the video-recording of the consultation in case they artificially prompted the discussion of fatigue and were referred to by participants. Previous research in oncology clinics had shown that patients completing questionnaires before the consultation promoted the discussion of symptoms in comparison to usual care (Takeuchi et al., 2011). This study wished to record naturally occurring encounters in the oncology outpatient clinic and minimise the effect of study on patient-doctor communication.

3.6.8. Dual identity of the researcher and reflexivity

The researcher had a dual identity, that of a researcher and a trainee palliative care doctor. Participating doctors were fully aware of the dual role as this was made clear on invitation to participate in the study, the PIS for clinicians and in face-to-face meetings. Although the PIS for patient or patient companion participants did not mention the dual role of the researcher, this information was sometimes revealed by clinicians when introducing the study to potential participants. The researcher was always honest when questioned from potential participants about his background experience. Hence, the influence of the dual identity in this study may have introduced selection bias with the participants recruited and response bias with the qualitative interview data collected (Murphy et al., 1998). This is discussed in more detail in Chapter 7 (section 7.2.2.2).

A reflective diary was kept by the researcher to document his feelings and experiences during the data collection period. These reflective entries and ethnographic field notes were completed at any step in the research process and related to: the recruitment of participants to any part of the study, the consent of participants and the gathering of observational and interview data. Arber (2006) reported how these strategies enabled reflexivity and resulted in a closeness to the research process but also helped to maintain a distance. These reflections were evaluated by turning the gaze back on oneself, to understand their meaning and the potential effect on the research (Shaw, 2010). This reflexive approach was used throughout the interpretative analysis of the qualitative interview data and attempted to limit the analytic bias of the dual identity of this researcher (Holloway & Todres, 2003; Shaw, 2010).

3.6.9. Data analysis

The video data was transcribed verbatim and anonymised so that any identifiable details, such as names or places were changed. Due to the considerable volume of data in this study, professional transcribers were enlisted and all signed confidentiality agreements. After the data had been transcribed, the researcher conducted a quality check to ensure accuracy in the data. This process also contributed to the analysis, as the researcher had made ongoing analytical notes at that time.

3.6.9.1. Content analysis

Firstly, a summative approach to qualitative content analysis was used to help identify and quantify the topics of conversations about fatigue in the data. The entire transcripts were examined line by line for any descriptions or euphemisms for fatigue that were used by participants. These were then quantified and grouped together by relevance to allow for some interpretation and extraction of meaning (Hsieh & Shannon, 2005). Secondly, a directed content analysis approach was used to provide a broad description of the observational data. The basis for an initial coding strategy was provided for from the literature and this was developed further by examining the transcripts line by line (Hsieh & Shannon, 2005). The coding categories focused specifically on the issues relevant to this study and were refined following the coding of four consultations (Figure 3.4). The coding frame was tested and refined further to ensure consistent results were reproduced on coding the data. The supervisory team reproduced the same results from coding several consultations with the coding frame and this attempted to replicate inter-coder reliability (Jackson, 2008). Finally, the findings from both of these approaches were continuously related to the research questions and basic descriptive statistical analysis was performed.

The first three codes which concerned the reporting of fatigue by the patient/carer and screen of fatigue by the doctor were mutually exclusive. This means the first participant that introduced the topic of fatigue in the interaction data was coded. However, when the carer shared their perspective of fatigue in the interaction this was also coded.

Figure 3.4: Coding scheme for categorising the utterances of speakers

Code	**Definition**
Fatigue reported by patient	The patient voluntarily reported fatigue to the doctor without being prompted to do so (i.e. first to introduce the topic of fatigue).
Fatigue reported by carer	The carer reported fatigue on behalf of the patient (i.e. first to introduce the topic of fatigue) and/or shared their perspective of the symptom.
Fatigue screened by doctor	The doctor screened for fatigue in their symptom assessment of the patient (i.e. first to introduce the topic of fatigue).
Fatigue assessed by doctor	The doctor assessed the impact of fatigue on the patient and its’ relationship with sleep and activity.
Cause(s) of fatigue outlined	The patient and/or doctor described the cause(s) of fatigue
Understanding of fatigue	The doctor explained the cause(s) of fatigue and/or the patient has shown that they have understood the cause(s)
Fatigue and palliative cancer treatment decisions	Fatigue was discussed as having the potential to *or* had an actual impact on cancer treatment options
Treatments offered for fatigue	The doctor outlined approaches to manage fatigue and/or offered treatments for fatigue (e.g. exercise)

3.6.9.2 Conversation analysis

Content analysis identified interactions in which fatigue was discussed and these segments of talk were professionally transcribed using Jeffersonian orthography (see appendix 3.10). This annotation captured micro-level features of interaction which facilitated the micro-analysis of utterances using the method of CA (Hepburn & Bolden, 2013; Jefferson, 2004). The analysis initially focused on sequence organisation and the overall structural organisation of the episodes before then turning to actions in talk. Patients and clinicians designed their talk in ways which were organised and shared during talk connected to fatigue. CA identified these shared organisations which were apparent in patterns of talk and these became phenomena of interest to study further (Drew, 2007).

These instances of a phenomenon were then analysed, collated and grouped together by their shared features. Once a group was identified, the entire data set was then examined to quantify these instances and determine if they were common or not. Phenomena of interest were initially identified and analysed by the researcher. The main phenomenon of interest presented in this thesis and the analytic claims were clarified with the guidance of the academic advisory team. This also prompted the analysis of cases where the phenomenon did not occur and the possible reasons for this were examined. Further detailed analysis and interpretation of the findings were finally determined by the researcher.

Over the course of the analytic process, data were presented at many dedicated CA data sessions with other CA researchers at organised groups, PhD student seminars, dedicated courses on analysing medical interactions and CA conferences. These data sessions provided a number of functions for this researcher. First, they facilitated further learning about the method of CA and broadened the scope of understanding of the methodological and empirical features of CA. These sessions were often led and attended by experienced applied CA researchers in the field. Second, these sessions helped to identify or confirm phenomena of interest to explore and examine further. Examining these phenomena broadened the researcher’s knowledge of CA and the focus of this study. Finally, these data sessions helped to validate the findings of this study.

Peräkylä (2011) outlined a number issues that concerned validity in research based on video recordings and transcripts, and when CA was used. The first of these features was the transparency of the analytic claims, meaning the findings of CA should be apparent to any researcher examining the data. The second feature was validation through 'next turn' which meant that any interpretation of an utterance by the CA researcher should be proved in the next turn by the recipient in the interaction data. Third, once the phenomenon has been identified, he advised deviant case analysis which concerned searching for and examining cases where an element of the suggested pattern is not associated with the other expected elements. Rather than placing these examples aside he encouraged a focus on them. Fourth, he suggested that questions about the institutional character of the interaction should be addressed by the researcher, for example, by focusing on sequence organisation and overall structural organisation. Fifth, he advised comparing the findings with other earlier studies concerned with medical interactions to explore if the findings are generalisable. Finally, he suggested using basic statistical techniques to ensure generalisability of the findings (Peräkylä, 2011).

3.6.10 Data management

The management and maintaining confidentiality of data were important aspects of this study and were considered carefully in line with best practice (Heath et al., 2010; Rushmer, 2011). Participants were fully informed about the use, retention and destruction of data. Data was stored in keeping with the Data Protection Act 1998. All data was stored with its own unique identifying code and not with the participant's name. The corresponding linkage details were stored separately with the consent forms in a locked cabinet with access limited to the researcher. The video and audio data were stored on password-protected personal computers and access was limited to the research team. The audio recordings were transcribed by professional transcribers, who had experience of working with confidential data and signed confidentiality agreements. At the point of transcription, all data were anonymised, pseudonyms were used in place of participants' names and identifying features such as address or place names were anonymised. This process of transcription and anonymisation was similar for the interviews with participants.

3.7 Part B – Interviews with patients with fatigue

3.7.1 Selection and Recruitment of Patients

Patient participants with fatigue were identified from Part A after indicating their level of fatigue on the Fatigue VAS. Participants with moderate fatigue or worse (NRS ≥ 4) were selected and invited for interview by the researcher. If they were interested in the interview study, all their questions were answered and they were given a PIS (see Appendix 3.11). The researcher asked for permission to contact potential participants by telephone within a few days to establish if they wished to take part. If they agreed to an interview, this was arranged and took place at the participant's home.

3.7.2 Issues of Consent

Written informed consent was obtained from patient participants prior to the interview to make sure that they still agreed to take part. It was made clear by the researcher that they were free to ask for the recording to be stopped at any time during the interview appointment and if they wished, the recording could be deleted immediately. They were also reminded that there was no obligation to take part in the interview study and they could withdraw their consent at any time. No participant withdrew from the interview study.

3.7.3 Interviews with patients

The semi-structured interviews started with the researcher asking the participant to tell their story about their disease and treatment history. A topic guide was used to help explore their experience of fatigue in-depth (Appendix 3.12). The interview was paced to meet the needs of the individual and breaks were frequently offered by the researcher to try to limit fatigue. The interview was ended when all the topic guide questions were asked or when the participant directed the researcher that they were too fatigued to continue.

Development of interview topic guide

The interview topic guide was informed by the research question, how patients with advanced cancer deal with fatigue. This meant the interview explored how participants coped with fatigue and managed the symptom in their daily lives. The scoping literature review that was undertaken on fatigue in advanced cancer further informed the interview topic guide. This prompted the exploration of the impact of fatigue on their daily lives and how participants received support on the management of fatigue in the research interview. The topic guide was reviewed and revised after the first and second patient interview. The topic guide allowed for an exploration of issues relevant to the research question and for the most part this was followed consistently across the whole sample. However, there was flexibility in the application of the topic guide as the participant was permitted to take the conversation where they wanted it to. This sometimes led to the exploration of sensitive issues such as end of life and great care was taken to ensure questions were asked in a delicate manner.

Sensitive interviews

On several occasions, participants became upset when they were discussing the impact of their illness on their lives and sometimes the conversation moved to end of life issues. The researcher's background as a clinician, an StR in Palliative Medicine, meant that he had received accredited advanced communication skills training to aid discussing sensitive and difficult topics. If the patient became upset during the interview, the interview was stopped until the patient was ready to continue, or abandoned if the patient did not want to continue. If the researcher, in his professional capacity, felt that the patient needed further support, with the patient's permission, a referral would have been made to the relevant nurse specialist or another appropriate healthcare professional (e.g. the patient's family doctor). If the patient decided they wished to have support after the researcher had left, the researcher ensured that they had the contact details for the relevant cancer nurse specialist or cancer support services.

3.7.4 Data analysis

The qualitative data resulting from the semi-structured interviews were analysed using thematic analysis. The systematic method of six phases of analysis (see Figure 3.2.) as proposed by Braun and Clarke (2006) were applied rigorously to the data. An inductive approach to analysis was adopted ensuring the themes identified were strongly linked to the data themselves rather than any preconceived ideas or presumptions from the literature (Braun & Clarke, 2006; Rivas, 2011). Following verbatim transcription, the interviews were listened to and the transcripts were re-read to check for accuracy. The researcher immersed himself in the data by actively reading and re-reading the data several times before coding it (Rivas, 2011). This time-consuming process led to familiarity with the breadth of the data as professional transcription had been sourced. Informal notes or memos were also made to give ideas for coding, to develop the coding process and to search for themes (Rivas, 2011).

Coding was performed manually line by line on the entire data set and then collated separately for each interview in a word document. Each sentence or group of words was assigned a code that summarised its meaning. Often, more than one single code was assigned to a sentence or paragraph because more than one single concept was identified. The supervisory team coded several interviews, and this was cross-referenced with the researcher to provide verification of the coding process. After all the data was coded and grouped together by relevance, the codes were reviewed and refined and sorted into potential themes and overarching themes. The codes for each potential theme were placed in tables in a word document and grouped together, sometimes merged and developed into categories. Organising the codes and categories in these tables facilitated a visual depiction of the data and this supported interpretation. The relationship and associations between codes and categories were searched for and reviewed. These codes and categories were continuously analysed, being regularly checked and refined while making sure they related to the data. These developed into basic sub-themes and themes until, finally, a collection of several candidate themes and sub-themes were generated from the data. The analysis was not linear through the phases as described in Figure 3.2 but a back and forth process with constant development and refinement, that is, an iterative process.

The next phase concerned the reviewing of these candidate themes and sub-themes. Some themes were merged and collapsed into one theme. The themes were reviewed at the level of the codes and categories to ensure they were based on the data and formed a coherent pattern. After this, the sub-themes and themes were defined and further refined as part of analysis and the verification process. This occurred as the interpreted findings were written for presentation in this thesis and this was an important part of the analytic process. The defining and naming of themes and overarching themes continued to evolve with each review of the written report. Furthermore, the supervisory team played a significant role in the verification process, in the defining and refining of the overarching themes and themes.

Rigor

Morse et al. (2002) discussed how rigour could be demonstrated in qualitative research. They proposed measures that could ensure the reliability and validity of the completed research study. The first of these features was verification, which was the process of checking, confirming and re-checking, throughout the entire period of data analysis. The authors suggested the verification process could identify and correct errors before they became embedded within the complete analysis and were too difficult to resolve. The second feature was investigator responsiveness, which related to whether the categorisation scheme or themes were clear and represented in the data. The lack of responsiveness could occur if the investigator was not immersed in the data, had an inability to abstract, worked deductively either implicitly or explicitly from previously held assumptions and followed rote instructions instead of using creative or strategic decision making. They also suggested several verification strategies which included: ensuring methodological coherence; appropriate sampling; collecting and analysing data concurrently; thinking theoretically; and theory development (Morse et al., 2002).

Shenton (2004) discussed Guba's (1981) criteria for trustworthiness or rigor in qualitative research and suggested some features for the PhD researcher to consider with three mentioned here. First, triangulation involves the use of different research methods to answer the research questions and this could enhance credibility or validity. This process can increase the depth of the study through complementary findings in the datasets and can enhance objectivity. Second, the researcher should employ reflective commentary or reflexivity throughout the research project to enhance validity. This process increases awareness of subjectivity and helps the researcher to develop objectivity. Finally, transparency of the research process should provide an audit trail for other researchers to follow the analysis process (Shenton, 2004).

3.8 Part C – Interviews with doctors

3.8.1 Selection and Recruitment of doctors

The doctors who took part in the observational study (Part A) were approached for an interview several weeks or months after data collection had ceased in the outpatient clinics. Invitation requests were sent by email and this included the PIS as an attachment (see Appendix 3.13). A reminder was sent after 2 weeks if there was no reply to the researcher. If they were willing, an interview was arranged and took place on the hospital site.

3.8.2 Issues of Consent

Written informed consent was obtained from clinician participants prior to the interview and the consent process was comparable to section 3.7.2.

3.8.3 Interviews with doctors

The semi-structured interviews commenced with the researcher asking the participant to talk about their background oncological experience and the disease-specific cancer patient population that they provide care for. A topic guide was used to help explore their beliefs and attitudes to fatigue and their approach to its' management in the cohort of cancer patients that they treat (see Appendix 3.14). The interview was finished when all the topic guide questions had been asked.

Development of interview topic guide

The interview topic guide was informed by the research question, how oncologists approach fatigue in those with advanced cancer. This meant the interview explored how clinician participants assessed and managed fatigue in their oncology clinics. The literature review in Chapter 2 further informed the interview topic guide. For example, the views of clinician participants were sought on whether other healthcare professionals could help in the management of fatigue in advanced cancer care. The topic guide was reviewed after the first clinician interview and was followed consistently across the whole sample.

3.8.4 Data analysis

The qualitative data resulting from the semi-structured interviews were analysed using thematic analysis and similarly followed the process as outlined in section 3.7.4.

3.9. Mixed methods: the integration of the methods

As outlined in section 3.2, this study used a concurrent mixed methods design that was qualitatively driven with a quantitative element embedded within the primary component. This study contained three parts (Part A, B & C) and each study answered complimentary and different facets of the research questions in this study. For example, Part A examined how participants talked about fatigue and how it was approached by participants in palliative oncology visits. Part B, explored how patient participants dealt with fatigue in their daily lives and this could not have been adequately explored in Part A. This section will first describe the integration of methods in Part A and then describe the integration of the findings from the three study parts.

3.9.1 The integration of methods in Part A

The integration of quantitative and qualitative data occurred in the observational study, the primary component of the study. The measurements of fatigue from the questionnaires were linked with the coding of consultations and descriptive statistics were used. Content analysis identified segments of talk where fatigue was discussed (i.e. fatigue-talk). Segments of fatigue-talk that related to patients with clinically relevant fatigue (i.e. NRS ≥4) were then analysed with CA. The micro-analysis of talk occurred independently and separately from the quantitative data. After segments had been analysed the fatigue measurements were added to the extracts of data and these were presented in the data in this PhD (see extracts in Chapter 4). Occasionally the questionnaire data provided further context and relevance to the observed findings in the data and these were highlighted in the presentation of data.

3.9.2 The integration of the findings from Part A, B & C

The observational study (Part A) in this PhD was the primary component and the interviews of patients (Part B) and clinicians (Part C) were supplementary components. This was reflected in how the findings from each component were integrated. The findings from Part A were given the most weight because they were observed in the data and could be validated by other researchers (Morse, 2010; Murphy et al., 1998). The findings from Part B & C were given less weight because, first, they were interpreted from the data collected and, second, there were limitations in the data collected which has been discussed in earlier sections of this chapter (Murphy et al., 1998; Potter & Hepburn, 2005). Hence, the CA findings took precedence over the interview findings and this guided their integration and presentation in this thesis. The interview findings were not used to interpret or contradict the CA findings. The interview findings provided complementary aspects and insights to what was already observed in the interaction data. However, the interview findings provided different aspects and dimensions to the research questions which were not adequately explored in Part A. These findings were integrated alongside the observed findings from Part A and in the summary of findings. In sum, the CA findings formed the basis of the integration of the study findings and their presentation in the final Chapter of this thesis.

Summary of findings and provisional framework for clinical practice

The entire findings from this study were integrated in a summary of findings and this culminated in a provisional framework for clinical practice. The summary of findings was based on the findings elicited from the literature review, the observed findings in Part A and the interpreted findings from Parts B and C. The aim was to consult patients who had lived experience of fatigue and cancer clinicians about the provisional framework for clinical practice. This process would have examined the accuracy of the study findings and perhaps increased the potential relevance of the provisional framework for clinical practice. However, the consultation has not yet happened and this will form the basis of post PhD work.

3.10 Summary

This chapter has provided an account of the methods used in this PhD project. The chapter began by discussing the research questions of the study. Next, the rationale to choose a mixed methods design was explained: by gathering data from quantitative and qualitative methods, richer understandings of the research phenomenon can be provided, with multiple insights gained through complementary approaches. The methods of data collection were then detailed. The video-recording of consultations provided accurate data for analysis of communication. In patient participants, fatigue was measured using Fatigue VAS and Fatigue Subscale FACIT-F and, also selected potential participants with clinically relevant fatigue for interview. Semi-structured qualitative interviews were conducted to gather rich data and explore how patients and doctors approached fatigue in advanced cancer.

The methods of data analysis were then described. The observational data were analysed using content analysis and segments of talk connected with fatigue were examined using conversation analysis. The interview data were analysed using thematic analysis and this complemented the micro-analysis of talk. Next, the ethical considerations of the study were considered and were reflected in the study design. After that, each component of the study was outlined separately, and included the recruitment of participants, consent and how the methods for data collection were used. An outline of how the analysis was performed was provided and included the measures taken to ensure validity, such as reflexivity. Finally, the integration of the three components contributed to a multifaceted and nuanced account of the fatigue in advanced cancer.

Chapter 4: Fatigue-talk in palliative oncology visits

4.1 Introduction to chapter

In this chapter, I present the findings from Part A, the observational study. First, I describe the participants and their recruitment in oncology clinics. Second, I outline how oncology consultations are structurally organised and provide an overview of fatigue-talk in the data. I interweave the findings from the coding of interactions with micro-analysis of talk to provide a better understanding of the reporting of fatigue and how it is assessed or screened by doctors. I show that fatigue-talk is recurrently integral to discussions concerning cancer treatment decision and this occasionally leads to a dialogue about end-of-life issues. Finally, I describe the occurrence of some recurrent patterns observed in the data, misalignment in the orientations of doctors and patients with clinically relevant fatigue (moderate to severe fatigue). Misalignment in this context usually comprised a differing in perspectives of participants on the current or expected impact of fatigue on quality of life and the goals of palliative chemotherapy.

4.2 Oncology clinics

4.2.1 Recruitment

Recruitment took place in six site-specific oncology clinics across three hospital sites and over a period of 14 months (see Table 4.1). The period of recruitment varied for each oncology clinic and ranged from 1 month to 8.3 months. Recruitment was dependent on several factors including the design and location of the clinic, the number and seniority of doctors, the patient population and the researcher. For example, recruitment was abandoned in the breast clinic 2 after 1 month because as a sole researcher, it was impractical to recruit across 3 oncology clinics on different sites and there were less potentially eligible patients than anticipated. Furthermore, some clinics and appointments routinely overran beyond the allocated time which led to challenges in recruitment.

This PhD study was originally designed to include the exploration of fatigue in patients with heart failure attending specialist outpatient clinics. Clinicians provided access and ethical approval was granted. However, a decision was made several months in to recruitment in palliative oncology clinics to abandon this part of the study because recruitment was slow.

Doctor participants

Seventeen doctors participated and consisted of ten consultant oncologists, two clinical fellows and five specialty doctors (see Table 4.1). The number of video-recorded clinical encounters per doctor ranged from 1 to 13. The recruitment process was dependent on doctors and therefore absences of doctors sometimes had negative effects on recruitment. For example, the lead clinician in the Upper GI clinic was absent for some time and this resulted in two separate pauses in recruitment, each lasting 1 month.

Patient participants

A total of 113 eligible patient participants were introduced to the study and 60 took part in the consultation study. Overall 23 declined to take part: a few declined during or soon after the researcher introduced the study but most declined at the next face-to-face contact with the researcher prior to their scheduled appointment. Many volunteered no reason for declining but a few shared concerns about being filmed and others were too anxious about scan results. Of note, some patients were initially very interested in the study but later declined and the researcher observed them becoming much frailer and weaker in the intervening period. One declined because she had no symptoms to report to the doctor.

The remaining 30 potential participants were deemed missed: some of these (17/30) were because appointments were scheduled for the future, between 1 week to 4 months but did not take place as scheduled. Following the first face-to-face contact, it was not unusual for patients to become less well as a result of their disease, side effect of cancer treatments or a separate illness which led to rescheduled or cancelled appointments. Moreover, clinicians occasionally rescheduled appointments if the clinic was overbooked or clinical staffing levels were low because of sickness or leave. If appointments were rescheduled, the researcher may not have been aware of these specific dates or in the case of the Lung clinic, appointments could have been made in a separate clinic as it occurred on three days during the week. One potential participant was known to have died and two were no longer well enough to attend the clinic. Two had given consent but were missed because the researcher was recording elsewhere in the clinic at the time. Eight were also missed when the researcher was unable to attend on a specific day or when recruitment had ended.

Table 4.1: Summary of recruitment in the observational study

Oncology Clinic	Doctors recruited	Patients recruited	Patients declined	Patients missed	Time (months)
Colorectal	5	19	3	6	8.3
Upper GI	3	10	7	6	6
Lung	1	13	4	2	7
Breast 1	5	12	5	9	4
Breast 2	1*	1	1	0	1
Prostate	3	5	3	7	2.5
Total	**17**	**60**	**23**	**30**	**14**

*duplicate as 1 doctor worked across 2 sites

Video-recorded consultations

In total, 60 consultations were video-recorded. All except one (59/60) patient participant experienced some fatigue and 62% (37/60) reported clinically relevant fatigue (i.e. NRS ≥4). Fifty-one patient companions participated in the study and accompanied 44 patients. Eight other clinicians also participated: one was a consultant pharmacist and seven were clinical nurse specialists in upper GI and lung cancer respectively. The average length of recorded consultation, calculated from the opening phase to the closing phase, was 21 minutes (range 6 – 42 minutes).

Patient participant characteristics

The average age of patient participants was 67.7 years (range 46 – 93 years) and over half of the participants were male (see Table 4.2). Almost a third of the patient sample had colorectal cancer and this represented the largest cancer group in the sample. Overall, 59 patients experienced some fatigue on the Fatigue-NRS and 37 experienced clinically relevant fatigue (moderate or severe fatigue). FACIT-F scores in the sample ranged from 52 to 0. The average FACIT-F scores in the Fatigue-NRS groups were: mild, 43; moderate, 33; and severe, 18. Individual Fatigue-NRS scores did not always correlate with the severity on the FACIT-F scale and vice versa. Over half of patients (68%) had received some cancer treatment within the last month and two had further assessments for treatment after a recent diagnosis of metastatic lung cancer. Three patients with metastatic lung cancer attended the clinic for ongoing review of symptoms after previously receiving palliative radiotherapy.

Table 4.2: Patient participants in observational study

	Number	**Percentage**
Gender		
Male	33	55%
Female	27	45%
Cancer type		
Breast	13	21.6%
Colorectal	19	31.6%
Hepatocellular	1	1.6%
Lung	12	20%
Mesothelioma	1	1.6%
Oesophageal	4	6.6%
Pancreatic	5	8.3%
Prostate	5	8.3%
Fatigue Numerical Rating Scale		
0 = None	1	1.6%
1 – 3.5 = Mild	22	36.6%
4 – 6.5 = Moderate	26	43.3%
7 – 10 = Severe	11	18.3%
Cancer treatment		
Assessed for treatment	2	3.3%
In treatment – Chemotherapy	31	51.6%
In treatment – Other	10	16.6%
Post treatment – Surveillance	14	23.3%
Post treatment – Palliative care	3	5%
Total	**60**	**100%**

4.2.2. The structural organisation of oncology interactions

Medical consultations follow a structure of organised interaction and a trajectory of activities. Robinson (2003) studied new medical problems in primary care interactions and identified a roughly ordered sequence of activities as part of a medically institutionalised project: (1) opening; (2) problem presentation; (3) information gathering; (4) diagnosis; (5) treatment; and (6) closing. He argued that the ultimate objective of the project is the solution to the patients' problems, which is treatment. However, treatment decision is dependent on each preceding activity, which in turn, are sequentially dependent on one another. Both patients and doctors, independently and jointly, fully recognise the ordering of activities and their functions (Robinson, 2003; Heritage & Maynard, 2006).

Oncology care has a phase structure and components of activities. Maynard et al. (2016) reported three central components that regularly follow this order: a review of symptoms (including medication/treatment side effects); presentation of imaging test results (e.g. X-ray, computerised axial tomography or CAT scan); and treatment discussions and/or recommendations. Singh et al. (2017) identified a fourth component and further defined this phase structure: symptom-talk, scan-talk, treatment-talk and logistic-talk, which consists of coordination and organisation of care. In summary, oncologists monitor the disease and side effects of treatments progress using their symptom reviews and scan results, which together, form the basis of treatment discussions and recommendations.

In this study, the oncology care phase structure was broadly similar in most cases to Maynard's phase structure but deviated in several cases. It was usual for some doctors to routinely start with scan results and this was often done with the introduction of a 'good news' segment (Maynard, 2016). This phase usually led to some treatment-talk about how the cancer was responding to treatment which could lead to a treatment proposal before returning to symptom-talk. Furthermore, the phase structure was not always linear, specifically in relation to talk concerning fatigue when scan or treatment-talk could then return to symptom-talk especially when fatigue was viewed to be problematic by any participant. Therefore, talk surrounding fatigue or fatigue-talk in the data was often not just confined to symptom-talk. Fatigue-talk was frequently embedded in treatment-talk when fatigue was deemed to impact on the goals of palliative treatment, and when treatment decisions were considered or agreed. Occasionally fatigue-talk was closely associated with scan-talk when the results of scans were used to highlight the likely causes of fatigue.

4.3. Overview of fatigue-talk in the data

In this section, I introduce and describe the talk related to fatigue in the corpus of data by summarising the findings of the content analysis (see Table 4.3). Overall, talk connected with fatigue occurred in 82% (49/60) of consultations and in all consultations with participants who reported clinically relevant fatigue (37/60). Fatigue-talk was initiated by oncologists (43%, 26/60) more often than patients (32%, 19/60) and patient companions (7%, 4/60). However, the content analysis does not reveal how participants talked about fatigue and therefore I include extracts of micro-analysis of talk to understand and highlight this in more depth.

The integrated findings of the content analysis and the micro-analysis of talk are presented together under each heading from the coding framework. These include: the reporting of fatigue by patients; the reporting of fatigue by patient companions; doctors screening and assessing fatigue; causes of fatigue; fatigue and palliative cancer treatment decisions; treatments offered for fatigue; and advice-giving for fatigue.

The CA findings presented in this chapter are only from those patients who reported clinically relevant fatigue (i.e. NRS $\geq$4). The selected extracts were representative of several examples from the data set and were chosen because they were clear examples. Each extract will be accompanied by the fatigue NRS and FACIT-F score to illustrate the reported severity of fatigue by the patient.

The final section of this chapter outlines cases of misalignment that were concerned with patients: resisting treatment recommendations to lessen the burden of fatigue through the adjustment of chemotherapy treatments; and resisting advice giving for fatigue.

Table 4.3: Coding of the utterances of speakers

Fatigue reported by patient	Fatigue introduced as topic by patient – 19 (32%) • Problem presentation – 13 (22%) • Euphemisms used by patients – 17 (28%) • Mitigated and/or normalised – 9 (15%)
Fatigue reported by patient companion	Fatigue introduced as topic by companion – 4 (7%) • Companion gave perspective – 19 (32%) • Companion upgraded fatigue – 9 (15%)
Fatigue screened by doctor	Fatigue introduced as topic by companion – 26 (43%) • Tiredness and/or fatigue – 13 (22%) • Energy levels – 13 (22%)
Fatigue assessed by doctor when identified	Activity levels and/or sleep assessed 27 (45%) • Activity levels – 20 (33%) • Daytime or nocturnal sleep – 18 (30%)
Cause(s) of fatigue outlined	Patient and/or Doctor attributed causes – 40 (67%) • Treatments likely or possibly – 30 (50%) • Cancer likely or possibly – 7 (12%)
Fatigue and cancer treatment decisions	Fatigue connected to treatment decisions – 19 (32%) • Treatment dose reduced – 5 (8%) • Treatments stopped – 2 (3%) • Forecast future treatment decisions – 8 (13%) • End-of-life discussions – 5 (8%)
Treatments offered for fatigue	Treatments offered: 3 (5%) • Steroid – 1 • Nutrition supplement – 1 • Transfusion – 1
Advice-giving for fatigue	Advice-giving – 5 (8%) • Exercise – 2 (3%) • Pacing – 1 (2%) • Permission to rest – 2 (3%) Endorsed activity or pacing introduced as topic by patient – 5 (8%)

4.3.1 The reporting of fatigue by patients

In 32% (19/60) cases, the patient was first to introduce the topic of fatigue and of these, 13 (22%) occurred within the problem presentation of the encounter. In only one of these cases was the word fatigue used as a descriptor by the patient to relay their experience of fatigue to the doctor. Patients routinely used a variety of descriptors and terms for fatigue and the most common was an upgraded account of tiredness such as ‘quite tired’. Other descriptors included: ‘exhausted’, ‘weary’, ‘weak’, ‘heavy’ and a depletion of ‘energy’. Occasionally patients used specific phrases such as ‘haven’t got any get up and go’ or ‘knocked the stuffing’ or ‘feel washed out’ or ‘bit threadbare’. More than 20 separate descriptors and terms for fatigue were used by 17 patients. This suggested that fatigue was not the language used by patients when they described their experience of fatigue to the clinician.

In cases where the patient was the first to introduce the topic of fatigue, the reporting of fatigue was commonly associated with actions such as minimising and acceptance (9/60, 15%). In extract 1, the reporting of fatigue was mitigated and a candidate diagnosis for the cause of fatigue was proposed by the patient. The consultation commenced with a good news segment with a confirmation that cancer responded to chemotherapy treatment as evidenced by radiological investigations. This was followed a review of symptoms segment by the clinician.

Extract: 1 ***PAT45: Fatigue NRS = 5; FACIT-F = 25***

```
VO45 – PAT45/DOC10
1    DOC:  all of that's o↑ka::y (0.6) nothing giving you::? (0.6)
2          too much [bo↑ther
3    PAT:           [↑no::, (0.4) ↑no: (.) ↑um (0.4) the ↑on↑ly:
4            (1.0) u:::m (0.6) it’s (.) it’s the ↑chemo:: [↑that=
5    DOC:                                                 [hm ↑mm
6    PAT:  =makes me ↑ti:::red (ful-) tired all the time (0.4) .hhh
7          which is the only symptom that’s, (0.4) >sort of<
8          annoying (0.4) >that you< can’t do as much as you want
9          ↑to ↑do,
```

The general enquiry question from the doctor was grammatically a yes-no interrogative and the preferred response was a negative (Heritage et al., 2007). The patient gave a preferred response and then introduced a concern which was associated with some hesitancy and hedging in lines 3-4. Fatigue was attributed to chemotherapy, labelled as the 'only symptom' and was mitigated 'sort of annoying'. In the sequences that followed, fatigue was further minimised by the patient and was associated with acceptance. Patient-participants mitigating the problem of fatigue was frequently observed in the data. This was usually associated with actions which confirmed acceptance of fatigue as a normal side effect or consequence of cancer treatments.

The minimising and acceptance of fatigue by patient participants sometimes made it difficult for doctors to assess the impact of fatigue on performance status (ECOG PS) which informed the fitness for treatment. There a few examples of patients and doctors using different terms for fatigue and this occasionally interfered with the assessment of fatigue because the language was misunderstood by the doctor. The following two extracts come from the same interaction and are labelled 2.1 and 2.2. In this extract, the patient minimised fatigue and accepted it as a normal experience of cancer treatment. The patient and doctor were using different language for fatigue and hence this interfered with the assessment of fatigue.

Extract: 2.1 ***PAT07: Fatigue NRS = 5; FACIT-F = 45***

VO07 – PAT07/DOC04
1 DOC: .hhh (0.4) >how are you< doing,
2 PAT: mm ↑fai::r, (0.6) fai:r fair fai::r
3 DOC: ↓okay (0.6) .hh describe fai::r,
4 PAT: ↑mm:::: (0.6) .hhh well the ↑chemo knocks me ↑fla:t (0.6)
5 [↑absol]utely knocks me flat (0.6) .hh u:::m,
6 DOC: [°okay°]
7 DOC: °°okay°°
8 PAT: makes me feel very ↑ill,
9 DOC: o::h
10 PAT: obviously, (0.4) a::nd (.) puts me off me ↑foo:::d an-,
11 (0.4) .hh and gives me funny tastes in me ↑mouth ↑and,
12 (.) ↑everything ↑that, (0.4) ↑they ↑say in the ↑boo::ks,
13 (0.4) ↑you ↑↑get (0.6) .hhh ↑so:::: ↑e:::rm ↑↑yeah
14 DOC: .hhhh [tired?]

15 PAT: [e::::r]
16 PAT: °↑oo:f° (.) ↑no not ↑really, (0.6) >↑I mean I< (0.4) get
17 up early in the ↑↑morni::ng, (0.6) ↑↑yeah (0.6) ↑not (.)
18 ↑you ↑know (.) not too ba:d

In line 1, the doctor opened with a general how are you enquiry and the patient responded with a downgraded form of response ‘fair’ with repetition that indicated trouble (Jefferson, 1988). After a clarification question, troubles telling followed with fatigue attributed to chemotherapy and the term ‘knocks me flat’ was a descriptor for fatigue. The patient elaborated further with ‘very ill’ and reported other symptoms. In line 12, he explained that these symptoms experienced were expected and normal on cancer treatment ‘everything that they say in the books’ which mitigated the concerns. In line 14, the doctor made an enquiry about fatigue with a closed question ‘tired?’. The patient gave a negative response followed by ‘not really’ and an account about waking up early. Several minutes later in the interaction the doctor returned to clarify the meaning of the term used for fatigue but this appeared to be problematic for the patient to describe. In extract 2.2, the attending specialist cancer nurse in the consultation clarified the meaning of the term with the help of the patient’s companion, his wife.

Extract: 2.2 ***PAT07: Fatigue NRS = 5; FACIT-F = 45***

```
VO07 – PAT07/DOC04
1    DOC:  ↑u::m, (2.8) okay (0.6) >I ↑mea-< hhh (0.8) .tch ↑how are
2          you mana↑ging with the chemo>therapy I mean< you say >it
3          sort of< knocks you flat for five [da:ys ↑afterwards
4    PAT:                                    [well it ↑does knock me
5          flat (0.4) it ↑makes you ↑fee:l (0.4) pretty rough hhh
6          (0.6) ↑you kno:w  °↑it's°
7    DOC:  okay (.) but it’s ↑mo::re (0.6) .hhh it’s mo:re the (0.4)
8          the not eating and the taste disturbance any ↑sickness
9          °↑at ↑↑a:ll any ↑nausea?°
10   PAT:  ↑u::::m, (0.6) I ↑have been sick I wasn’t this ti:me
11         (0.6) <I: wa:s> sick the last time (0.6) they’re pretty
12   16 lines omitted: the patient gave an account of receiving anti-emetics, having mouth ulcers
13   and his experience at the Day Treatment Unit before the doctor turned away to write notes
14   NUR:  but on those ↑da::ys where you’re feeling so wiped out
15         are you literally in bed f- (0.4) [for a few days
16   PAT:                                    [↑yea::h I ju::st (.)
17         go to bed and just sit, (.) sit (on it) I mean christmas
18         da::y >was a< (.) we ‘ad a two days £before christmas
19         da:(h):y£ and (?)
20   CAR:  £°he was ↑fla(h)t on his back°£
```

PAT: I was (.) flat on my ba:::ck
DOC: .hh is that because you fi:nd (0.4) getting out of bed to
be:: (0.6) diffi↑cu::lt?
PAT: yea::h [it’s
DOC: [and up about
PAT: i::t er it’s just (layer) to lay sti:ll and lay ↑flat
a:nd (0.6) let it (0.4) do whatever it’s got to ↑do::
↑then (0.6) y’kno::w (.) after so many ↑days you can
↑↑sort ↑↑of ↑start ↑to ↑↑mo::ve

The doctor returned to the review of symptoms on treatment and worked to clarify the meaning of ‘knocks me flat’. The patient repeated this euphemism for fatigue perhaps for it to be taken literally and attempted to elaborate further on the experience of fatigue with some hesistancy and hedging before adding another descriptor ‘pretty rough’. In line 7, there was some turbulence and hesitancy in the delivery as the doctor interpreted the term as corresponding to other symptoms mentioned in the problem presentation and then assessed for nausea. The patient responded indirectly with a confirmation of sickness on the first cycle of treatment before he proceeded with an account from the chemotherapy day unit. There was a pause for 8 seconds as the doctor had his head down writing in the clinical notes and this gave an opportunity the nurse to inquire about fatigue in line 14. She used a descriptor for fatigue ‘so wiped out’ and clarified whether the patient’s term was a literal description. He responded indirectly and gave a mitigated account ‘just go to bed and just sit’. In line 20, his wife interjected with the clarification response and he gave an agreement. The doctor then assessed the severity of fatigue and projected difficulty getting out of bed. The patient affirmed fatigue and associated it with chemotherapy treatment ‘let it do whatever it’s got to do’. In the sequences that followed, a treatment recommendation to reduce the burden of fatigue by adjusting chemotherapy treatment was initially resisted by the patient but agreement was eventually reached. In summary, this case examined how the patient’s actions in the reporting of fatigue led to some difficulties in the initial assessment of fatigue by the doctor. It was important that a correct assessment of fatigue was made by the doctor because this led to treatment recommendations to reduce the burden of fatigue through the adjustment in chemotherapy treatment.

As stated earlier, when patients introduced the topic of fatigue, they used many different descriptors and terms for fatigue in the reporting of this symptom. In the data corpus, the reporting of fatigue by patients, particularly the experiential description of fatigue, was frequently associated with hedging and hesitancy. In some cases, the reported numerical rating score (NRS) on the Fatigue-VAS and FACIT-F questionnaires corresponded with the reported experiential description of fatigue. For example, severe fatigue on NRS and FACIT-F was associated with upgrading and moderate fatigue was associated with minimising. However, there were several exceptions including:

- PAT04 (NRS = 8.5; FACIT-F = 16) who mitigated fatigue when his wife and doctor orientated to severe intolerable fatigue while receiving cancer treatment. He also resisted treatment recommendations to reduce the burden of fatigue.

- PAT28 (NRS = 6; FACIT-F = 28) who did not report fatigue when assessed by the doctor.

These exceptions provided interesting observations in the data. Some patients experienced severe levels of fatigue but did not report fatigue as a concern or a problem to the doctor. Later sections in this chapter provide some evidence that the reporting of fatigue as a problem meant the doctor responded with treatment recommendations to reduce the burden of fatigue by the adjustment of cancer treatments.

In extract 3, the reporting of fatigue was upgraded and corresponded with severe disabling fatigue (NRS = 8.5; FACIT-F = 0). This extract starts at the beginning of the consultation. The patient received palliative radiotherapy several weeks previously and he had not tolerated a trial of palliative chemotherapy in the past.

Extract: 3 ***PAT33: Fatigue NRS = 8.5; FACIT-F = 0***

VO33 – PAT33/DOC06
00:00 DR: °mm° ↑ha: good yea:h good to [see] you ↑how ↑have things=
CR: [↑mm]
DR: =bee:n, [(?)]
PT: [not good]
DR: have they not
CR: ↑mm:
DR: [ri:]ght
PT: [no:]
DR: .hh what ha- what have been the main problems,
PT: ↑over↑whelmingly th- the sheer exhau::stion,
DR: ri:gh[t, °okay°]
PT: [>I mean<] ↑I'm spending ↑more time ↑sleeping during
the day than I am a↑wake, (0.6) .hhh um, (0.4) I just
haven't got an ounce of energy
DR: °ri:ght°
PT: no- not an [↑ounce] of energy
DR: [°right°]

In line 10, the patient introduced the concern of fatigue with the descriptor “sheer exhaustion” and then an account was given about abnormal day time sleeping. The complaint was upgraded with repetition “not an ounce of energy”. In the sequences that followed, the patient offered a candidate diagnosis for fatigue caused by cancer rather than cancer treatments which the doctor affirmed. The doctor explained how the experience of fatigue was normal in patients with lung cancer and the complaint was upgraded. The doctor’s actions continued with empathising from clinical experience and agreement from the patient.

To recap, patients were first to introduce the topic of fatigue in nearly a third of cases (32%, 19/60) and in doing so used more than 20 different descriptors with the word fatigue used once. This suggests the term fatigue may resemble medical terminology rather than the language used by patients. In the data, the reporting of fatigue was commonly associated with minimising and acceptance. In some cases, these actions related to fatigue being described as an acceptable trade-off for the control of cancer. Occasionally, the terms used for fatigue and the actions of minimising and acceptance interfered with the assessment of fatigue. This was important because this study has shown that fatigue often influences cancer treatment decisions. Therefore, if fatigue was not properly assessed, then cancer treatment decision-making would not be properly informed or indeed may not occur.

4.3.2 The reporting of fatigue by patient companions

Patient companions frequently had a part to play in the reporting of fatigue. Companions introduced the topic of fatigue in four cases (7%; 4/60) and in total provided their observations of fatigue to the doctor in 32% cases (19/60). The actions of companions in the reporting of fatigue included: upgrading the complaint; describing or reporting on their observed impact of fatigue on quality of life, sleep or activity; minimising fatigue with actions of acceptance; giving alternative explanations for fatigue such as aging; and seeking a diagnostic explanation for fatigue from the doctor. Thus the actions of companions were many and they did not always align with the patient.

In some cases, the companions aligned with the patient’s reporting of fatigue and an example is given here. In extract 4, the doctor assessed fatigue after the patient had introduced the topic of fatigue in a list of concerns. The actions of the companion, his wife, upgraded the complaint and added the descriptor fatigue.

Extract: 4 ***PAT53: Fatigue NRS = 7; FACIT-F = 17***

```
VO53 – PAT01/DOC01
1    DOC:  °okay° (0.4) .hhh °ri:ght° (1.0) >any other symptoms< (.)
2          er fa↑ti::gue how’s that affecting you
3    PAT:  e::::rm, (0.6) we:ll i- it’s fa↑tigue it’s making me feel
4          tired er I ↑can’t ↑really::, (0.4) do very much I can sit
5          up in a ↑chai::r (0.4) ↑for ↑a, (0.4) period of time
6          ↑bu:t,
7    CAR:  and that’s kind o::f (.) getting shorter and ↑shorter
8          tho:se periods >as I< sa:y ↑just a (0.4) >for the< ↑la:st
9          ↑week I would sa::y just [e:r you’ve ↑been ↑really=
10   PAT:                           [↑mm::::
11   CAR:  =↑really ↑↑wea::k,
12   PAT:  yea::h
```

In line 1, the doctor used a compound question with two components and following a delay the patient provided an account of fatigue with some hedging and hesitancy. The patient companion then provided a joint account and upgraded fatigue with the patient in agreement. In this case, the patient reported severe fatigue on the fatigue questionnaires and in the consultation with the oncologist. The companion provided further information to the doctor to support this.

Occasionally, there were differences in the perspectives of the impact of fatigue on quality of life between patients and their companions. In five cases (5/60), the patient minimised fatigue and the companion upgraded the complaint. Doctors usually responded by unpicking these differing perspectives and assessing fatigue. In extract 5, the patient introduced the topic fatigue in the problem presentation but minimised the complaint. In contrast, the patient companion, her sister, upgraded the complaint and problematises fatigue on cancer treatment.

Extract: 5 ***PAT53: Fatigue NRS = 4; FACIT-F = 40***

VO01 – PAT01/DOC01

1 DR: pre↑su::me you’re feeling we:ll
2 PT: ye:s, (0.4) ↑ju:st I ↑just (0.4) >I was< just saying to
3 the: (.) ↑cha:p I just get fa↑ti::gued that’s all
4 DR: how long does that last fo::r,
5 PT: .hhh (0.6)
6 CR: all the time now
7 PT: yea[::::h]
8 CR: [come on] be honest
9 PT: yea:h
10 CR: today she’s still tired and it’s two weeks after the
11 event
12 PT: yea:h,
13 DR: oka:y
14 PT: but ↑tha:t’s (.) a::ll (0.6) just t[hat

The doctor walked the patient in from the waiting room and her opening question was formulated as a yes-no interrogative projecting a yes response. The patient gave a preferred response prior to minimising fatigue as a concern by repeatedly using “just” and “that’s all”.

In line 6, the companion responded to the doctor's enquiry after the patient turned her gaze away from the doctor and gave an in-breath in line 5. In line 10-11, the patient companion upgraded fatigue and the patient explains this was the only symptom. In subsequent sequences the companion continued to problematise fatigue. The doctor then offered to adjust cancer treatments to lessen the burden of fatigue and this treatment recommendation was resisted by the patient and companion. The patient was explicit that fatigue attributed to cancer treatments was an acceptable trade-off for the control of the disease.

In three cases (5%, 3/60), the companion was the first to introduce fatigue as a concern and upgraded the complaint, but the patient's actions resulted in minimising fatigue (see for example extract 6). The role of the companion was important in this case because it led to the assessment of fatigue and recommendations to investigate the cause of fatigue.

Extract: 6 ***PAT53: Fatigue NRS = 5.5; FACIT-F = 12***

```
VO16 – PAT16/DOC
 1   DOC:  ↑fevers or high temperatu[res at all
 2   CAR:                           [no:e
 3         (4.6)
 4   CAR:  .hh but you're very ↑ti:red and, (0.4) all the time ↑aint
 5         ya:: a::nd ↑sleep a lot
 6   DOC:  ri:ght
 7   PAT:  ↑o::h [↓yeah
 8   DOC:        [°okay°
 9   PAT:  I don't worry about that (0.4) uh ↑huh
10         (3.6)
```

While reviewing symptoms the doctor was intermittently writing in the clinical notes with his gaze averted. In line 4, the companion introduced fatigue by seeking agreement from the patient and prompting her to report it. The patient agreed with this account but mitigated any concern from her perspective which insinuated that fatigue was not a concern and this closed the line of enquiry. In the sequences that followed, the companion again raised fatigue as a concern and this led to the doctor recommending investigations to assess for progressive cancer. This example shows how the role of the companion can help the doctor to accurately assess fatigue.

This study has shown how patient companions had a role in the reporting of fatigue in palliative oncology visits as evidenced by them sharing their observations with the doctor in nearly a third of cases (32%, 19/60). Patients and companions did not always agree on the impact of fatigue on quality of life and function ability. The information the oncologist gains from the companion can be helpful in correctly assessing the burden of fatigue which can inform treatment decision discussions.

4.3.3 Doctor screening and assessing fatigue

In most cases where fatigue was not first raised by patients or patient companions, doctors screened for fatigue (26/37). Some doctors screened for fatigue using the descriptors tiredness and/or fatigue (13/26) and others screened for fatigue using ‘energy levels’ (13/26). In the 11 cases where fatigue wasn’t specifically screened for, doctors screened for activity levels in the majority (7/11). Fatigue wasn’t discussed at all in four consultations (4/60).

Fatigue that was reported as a concern or identified by the doctor was often closely followed by an assessment of the symptom and this fitted to what the patient had said in the initial account given. For example, a mitigated account of fatigue with acceptance meant the symptom may not be assessed further or perhaps the account given of fatigue provided sufficient information for the assessment. Doctors assessed the impact of fatigue on activity levels and/or sleep patterns in 27 cases (45%, 27/60).

In the data, the screening of fatigue using the descriptor ‘tiredness’ was usually followed by and associated with responses and/or questioning related to resting or sleeping. This was a common occurrence in the data but the numbers were insufficient to explore significance. In extract 7, the doctor screened for fatigue and the patient’s account guided the assessment. The patient proposed fatigue was tolerable and described coping strategies of resting for periods as needed. The patient reported moderate fatigue and was receiving palliative chemotherapy.

Extract: 7 ***PAT49: Fatigue NRS = 5; FACIT-F = 33***

VO49 – PAT49/DOC13

DOC: .hh and tired↑ness ↑wise ↑how’s ↑↑i::t?

```
2          PAT:  .hhh I still feel tire::d (0.6) bu:t u::m, (0.6) ↑↑you
3                ↑can cope with i::t >you know< ↑have a little rest then
4                sort of carry on an-
5          DOC:  .hh and how much time of the day are you:: (.) having
6                rest
7          PAT:  hhhh (.) ↑u:::m, (2.0) what (.) ↓we:ll (0.6) ↑two or
8                three times a ↑day,
9          DOC:  >two or< three ti:mes
10         PAT:  yeah
```

The patient outlined that fatigue remained a concern but described it as tolerable and reported coping strategies. The doctor asked a clarification question on the amount of time needed to rest. A significant pause indicated difficulty with the terms of questioning and the patient responded with occurrences but without a clarification on time. The doctor treated this as a sufficient response to move on to the next action. This example outlined how screening for fatigue with the word tiredness led to responses from the patient related to resting.

In contrast, when doctors used the term ‘energy levels’ to screen for fatigue, this was usually followed by and associated with responses and/or questioning related to activity. In extract 8, the doctor screened for fatigue and then assessed the impact of fatigue on activity levels. Previously the doctor has elicited concerns about nausea/vomiting and constipation which resulted in a treatment recommendation and prescription in line 1-2.

Extract: 8 ***PAT39: Fatigue NRS = 5; FACIT-F = 25***

VO39 – PAT39/DOC09 (lines 1-16)

```
1    10:30 DOC:  .hhhhh (.) oka::y so ↑that’s for your ↑docto:r’s u::m,
2                (0.4) reception to ge:t (.) some of tha:t (0.6) .hh now
3                ↑what a↑bout your energy levels ↑how are tho::se.
4          PAT:  very low
5          DOC:  .hh ri::ght (0.40 [oka::y
6          PAT:                    [↑u:::m, (0.6) I ca- it’s not that I
7                can’t ↑do anythi:ng but as soon as I do: (1.0) I ↑hav’n-
8                got any::, (0.6) get up and [go
9          DOC:                              [get up and go:::
10         PAT:  ↑yeah
11         DOC:  ↑what >sort of< things have you trie::d to do::
```

```
12   PAT:  not a lot [hu::h ha ha ha ha
13   DOC:            [not a not very mu:ch >are ↑you< ↑just sitting
14         around most of the da::y th[e::n
15   PAT:                             [I’m afraid I ↑a:m ye:s
16   DOC:  ri::ght o[kay
17   CAR:           [you ↑do ↑try to go ou:t [every da:y
18   PAT:                                    [I ↑try to get ou:t for
19         a wa:lk (0.6) [↑even if i:t’s
20   DOC:                [>so ↑that’s< an effo::rt (0.6) .hh so (.)
```

In line 3, the doctor formulated an open question about energy levels to screen for fatigue. The patient’s response indicated the severity and he used a descriptor for fatigue “haven’t got any get up and go”. The doctor part-repeated the descriptor and made an enquiry about activity levels in line 11. The patient’s response “not a lot” gave an indication of severity. The doctor framed a clarification question on activity levels pessimistically which the patient affirmed. However, this enquiry could also come across as suggesting laziness and this was understood by the patient companion, his wife, who confirmed there was no lack of motivation in line 17. The association of fatigue with laziness in the explanations of participants raised fatigue as moral issue for patients. This example, showed the term ‘energy levels’ was followed by responses and questioning related to activity.

In the data, doctors mostly screened for fatigue (70%, 26/37) when it had not already been introduced by patients or their companions. And when fatigue wasn’t screened for, doctors usually assessed activity levels (7/11). Screening for fatigue using tiredness or energy levels was usually associated with different response and questioning. These findings may have clinical relevance because oncologists may wish to regularly assess fatigue against fitness for treatment which is based on functional ability.

4.3.4 Causes of fatigue

The causes of fatigue were often discussed by participants and occurred in 67% of cases (40/60). Fatigue attributed to palliative cancer treatments was the most common sole or contributory cause mentioned in 50% (30/60). Cancer as the likely attributable sole or contributory cause for fatigue was reported much less (12%; 7/60). Alternative explanations other than cancer or cancer treatments for fatigue were occasionally proposed by patients and doctors. These included heart failure or heart failure treatments, Parkinson's disease and viral illness.

Examples of how patients and doctors attributed the cause of fatigue are not presented here. However, some commonly found examples in the data are contained in other sections:

- Extract 1, line 4, page 108
- Extract 2.1, line 4, page 109
- Extract 9, line 4, page 124

4.3.5 Fatigue and palliative cancer treatment decisions

Talk connected with fatigue was central or contributory to discussions around palliative cancer treatment decisions in 32% of cases (19/60). Fatigue was implicated in the reduction of chemotherapy, either on commencement of a new cancer treatment or during treatment cycles. In addition, fatigue was treated as solely or partly responsible for the lengthening of treatment cycles and the pausing or withdrawal treatment. Frequently these treatment decision discussions were initiated by the doctor when the burden of fatigue was perceived or forecasted to interfere with quality of life and function by any participant in the consultation.

Treatment recommendations to lessen the burden of fatigue through the adjustment of cancer treatments were usually formulated as proposals and this promoted joint decision-making, with the patient and doctor having equal agency or responsibility in the decision-making process (Stivers et al., 2018). These recommendations to adjust cancer treatments to lessen fatigue were occasionally formulated as pronouncements and suggestions, which placed either more responsibility on the patient or the doctor in the decision-making process (Stivers et al., 2018). When new cancer treatments

In the corpus of data, when new palliative cancer treatments were recommended by the doctor, they were usually formulated as proposals and sometimes as suggestions or offers. These formulations of recommendations promoted patient engagement and patient choice (Stivers et al., 2018). However, within these new treatment proposals, the chemotherapy was sometimes specifically adjusted because of fatigue and this was made clear to the patient. Moreover, the reduction of the chemotherapy was within the doctor's epistemic remit. Hence, within these proposals for new treatments, the doctor was more authoritative about the adjustment of chemotherapy and the patient did not have any say over this.

Treatment recommendations to lessen the burden of fatigue that occurred during the treatment schedule (i.e. mid-course treatment recommendations) were usually formulated as proposals in the first instance. However, treatment recommendations were generally reformulated by the oncologist when resistance occurred. This is described in-depth in the next section of this chapter when examples of misalignment are analysed.

The outcome of recommendations to adjust cancer treatments to lessen the burden of fatigue led to:

- dose reductions in cancer treatments in five cases (5/60)
- the pausing or cessation of treatments in four cases (4/60)
- doctors forecasting future treatment decisions at the next palliative oncology visit should fatigue continue to worsen on cancer treatment in eight cases (8/60)

Treatment decision discussions were often lengthy and occurred over many sequences which lead to the reformulations of treatment recommendations for fatigue. This particularly occurred when doctors and patients took different stances on how fatigue was impacting on the goals of palliative cancer treatment, quality of life and fitness for treatment. Misalignment or resistance to treatment recommendations usually occurred when patients and doctors took opposing stances on how fatigue was beginning to or did impact on fitness for treatment.

Fatigue-talk which led to treatment decision discussions was often sequentially linked with actions in talk related to goals of palliative treatment. The goals of palliative cancer treatments were usually explicitly referred to by doctors but less so by patients. Doctors often predicted the worsening of fatigue with the accumulation of cancer treatments, linking fatigue with a detrimental effect on quality of life and forecasting a review of treatment decisions. On occasions when further treatment options for disease control were limited, end of life issues were introduced by either party and occurred in 12% (5/60) cases.

This next example outlines how worsening fatigue was sequentially linked with stopping cancer treatment, worsening quality of life, principles of palliative treatment and end of life discussions. In extract 9, a treatment proposal for a new chemotherapy treatment has just been agreed after the patient expressed a preference for more treatment. The doctor forecasts the possibility of fatigue worsening on treatment and this would lead to treatment decision discussions about the withdrawal of treatment. The patient then introduces the topic of end of life issues if treatment were withdrawn.

Extract: 9 ***PAT39: Fatigue NRS = 4; FACIT-F = 29***

```
VO20 – PAT20/DOC01 (lines 44-69)
1         DOC:  I ↑think we need to see how you get on with one dose at
2               a:ll.
3         CAR:  ↑fi:rst,
4         DOC:  and I think >if it< (.) ↑rea::lly (.) knocks you for si:x
5               (0.4) you should think about whether it’s the right thing
6               to do or not
7         PAT:  ri:ght,
8         CAR:  okay
9         PAT:  ↑yea:h
10        DOC:  cos it’s a↑bout, (.) quality of li:fe
11        CAR:  it [is hhh
12        PAT:     [↑yeah
13        DOC:  and if ↑having chemo destroys your quality of li:fe (0.6)
14              for some po↑tential future quality of life
15        PAT:  if you ↑don’t have it,  (0.6) mm- ↑e::::r I mean are we
16              biting the bullet and saying well ↑that’s e:::r ↑that’s
17              the ↑end of the ↑↑£life£ huh
```

The doctor outlined a review of treatment decisions after the first treatment with a hypothetical scenario of worsening fatigue, using a term “really knocks you for six”. In line 4 the projected treatment decision was conveyed as a decision for the patient to make about whether chemotherapy was the “right thing to do or not”. The treatment recommendation was formulated as a suggestion and presented as a clear decision for the patient to act upon (Stivers et al., 2018). In line 10, the doctor outlined a principle of palliative treatment and explicitly mentions “quality of life”. Worsening severe fatigue on treatment was sequentially linked with “destroys quality of life” in line 13. The patient’s wife explicitly agreed and aligned with the doctor. The patient understood stopping treatment equated to “the end of life”. Continuing with cancer treatment therefore equated with living and the treatment decision for the patient became a binary choice between living or dying.

To summarise, this section has described how talk connected with fatigue was often integral to discussions around palliative cancer treatment decisions in nearly a third of cases (32%; 19/60). Fatigue influenced palliative cancer treatment decisions and this frequently led to the adjustments of cancer treatments with the stated aim of lessening the burden of fatigue. Therefore, if fatigue was reported as a problem to the oncologist or was identified by the oncologist as a problem, this was likely to lead to treatment decision discussions. Thus, some patients who prioritised cancer treatments over the effects of fatigue may have chosen not to report fatigue as a problem to the doctor to avoid such treatment decision discussions. This section also outlined how oncologists sometimes reduced the chemotherapy treatment within the recommendations for new palliative cancer treatments to patients with fatigue. In addition, during mid-treatment cancer decision discussions, patients with fatigue often played a role in the decision making about whether cancer treatments were adjusted to lessen the impact of fatigue on quality of life. Finally, the worsening of fatigue was linked with oncologists outlining the principle of palliative treatment and occasionally end of life discussions.

4.3.6 Treatments offered for fatigue

In three cases, doctors offered treatments specifically for fatigue and these included: steroid therapy (dexamethasone), prescribed nutritional support and the possibility of a transfusion for borderline anaemia. In a further three cases, doctors offered treatments to improve symptoms that disrupted sleep, hoping to improve fatigue. These treatments included increased loperamide to limit stoma output overnight; analgesics for back pain disrupting sleep and an SSRI for hot flushes.

Examples of how treatments were offered or proposed for fatigue are not presented here but an example can be found in extract 14.2, page 151.

4.3.7 Advice giving for fatigue

In five cases (5/60, 12%), advice giving for fatigue occurred which consisted of: a specified graduated exercise regime in two cases; an explanation on pacing in one case, and; permission to rest or sleep in the day in two cases. Advice giving occurred in response to fatigue being reported as a concern and the advice was sometimes accepted by patients. In another five cases (5/60), the patient reported their coping strategies for fatigue through the adjustment of activity levels and/or the description of pacing. The doctors responded with an endorsement of this self-management and sometimes followed this up with further advice giving.

In the data, there were only two cases with advice giving as a graduated exercise. In one case, the advice giving was resisted and in the other there was alignment. In extract 10, the patient aligns with the advice of exercise for fatigue. The patient had recently completed her scheduled course of palliative chemotherapy and attended for follow up radiological scan to assess treatment response. The doctor had already confirmed the cancer treatment had controlled the disease immediately prior to this extract. The doctor described a graduated exercise regime in the action of advice giving for fatigue.

Extract: 10 ***PAT38: Fatigue NRS = 4; FACIT-F = 41***

```
VO38 – PAT38/DOC03
PT:   I ↑am quite tired I do get weary don’t I
CR:   mm,
PT:   ↑u:::m (.) and I pre↑sume that is the::: (0.6) effect of
      the chemo (.) no:t, (0.4) cancer (0.6) increasing o::r
DR:   ↑↑yep I would say that’s the effect of the chemo
PT:   [mm:
DR:   [and I ↑think the wa:y you’re gonna ↑fight tha:t (0.4) is
      by getting more active
PT:   ↑ye:s
DR:   so::, (0.4) strange[ly enough
PT:                      [see I ↑ca:n overdo i:t, (.) hm
DR:   resting arou:nd (.) so lying around (0.4) [i:::s
PT:                                             [doesn’t
DR:   doesn’t particularly help
PT:   well it’s al↑right I’m not very good at
      [doing that ↑so:: huh
DR:   [so, (.) ↑do you did I say this last ↑↑ti:me? (0.4) half
      an hour of pulse raising exercise three times a week
PT:   ↑oh ↑no you didn’t say that
DR:   okay that’s [the target (0.4) that
PT:               [okay
```

```
22    DR:   that’s what’s been empirically sho↑wn,
23    PT:   okay
24    DR:   to benefit (0.4) chemo related (.) u::m, (0.4) fati::gue
25    PT:   fatigue yeah,
```

30 lines omitted: the doctor goes on to further explain what pulse raising exercise is and makes an enquiry about whether she has a dog

```
26    PT:   [well actually I ↑do: enjoy my swimming (0.4) a:n[d
27    DR:                                                    [yes
28    PT:   of course I’ve missed that having the PICC line and
29          ↑every[thing
30    DR:         [ye::s yeah
31    PT:   so::::,   w- I will get back to that ↑no:w
32    DR:   yes great
```

The patient reported fatigue and outlined a candidate diagnosis in lines 3-4. The doctor confidently confirmed that fatigue was caused by chemotherapy. In lines 7-8, the doctor’s action turned to advice giving with “fight” talk used as a metaphor to overcome fatigue exercise (Byrne et al., 2002). He continued with information giving about how “lying around” doesn’t help fatigue which could seem contrary to common sense. In lines 15-16, there was agreement from the patient as inactivity and resting were dispreferred. In lines 17-18, the doctor specified the exercise advice and inserted reference about whether this was discussed previously. Exercise was qualified as “pulse raising” and an evidence based treatment “empirically shown” to improve fatigue. In line 26, the patient aligned with the advice giving with swimming described as a preference for exercise with an account that she was no longer constrained by the chemotherapy treatment regimen. In line 30, there is explicit agreement with a commitment to exercise and this confirmed alignment. This case showed alignment for the advice of exercise for fatigue. Notably, the patient had completed the course of cancer treatments some weeks previously so fatigue was less likely to worsen further. Moreover, the confident delivery of the advice giving by the oncologist with supporting evidence was accepted by the patient.

In the data, advice giving for fatigue occurred in 12% cases (5/60) in response to the patient reporting fatigue as a concern and sometimes this advice was accepted by the patient. In the example of alignment for advice giving, the trajectory of fatigue was likely to improve as cancer treatments had completed.

4.4 Misalignments in oncologists and patients with clinically relevant fatigue

4.4.1 Misalignment

In the interactions of patients with clinically relevant fatigue (37/60), fatigue-talk was intricately associated and sequentially linked with discussions concerned about: treatment recommendations; the goals of palliative cancer treatment; advice-giving; and end-of-life issues. During these phases of actions and sequences in the dataset, misalignment between patients and doctors recurrently occurred. Misalignment, in this context, could refer to an asymmetry of perspective between the patient and doctor regarding fatigue and its' interrelationship with said actions and sequences (Drew, 2006). Misalignment does not represent overt disagreement or discord in the interaction and talk related to fatigue. In most cases, the doctor and patient maintained social solidarity by constructing their talk so as to minimise disagreement and both parties strived to move towards agreement in the interaction (Silverman, 1996).

Misalignment was observed in the actions of patients and doctors in 10 cases (17%; 10/60). Patients resisted the actions of doctors in several ways:

- treatment recommendations to lessen the burden of fatigue through the adjustment of palliative cancer treatments (n=6)
- advice giving for fatigue (n=3)
- treatment recommendation for new palliative cancer treatment (n=1)

In the data, when patients resisted the recommendations to reduce or withdraw cancer treatments to lessen the burden of fatigue, they usually described the impact of fatigue on quality of life and function as bearable. However, the doctors generally proposed that the impact of fatigue on quality of life and function was becoming more burdensome and/or was interfering with fitness for treatment. In addition, the doctors reflected on the goals of palliative treatment with an emphasis on maintaining quality of life and less about prolonging life. In some cases, patients described their goals of palliative treatment was to prolong life and postpone end-of-life.

Preference organisation in CA involves the distinction of two formats of action and certain actions that occur in response to other actions such as offers, invitations or assessments can be preferred or dispreferred (Heritage, 1984). In everyday talk, rejections of invitations or offers, or disagreements with assessments, are dispreferred responses and can be viewed as problematic to the recipient. The dispreferred status of an action has been identified from CA research and translates to medical interactions. In this dataset, doctors made treatment recommendations to lessen the burden of fatigue through the adjustments of cancer treatments with agreement on the preferred response. However, in many of the cases of misalignment (see Table 4.5), the actions of patients were dispreferred which indicate disagreement or resistance. Doctors used several strategies to gain agreement or minimise disagreement when faced with some resistance from patients.

In medical interactions, treatment recommendations as actions can be classified based on the epistemic and deontic authority that is encoded in their design. Stivers et al. (2016) classified treatment recommendations into five typologies. These definitions were used in the analysis of the data and are defined in Table 4.4.

Table 4.4: Treatment recommendation as actions. (Adapted from Tate, 2018; Stivers et al., 2016)

	Explanation	**Example**
Pronouncement	Doctor asserts recommendation as instigator, decision maker and presents as already determined	“I’ll start you on X”
Suggestion	Doctor recommends as instigator but treats patient as decision maker and chemo as optional.	“You could try X”
Proposal	Doctor recommends as instigator but decision making is treated as shared by doctor and patient. Proposals highlight the recommendation as speculative.	“Let’s try X and see how that goes”
Offer	Patient is treated as instigator of recommendation and as the decision maker, thus treating chemo as having been occasioned.	“Would you like me to give you X”
Assertion	Doctor asserts a generalisation about chemo’s benefit implying a recommendation but not proffering an overt directive.	“X is good for this”

*chemo = chemotherapy

In the dataset, treatment recommendations for the adjustment of cancer treatments to lessen the burden of fatigue were most often formulated as proposals, which were instigated by the doctor and promoted the decision to be made jointly by the patient and doctor. Pronouncements and suggestions were less frequent. In the cases of misalignment, when resistance occurred, doctors pursued agreement by modifying or reformulating their treatment recommendations, to stronger or weaker forms within the same formulation or, changed to a different formulation. Other strategies were used such as personalising the treatment recommendation or using external factors to broaden the agency of the decision making so that it did not rest solely on the doctor. The actions of doctors to gain agreement and minimise disagreement in the cases of misalignment will be described and highlighted in the analysis.

In the paragraphs that follow, I describe two distinct contexts of misalignment in discussions that concern fatigue and relate to the following:

- treatments recommendations to lessen the burden of fatigue through adjustments in cancer treatments
- advice-giving for fatigue

4.4.2 Misalignment in treatment recommendations to lessen burden of fatigue

In the data, there were six (6/60) cases of patients resisting recommendations to reduce or withdraw cancer treatments with the stated aim by the oncologist of lessening the burden of fatigue. These cases are listed in Table 4.5. In every case, the patient reported that the level of fatigue experienced and the impact it had on quality of life was acceptable. Similarly, in every case the doctor proposed that fatigue was becoming too burdensome on quality of life and functional ability. The doctors usually reflected on the goals of palliative chemotherapy and stated quality of life needed to be maintained while receiving treatment and avoid the consequence of severe disabling fatigue. In some cases, patients stated their goals of palliative treatment was to continue living and postpone death for as long as possible.

This section will describe three separate examples of misalignment in the data. The treatment recommendations to lessen the burden of fatigue consisted of: altering the treatment schedule, reducing the dose and the withdrawal of treatment. When resistance occurred, doctors used many strategies with the aim of gaining agreement or alignment with their treatment recommendations. These strategies will be described and highlighted including the outcomes of the treatment decisions.

Table 4.5: Cases of resistance observed to treatment recommendations and outcomes

	Resistance observed	Outcome
PAT03 *F-NRS 4* *FACIT-F 27* ***DOC01***	The patient resisted to: • to stop chemo • to stop chemo after 2 more cycles	A short pause in chemo* was agreed
PAT04 *F-NRS 8.5* *FACIT-F 16* ***DOC03***	The patient resisted: • to reduce chemo • treatment holiday	A short pause in chemo was agreed
PAT07 *F-NRS 5* *FACIT-F 45* ***DOC04***	The patient resisted: • to reduce chemo	The patient agreed to reduce the dose of chemotherapy drugs
PAT39 *F-NRS 5* *FACIT-F 25* ***DOC09***	The patient resisted: • to reduce chemo	The patient agreed to reduce the dose of chemotherapy drugs
PAT45 *F-NRS 5* *FACIT-F 25* ***DOC10***	The patient resisted: • omission of chemo treatments	Treatments continued as scheduled
PAT48 *F-NRS 7* *FACIT-F 3* ***DOC10***	The patient resisted: • withdrawal of chemo	Agreement to stop chemotherapy and continue with hormonal treatment

**chemotherapy was abbreviated to chemo*

In the first case of misalignment, resistance was noted as the doctor suggested fatigue was becoming more burdensome and proposed the adjustment of the scheduling of cancer treatments to compensate for this. The case related a 76 year old lady with advanced breast cancer who attended her oncologist accompanied by her husband. She was receiving palliative chemotherapy (chemo session every week for 3 weeks and then 1 week break = 1 cycle) and had recently completed radiological investigations to assess the treatment response. The consultation commenced with the doctor introducing good news as restaging scans after 3 cycles of chemotherapy confirmed a reduction in liver disease (Maynard & Frankel, 2006). In the problem presentation, the patient reported constant fatigue which was associated with actions of acceptance and the doctor gave permission to rest (see extract 1 for beginning of case). In this extract (11.1), the doctor attempted to revise the patient and patient companion’s expectation about completing another 3 cycles of chemotherapy. The doctor provided information about: forecasting worsening fatigue; best response with treatment was in first few cycles; revising treatment was normal practice; and alternative treatment options that might cause less fatigue. The doctor used these strategies to gain agreement with her treatment recommendation to alter the treatment schedule.

Extract: 11.1 ***PAT45: Fatigue NRS = 5; FACIT-F = 25***

VO45 – PAT45/DOC10 (lines 4-83)

4 CAR: we’re just ha:lf the way throu:gh aren’t we .hh e:::r,
5 DOC: .hhh [yea::h
6 CAR: [the initial (eightee:n)
7 DOC: ↑↑so::::, (0.8) what ↑tends to happen with chemotherapy
8 >is you< get the ↑best response early o::n (.) .hh and
9 then as ↑time goes o:::n (.) you: (.) you ge:t (.) a ↑bit
10 less response but people get (.) more tired (0.4) .hhhh
11 a:nd, (0.4) run into more problems from it
12 CAR: ↑mm::.
13 DOC: ↑so:::, (0.4) er you ↑had a great res↑po:nse, (0.4) I
14 would very much like to continue with your fourth cyc↑le
15 (0.4) if that’s [al↑ri::ght?
16 PAT: [°↑mm°
17 PAT: ↑↑mm::↓:: (0.4) su:re
18 DOC: we should see you agai:n (0.4) in a month’s ti:↑me (0.4)
19 and depending on how you a::re (0.6) decide whether to go
20 o:n (0.4) to a (0.4) a fifth cyc↑↑le (0.4) and likewise a
21 sixth cycle [↑I would say it i:s (0.4) pretty unusual=
22 CAR: [mm:::
23 DOC: =(0.4) for me to give more than sixtee::n (1.0) dollops
24 of chemo:: and [you’ve ha:d
25 CAR: [oh ri:ght
26 PAT: oka[y

DOC: [ni:↑:ne (0.4) .hh u:::m, (0.4) er >th- [the the<=
CAR: [mm::
DOC: =↑↑absolute maximum anyone would twist ↑my arm to is the
eighteen that's ↑on the:re (0.4) .hhh I quite often stop
between twelve and sixtee:n
CAR: ri:ght
DOC: ↑s[o::: >i- it< depends how you're ↑↑fee:li::ng, (0.4)=
PAT: [oka::y
DOC: .hhh how it's goi:ng, (1.8) >you know< ↑and how you a::re
PAT: ↑o::h ↑could you pick it up agai::n at some point in the
futu::re if
DOC: ↑↑↑probably ↑↑try ↑something ↑else there are lots of
[different ↑treatments so:::, (.) it's not that one=
PAT: [oka::y, (.) ↑ri:ght
DOC: =couldn:'t it's just that there are usually
PAT: °okay°
DOC: newe:r (0.4) b- [better different optio:ns
PAT: [↑ri:ght (.) ye:s
PAT: yeah
DOC: .hhhh um (.) so:::: (.) it's im↑portant that we don't (.)
wea:r you out so ↑mu:ch
PAT: .hhh hhh huh
DOC: tha[:t (0.6) that [you really you know that (.) so it=
CAR: [mm::
PAT: [ye:s
DOC: =↑↑it's ↑↑getting the balance ri:ght and ↑we just need to
decide that between us (0.4) .hhh as time goes o::n (0.6)
.hhhhhh (0.8) al↑though it's scheduled fo::r, (0.8) week
one week two week three (0.4) week o::ff (0.6) I'm ↑very
easy about tha:t ↑so:::, (0.4) if ↑you ↑have something
nice that you want a bit more ene[rgy fo::r
CAR: [mm
CAR: °mm:::°
DOC: have a (.) have a week off (0.6) and pick [it up agai:n=
PAT: [↑oka::y
DOC: =(0.4) a:fterwards >you know< as long as the nurses (0.6)
>sort it out< and know when you're coming (0.4) .hhh I
02:00 DOC: do:n't (0.4) ↑I don't [mind if you go: (0.4) week ↑o:n=

65 CAR: [(°yea:h°
66 DOC: =week o:n (0.4) week off (0.4) week o:::n
67 PAT: .tch oka::y [that's interesting (↑fact)

8 lines omitted: husband enquires if the breaks in treatment are to help the immune system

68 DOC: a::nd, (0.6) .hhh (.) the chemotherapy's about ↑↑treating
69 the breast cancer which it's doing really we:ll (0.6) but
70 it's also (.) ↑got to be tolerab:le and give you good
71 quality of life
72 PAT: okay
73 DOC: while you are on i**t** .hhh a::nd, (0.6) par↑ticularly in
74 ↑this, (0.4) second ↑ha::lf of the ↑chemo::, (0.4) .hh if
75 you ↑need the odd extra week o:ff

Following a clarification question about the treatment schedule by the patient's husband, the doctor responded by giving information about the effectiveness of chemotherapy "best response early on" and forecasted worsening fatigue with "a bit less response" in lines 8-10. In lines 13-15, the doctor gave a personalised treatment recommendation to continue treatment and this was accepted. The doctor foreshadowed the fifth and sixth cycles would not be a given in lines 20-21. And attempted to revise down the treatment schedule to alter expectations 'quite often stop between 12 and 16 dollops'. The treatment schedule was qualified to the patient as it 'depends how you're feeling'. In line 36, the patient indirectly asked about future treatment options which indicated a preference for treatment. The doctor proposed that more treatment options existed with an upgrade 'newer better different options'. In line 46, the doctor used a term for fatigue 'it's important that we don't wear you out so much' and this was a strategy to gain shared agreement for the treatment recommendation. In lines 52-53, fatigue was a proxy for quality of life with the emphasis on 'getting the balance right' for the continuation of treatment and a collaborative treatment decision process was explicitly referred to 'decide that between us'. In lines 55-57, the doctor suggested altering the schedule was acceptable to her for quality of life reasons, to have 'a bit more energy' for quality of life purposes and this supported patient autonomy. In lines 70-71, the goals of treatment were explained and qualified 'got to be tolerable' with 'good quality of life'. In the sequences that followed, the doctor introduced age as reason to adjust the treatment schedule.

In **Extract 11.2**, the doctor highlighted the positives of alternative treatment options potentially causing less fatigue.

Extract: 11.2 ***PAT45: Fatigue NRS = 5; FACIT-F = 25***

VO45 – PAT45/DOC10 (lines 142-155)

```
142   DOC:  u::m and actually we could always go ↑back to the most
143         important drug ↑in the (↑FE:C) (0.4) .hhh and give that
144         week↑ly,
145         (0.6)
146   PAT:  [ok[ay
147   DOC:  [u:[::m and there a:re (.) you know there are (.) ↑lots
148         of other
149   CAR:     [mm::
150   PAT:  ↑that's interesting
151   DOC:  goo:d
152   PAT:  hm ↑mm,
153   DOC:  but, (.) ↑le:ss (0.6) rug from under the ↑feet, (0.4)
154         options for you:
155   PAT:  o↑kay
```

A proposal was outlined and followed by 'lots of other' options. In line 150, the patient revealed an understanding and agreement 'that's interesting'. The proposal was strengthened further with 'less rug from under the feet' a term for treatments that cause less fatigue in lines 153-154. (This description for fatigue also links back to line 47). In the sequences that followed a proposal with hormonal treatment options was explained and hormonal treatments cause less cancer treatment related fatigue in comparison to chemotherapy. In **Extract 11.3**, the patient resists the treatment recommendation to lessen the burden of fatigue by altering the treatment schedule because she states that fatigue is tolerable in 195. Misalignment occurred as the patient pushed back against the doctor's treatment recommendation. The doctor orientated to fatigue becoming intolerable with a detrimental impact on quality of life and the patient orientated to fatigue being tolerable with quality of life maintained.

Extract: 11.3 ***PAT45: Fatigue NRS = 5; FACIT-F = 25***

VO45 – PAT45/DOC10 (lines 179-222)

```
179   DOC:  it's done we:ll (0.6) your liver's working (0.4)
180         brilliantly (0.6) we know it's working in you (0.8) .hhh
181         think we should continue:: (0.4) but I would
182         [↑like it to be:::: (0.6) thoroughly tolerable (0.6)=
```

```
183    PAT:  [↑mm (.) that’s fi::ne
184    DOC:  =.hh hh not [↑only in terms of blood tests but also in=
185    PAT:              [↑OH YE::S
186    DOC:  =terms of [your energy levels (.) .hhh u:::m (0.4) a::nd=
187    PAT:            [↑mm::
188    DOC:  =[so::, (0.6) i- if it ↑works that you (2.0)=
189    CAR:   [mm::
190    DOC:  =go:: (0.6) week one week two week ↑↑off week one week
191          week two week ↑↑off that’s fi:ne by ↑me:: it ↑really i:s
192          (0.4) whateve::r,
193    PAT:  ↑mm ↓mm: (0.8) ↑well at the ↑↑mome:nt (0.4) ↑i:t’s
194    DOC:  ↑↑brilliant
195    PAT:  ↑quite tolerable (0.6) [ye:s
```

17 lines omitted: the doctor orientates to the quality of life agenda by suggesting they may wish to celebrate her 75th birthday with a family party or go away for a weekend

```
196    DOC:  ↑I’m, very happy for you to::, (0.6) jiggle with [the=
197    CAR:                                                  [°ye:s°
198    DOC:  =[chemotherapy a bit
199    PAT:   [↑oka:y
200          (1.0)
201    DOC:  .hhhh (0.8) >cos it’s< (0.6) °you know° (0.4) .hhh
202    CAR:  ↑we::,
203    DOC:  I ↑can’t do much about the fati::gue (0.6) other tha::n,
204    PAT:  no:: [↑I ↑mea:n
205    DOC:       [top you up with blood if you become very a↑naemic
```

The actions of the doctor in this extract were building towards strengthening a treatment recommendation to alter the treatment schedule and it begins with a proposal in 179-181. The doctor summarised the rationale to support the treatment recommendation with a qualification ‘thoroughly tolerable’ in 182. There was explicit agreement from the patient in line 185. Fatigue was referenced to tolerability with chemo in line 186 with ‘energy levels’. The treatment recommendation was then designed to support more patient autonomy ‘if it works that you’ with encouragement to alter the schedule and the patient had more agency over the decision making in 190-192. In line 193, the patient pushed back with a pause followed by a disagreement (Pomerantz, 1984). The patient mirrored the language of the doctor ‘quite tolerable’. In the sequences that followed, the doctor used an idiom which had the effect of minimising the disagreement and the husband aligned with his wife (Drew &

Holt, 1995). The doctor pursued the quality of life agenda and personalised the treatment recommendation by alluding to the patient's impending 75th birthday but the patient passively accepted in line 199. A significant pause of 1 second followed and the doctor made a general statement about the lack of treatments for fatigue.

In this example, the doctor failed to gain agreement or alignment with the treatment recommendation to adjust the treatment schedule. The treatment recommendation was modified and eventually designed as a personal volition and the patient declined as she perceived fatigue was tolerable. The doctor used several strategies to gain agreement and these actions included:

- Information giving – forecasted worsening fatigue with treatment (lines 10-11)
- Information giving – best response to treatment was in first few cycles (lines 7-8)
- Information giving - revised the treatment schedule by explaining usual practice (lines 18-31)
- Information giving - chemotherapy was more difficult in older age
- Offering future and alternative cancer treatments that caused less fatigue (lines 38-39; lines 153-154)
- Giving permission to alter treatment schedule with autonomous decision making (lines 55-57; lines 62-64; lines 73-75; lines 190-192)
- Personalising the treatment proposal to quality of life and important life events (lines 13-15; lines 195-196)
- Information giving – there are few treatments for fatigue (lines 203-205)

To summarise, this case has shown that patients with clinically relevant fatigue can resist treatment recommendations to lessen the burden of fatigue. In this instance, the doctor forecasted fatigue to worsen and suggested fatigue was becoming more burdensome with a detrimental impact to quality of life. However, the patient deemed that fatigue was bearable and her quality of life was manageable. Fatigue was not deemed by the doctor to interfere with fitness for treatment and quality of life may have therefore been in the patient's remit. The treatment recommendation formulations that were used promoted patient choice and hence the patient chose to continue with treatments unaltered. In this instance, the strategies that were used to strengthen the treatment recommendation were not successful.

The second example of misalignment differed from the first example, by the way the doctor reformulated the initial treatment recommendation from proposal to a pronouncement when resistance occurred. Therefore, the patient no longer participated in the decision making process and the cancer treatments were reduced to lessen the burden of fatigue. The case concerned a 73 years old man with advanced oesophageal cancer who had completed 4 cycles of chemotherapy and was accompanied by his wife. In the problem presentation, the patient reported nausea and constipation which were addressed by the doctor with a treatment recommendation for an antiemetic and laxative. In the assessment of fatigue the patient described his energy levels as 'very low' and concurred that he was 'sitting around most of the day' (see extract 8). In **extract 12.1**, the doctor described the time gained in survival with chemotherapy including the time while having treatment and therefore quality of life should be maintained. The doctor associated disabling fatigue with poor quality of life and this strategy was utilised to gain agreement for a treatment recommendation to reduce chemotherapy.

Extract: 12.1 ***PAT39: Fatigue NRS = 5; FACIT-F = 25***

VO39 – PAT39/DOC09 (lines 49-81)

49 DOC: ↑we:::ll, (0.4) >so there's< no questio:n (0.6) that
50 (0.4) what you're fee::ling (0.6) is the side effects of
51 the chemo↑therapy:: (0.4) rather tha:n (0.6) the cancer
52 causing the tiredne:ss (0.6) and the bowel problems and
53 thi:ngs (0.6) >now the< ↑question for u::s, (.) really
54 i::s (0.4) .hh >you know< are you ↑happy to con↑tinue
55 because the tiredness will get ↑wo::rse (0.6) .hhh
56 a::::nd, (0.6) I ↑would say to you:: that (0.6) ↑what,
57 (0.4) the ti::me that we're trying to buy for you:: (0.8)
58 in↑cludes the ti:me that you're on ↑treatme:nt (0.4) so
59 it's not about having the treatme:nt (0.4) being stuck in
60 the house not being able to do anything and then having a
61 li:fe ↑↑afterwa:rds it's ↑all about no:::w, (0.4) .hhhhh
62 a::nd so the ↑real question >is is whether< we: er (.) r-
63 reduce the dru:g (.) do:se of the ↑other two drugs (0.6)
64 .tch to ↑see: if >we can< keep make it a bit mo:re of a
65 bea:rable experience >because I think< ↑after this n↑ext

66 lo::t (0.4) .hhhh of ↑treatme:nt I:: would be worrie:d
67 (0.4) that you might end up >just doing< nothing at a:ll
68 (1.6)
69 PAT: .hhh [I have only got two to go
70 DOC: [and the fati::gue
71 12:30 (2.0)
72 PAT: [.hhh e:::r
73 DOC: [>but it< ↑will hit you:: (.) I’ve seen it happen so:
74 many times in situations like this whe:re .hhhh (0.4)
75 >you know< how old are you sixty eight plus e::r
76 [f- seventy tw- yea::h
77 PAT: [seventy ↑thr- seventy three
78 DOC: so you kno:::w (.) >↑i- it< is asking a lot of you at
79 you're a::ge >to be able to< get through these (.)
80 treatments completely and also at the fu:ll (.) dose:s
81 (0.6) .hhh u::::m and you a::re (0.4) I think quite
82 ↑sensi↑tive to this (.) to this ↑tablet chemotherapy::
83 (0.6) because it’s causi:ng (.) a lot m[ore proble:ms
84 PAT: [I I ↑am still
85 getting the tingle::s (0.4) ↑not s- (.) not a lot now

In lines 49-53, a definitive diagnostic explanation for fatigue was given by the doctor. A proposal was then constructed collaboratively that was personalised “are you happy to continue” in line 54. An explanation followed with a caution that fatigue would worsen with treatment. The goals of palliative treatment were explicitly outlined with extending life balanced with maintaining quality of life. Fatigue with a detrimental impact on quality of life was constructed by the narrative “being stuck in the house not being able to do anything”. There was an emphasis on living in the present rather than postponing for a future life. In lines 64-65, a proposal was formulated to make fatigue more tolerable “a bit more of a bearable experience”. A concern was introduced to build the case and strengthen the treatment proposal, worsening fatigue was anticipated ‘just doing nothing at all’. In line 68, there followed a significant pause of 1.6 seconds which was the first indication of a disagreement and the patient indirectly pushed back ‘only got two to go’ (Pomerantz, 1984). This revealed misalignment on the perceived tolerability of fatigue and goals of treatment. The doctor used her epistemic authority from clinical experience to repeat fatigue would worsen: ‘hit you’. In line 75, the doctor introduced another persuasive strategy to gain agreement with her treatment recommendation by explaining age is a factor to reduce chemotherapy. In lines 79-81, The doctor pursued persuasion by explaining the treatment caused more problems besides fatigue. In the sequence that followed, the patient reported peripheral neuropathy as a problem and the doctor explained this would also worsen on treatment. In **extract 12.2**, the treatment recommendation was reformulated and it becomes clear the doctor was not seeking alignment but informed concurrence.

Extract: 12.2 ***PAT39: Fatigue NRS = 5; FACIT-F = 25***

VO39 – PAT39/DOC09 (lines 96-132)

96 DOC: ↑so::: (.) ↑↑u::::m, (0.6) ↑I'd ↑I ↑↑personally:: fee:::l
97 (0.4) that you're probably better just to reduce the::
98 (0.6) the doses of the other two intre↑venous drugs not
99 the tablet o::ne, (0.4) so that everything is a::t (.) a
100 slightly lowe::r (1.0) do::se to get you through the
101 ne:xt
102 PAT: ↑okay
103 DOC: next period of ↑ti:me
104 PAT: ↑we::ll (.) I can only be guided by you on that
105 [I can't sa:y
106 DOC: [yea::h
107 (0.6)
108 DOC: .hhh ↑some of the tiredness is partly becau::se (1.0) the
109 chemotherapy's probably affecting you:::r (0.6) blood
110 counts (0.4) quite a lo::t (0.6) >it will be<
111 ↑interesting to see:: whether you go ahead next week
112 (0.6) [because it could be a-
113 PAT: [I su- um,
114 PAT: I've booked m- (0.6) monday I've got a blood [test
115 DOC: [yea::h
116 (0.4) .hh and and I (.) I h- I ↑have found that people
117 >who are starting to get< more tired on chemo↑therapy::
118 (0.6) .hhh it's partly becau::se (0.4) the white cell
119 count has been affected mo::::re (.) on the chemo .hhhh
120 (.) and quite ofte::n when they come up to the next
121 ↑cycle (0.4) th- the body hasn't quite re↑cove:red (0.4)
122 so ↑I I I: ↑wo::nder whether that's what's happening
123 no::w
124 PAT: ↑i-

```
125    DOC:   and then we automatically have to reduce the dose
126           ↑anywa::y,
127    PAT:  ↑ye[s
128    DOC:     [yea:h
129           (0.4)
130    PAT:  ↑will it still go ahead if it’s, (0.4) [i-
```

In lines 96-100, the doctor deployed more agency and was more authoritative in the reformulated treatment recommendation and adjustments mitigated “slightly lower dose”. In line 104, the patient gave a dispreferred response with a well prefaced statement. He shifted the agency of the decision-making to the doctor and away from himself “I can’t say”. The doctor introduced neutropenia as a diagnostic explanation for fatigue and raised uncertainty about the next cycle proceeding as planned. She then switched from wider clinical experience back to the patient and forecasted neutropenia. In lines 125-126, the decision was conveyed as non-negotiable and definitive “we automatically have to reduce”. Therefore, the decision changed from a collaborative one with patient participation to a decision that was decided solely by the doctor (i.e. a pronouncement). In line 130, the patient’s response was relevant but not what was expected and could be interpreted as indirectly pushing back.

In this example, the doctor gained agreement with the treatment recommendation through informed concurrence and not alignment. The treatment recommendation was initially designed as a proposal with patient participation in the decision making but was modified when resistance occurred to a non-negotiable decision or pronouncement. The doctor used several strategies to gain agreement and these actions included:

- Information giving – forecasting worsening fatigue on treatment (line 55, lines 73-75)
- Information giving – the potential survival benefit from cancer treatments includes (75-the time on treatment and not a future time once treatments are completed (lines 57-60)
- Information giving - chemotherapy is more difficult in older age (lines 75-80)
- Information giving – forecasting worsening peripheral neuropathy (lines 78-79)
- Treatment recommendation with more agency (lines 96-97)
- Treatment decision changes from choice to non-negotiable (lines 125-126)

To recap, this example of misalignment differed from the previous example because when resistance occurred the doctor deployed more agency and was more authoritative in reformulated treatment recommendations to alter cancer treatments to lessen the burden of fatigue. Similar persuasive strategies were used to gain agreement but the reformulation of treatment recommendations to limit patient participation in the decision making process meant the cancer treatments were reduced. This may have implications for clinical practice as doctors may find this useful should they encounter resistance from patients.

The third and final example of misalignment for treatment recommendations occurred when chemotherapy treatments were withdrawn because the patient was no longer fit enough for palliative cancer treatments and end of life was imminent. The example differed from the previous ones because the doctor had to deploy stronger and stronger pronouncements in the face of recurrent resistance to the withdrawal of cancer treatments. The case concerned a 67-year-old woman with advanced metastatic breast cancer who had become less well over the preceding 4 weeks following the commencement of oral palliative chemotherapy. She lived alone and attended the clinic by herself with the assistance of hospital transport. The ethnographic observations were important to note: the outpatient staff were concerned when she reported feeling weak in the waiting room and helped her to lay down on an outpatient consulting bed. In the problem presentation, she reported severe disabling fatigue and this was also evidenced on fatigue on questionnaires. The doctor's strategy was clearly observed in the data: withdraw chemotherapy because the patient was not fit enough for treatment and once agreement gained then progress to address end of life issues. The patient wished for the continuation of chemotherapy and repeatedly delayed the progression of the conversation towards end of life issues. In **extract 13.1**, misalignment occurred as the patient outlined a preference to continue with treatment despite the worsening of disabling fatigue and the doctor pushed back against this.

Extract: 13.1 ***PAT48: Fatigue NRS = 9; FACIT-F = 3***

VO48 – PAT48/DOC10 (lines 4-18)

```
4     DOC:  and then we:'ll,(0.6) come to a pla:::n about what we
5           do:: (0.6) .hhhh [↑um hhhh
6     PAT:                   [↑well, (0.6) I'm pre↑pared to try:::
7           (0.6) the::, (0.6) capceta::n (0.6) at the lower do:se
8           (0.4) agai::n, (0.6) .hhhh ↑u::::m, (0.6) it puts me i:n
```

9 (.) bed for a ↑wee:k (.) ↑so ↑be ↑i::t, (0.8) ↑u:::m,
10 (0.6) w- you know (.) just curiosity see whether that
11 lower dose of twe:lve,
12 DOC: mm::,
13 PAT: ↑twelve ↑hundred ↑would ↑e::r, (0.6) ↑↑would ↑↑do ↑↑it,
14 (0.6) with↑out upsetting me, (0.6) but I don’t know how
15 you feel about that
16 (0.8)
17 DOC: we::ll, (0.8) [thank you::
18 NUR: [I have ↑all my equip↑me:n**t**, [hh ↑hu::

In line 4, the doctor explained a proposal would occur after the gathering of clinical information (e.g. temperature, pulse, blood pressure and oxygen saturations). The patient outlined a preference to continue with chemotherapy and stated the consequences of worsening fatigue were acceptable “puts me in bed for a week so be it”. In line 17, a well prefaced response indicated a disagreement which became fully apparent in **extract 13.2** with the explanation that fatigue precluded the offer of chemotherapy.

Extract: 13.2 ***PAT48: Fatigue NRS = 9; FACIT-F = 3***

VO48 - PAT48/DOC10 (lines 53-64)

53 DOC: (0.6) ↑giving ↑you ↑treatment (.) that knocks you do:wn
54 so that you are, (0.6) ↑↑you ↑↑know hh (.) managi:ng, (.)
55 bu:t,
56 PAT: o::h
57 DOC: but resting a bit more is ↑reasonable
58 PAT: mm
59 (0.8)
60 DOC: .hhhh ↑if actually:: (.) you’re really resting all the
61 ti::me
62 PAT: °mm°
63 (0.8)
64 02:00 DOC: then knocking you down further is going to mean that (.)
65 you a:re absolutely ↑bed ↑bou:nd (0.4) .hhh and ↑that’s
66 ↑no- (0.4) ↑that’s just not a safe thing to do::
67 PAT: ↑no::
68 DOC: so:: (0.4) ↑I don’t think at the mom↑e::nt, (0.6) that
69 <you:: a:::re> (0.4) ↑well enou:::gh, (0.4) to (.) to
70 treat with chemotherapy

```
71        PAT:  °mm°
```

A step wise agreement in the interaction to stopping chemotherapy and exploring end of life issues began in line 53. The doctor explained worsening fatigue with treatment ‘knocks you down’ and described acceptable levels of fatigue ‘resting a bit more’. This was contrasted with the patient’s fatigue ‘resting all the time’ and further treatment would cause disabling fatigue ‘absolutely bedbound’. The doctor exerted epistemic authority by stating further treatment was ‘just not a safe thing to do’ with a qualification ‘at the moment’. In the sequences that followed, diagnostic uncertainty for the causes of fatigue was introduced and clinical information was used to support the treatment recommendation to withdraw chemotherapy which were designed as weak pronouncements. In **extract 13.3**, the doctor pursued an agreement to withdraw chemotherapy with stronger pronouncements and then moved on to the next step, proposed that fatigue was caused by cancer.

Extract: 13.3 ***PAT48: Fatigue NRS = 9; FACIT-F = 3***

VO48 – PAT48/DOC10 (lines 228-282)

```
228       PAT:  that might account for why I’m feeling particularly
229             ↑li:mp this morning,
230             (1.6)
231       DOC:  .hh ↑er at the moment you’re not fit fo:r (.0 for
232             chemothera[py
233       PAT:            [↑no I realise [that
234       DOC:                           [>that that< would (0.6) just be
235             dangerou:s
236       PAT:  mm
237             (1.4)
238       DOC:  and I ↑gue:::ss, (0.6) my con↑ce::rn, (0.6) is tha:t
239             (0.6) is whether you wi:ll (0.6) ↑get to be fit for
240             chemotherapy
241       PAT:  whether I will ge-
242       DOC:  whether you wi:::ll, (0.6) re↑cover
243       PAT:  yeah
244       DOC:  from thi:s
245       PAT:  to have it
246       DOC:  to have chemotherapy or ↑whether (0.8) this is ↑mo:re the
247             disea::se
248       PAT:  mm
```

```
249   DOC:  taking ↑ho:::ld,
250   PAT:  yes
251   DOC:  and whether you may not get (.) fit for [more treatment
252   PAT:                                          [mm:::
253   DOC:  I'm ↑not saying that we should (.) stop the exemes↑ta::ne
254         I think [↑tha:t
255   PAT:          [↑no:
256   DOC:  you know
257   PAT:  helps ,
```

The patient postulated a chest infection as the cause for fatigue and a significant pause of 1.6 seconds occurred before the doctor repeated the treatment recommendation as strong pronouncement in lines 231-235. There was implied acceptance by the patient with some overlap in talk before the concern of safety was upgraded "dangerous". The treatment recommendation was then qualified more pessimistically "you may not get fit" and the doctor orientates to a diagnostic explanation for fatigue "more the disease taking hold". In lines 253-254, the doctor used a strategy to gain agreement: continue with some cancer treatment but stop chemotherapy. This case has shown that the doctor was obliged to use a stronger form of pronouncement when severe recurrent resistance was encountered. The patient was unconcerned about disabling fatigue and that chemotherapy was not safe and continued to pursue chemotherapy. Notably, despite the resistance observed, agreement and the therapeutic relationship was maintained through the use of strategies to maintain hope – by continuing on some cancer treatment.

In summary, this example revealed misalignment with the doctor orientated to the end of life care agenda and the patient resisting to pursue the treatment or survival agenda. Fatigue was integral throughout the sequences and the step wise progression in actions to address end of life issues. The doctor modified the treatment recommendation so the patient had no choice and the outcome was agreement to stop chemotherapy, and prepare for disabling fatigue at the end of life with more care and support.

- Treatment proposal - (lines 4-5)
- Information giving - chemotherapy not safe (lines 64 – 68)
- Weak Pronouncement – not strong enough for treatment (lines 68-70)
- Strong pronouncement – chemotherapy dangerous (lines 231-235)
- Persuasion strategy – continue with hormonal therapy (lines 253-254)

This section has shown that resistance to treatment recommendations for the adjustment of palliative cancer treatments to lessen the burden of fatigue occurred in routine palliative oncology visits. Importantly, the findings have described that when resistance occurred and patient choice was continually promoted, then the outcome was the continuation of treatment unchanged. Thus, doctors needed to take more responsibility in the decision-making process and exert more authority in their treatment recommendations when resistance was recurrent and cancer treatments needed to be reduced or withdrawn because of fatigue interfering with fitness for treatment.

4.4.3 Misalignment in advice giving for fatigue

There were several examples in the dataset of advice giving for fatigue and this was mostly concerned with resting, pacing or exercise to help manage fatigue. Misalignment occurred in three separate interactions with advice giving for fatigue but in one instance a change in strategy by the doctor resulted in alignment (see Table 4.6). The three examples of resistance all occurred with in patients where fatigue was constant and the trajectory of fatigue was expected to worsen. Only one example will be highlighted in this section: misalignment in advice giving and alignment with treatment recommendation.

Table 4.6: Cases of resistance observed to advice giving for fatigue

	Advice giving for fatigue	**Resistance observed**
PAT09 *F-NRS 5.5* *FACIT-F 32* ***DOC06***	The doctor advised to increase activity for fatigue but the patient suggested diminishing ability to perform tasks on treatment	- Passive resistance
PAT26 *F-NRS 7* *FACIT-F 16* ***DOC06***	The patient reported fatigue as a concern and the doctor advised exercise. However, the advice did not address the concern.	- Passive resistance
PAT33 *F-NRS 8.5* *FACIT-F 0* ***DOC06***	The patient reported severe disabling fatigue. The doctor advised practical strategies which were rejected. Treatment recommendation for steroids was agreed.	- Active resistance

This **example** concerned a 71 years old man with metastatic lung cancer who received palliative radiotherapy and was on surveillance. He attended the consultation with his nephew and saw his usual Consultant. He reported fatigue in the problem presentation (see extract 3) and reported severe disabling fatigue on fatigue questionnaires. In this **extract 14.1**, misalignment occurred as the doctor recommended practical strategies to help manage fatigue and the patient rejected this advice giving. The doctor then changed tack and formulated a treatment recommendation with a drug therapeutic option.

Extract: 14.1 ***PAT33: Fatigue NRS = 8.5; FACIT-F = 0***

```
VO33 – PAT33/DOC06 (lines 60-83)
60    DR:   .hhhh one of the things there is to try and take things
61          i:n (0.6) >you know< a burst of activity and then a rest
62          burst of activity,
63    PT:   mm:
64    DR:   but it, (.) doe:s (0.4) ↑often you do have to tailor what
65          you do:: (0.4) around ↑what your energy levels a:re,
66    PT:   yeah
67    DR:   I’m a↑fraid it is a question of adapting [to the:] (.)=
68    PT:                                            [yeah,  ]
69    DR:   =>you know the am[ount] of energy [that’s] there .hhh
70    PT:                    [yeah]           [yeah, ]
71    PT:   and I mean I (↑take it) there’s nothing that can be ↑done
72          to alleviate #tha::t#
73    DR:   w- we’ll have a look through the tablets, because
74          some↑ti::mes, (0.4) changing steroids and things like
75          that can make a differe:nce
```

In line 60, the doctor commenced the action of advice giving and outlined pacing to help manage fatigue. In line 67, he conveyed energy levels would not improve “I’m afraid” and the patient needed to adapt to “the amount of energy that’s there”. In line 71, the patient responded with a push back and this indicated he did not see it as advice or a helpful treatment for fatigue. The response is formulated as a disclaimer which are often done to be corrected, meaning he hoped that fatigue could be alleviated (Sacks, 1987). The doctor changed tack and formulated a treatment recommendation by suggesting a change in drug therapy “can make a difference”. The interaction progressed with the assessment of other symptoms and investigations (chest X-ray and bloods tests) were reviewed. In **extract 14.2**, alignment occurred following a treatment recommendation of steroids for fatigue.

Extract: 14.2 ***PAT33: Fatigue NRS = 8.5; FACIT-F = 0***

VO33 – PAT33/DOC06 (lines 7-31)

1 DOC: ↑tiredness is quite a difficult one I’m afraid becau:se
2 u:::m, (0.6) there ↑isn’t a single tablet that will >sort
3 of< get rid of it (0.4) .hhh (1.0) people have looked at
4 things like stimula::nts, (0.6) >you know< to see if that
5 does he:lp but (.) ↑they ↑they haven’t really been of
6 bene[fi:t
7 PAT: [↑no: no
8 DOC: but ↑one ↑of ↑the ↑things we ↑do: find sometimes >is
9 that< if (.) the prednisolo:ne he::lped (0.6) which it
10 did originally
11 PAT: mm
12 DOC: sometimes a slightly more potent steroid called
13 dexamethaso::ne (0.4) can be a bit more effective
14 PAT: ↑oh ↑ri:ght
15 DOC: and I think it’s ↑worth trying tha::t (.) instead of the
16 prednisolo:ne (0.6) .hhh and see if that actually helps
17 with your appetite a bit [and with the::
18 PAT: [oka::y
19 DOC: .hhh it vir- (0.4) virtually always goes together so the
20 ↑tiredness and the poor appetite
21 PAT: °yeah°
22 DOC: they virtually always go together
23 PAT: yeah
24 DOC: a:::nd er
25 PAT: ↑well ↑↑that’s ↑↑certainly ↑↑worth ↑trying

In line 1, the doctor provided information about the empirical evidence on drug therapies for fatigue and this is qualified. He then switched to a more positive outlook before he formulated a treatment recommendation for steroid treatment, personalised to the patient. The treatment recommendation was mitigated by "slightly" and "a bit more effective" but this was enough for the patient to respond with interest and acknowledgement in line 14. A treatment recommendation to switch steroid treatment was outlined to help both fatigue and appetite. There followed explicit agreement by the patient which indicated alignment with the treatment recommendation. This example showed that resistance to advice giving occurred palliative oncology clinics. The doctor on this occasion changed tack to a treatment recommendation for steroids and the patient aligned with this. This man reported severe disabling fatigue on his fatigue measurement scores and in his descriptions of fatigue to the doctor. It was uncertain whether the presence of severe disabling fatigue was a contributing factor for why he resisted advice giving for fatigue. Therefore, it was unknown whether the temporal experience and expected trajectory of fatigue played a contributory role in the resistance of advice giving for fatigue.

4.5 Summary

This chapter has presented the results from the observational study. A sample of mostly experienced oncology doctors working across 6 separate specialist oncology clinics took part. Patient participants were more likely to be older, male and receiving cancer treatments. A variety of cancer types were represented in the patient sample and almost all reported experiencing some fatigue, with clinically relevant fatigue recorded in 62%.

Fatigue-talk was not just confined to symptom-talk in the phase structure of oncology care but was routinely encompassed in treatment-talk and occasionally referenced in scan-talk. Fatigue was introduced as a topic by a third of patient participants and in nearly half of these, fatigue was minimised and associated with acceptance. The narrative descriptors for fatigue used were many and various, with the word fatigue only used by one patient. Companions participated in 73% of recorded visits and reported their perspective of fatigue in nearly half of these. Companions commonly upgraded fatigue and on a few occasions introduced fatigue as a topic. Some doctors screened for fatigue by using tiredness/fatigue and/or energy levels. Doctors routinely assessed the impact of fatigue on activity and/or sleep patterns.

Fatigue was integral to cancer treatment decision discussions in nearly a third of cases. These discussions occurred when any participant believed fatigue was having or could have a negative effect on quality of life and/or fitness for treatment. Sometimes the doctor explicitly mentioned the goals of palliative chemotherapy with fatigue referenced in quality of life discussions. In cases where treatment options were limited due to advanced disease or severe fatigue, highlighting the goals of palliative treatment led to end-of-life discussions.

Specific treatments for fatigue were offered by doctors on a few occasions. Specific treatments included steroid therapy, prescribed nutritional support and a blood transfusion. Similarly, doctors provided advice-giving for fatigue on a few occasions and this consisted of: exercise, pacing and giving permission to rest. In addition, doctors sometimes endorsed and supported the patients reported coping strategies.

Misalignment between patient participants with clinically relevant fatigue and doctors was observed and the evidence to support this was the regular occurrence of resistance in talk. Misalignment was significant in revealing the contrasting perspectives of patients and doctors on the tolerability of fatigue and its' impact on quality of life. Furthermore, misalignment showed some patients prioritised survival over severe disabling fatigue. The various persuasive strategies that doctors used to gain agreement with their treatment recommendations were highlighted. The findings have described that when resistance occurred and patient choice was continually promoted, then the outcome remained the continuation of treatment unchanged. Thus, doctors sometimes needed to take more responsibility in the decision-making process and some exerted more authority in their treatment recommendations when resistance was recurrent. Doctors exerted more authority when fitness for treatment or patient safety was at risk. These findings may have clinical significance and will be explored further in Chapter 7. Finally, doctors promoted exercise as advice-giving for fatigue and misalignment occurred in three cases. In one case, the doctor changed tack to offer steroid treatment.

The next chapter will present the results from the patient interviews and will outline how these individuals coped with clinically relevant fatigue. The results of the patient interviews may provide some insights for why misalignment might have occurred.

Chapter 5: Findings from patient interviews

5.1 Introduction to chapter

In this chapter, the findings from the patient interviews are presented. First, the participants who contributed to this part of the study are described and a pen portrait of participants provides a narrative description (see Appendix 5.1). Second, the overarching theme to be identified from the interviews that describe how patients approached fatigue is presented. The interconnectedness of fatigue comprises of three sub-themes: psychological strategies for enduring fatigue; navigating fatigue through practical strategies; and the complex nature of fatigue and self. These three sub-themes were interconnected and related to one another to varying degrees depending on the uniqueness of the individual, the intensity or trajectory of fatigue experienced over time and the individual cancer journey.

5.2 Patient participants

5.2.1 Response rate

Thirty-seven participants were potentially eligible (i.e. NRS ≥4) to take part in the patient interview study and 22 were interviewed. Three were excluded by the researcher after patients reported that fatigue was caused by specific conditions other than cancer or cancer treatments, and were hesitant about taking part. Two were missed due to death or acute deterioration. Of the 32 patients approached, 22 were interviewed and ten declined (69% response rate).

Of the ten participants who declined to take part, one declined immediately at the outpatient clinic and another by not contacting the researcher to confirm interest. Five were initially interested but an interview date could not be arranged after one or two telephone contacts. One gentleman was very hard of hearing and telephone communication was unsuccessful. Finally, two participants developed worsening fatigue and cognition secondary to metastatic brain disease.

5.2.2 Interviews

Twenty-two participants were interviewed and the time taken to interview from date of recorded consultation ranged from 1 day to 7 weeks. The delay in interviewing was dependent on many factors related to the researcher and the patient. As the researcher was concurrently recruiting and data collecting from oncology outpatient clinics, this restricted availability to interview. Patients often preferred a delay in scheduling the interview, to allow time for some recovery from cycles of chemotherapy treatment or an unexpected inter-current illness. Patients also described busy lives with frequent hospital visits and family commitments so interview dates needed to work around their schedule. The mean length of the interview was 56 minutes with a range of 34 to 80 minutes.

5.2.3 Participant characteristics

Participants were split evenly between male and female, 11 each (see Table 5.1), with an average age of 68.8 years. Half of them fell into the age group 65 to 74 years and almost half had a diagnosis of colorectal cancer. At interview: 15 patients had received chemotherapy within the last three weeks; five recently had treatment paused or stopped due to worsening fatigue, two were on surveillance with the possibility of further palliative chemotherapy treatment and; two were receiving palliative care at the oncology clinic (see Appendix 5.1). Over half (n = 14) died within 12 months of participating in the consultation study and over a quarter (n = 7) died within 6 months.

Table 5.1: Participant characteristics for patient interview study

Code	***Pseudonym***	***Sex***	***Age***	***Diagnosis***	***Occupation***
PI01VO01	Sharon	Female	67	Colorectal	Retired
PI02VO04	Stephen	Male	54	Colorectal	Self-employed
PI03VO03	Cecil	Male	74	Colorectal	Retired
PI04VO05	Michael	Male	59	Colorectal	Retired
PI05VO08	Conor	Male	59	Colorectal	Retired
PI06VO07	Gordon	Male	60	Pancreatic	Self-employed
PI07VO18	Brian	Male	68	Pancreatic	Retired
PI08V020	Clive	Male	81	Colorectal	Retired
PI09V022	Eileen	Female	93	Colorectal	Retired
PI10VO29	Shay	Male	69	Colorectal	Retired
PI11VO26	Claire	Female	67	Lung	Retired
PI12VO28	Sonya	Female	75	Colorectal	Retired
PI13VO31	Daniel	Male	82	Mesothelioma	Retired
PI14VO35	Larry	Male	85	Lung	Retired
PI15VO39	Tom	Male	73	Oesophageal	Retired
PI16VO38	Pandora	Female	59	Colorectal	Paid work
PI17VO48	Jane	Female	67	Breast	Retired
PI18VO44	Chloe	Female	66	Breast	Retired
PI19VO46	Clodagh	Female	47	Breast	Paid work
PI20VO43	Peggy	Female	68	Breast	Retired
PI21VO45	Gloria	Female	75	Breast	Retired
PI22VO49	Mary	Female	66	Breast	Retired

5.2.4 Patterns of fatigue in participants

In this sample, the patterns of fatigue described by participants consisted of transient or episodic worsening of fatigue related to cancer treatments with constant background fatigue (11/22) and constant fatigue of varying intensities (11/22). All participants experienced clinically relevant fatigue as measured at the consultation. However, at the interview, the severity or intensity of fatigue could have worsened, stayed the same or improved.

5.3 Overarching themes

Three overarching themes were identified from the analysis of the patient interview data: the interconnectedness of fatigue, support and fatigue are perceived as different. The interconnectedness of fatigue largely relates to how participants coped with and managed fatigue. This overarching theme is presented in the next section of this chapter and for brevity, the other two themes are not presented in this thesis.

5.3.1 The interconnectedness of fatigue

The interconnectedness of fatigue was the predominant overarching theme in the analysis and was widely concerned with how participants approached and dealt with fatigue in their day to day lives. Sub-themes were generated from the findings and were grouped into themes. Three themes coalesced to form an overarching theme: the interconnectedness of fatigue (see Figure 5.1). These three themes were interconnected to one another to varying degrees depending on the uniqueness of the individual, the level or trajectory of fatigue experienced and the individual cancer journey. For example, a participant may utilise only one aspect of psychological strategies to cope with fatigue as they commence on palliative cancer treatments for the first time but as fatigue worsens they may then develop or utilise other psychological/practical strategies for fatigue. Importantly, how an individual might be able to access, utilise, develop or learn these psychological or practical strategies for fatigue may be somewhat enhanced or inhibited by factors such as: their personality; life habits/experience; cancer experience/journey; and the trajectory of fatigue itself. Therefore, these strategies can be interdependent or related to one another in some way and this can change or oscillate over time. In summary, any individual with clinically relevant fatigue may utilise various practical or psychological strategies for fatigue that are appropriate for the temporal and impact of fatigue on quality of life or functional ability and these will depend on how these related to the complex nature of self and fatigue.

Figure 5.1: The interconnectedness of fatigue

Theme	***Sub-theme***
Psychological strategies for enduring fatigue	Normalising fatigue Fatigue offset by the will to live Staying positive about recovery from fatigue
Navigating fatigue through practical strategies	Redefining body through movement and goal setting Nutrition and supplements Being in tune with the body Adapting and reframing the world
Complex nature of self and fatigue	The interaction of self and fatigue Perceiving changes in self Life experience and cancer journey Comparing internal and external worlds

5.3.2. Psychological strategies for enduring fatigue

Psychological strategies for enduring fatigue reflected the psychological strategies that participants with fatigue utilised and comprised of: normalising fatigue; fatigue offset by the will to live; and staying positive about recovery from fatigue. Normalising was defined as participants feeling reassured that the fatigue they were experiencing was expected and usual. Fatigue offset by the will to live, meant the experience of fatigue was resisted or accepted as part of the potential benefits of cancer treatments. Staying positive about the recovery of fatigue concerned the held belief that fatigue was temporary and would resolve once the schedule of treatments had completed or controlled the disease.

All participants in the interviews mentioned how they utilised some psychological strategies to help them endure the fatigue they experienced as part of their cancer treatments or the cancer itself. These psychological strategies were used regularly or at various points along the course of fatigue and the cancer journey. Many perceived fatigue as being expected or normal on treatment and sometimes other explanations such as ageing or cancer were sought to normalise fatigue. Most participants displayed a preference to live longer through cancer treatment and some were explicit in how this will to live offset the effects of fatigue on their quality of life. Finally, it was common for participants to believe fatigue was temporary while receiving treatment and they planned life events for when treatments were completed to help cope with fatigue.

5.3.2.1. Normalising fatigue

Normalising was often used as an internal process by participants to help cope with the experience of fatigue and the impact it had on their lives. In essence, normalising was defined as patients feeling reassured and comforted that the fatigue they experienced was a normal and expected experience either as part of: receiving cancer treatment; the cancer; an advanced progressive illness; and the ageing process. Fatigue was normalised through age and ageing, cancer treatment and the disease process. Over half of the participants were over retirement age and they often mentioned how hard it was to decipher whether fatigue was predominantly attributable to treatment or the ageing process. Most acknowledged how fatigue was expected on chemotherapy but then also searched for other explanations, to make sense of how they were feeling. Often, they reflected on their age and, sometimes reluctantly, this led them to think about and accept the inevitability of the ageing process.

> *PI08VO20, Page 3 – But it's, you do get tired, it's difficult to know at this juncture, when I am still in various aspects of treatment, whether the tiredness is due to the chemo, which it's accepted to be, you get a certain amount of lethargy and tiredness from the different types of chemo. I've got to begin to accept the fact that I'm 82 in a week or two's time, and therefore I can expect to start feeling a bit tired probably! Which comes against the grain, because I mean I worked until I was 75 I think. I didn't retire until I was 75.*

Even though some participants experienced changes in their physical or cognitive capabilities over a relatively short period of time and it was closely linked with their chemotherapy treatment, they might still use the ageing process as a contributory explanation for their fatigue. They reflected on their understanding and expectations of what 'old age' would feel like perhaps from direct experience and use this as a coping mechanism for fatigue. A few participants went as far as postulating that how they were feeling might have been inevitable due to the ageing process, even if they were not to have had incurable cancer and cancer treatments.

> *PI10VO29, Page 2 – And of course you never know whether some of the restrictions (fatigue) are just getting that bit older. You know, you can never tell whether I might have been like, feeling like this anyway, or whether it's the, you know, the medical problems that have made it so.*

Many participants normalised fatigue as an expected consequence of their cancer treatments and how they approached this was based on: their perception of the treatments themselves; their previous experience of receiving chemotherapy treatment; the advice that they had received from either family or friends who had experienced cancer treatments; the information gained from visiting the cancer treatment units or the clinicians delivering their care. Some expressed an understanding that chemotherapy was a toxic treatment, with several describing it as 'poisonous' and therefore some side effects, such as fatigue, were to be expected and perhaps inevitable. For others, they had experienced fatigue with previous treatments and therefore knew to expect it.

> *PI12VO28, Page 9 – I mean you know you're going to feel like it, so it's not extraordinary, it's nothing out of the, it's one of the things you know is going to happen. And if it does, well that's all part of the treatment. Really, if it is a way of protecting your body, it's perhaps a better way than, rather than… It's better to have fatigue than it is to have some of the other symptoms that happen. Yeah, you just learn to cope.*

Many talked about their clinicians advising them about the likelihood of fatigue occurring while receiving cancer treatments and normalising their experience of fatigue. A few mentioned that patient information leaflets were a source of information. Some felt that normalising fatigue offered them reassurance that what they were experiencing was typical and this facilitated acceptance.

> *PI21VO45, Page 11 – you've just not got the energy, it isn't there. But it, it doesn't make me feel ill in any way, and it doesn't make me, I don't worry about it. Because they warned me when I started on the chemo, that one of its major side effects was feeling tired. So I thought that's what it is.*

A few participants mentioned that they had initially resisted the normalising of fatigue by doctors or nurses from the oncology clinical team because they felt they would be an exception, that positivity precluded the development of fatigue and acknowledging fatigue could occur would lead to it happening, and fatigue represented deterioration and death which they wished to avoid. Sharon resisted the normalising of fatigue because she felt that it offered no solution to her problem.

> *PI01VO01, Page 25 – No, I brought it up with Evelyn (consultant) last time, probably because you were doing the study. And I think I said the time before, I just feel so tired, and they seem to think that that's normal. But I think something could be done about it, you know, I don't know what, but. Perhaps some people it doesn't bother, if they're in a, if they're a lazier sort of person, I don't know, but it bothers me.*

A few participants normalised fatigue in the context of advanced cancer and when they did, it was usually associated with end-of-life issues. Jane normalised her severe fatigue with advancing disease with a sense of acceptance and resignation.

> *PI17VO48, Page 16 – I mean it seems logical to me that this disease is rapidly progressing, and obviously the first thing it's going to do is sap your energy. So, there we are.*

The normalising of severe fatigue at the end-of-life could be a comfort to those who were soon facing their death. Although Jane did not have the energy to sort out some of her affairs as she approached the end of her life, she gained some comfort that she would likely have a slow death with worsening fatigue rather than sudden or violent death.

> *PI17VO48, Page 5 – Well just total lack of energy. Complete lack of energy. All I want to do is, frankly is lie on the bed. And I've been told that is probably what will happen, I will take to my bed and very gradually slip away! Which actually is a rather good way to die! It's not a, you know, violent death, which is always much more shocking. So if I sort of slip quietly into oblivion in my own bed, be fine.*

5.3.2.2. Fatigue offset by the will to live

Fatigue offset by the will to live was defined as participants using the hope for cancer treatments as a coping mechanism to offset the experience of fatigue. Participants frequently negated or minimised the effects of fatigue through a preference for survival, positivity and retaining hope in cancer treatments. Fatigue was generally an acceptable compromise for controlling the cancer with the expectation of prolonging survival. Even though for some participants, fatigue was a disheartening experience with a significant negative impact on their quality of life, the potential net gain from chemotherapy was more important and alluring than the side effects. This approach helped some participants cope with the negative effects of fatigue.

> *PI07VO18, Page 7 – Well really fed up, and you start thinking, is it (fatigue) worth it? But the willing to live longer makes me keep going, yeah, just depends how much you can take, yeah. That's about all I can say. (…) Oh, I'll keep going, I'll keep going now, yeah, unless they (doctors) tell me it's a waste of time or something, yeah, yeah, but I will keep going, yeah*

Some participants were clear that there was a limit to the repercussions on their quality of life from fatigue they were willing to accept. They described an individual threshold for tolerable fatigue which depended on several factors including: their current level of activity and how they had adapted to this; the level of support available to them from family and friends; their experience of cancer treatments and whether they had been effective; and most importantly, the weight they placed on survival over quality of life.

> *PI22VO49, Page 36 – Yeah. Put up with anything. Yeah, not saying, I shouldn't say, within reason, but I mean as long as it's bearable I don't mind. … That if I couldn't do anything. You know what I mean? If I was really tired and I thought oh, I can't*

> *do any craftwork or any cooking or anything like that, or any housework, and just do nothing through tiredness, that, oh no, I couldn't hack that.*

However, a few participants expressed regret that their preference for survival over quality of life had reduced their awareness of fatigue worsening. In one case, Peggy continued taking oral cancer treatments despite fatigue worsening and this contributed to a late presentation to hospital with pneumonia, resulting in a near-death experience. Pandora, expressed regret at not having listened to her doctor when advised to stop chemotherapy earlier than scheduled because of severe fatigue. She had believed continuing treatment would outweigh any potential negatives.

> *PI16VO38, Page 15 – I had had enough by then. And really I think [Professor] saw that, and I should have taken his advice and said at number nine, yes, OK. But again you see it's my stubbornness in this case, it was a sort of, I'd started so… (…) Well, I sort of felt I've started so I'll finish. Surely it can only do good. Whether it did or not.*

It appeared that how some participants approached their cancer or illness, was sometimes mirrored in how they approached fatigue. For example, participants with an optimistic and positive approach to their illness were perhaps less likely to acknowledge or report to others the impact fatigue had on their daily lives. Stephen explained how fatigue was a negative symptom and acknowledging it with healthcare professionals would interfere with his positive world so he avoided this. Hence, he would tend to underreport his symptom burden to healthcare professionals.

> *PI02VO04, Page 13 – OK, tell us what your worst day is like. And that's the one, the worst day I can't get out of bed, and on a second to worst day I can walk 20 yards. And they filled it in from that perspective, whereas my natural way of filling in a form like that would be oh look, I feel fine, bounce in when you see the prof, you don't sit down and say right, I've had diarrhoea for two days mate and it's been crap and I feel awful. You actually build, you know, you want to say that actually no, you've got a positive attitude to all of this.*

Two participants used their religious faith to help them cope with cancer and this mirrored how they coped with fatigue. They gained strength from knowing that others were praying with and for them. Cecil believed that fatigue was overcome through the power of prayer.

> *PI03VO03, Page 9 – Lots of people are praying for me, I know that, and they were praying for me in church on Sunday, and they didn't believe it was coming, and I walked through the door. Never come on the low scale (fatigue) of my chemo cycle ever before! So I believe in the power of prayer.*

Some mentioned the hope they derived from the trust they placed in their oncology clinical team and this helped them to cope with fatigue. Some felt they were not 'given up' on or deemed a 'lost cause' by their doctors and this gave them the strength to persevere with fatigue. This trust contributed to a very positive outlook in a few participants and this minimised their fatigue.

> *PI16VO38, Page 20 – [Professor], the hope that there is things, there are things that they can still do, the determination that I'm going to be in that five per cent, and see my grandchildren, because I haven't got any. I think it's almost, no, I'm not tired, because if I'm tired I'm ill, and I'm not ill, so therefore I won't accept that I'm tired.*

Several participants retained hope for potential treatment options and this helped them cope with fatigue. Gloria had severe fatigue but believed more treatment was a possibility. However, she also knew that worsening fatigue could mean that the end-of-life was approaching.

> *PI21VO45, Page 41 – Maybe as things go on, as there's less things (treatments) to try, maybe I shan't feel quite so, you know, I wouldn't say optimistic, but I'm not worrying at the moment about it. But if, if I started, if my health started to go downhill and I couldn't, say couldn't get up in the morning (worsening severe fatigue), then I think I would feel low, a bit low, a bit bothered. But it's not like that at the moment, so.*

5.3.2.3. Staying positive about recovery from fatigue

Staying positive about recover from fatigue was defined as participants believing and hoping that fatigue was a temporary experience. Many participants persevered with fatigue by believing it was temporary and remained positive by imagining or planning future life events for when treatments were completed. These future life events were often designed to benefit quality of life and were a reward for the sacrifices of enduring fatigue on treatment. Over half of participants had received cancer treatments previously and some talked about fatigue gradually improving over time following the cessation of treatment with the recovery time sometimes lasting months. However, a few noticed some residual level of fatigue could remain and eventually came to accept this. They expected a similar pattern to occur once treatment had finished and felt reassured as their energy levels began to slowly improve.

> *PI12VO28, Page 7 – I'm just getting a bit more energy now, to do things. Probably a month's time I shall be really good. Certainly last year I got back most of my energy, if you can…. (…) All in all it's (fatigue) liveable with, because you know it's not going to last forever. It's no bad thing to sit down a bit and not rush around and do so much.*

Seven participants were receiving chemotherapy for the first time and most had severe transient fatigue lasting some days after chemotherapy treatment, which was usually incremental with each treatment cycle. Some talked about fatigue being psychologically and emotionally demanding during this period. They often coped by believing that fatigue would improve before their next cycle or once their treatment course had been completed.

> *PI18VO44, Page 16 – But I must admit, I didn't realise quite how much it (fatigue) would take it out of you really. That I would feel quite that tired and sleepy a lot of the time. Yeah, and just struggling physically a little bit, you know, the aching and getting up and down stairs. But it, nothing, it doesn't last forever, that's how, I think your spirit is as important, and I think well each day I'm a little bit better. And I know it will, probably by the middle of this week I'll be feeling a lot better.*

Retaining positive thoughts about the future recovery from fatigue was important as uncertainty about recovery was occasionally difficult for those who lived on their own or aimed to return to work. Clodagh's thoughts oscillated between positive and negative depending on the severity of fatigue. She took great pride in her role as an English teacher at a special needs school, but was concerned about the lingering effects of mental fatigue as this interfered with her ability to communicate effectively and therefore teach.

> *PI19VO46, Page 10 – If, I try not to let it (fatigue) panic me, because at the moment I'm thinking oh god, I'm going to be like this forever, I'm never going to be able to go back to work. Not that I want to! Can think of nothing worse! And it's quite, so I have to try and be rational about it. This is the worst that it is, and it will get better.*

Five participants had their treatment stopped or paused owing to worsening severe fatigue. Some recalled being consumed by fatigue with a focus on getting through the day and sometimes losing all hope. But as they noticed improvements in fatigue, positive thoughts gradually retuned with a hope that fatigue could further improve in time.

> *PI13VO31, Page 15 – Well I feel, yeah, I do, I feel the prospect is brighter and I can see the light at the end of the tunnel is brighter, and so you can see a way out of it, whereas when you're feeling sick and weak and wretched you're preoccupied with handling the situation at the time, and the longer-term doesn't seem so important. You're dealing more with the immediacy, just trying to feel better. So yes, you become more ambitious as you recover.*

Several participants coped with fatigue by having something positive or special to look forward to once they believed their lives would be free from fatigue at the end of treatment. Those who were receiving chemotherapy for the first time utilised this strategy more often. For some, this might be a planned holiday with their partner and family or perhaps an important life event on a 'bucket list'. They felt the holiday was a reward for the consequences of fatigue on quality of life and loved ones. Some remarked their lives were on hold while experiencing fatigue and could 'start living again' once they were fatigue-free. Chloe's spirits became low with the accumulation of fatigue on treatment and the impact it had on family life, so the holiday was something positive.

> *PI18VO44, Page 17 – Well, it's, yeah, I find it (fatigue) hard, just because I like looking after the home, and cooking, doing those things generally, and keep the family going, having the children over for dinner. So not being able to do it is annoying. And it has seemed a long time, I have to say. But we've tried to get round it with other things. You know, we've got a little holiday now coming up, just for a few days, and we're all going to be together. So my son and daughter and their partners, we're going away together. So that helps keep the family spirit, and lifts your spirits a bit, something to think about.*

However, a few recalled their experience of not having anticipated the worsening of fatigue on previous treatments which was also accompanied by an unexpected prolonged recovery. They described holidays or planned events that were marred by severe fatigue or cancelled because of the slow recovery. As a result, Peggy organised several holidays with family and friends on commencing a new treatment, but this contributed to severe fatigue and a pause in treatment.

> *PI20VO43, Page 7 – Because at least in the past, when I had (fatigue), the first time round I had masses of chemo, I had a really big dose, and that knocked me absolutely flying. But it was cumulative, so after the chemo had finished, I was on a heavy one for three doses, and then about six on another one. After that had finished I went on getting more tired. I didn't expect that, that it would. So this time I was almost in advance thinking well if I'm going to be like that on this chemo, I'd better do all the things I want to do in my life, which included going to Greece. And that's why I got extra overtired.*

5.3.3. Navigating fatigue through practical strategies

Navigating fatigue through practical strategies identified the practical strategies that participants used to manage fatigue and these were comprised of: redefining body through movement and goal setting; nutrition and supplements; being in tune with the body; and adapting and reframing the world. Redefining body through movement and goal setting was defined as the active strategies that participants used to manage fatigue: such as learning to gradually exercise; and when to begin to set goals to achieve through tasks or activity.

Nutrition and supplements related to participants focusing on optimising their nutrition at home, utilising nutritional support and utilising complementary therapies or herbal remedies for fatigue. Being in tune with the body meant participants were listening and feeling what their body was telling them with respects to energy levels or need to rest. Finally, adapting and reframing the world, was defined as the adaptive strategies that participants used in their daily lives and how they came to terms with their new normal self.

All participants described using some practical strategies to help manage fatigue and how or when these strategies were utilised could be related to the trajectory and severity of fatigue. Some used active strategies such as exercise or goal setting for fatigue as they sensed their energy levels beginning to improve. Several tried to improve their fatigue levels by optimising their nutrition intake or through taking supplements. The most common practical strategy mentioned by and employed by participants was modifying their activity levels through increased awareness of fatigue. Finally, some participants outlined how they had adapted their lives as an attempt to limit the effects of fatigue.

*5.3.3.1. **Redefining body through movement and goal setting***

Redefining body through movement and goal setting was concerned with the active strategies that participants used to manage fatigue such as: learning how to and when to gradually exercise with fatigue; and when to and when not to set goals to achieve through tasks or activity. A few participants used exercise as a strategy to manage fatigue but usually when chemotherapy treatment had stopped and as their energy levels slowly improved. They described gradually building up activity levels through exercise and found this helped with improving stamina, sleep and psychological well-being. After completing her treatment schedule, Pandora followed the doctor’s recommendation to improve fatigue through a graduated exercise programme and began swimming again.

> *PI16VO38 Page 7 – What I found, one thing [doctor] said last time we saw him about six weeks ago, was that exercise would help this (fatigue). So I’ve just started my swimming again, which I really enjoy. And it was 10 days ago I could only just do 10 lengths, whereas before I used to be up to 50, 60. It’s only a small pool. And then on Monday this week I did 24, 26… So again though it’s my determination.*

In general, participants talked about struggling to maintain the same activity levels and exercise tolerance as fatigue worsened with the accumulation of chemotherapy cycles or advancing disease. Even for those participants where daily exercise was of huge importance in their lives, inevitably they felt unable to exercise and their activity levels diminished considerably. Participants with variable fatigue tried to exercise when they felt able; but for others with constant fatigue, this just felt impossible. Some participants noted physical changes in themselves which related to changes in their strength and stamina.

> *PI13VO31, Page 5 – it sounds pathetic and it sounds weak, but it's almost as though it (fatigue) destroys the motivation to want to do anything. So it's, it's a physical tiredness, I mean I've lost muscle tone and strength in my arms. Lost a fair amount of weight, about, almost a stone at one point, although that's coming back on again now, thanks to Jaffa Cakes and things like that.*

Goal setting was used by several participants once fatigue was improving following a pause in treatment or completion of the schedule. Some participants found that goal setting with achievable tasks could be motivational and provide positive feedback. Goal setting could take the form of routine everyday tasks, measuring activity levels with incremental distance or re-connecting with social activities. Daniel began to write down the goals he wished to achieve daily and tick them off once achieved.

> *PI13VO31, Page 14 – It's five or six weeks now and it's (fatigue) definitely, definitely an improvement. I set myself little goals each day. That's important, I actually write them down and cross them off, a little to-do list, and that gets, looking back, the goals are getting a little bit more challenging and demanding now than they were a couple of weeks ago. And that's motivational, that's quite good, you get a satisfaction out of crossing something off at the end of the day.*

5.3.3.2. Nutrition and supplements

Nutrition and supplements was concerned with participants optimising their nutritional with diet or supplements to manage fatigue levels and considering complementary therapies or herbal remedies for fatigue. A few participants used dietary measures or supplements to help manage fatigue either whilst on treatment or after treatment had been paused or completed. Simple adjustments in diet, such as using caffeine and sugars, might have helped initially but were not helpful as fatigue worsened on treatment. Some participants believed a limited dietary intake had contributed to the worsening of fatigue, particularly when appetite had reduced because of a viral illness or pneumonia. Stephen viewed dietary intake and supplements as something within his control to monitor and do something to help fatigue.

> *PI02VO04, Page 11 – I think there's, you've got to be a bit careful, because there's obviously, there's a bit, bit of a, if your energy levels drop and your appetite drops then you don't eat properly, which makes your energy levels drop and your fatigue stronger. Which is why we've been quite intense on getting food into me, in small amounts, and monitoring my weight. So I monitor my weight every single morning and evening, just to mentally focus myself. And, yeah, so I wouldn't say there's any change, but I think it can, we can probably improve the situation(fatigue) by the time I start getting food into me again, some supplements and things.*

Occasionally participants explained how clinicians had recommended and prescribed calorie and protein-rich dietary supplements for severe fatigue. Some attributed modest improvements in energy levels to these supplements which also perhaps enhanced quality of life.

> *PI21VO45, Page 6 – And since the doctor suggested these, these drinks, (supplements) I have felt I can do more. Not a lot, little jobs, but I can do more. One of the things that was difficult was just standing, doing a job standing up. I would get backache. But I can do that for a bit longer now. So on the whole I feel it's (fatigue) improved. There's not any great change.*

In addition, two participants used complementary and alternative treatments to help manage fatigue. Conor used apricot kernels and reiki, with permission from his doctors and believed they could 're-energise' the body. Peggy had to stop using Chinese herbal medicine when she commenced a clinical trial which she resented as she felt it had helped fatigue previously.

> *PI20VO43 Page 25 – But, I do, I do think about, you know, with the tiredness, that some sort of herbal thing would be good, because I think that it was before.*

5.3.3.3. ***Being in tune with the body***

Being in tune with the body was defined as participants feeling and listening to their mind and body, understanding when they needed to rest or relax and when they could be more active or do everyday tasks. Many participants employed practical strategies to manage fatigue which involved participants being in tune with how their body was feeling and included pacing and conserving energy, listening to your body and sleep. Frequently, participants used energy conservation measures from learned experience as a strategy to help manage fatigue. These might be measures that they might use daily or around specific days during their treatment schedule. Any task would be assessed for the energy that might be expended, if it was deemed to be too much, the task would then be avoided.

> *PI13VO31, Page 8 – So I'm consciously avoiding things I think, which you might say would be hard work, because they're more demanding, they take more energy, more concentration. If you feel lacking, then you try and conserve what you've got, I suppose.*

Pacing was closely associated with energy conservation behaviour but was sometimes a difficult technique to learn for participants who had not come to terms with their new physical self. Pacing might be a technique that was self-learned through experience, suggested by family members or recommended through healthcare professionals. During Larry's post-operative recovery in hospital following a pathological hip fracture, he recalled learning to pace from the physiotherapist.

> *PI14VO35, Page 10 – And when I wake up of a morning, sometimes I get up, I feel as fit as anything. Then I go and do something which I shouldn't do, then it knocks me back a bit. But if I just pace myself once I get up, just do what I want to do, but I've found once or twice I have overdone it, I've got up, had my breakfast, gone out in the garden.*

Participants often mentioned how the experience of fatigue was different from tiredness and it forced them to listen to their body. They felt the fatigue differed because of the inability to push through it. Many felt overwhelmed with fatigue and they managed it by not trying to challenge it.

> *PI18VO44, Page 29 – Well I was anyway, normal tiredness, sort of after a day of being out and about doing things, and that when you're ready for bed. But this (fatigue) is, yeah, quite a different thing, quite overwhelming. That's, for me, I know I keep saying that probably, but that describes it. It takes over, and there's nothing, you might as well not fight it, because there's nothing to stop it.*

With the experience of fatigue over time, participants learned how to listen to their body and this helped to manage fatigue in their daily lives. Some talked about the need to 'give in' to fatigue and listed this as advice they would give others with fatigue. Because if they ignored what their body was telling them and tried to push through fatigue then they suffered the consequences of feeling worse afterwards. Listening to their body sometimes informed them how they should plan the day ahead.

> *PI21VO45, Page 33 – Oh. One thing is, don't pretend you aren't tired and do too much, because you just feel worse. So if you feel bad, you feel exhausted or something, just have an easy day. Don't try and kid yourself you can work through it, because I certainly don't find I can do that.*

For some participants, listening to their body was a balance between giving in to it and being active depending on how they were feeling. They understood when they needed to rest or limit activity and, also when they should be more active. This alternating strategy was needed when fatigue was variable from day to day or week to week which was a pattern of fatigue commonly experienced.

> *PI13VO31, Page 23 – Half of me says cave into it, just have a rest, there's no point in putting too much strain on, by driving yourself too hard. But on the other hand you don't want to be too soft either, so you try and find a balance between intelligent reaction to how you're feeling, and a bit of positive thought to give you something to look forward to on the way up.*

Sleep was utilised by most participants as a strategy for coping with fatigue. Nighttime sleep habits were optimised and occasionally prioritised as a poor night's sleep usually had a negative impact on fatigue the following day. Some participants used day time sleep habits as fatigue worsened and this could sometimes provide some alleviation of fatigue for the evening ahead.

> *PI15VO39, Page 12 – Well I'm so wacked out, yes, I'm falling asleep, and it does benefit me. I don't get told off for falling asleep anymore! …. Even sleeping during the day, I don't have trouble sleeping at night. As I'm lying in bed there, thinking oh, here we go again, yet another day of, can't wait till this lot's finished.*

However, as fatigue became more constant and pronounced, this need to rest during the day time heightened and the overall benefits of sleep appeared to reduce. Participants described not being refreshed on waking in the morning and for some, they felt the need to return to bed again after breakfast. Daniel struggled with this excessive and unrelenting need to rest which felt so abnormal.

> *PI13VO31, Page 20 – And sleep, hitherto, I mean there's nothing nicer, getting into bed and hitting the pillow and being asleep within two minutes, because that's the only place you want to be, because you're tired and you have a really sound sleep and wake up refreshed in the morning, yeah that's a lovely state to be in. But to have a good, I wouldn't say a good night's sleep, but to have a night's sleep and then to get up and have breakfast, and then to sit down in a chair and then go to sleep again, it's unnatural, and I don't feel good about it. It's like, it's like a death wish, isn't it? It's like shutting your eyes to escape, it's a kind of escape. You're better off being asleep because then you can't consciously think about it.*

For those with constant and steadily worsening fatigue, sleeping or resting appeared to be the only strategy that they had to manage fatigue. Jane was approaching the end of her life and sleep provided only a modest respite from fatigue.

> *PI17VO48, Page 12 – I mean the only thing to do is sleep, lie on the bed and have a snooze, or just lie there and wait until the worst of the fatigue passes. I find it quite difficult now to stay up later than nine o'clock. (..) There's nothing that will alleviate the fatigue I'm afraid, nothing.*

*5.3.3.4. **Adapting and reframing the world***

Adapting and reframing the world, was concerned with how participants learned to adapt to their new normal self with fatigue and how they adapted themselves or the world around them to every day life fatigue. Participants used several adaptive strategies to moderate the effects of fatigue in their lives and these included: working around fatigue; learning to adapt to the unpredictability and variability of fatigue; reframing the world and adapting to a new normal. Participants often mentioned how they had to work around fatigue by adapting their daily routine and planned activity accordingly. For those with constant fatigue, they gradually adapted their daily routine and the structure to their day to meet the demands of their fatigue. Some also adapted their behaviour by switching to internet shopping for groceries or recording evening programmes on TV. Stephen also had mental fatigue which restricted his cognitive ability to do what previously would have been simple everyday tasks for him and found it more difficult to adapt to this.

> *PI02VO04, Page 4 – We have to work around it (fatigue). So, if I have a good night's sleep I'll wake up around 11 o'clock, and be out of bed and fine and that's OK. (…) And so basically we right off the first half of the day, every day. (…) It (fatigue) affects, so that's in terms of your time available in the day. There is now a, quite a, an issue with fatigue, combined with a lack of ability to concentrate, and to either move projects forward or respond to letters or do things, which can be, it can be infuriating, and it can also have direct negative effects.*

For some participants, the intensity of fatigue was unpredictable and could vary from day to day. They adapted by making plans and future commitments with others, vague and flexible so that they could be modified at short notice. Therefore, it was also important that their partner or family member similarly understood the need to adapt to the unpredictable nature of fatigue.

> *PI21VO45, Page 30 – [Husband] wanted to go and see the James Bond film, and he said tomorrow, if you feel well, can we go and see it while it's on? The tomorrow came and I felt OK, so we went off and saw it. But sometimes I just feel it's too much effort to go out, and so we won't do it, or we'll postpone it or something. So it varies a lot.*

A recurring theme of missing social engagements or re-arranging commitments had a psychological impact on some participants. They recalled feelings of anxiety about impending plans or disappointment because of letting others down. A few found the process of learning to adapt to the variability and unpredictability of fatigue quite difficult. Larry learned never to make concrete plans and felt much better for it.

> *PI14VO35, Page 38 – The less I worry the better I feel. So I've stopped that now. That's really why I haven't made arrangements to do this and do that, until the day comes, otherwise sometimes you look forward to it. And I don't know. I don't seem the same, I would rather do it, just straight off the mark just do it, rather than make arrangements, if you follow what I mean….. You make the arrangements for things, and then the time comes, something else crops up, then you worry because you haven't done it. So just take each day as it comes. I've found that the best way.*

Participants often adapted to the ramifications of fatigue by reframing the world around them and adopting a new normal life. For example, a participant's identity and quality of life might be reflected by their: role in the family and the home; hobbies and passions in life; social environment and social network; and, independence from others. Fatigue inevitably had an impact on their ability to maintain these roles and interests, meaning they had to learn to adapt by conceding on some things and altering their behaviour to preserve quality of life. This technique sometimes helped them to come to terms with the loss of their old world and encouraged them to reflect positively on their new normal.

> *PI19VO46, Page 10 – I think on the whole I've managed alright. I get depressed and I get lonely, because my normal has kind of, has all gone. But also to a certain extent I now have a new normal, which is just gentle, gentle pottering around, staring out the window like a cat! Looking at the birds. It's just, I've just developed*

> *a different way of doing things, because I don't know what else to do really.*

Adapting to this new normal, frequently helped participants to recognise their need for assistance and accept the offers of help from others. For some participants, the impact of fatigue limited their ability to provide the same role in their relationship or family as before. Some were of a generational age where traditional and stereotypical roles in the home were clearly identified. In several cases, fatigue led a complete role reversal in the home and some participants adapted by ceding control of previous responsibilities.

> *PI21VO45, Page 24 – It's lovely. Being waited on hand and foot, after 50 years of marriage, it's wonderful! It's alright. As long as, as long as he's OK, (…) You know, so I think at the moment it's OK. It doesn't matter. As long as it gets done, I don't care! If you're going to get worried about how things, how he does the washing, or… We have a lot of ready meals, which I don't particularly like, but that's how he copes. So I'm not going to make a fuss about it, you know.*

Often fatigue reduced the participant's capacity to attend social events or gatherings with family, friends or support groups. They adapted in different ways but many accepted the need to adhere to the routine they found helpful to manage fatigue. Previously, Claire had quite an active social life most evenings but was resigned to her new normal.

> *PI11VO26, Page 9 – I very rarely go to that (woman's group). It's just going out in the evenings I wouldn't want to do that, I'd just get too tired. And I went, I suppose I've just sort of settled into a comfortable life where I get up late, watch my telly, read the paper, talk to friends on the phone. I've always got my phone here and texting. (…) I'm just a different person. I miss being that person that was up for anything, chatty and, yeah, I think that's, I miss that, but now I've got to the stage where I don't really want to do anything anymore.*

5.3.4. Complex nature of self and fatigue

Complex nature of self and fatigue was concerned with how the perception of fatigue was related the experience of fatigue, the individual, their life and the cancer treatment journey. The theme was comprised of: the interaction of self and fatigue; perceiving changes in self; life experience and cancer journey; and comparing internal and external worlds. The interaction of self and fatigue was reflected by the coming together of the personal characteristics of the individual and the experience of fatigue. Perceiving changes in self was concerned with the temporal changes in fatigue over time and how this pattern could influence the coping mechanisms of fatigue. Cancer journey and life experience identified how certain experiences could influence the perception and tolerability of fatigue in the individual. Finally, comparing internal and external worlds, was concerned with the cognitive processing participants commonly used to help them come to terms with fatigue.

The interaction between the individual and fatigue was complicated, with certain qualities or characteristics in either, having an influence on how fatigue was perceived and managed by participants. Some identified individual characteristics in themselves which could either help or hinder their ability to engage with psychological or practical strategies to cope with and manage fatigue. Specific temporal patterns of fatigue and the individual life or cancer journey experience were also described by some as relevant for how fatigue could be perceived and tolerated. Finally, participants sometimes compared themselves against their younger selves or others when they talked about the acceptance of fatigue.

*5.3.4.1. **Interaction of self and fatigue***

The interaction of self and fatigue identified certain personal characteristics that could help or hinder the perception and management of fatigue. Some participants identified certain individual qualities and characteristics in themselves which they felt had an influence on how they tolerated and perhaps managed fatigue. These were usually based on how they had lived their lives prior to the onset of advanced illness and what they felt defined them as a person or what was important to them. For example, Cecil experienced fatigue which limited his mobility but these physical limitations were not bothersome as he was generally not very fond of exercise and was content to avail of assisted transport whenever possible.

> *PI03VO03, Page 18 – I haven't been a particularly low energy person, but I haven't been a particularly high energy person. I suppose I've been a bit of a lazy person, my wife is so active, so I've been a very calm and peaceful person. I mean the consultant just tells me it's (fatigue) a natural, a natural development of the cancer, so I can't sort of see what other causes there would be because it's not as though I'm going jogging for half an hour every day and getting completely exhausted! Because I go quite carefully and probably, I probably go a bit too carefully really. So probably that, and I don't think, I don't think I am a very good customer for you because I'm not really properly exhausted!*

For Cecil, his quality of life was influenced by and depended more on his mental agility rather than his physical strength or capabilities. He was a retired vicar who still occasionally gave a sermon at his former church. He felt that if he lost his capacity to read, then he would find fatigue more bothersome and less tolerable.

> *PI03VO03, Page 13 – I mean as I say, I love reading and I think that keeps my mind very occupied. I like reading newspapers and magazines, and quite like reading magazines like The Spectator and vaguely intellectual magazines still. I think, I would be very sad if my mind started getting tired.*

In contrast, other participants prided themselves on being active daily and, more than anything else, this provided them with much fulfilment in their lives. They talked about becoming deeply frustrated with the impact of physical fatigue on their quality of life and some felt fatigue contributed to their low mood. Fatigue was a problem to Sharon but she felt it might not bother 'a lazier sort of person', someone who found activity less important in their lives.

> *PI01VO01, Page 28 – But I think as long as, like Chloe (consultant oncologist) is aware that it (fatigue), to me it's a problem, it's important, isn't it. Even if they can't do anything, they need to know, it's not a nice side effect if you want to call it that. For me it's not, but the next person might say it doesn't bother me, I'm quite happy to lay in bed all day! It's how you are, isn't it.*

Similarly, physical activity formed a major part of Conor's life, through the sense of purpose and enjoyment he gained from being active and walking. He had little interest in sedentary tasks such as reading or watching TV. He no longer felt 'in control of my own body' and this ultimately led to feelings of anxiety about whether fatigue would improve.

> *PI05VO08, Page 23 – The tiredness I hate, that's probably a physical symptom. I don't like feeling tired all the time. I'm always one to get up and one to do things, but it's very frustrating that way, and also I'm just praying that obviously they can get me right*

5.3.4.2. ***Perceiving changes in self***

Perceiving changes in self was defined by the effect of the temporal experience of fatigue and how this could help or hinder the perception and management of fatigue. Participants experienced a spectrum of temporal patterns of fatigue in this study and these patterns could fluctuate. Some relayed a gradual onset of fatigue which was accompanied by slow and steady changes in their physical selves over time. Others described an abrupt or sudden onset of severe disabling fatigue which was accompanied by a rapid deterioration in physical ability and need for practical support. Some participants who perceived steady changes in self related to fatigue came to accept them gradually over time by incorporating them into their present life.

> *PI08VO20, Page 6 – It's (fatigue) been gradual I suppose I think is what you'd say, ever since it started. You've suddenly got to start accepting that you do feel tired…*

Insidious changes in energy levels or decline in capacity for activity that happened gently over time were felt by participants to possibly go unnoticed and therefore fatigue could be perceived as less of a problem. This pattern in fatigue was felt to help participants gradually accept and adapt to their new normal self. Occasionally, this gradual process was also felt to help their loved ones accept their new normal.

> *PI13VO31, Page 21 – I mean gradual deterioration (fatigue), almost by definition, unless you've got really good measures and benchmarks you don't notice it. It*

> *creeps up on you, and every day's norm becomes a few points lower than yesterday's.*

Participants who experienced sudden and unexpected changes in self because of the development of severe fatigue often mentioned how they found it difficult to cope with it. Some disclosed how this abrupt change in self made them feel more vulnerable and introduced negative thoughts which sometimes was in direct contrast to their positive and upbeat outlook previously. In a few participants, the abrupt diminishing of energy levels and capacity to perform tasks had a profound effect on them psychologically as they experienced a sudden loss of quality of life.

> *PI13VO31, Page 20 – You do tend, because you look back and you think of how you, the times when you were full of energy, and that becomes the benchmark and comparison. It might be unrealistic to compare if you're going to go back too far, but nevertheless, to have it foreshortened in an unexpected way, to suddenly go from where you are now, whatever standard that is in comparison to the past, to suddenly have that halved, is, I find disturbing.*

Sometimes the onset of severe fatigue occurred over a short number of days and participants found this difficult to manage. They described how suddenly they changed from being independently mobile and self-caring to struggling with mobility and needing support from loved ones for activities of daily of living. Some also mentioned how fatigue was difficult to comprehend until they experienced it for themselves as it was quite different from usual tiredness. Tom was taken aback by the sudden onset of severe fatigue but acknowledged that he was warned by healthcare professionals that fatigue could worsen.

> *PI15VO39, Page 2 – It's this last one, last week, my energy levels nosedived to very low, very low. Surprised me how quick it went down, in such a short time……. Well from being so-so, you felt tired, your energy levels were lower, but nothing that I couldn't cope with. Stairs weren't a problem. But suddenly, overnight, it went down to rock bottom. Everything was an effort to do, arms felt heavy just to lift up, my legs felt like lead. That has… Have a shower and I have to come down and sit down, because it tires you out. I'm falling asleep a lot more often. That's about it.*

5.3.4.3. *Cancer journey and life experience*

Cancer journey and life experience revealed how the life and cancer journey experiences of the individual could help or hinder the perception and management of fatigue. The individual cancer journey and the life experience of participants influenced how some perceived and coped with fatigue. For some, fatigue was a bearable symptom because they compared it much more favourably to other symptoms experienced along their cancer journey. Some recalled severe pain at the time of diagnosis which in cases was related to the cancer causing spinal nerve compression or bowel obstruction. Others vividly recalled the intensity of symptoms that were side effects of their cancer treatments which included nausea and vomiting or constipation.

> *PI21VO45, Page 15- I mean it was severe. I'd sit with a bowl, and people be talking to me, and I'd be sick. For no reason. I mean I hadn't eaten anything or drunk, I hardly, I lost a third of my body weight. Because I just couldn't, I couldn't face eating and drinking. I just, I'd look at it and I'd heave! Silly now it seems. But at the time it was very unpleasant. So being tired is nothing compared to that, you know.*

A few had feared and anticipated that the side effects of cancer treatments, which included fatigue, would be more severe than they experienced and this appeared to help.

> *PI19VO46, Page 16 – And actually, having said oh, chemo's the worst thing ever, it wasn't as, I have been able to do a hell of a lot more than I thought I was going to be able to do.*

Occasionally, some experiences along the cancer journey were deemed to be associated with fatigue and these could make fatigue more difficult to manage. In losing her hair during curative treatment, Claire felt this was 'the worst thing' and was her 'lowest point' until she was told that she had terminal cancer. Consequently, she felt she lost all hope and developed a persistent low mood which she believed possibly contributed to fatigue.

> *PI11VO26, Page 2 – I can usually cope with anything, but that word terminal, I think, I think is the hardest thing. I just wish somehow that it had been delayed, that that word… I know they have to be honest with you, obviously, they have to be honest with you, but to leave you with a little hope I think would be better, until, until the time when the truth does have to come out. Whether, I suppose that knocks the stuffing out of you whether that makes you more tired, I suppose. It affects you mentally obviously, there's no point doing anything, I've not shopped for three years.*

A few participants talked about and referenced their life experiences when mentioning how they dealt with fatigue. Sonya talked about a sense of resilience that she had developed in managing her fatigue and how this resonated with traits from her family life. Others talked about the learnings from life that they had gained from interacting with others who experienced fatigue and provided them with inspiration. Gloria was influenced by her professional life which gave her perspective on illness and limitations with fatigue.

> *PI21VO45, Page 20 – Being in, being a physio, being clinical, hearing people's tales, you don't (get) bothered by very much, you're used to listening to what people say, and not overreacting if they've got a rather, you know, if they've had a raw deal that way. So after years of doing that, you know, it's habit. I'm not going to have the screaming abdabs myself, you know.*

However, the relationship described between life experiences and fatigue was complex, with the negative feelings associated with fatigue sometimes resonating with other negative feelings such as those from troubled memories. For Peggy, some traumatic memories that she 'had buried in the past' came back to haunt her as she was feeling vulnerable and less resilient with severe fatigue. These feelings created a vicious circle with fatigue feeding into anxiety, which caused sleep disturbance, further worsening fatigue.

> *PI20VO43, Page 18 – These ghosts are falling out of the cupboard in the middle of the night, you know. And I'm regretting and I'm feeling I let the children down and all these sort of emotions, in the middle of the night, think goodness, if only, and that wasn't how I meant it to be. And I had a, I had a really, in some ways tough childhood.*

5.3.4.4. Comparing internal and external worlds

Finally, comparing internal and external worlds, identified how individuals often came to terms (or not) with fatigue by comparing how their previous selves would have found the experience of fatigue more difficult or how others were worse off than themselves. Participants often compared themselves against their younger selves, internal world comparison, and against others, external world comparison, and they routinely associated this with acceptance of fatigue. Several participants were thankful that they had not experienced fatigue at a younger age as they felt it would have been more difficult to cope with the greater impact of fatigue on their daily life. Some rationalised that their younger selves would have found fatigue more difficult to accept.

> *PI08VO20, Page 10 – But you come to accept it (fatigue) I think. Probably, I'm finding it easier to accept I think, don't want to keep harping on about age, but I'm probably finding it easier to accept because I am nearly 82, and so it's about time I started telling myself that I'm bloody well entitled to be a bit tired at 82! And I'm just lucky that I wasn't tired when I was 72! So I think that's got a lot to do with it, but you do get frustrated, certainly get frustrated.*

Similarly, some participants believed it would have been more difficult for their younger selves to meet the needs of managing fatigue. Claire, a single parent, managed fatigue with daytime sleeping once or twice a day and was thankful for the freedom to do this as needed.

> *PI19VO46, Page 9 – Yeah, yeah, or a, the two. Just whenever I, whenever I need to. Because I'm on my own a lot of the time, I don't have, I'm not, I mean thank goodness I'm not tied to small children or anything. I can, I can just, I can do what I like and it doesn't, it doesn't affect anybody else.*

Sometimes this internal world comparison model used by participants extended to a greater appreciation of the life they had before fatigue which appeared to lead to acceptance. Occasionally, participants compared their life with fatigue similarly with others, an external world comparison.

> *PI21VO45, Page 40 – Because it's (fatigue), it's not making my life that difficult, I just miss out on things. Well, so you miss out on things. I've got a friend in a wheelchair, she misses out on a lot of things, you know, that's life, isn't it. You know, I've had good health for 75 years, I don't think I should start complaining now really.*

Several participants compared themselves to other cancer patients with fatigue that they encountered or observed at a distance in the outpatient clinic and day treatment unit. Sometimes this comparison was more favourable towards themselves and led them to reflect on fatigue. Occasionally it provided inspiration and strength from a shared experience of fatigue.

> *PI10VO29, Page 19 – I mean it's, you know, whenever I've talked to doctors because I've got problems (fatigue), I've always felt a bit guilty about it, because you know, you sit in those, like that day treatment unit, and look around and think, I've had it rough but some of these poor sods, they've got nothing to look forward to, nothing at all. They're on a hiding to nothing because all that's happening is their problems are being kept in check, but they're never going to improve. So I always feel that my problems are… they're in a different league to some of those people, (…) So I always feel a little bit in awe of those sort of people. But it's a good atmosphere those units.*

When participants used an external world comparison they sometimes reflected on their life experience or the social support that was available to them. Two participants previously cared for family members who died from neurodegenerative diseases and in comparison, they talked positively about the level of independence they still enjoyed. Some felt 'lucky' to have social support available at home or nearby, which provided them with some reassurance and practical support when necessary. Jane viewed herself less favourably in comparison to others and reflected on her lack of social support which limited her ability to cope with severe disabling fatigue.

> *PI17VO48, Page 10 – So I've been very pragmatic, and, but I didn't expect this sudden sudden deterioration (fatigue). But I suppose I should have expected it, because presumably this is what happens with all cancer patients. You go to the*

> *day treatment unit, everyone looks as fit as a flea! They really do, they look terribly well. And of course they're all there having quite heavy treatments, and so unless the treatment they are having will cure what they've got, they'll be like me, they'll just begin to, to slow down and not be able to cope. But of course most of them have a husband, and most of them have several children to support them, and I haven't got that. So I just have to accept it.*

5.4. Chapter summary

This chapter has presented the most relevant findings from the patient interviews, the overarching theme being the interconnectedness of fatigue. This overarching theme broadly encompassed how participants coped with and managed fatigue in their day to day lives. This overarching theme comprised three themes: the psychological strategies for enduring fatigue, navigating fatigue through practical strategies and the complex nature of self and fatigue.

The theme 'the psychological strategies for enduring fatigue', analysed the mental coping strategies that all participants' utilised for fatigue caused by cancer treatments and the cancer itself. This theme consisted of three sub-themes. The first sub-theme was 'Normalising fatigue', which related to participants diminishing concerns or anxieties about fatigue through normalising the experience. They made sense of fatigue and sought explanations that it was caused by cancer treatments, the ageing process and sometimes advancing disease. The second sub-theme was 'Fatigue offset by the will to live', and this presented how participants' preference for pursuing cancer treatments and survival cancelled out some of the effects of fatigue on quality of life. Closely related to this, the third sub-theme was 'Staying positive about recovery from fatigue', which outlined the common belief that fatigue would improve in the future. This belief was usually associated with imagined or planned goals which benefited quality of life and were usually designed to be shared with loved ones.

The second theme was 'navigating fatigue through practical strategies', and this was concerned with all the various practical approaches that participants learned to use depending on the trajectory and intensity of fatigue. This theme comprised four sub-themes. The first sub-theme ‘redefining body through movement and goal setting’ described how participants managed fatigue through exercise and goal setting. This practical approach appeared successful as the course of fatigue was lessening. ‘Nutrition and supplements’ was the second sub-theme and was concerned with attempts to improve fatigue levels with dietary intake or natural supplements. The third sub-theme was ‘being in tune with the body’, and this described the universal practical strategies that participants learned to utilise through increased awareness of fatigue. These approaches to managing fatigue included pacing and conserving energy, listening to your body and sleep. This, in turn, led to the fourth sub-theme, ‘adapting and reframing the world’, and showed that participants adapted their daily lives and reframed their world to a new normal life with fatigue.

The third and final theme presented was the ‘complex nature of self and fatigue’, which highlighted the complicated interplay and relationship between the individual and the experience of fatigue. This theme consisted of four sub-themes. The first sub-theme was ‘the interaction of self and fatigue’ and related to participants’ self-identified individual characteristics which influenced how they coped with fatigue. The second sub-theme was ‘perceiving changes in self’ and concerned specific temporal patterns of fatigue described by participants as influencing the perception and tolerability of fatigue. Closely related to this, the third sub-theme was ‘life experience and cancer journey’, and reflected the relationship between participants’ individual cancer journey or life experience with the perception of fatigue. Lastly, the fourth sub-theme was ‘comparing internal and external worlds’, which described participants comparing themselves against their younger selves or others while coming to terms with fatigue.

Chapter 6: Findings from clinician interviews

6.1 Introduction to chapter

In this chapter, the findings from the clinician interview study are presented. First, the participants who contributed to this part of the study are described. Second, the themes identified from the interviews that describe how clinicians approached fatigue are presented. The over-arching theme was fatigue is perceived as different and this identified fatigue as different: in comparison to other cancer symptoms managed in the oncology clinic; and can be perceived and experienced with such wide variation in people with advanced cancer. This over-arching theme mirrored a theme from the patient interviews. The over-arching theme was comprised of three sub-themes: fatigue is challenging to assess; fatigue interacting with treatment decisions; and fatigue challenges the role of the cancer doctor.

6.2 Clinician participants

6.2.1 Response rate

Of the 17 clinician participants who took part in the video study, eight were interviewed. One consultant clinician from the prostate clinic who did not take part in the consultation study was approached for an interview. This consultant supported the initial design stage of the study and recruitment occurred in his outpatient clinic but it just happened that he was not video-recorded. Of the 14 clinicians approached, nine were interviewed and five declined (64% response rate). Of the five who declined to take part: three did not respond to email invitations to take part; and two clinicians were interested but an interview date could not be arranged after further contact was made. Four were missed: one specialist trainee had finished training; one clinical fellow was finishing their research studies; and two specialist trainees went on maternity leave.

6.2.2 Interviews

Nine participants were interviewed and the interval from the end of recruitment to interview ranged from 1 month to 16 months. The delay in interviewing was dependent on several factors related to the researcher which limited his availability and these included: a much longer than anticipated recruitment phase for the observational study and patient interview study; needing to complete preliminary analysis for PhD transfer; and clinical work commitments of the researcher. Most clinician interviews took place after the oncology clinic data collection period had ended and after preliminary analysis of the video and patient interview data. The mean length of interview was 35 minutes, with a range of 22 to 60 minutes.

6.2.3 Participant characteristics

Most participants were consultant oncologists (see Table 6.1). Their years of clinical experience ranged from 2 years to over 20 years. The sub-specialty oncological expertise of the participants included: breast, colorectal, upper gastrointestinal and urological cancers.

Table 6.1: Participant characteristics for clinician interview study

Code	***Sex***	***Grade***	***Specialty***
CI01	Male	Specialist Registrar	Medical Oncology
CI02	Female	Clinical Research Fellow	Clinical Oncology
CI03	Male	Consultant	Medical Oncology
CI04	Female	Consultant	Medical Oncology
CI05	Female	Consultant	Clinical Oncology
CI06	Male	Consultant	Clinical Oncology
CI07	Female	Consultant	Medical Oncology
CI08	Male	Consultant	Medical Oncology
CI09	Male	Consultant	Medical Oncology

6.3 Overarching theme

Three themes were generated from the analysis of the interviews and are presented: fatigue is challenging to assess; the interaction of fatigue with treatment decisions; and examining the role of doctor in managing fatigue. Sub-themes were identified from the findings and were grouped into themes. These three themes coalesced to form an overarching theme: fatigue is perceived as different (see Figure 6.1). Fatigue is perceived as different identified how: fatigue was different to other cancer symptoms; differently experienced and tolerated from person to person; this mirrored the patient theme fatigue is perceived as different to tiredness and other experiences.

Figure 6.1: Fatigue is perceived as different

Theme	***Sub-theme***
Fatigue is challenging to assess	Fatigue is individual and subjective Fatigue is hard to articulate Fatigue is complex to unravel and understand
Fatigue interacting with treatment decisions	Adjusting fatigue approach to treatment goals and disease response Balancing fatigue with the patient's priority for survival Negotiating treatment changes because of fatigue
Fatigue challenges the role of the cancer doctor	Feeling unsure about giving advice for fatigue Resigned to limited treatments for fatigue Facilitating the normalisation of fatigue

6.3.1 Fatigue is challenging to assess

Fatigue is challenging to assess identified how clinicians often had trouble determining the experience of fatigue in the individual. This theme was comprised of sub-themes: fatigue is individual and subjective; fatigue is hard to articulate; and fatigue is complex to unravel and understand. All clinician participants in the interviews mentioned how they routinely found fatigue challenging to assess in patients with advanced cancer. Although fatigue was considered the most common symptom they encountered in their day to day clinical practice, it was generally viewed as the most challenging symptom to decipher and assess. Clinician participants mentioned certain characteristics and some unique qualities in fatigue that were deemed relevant to the difficulty in assessing it. These included: the individual and subjective nature of fatigue; the language used to communicate the experience of fatigue; and not fully understanding the biological causes of fatigue and needing to unpick the many contributory causes of fatigue in individual patients.

6.3.1.1. Fatigue is individual and subjective

Fatigue is individual and subjective identified that fatigue was perceived as a unique symptom because how fatigue was tolerated and experienced amounted to huge variations among individual patients. Nearly all clinicians considered fatigue an almost inevitable consequence of cancer treatments and progressive disease but the variability in how patients experienced and coped with fatigue occasionally confounded them. Hence, fatigue was often viewed by clinicians as a subjective and individual symptom. A few believed fatigue might be acceptable to patients which meant it could be underreported unless severe.

> *CI02, Page 2 – I think it's (fatigue) a particularly common symptom, but one often that the patients don't mention unless you ask them about it. Because they see it as part and parcel of either having cancer or the treatment, because it's a common side effect of the treatment and also a common effect of having cancer itself. So I think it does affect people, but perhaps they don't mention it so much, unless you ask about it or if it's affecting them quite significantly.*

Some clinicians explained that fatigue meant different things to different people and this distinction between individual patients occasionally made it difficult to assess and objectively measure. For example, limited activity in an individual could just represent their normal baseline and a mobility aid did not always equate with fatigue. Conversely, an assumption could not be made that an individual with good activity levels and managing all activities of day-to-day living was not fatigued.

> *CI02, Page 2 – But there are some patients who've been used to functioning at a very high level for example, who really find it difficult, even with a small level of fatigue, to adjust their lifestyle, because they feel like they're having to give something up or make changes because of the cancer, and it's that loss of control I*

> *think they don't like. For example I saw a patient recently who told me his main problem was fatigue, but when I spoke to him, he was actually going to the gym every day. So people's definitions of fatigue and how it affects them are very different as well, and does depend on their level of functioning previously I think.*

Many viewed fatigue as more difficult to assess in comparison to other symptoms due to the subjective and individual nature of it. Clinicians commonly assessed symptoms in their day to day clinical practice by grading the severity as if the patient were on a clinical trial but often this felt more difficult with fatigue. A few clinicians compared fatigue to pain, another subjective symptom, but where a defined set of questions made it easier to categorise pain and numerical scoring could better illustrate severity and response to therapeutics.

> *CI01, Page 29 – There's that subjectivity of it (fatigue), the difficulty in measuring it. Almost all of the other side effects, they're much more measurable, they're much more sort of, if you're vomiting this many times a day, that's severe, if you've got diarrhoea this many times a day, that's severe. But the fatigue's a bit more woolly, and it's much more… And I think that's probably because it's much more tied to quality of life, and your ability to do stuff that divides those things away. And that's kind of difficult. Unless you're sort of saying well can you do this? Like a specific functional thing that you would say oh yes, can you do this. But, you know, a lot of patients will go I don't do that anyway…*

Most clinicians used the WHO or Eastern Cooperative Oncology Group (ECOG) performance status (PS) tool to assess fatigue and some felt the score was often a surrogate marker for measure of fatigue. However, it was also considered a blunt assessment tool as other symptoms could account for poor performance status and therefore further questioning was necessary to explore the reasons for functional impairment. Some clinicians routinely preferred to enquire about function rather than fatigue as this provided the more useful and essential information to assess fitness for treatment.

> *CI05, Page 3 – I mean it (fatigue) is difficult to assess. Our, our very basic measure is our sort of performance status. So I usually say to them, or the way I say is how much of the day do you spend sitting resting, and how much of that are you dozing off. And that really comes from trying to work out the performance status. But*

> *that's, that's the only real way I know of asking about it. (…) But that, it's very crude, and I mean we all know that one person's performance status one is somebody else's three. So it's not a great way of assessing it.*

However, some clinicians also mentioned that measuring the performance status for fatigue could be flawed because it did not eliminate the subjective and individual nature of fatigue. Specific fatigue assessment tools were sometimes postulated as potentially improving the assessment of fatigue but this was usually quickly followed up as being unrealistic to perform in a busy clinic environment. A few clinicians talked about needing to understand the baseline or previous activity levels of the patient and performing a longitudinal comparison to assess fatigue.

> *CI09, Page 4 – So I haven't got time to sit there for hours doing some score (fatigue). I'm just saying that, so the reality is is that, you know, it's (fatigue) not well assessed. And you know, you're right, the WHO performance status is a useful tool, but I don't have any follow-on from that. You know, some people are just completely inactive anyway. What do you do? Watch TV. But that's how some people live. (..) You would monitor for decline. So change in performance status is key.*

6.3.1.2. ***Fatigue is hard to articulate***

Fatigue is hard to articulate was defined as difficult to communicate and assess. In comparison to other symptoms, clinicians found the assessment of fatigue more challenging because the experience of fatigue was difficult to communicate and define. Some noted that patients used many different descriptors to explain their experience of fatigue which could be influenced by variations in dialect, culture and education. Occasionally the range of language for fatigue made it difficult for clinicians to comprehend and define in clinical practice. Fatigue with visible signs of weakness was felt to be much easier to communicate and measure.

> *CI01, Page 4 – But it's quite a difficult, it's often quite difficult for, or I feel it's quite difficult for the patients to articulate what their fatigue is like, unless it's very severe. And it's often hard for us to tease out how severe someone's fatigue is from*

> *their description. It's much… In a way it's more helpful when the patient comes to clinic and they're unwell, because you can see them and go oh yes, that is how unwell you are.*

Occasionally, clinicians could feel misunderstood during the assessment of fatigue where they felt they were not speaking the same language as patients and this could make it difficult to measure. Therefore, some clinicians thought carefully about how they talked about fatigue to ensure effective communication and that they were fully understood by patients. A few clinicians noted how relatives could influence the communication and assessment of fatigue.

> *CI01, Page 9 – And that's the difficult thing with the fatigue thing, trying to get them, there's not a measurable thing with the tiredness or the fatigue that they can say. And I tend to, and perhaps that's also why sometimes you have those conversations where they've come in with their spouse and you say did you feel tired since your last treatment? And they go not really. And then the spouse chips in and says well you hardly did anything the first few days, you sat in a chair, you dozed off at the slightest provocation. And they go oh yeah. As if it hadn't occurred to them that that was tiredness. But you also don't want to say sleepy or drowsy, because those sorts of things, again they mean different things. So you kind of end up asking the same question three or four different ways, to try and make sense of that.*

Most clinicians used fatigue and tiredness interchangeably in their interviews. A few clinicians translated the experience of fatigue to extreme levels of tiredness. However, several clinicians mentioned how there was a significant difference between the experience of fatigue and tiredness. One clinician felt she understood fatigue from her own personal experience with cancer treatments and pregnancy which helped her to understand the experience. She believed fatigue was difficult to articulate and this may have had an influence on how she assessed fatigue.

> *CI04, Page 23 – I would think perhaps that tiredness, you then go to bed and have a good night's sleep and you wake up refreshed. I don't think fatigue is always relieved by sleep. It's different. And I think, I think we really don't have very many*

> *words for it, or descriptors for it. I tend to, I tend to use the phrase, you know, when your get up and go has got up and gone. And try and describe the kind of, I don't know, maybe you quite fancy a cup of tea, but you just haven't got the energy to go down, go downstairs and boil the kettle. Just the energy to kind of do something. I think it's difficult to, I think it's probably different for different people, and I think it's difficult to describe.*

Two clinicians were less concerned about the language used to articulate the experiential nature of fatigue and the challenges this contributed to assessing it. They suggested a preference for routinely assessing fatigue by exploring functional ability rather than exploring the fatigue experience.

> *CI05, Page 5 – I've never really thought about there being a difference between fatigue and tiredness! So I therefore wouldn't have tried to figure out what the difference was! Yeah, do I specifically ask about fat… I don't know what words I would u… What words would I use? Do you feel… It's not so much I ask do you feel tired or fatigued, I would say what are you doing. You know, I would ask them about their functionality, rather than do you feel tired or do you feel fatigued.*

6.3.1.3. Fatigue is complex to unravel and understand

Fatigue is complex to unravel and understand related to the difficulty in comprehending the wider causes of fatigue. Many clinicians believed that it was complex to decipher and fully comprehend the causes of fatigue in advanced cancer which contributed to it being difficult to assess. Clinicians outlined that treatment-related fatigue had a 'chronological type pattern' which was predictable after receiving cancer treatments and this was the case with chemotherapy or radiotherapy. Once fatigue matched this recognised pattern then some considered that it was more straightforward 'to lay the blame a bit more' towards the cancer treatments. However, the presence of an underlying baseline of constant fatigue made it more difficult for the clinician to account for fatigue.

> *CI04, Page 3 – I think it's difficult to unpick what's causing it (fatigue)… I think that for most cancer patients it's that their energy levels just aren't such that it impacts on their ability to get out and do the things that they want to do. And I guess quite often it's, particularly with treatment, it's, it's a time within each cycle*

> *of chemotherapy. So that's relatively easy to describe. The rest of it is, is rather harder. And why, you know, why it should be so much worse in some women than others is really difficult.*

Often clinicians believed it was difficult to deduce how much of cancer and cancer treatments were each contributing to steadily worsening fatigue. Some felt that this diagnostic uncertainty usually resolved over several clinic visits and cycles of cancer treatments when other pieces of clinical evidence came to light from blood tests or radiological scans. For example, in clinician's minds, rising blood markers for cancer activity and disease progression on a scan pointed towards cancer as the predominant cause for fatigue. Many recognised the inevitability of severe fatigue developing in patients with advanced disease which ultimately led to the cessation of cancer treatments.

> *CI06, Page 21 – Well eventually it does (become clearer in time), because it's the cancer that's causing most of it (fatigue), and they stop treatment! So in that respect it becomes clearer, but I think it's, when you've got somebody on treatment in the metastatic setting, I think it's difficult to pick out how much of it (fatigue) is the cancer and how much is the chemo.*

Fatigue was sometimes viewed by clinicians as more complex than other symptoms because of the relationship between fatigue and the psychological well-being of the individual. Patients who were overly concerned or anxious about their cancer were occasionally considered to complain more about fatigue in comparison to those 'who just get on with living their lives'. One clinician also explained about the manifestation of fatigue as a symptom of depression.

> *CI07, Page 13 – What I forgot to mention, because I just thought of a patient recently, is that of course we mustn't forget about depression. Fatigue could be a symptom of depression. So I do, I do explore that if I think… Which is exactly what happened to this patient recently, and she was feeling very sad, and we kind of talked through that. So I am mindful of that, that that is quite common in our patient group.*

A few believed that fatigue in advanced cancer needed to be assessed by a senior experienced clinician because of the complexity in understanding the nuances of it. Several clinicians felt the causes of fatigue were often multifactorial and were rarely simply understood by a single reversible cause. Different disease processes were considered to have important contributory causes for fatigue such as nutritional deficiency in hepatobiliary cancers. There was also a feeling amongst some clinicians that the underlying biologically processes of fatigue were not yet fully understood and further research in this area was necessary.

> *CI09, Page 12 – Medicine's moving away from the model where only the doctor can decide what to do, but the reality is is that only a doctor, particularly a senior doctor, is likely to be able to put the different strands together into the bigger picture. And that's the difficulty now, is that you say well everybody jumps up and down says oh, it's the anaemia, you know, a blood transfusion, chuck in a litre of someone else's blood. And funnily enough the problem's still there. It takes a little bit more than that. So I think it's a consultant-led thing. And I think it's, I think the future is understanding it a bit more, the process. Because nobody knows why we're tired.*

6.3.2 The interaction of fatigue with treatment decisions

The interaction of fatigue and treatment decisions revealed how fatigue was associated with cancer treatment decisions in day to day practice. This theme comprised three sub-themes: adjusting fatigue approach to treatment goals and disease response; balancing fatigue with patient's priority for survival; and negotiating treatment changes because of fatigue. All clinician participants mentioned how fatigue routinely influenced and interacted with treatment decisions in their clinical practice. Both the intended goals of treatment and likely response of the cancer to cancer treatments were described by clinicians as important influences on their approach to fatigue on treatment decisions. Clinicians recalled how patients with fatigue approached treatment decisions based on their weighted priorities of survival and quality of life. In addition, it was felt by clinicians that treatment changes because of fatigue occurred frequently and sometimes required careful discussion with patients.

*6.3.2.1. **Adjusting fatigue approach to treatment goals and disease response***

Adjusting fatigue approach to treatment goals and disease response revealed how clinicians routinely changed their management of fatigue on cancer treatments depending on stage of disease and cancer type. Clinician participants in this study routinely cared for patients in the curative and palliative setting within the same outpatient clinic and many outlined their contrasting approach to fatigue for these patient groups. In the curative setting, the goal of treatment was to cure and clinicians aimed to give the maximum dose intensity of treatment while they minimised the risk of serious and life-threatening side effects. They perceived severe levels of fatigue were an acceptable consequence of curative treatment and some mentioned how they might encourage patients to tolerate severe levels of fatigue. Many clinicians described how they rarely reduced curative treatment solely for fatigue and only when associated with other side effects.

> *CI05, Page 8 – It's not so much that the fatigue will necessarily go away, because it doesn't always go away, but it's, you know, it's sort of a price that I think is more worth paying if you're going to have an extra 30 years of life, to be a bit... Especially, you know, they are most tired over the period of treatment. So you think right, well this is a short term pain for a long term gain. Whereas there isn't a big gain if you're, you know, sleeping for six months on chemotherapy and you're only going to live two years. So just the risks and benefits, you know, the sort of ratio of pros and cons is way more in the favour of the curative ones, so that's why I don't tend to dose reduce for fatigue if they're curable.*

However, in the palliative setting, clinicians often expressed that the goal of treatment was to improve symptoms and extend life while maintaining quality of life. They viewed fatigue as an acceptable side effect of treatment until it impeded on quality of life or resulted in functional impairment, thereby prompting a discussion around treatment goals with the patient. Clinicians described having a lower threshold to reduce or modify the treatment regimen based on the level of fatigue described by the patient. In certain circumstances, they would consider stopping chemotherapy or withdrawing treatment altogether.

> *CI02, Page 9 – With any treatment that you're giving, the point of a palliative treatment is to prolong life and improve symptoms. So in that situation, you know, if the treatment is really causing them significant fatigue, a dose reduction in their treatment is very reasonable, you know, and it's a perfectly good reason to reduce a dose of chemotherapy. Because you know, if you're making the patient take to their bed for a week because they're exhausted and can't do anything, then what advantage is the chemotherapy really giving, if they've got no quality of life for a third of their time?*

However, the palliative treatment goals outlined by clinicians with respect to fatigue differed in emphasis and were reflected by the cohort of cancer groups they usually treated. Some clinicians who cared for patients with advanced pancreatic and bladder cancers were particularly keen on maintaining sufficient energy for quality of life purposes during treatment as fatigue was predicted to worsen as treatment progressed. They perceived these patients often had fatigue on commencing cancer treatments and were less optimistic about the benefits, believing the gain in survival was modest. Fatigue that caused significant functional impairment also had an implication on the patient's fitness for commencing or continuing with treatment.

> *CI09, Page 6 – If somebody's not fit, then, they're not up and about as per normal and feeling well, then I won't treat them with chemo unless I think they'll get better. So… but that's how I do it. It's a balance there. Where some people whose tumours are cause… you know, fatigue is a major issue, and it will get better with treatment. But if you're so fatigued you can't function, chemo will only make you less well, and won't improve your quality of life. So I don't usually use it in those situations, unless there's a highly chemo response disease, which will be helped with treatment.*

Some clinicians viewed fatigue as different from other symptoms that could improve with palliative treatments as the cancer treatments themselves could cause fatigue which added further uncertainty and complexity. Clinicians who cared for patient groups with breast or colon cancer were more hopeful of cancer treatments improving fatigue once the disease burden receded. Some expected these patients to potentially live for years, sometimes many years, and experience a pattern of relapsing and remitting fatigue related to disease and cancer treatments. One clinician talked about sharing with patients the uncertainty of whether fatigue could improve or worsen in treatment decision discussions.

> *CI06, Page 3 – And if patients do describe, and lots of them do, you know, excessive fatigue at the beginning, then often I'll say well, you know, it sounds a little bit daft that you're going to give chemotherapy, and it actually may get better, but it doesn't for everybody. But a significant proportion it will get better once you start treating the cancer. But for some patients, and I, that's where I struggle, I don't know how to predict which ones will get better and which ones won't. So some patients you give the chemotherapy and it actually gets worse as the treatment goes on, because the chemotherapy causes it.*

*6.3.2.2. **Balancing fatigue with patient's priority for survival***

Balancing fatigue with patient's priority for survival was defined as clinicians respecting the individuals wishes with respect to treatment and quality of life but balancing these goals of palliative cancer treatment when necessary. Clinicians perceived patients as the arbitrators of quality of life and in their experience, there was a spectrum on how patients weighted the importance of quality of life against survival. Fatigue was viewed as synonymous with quality of life because having low levels of energy impeded on an individual's ability to maintain and enjoy family and social activities. Some clinicians revealed stereotypes from their clinical experience of older patients refusing treatment based on a belief that they had had a 'good innings' and younger patients with young families exhausting every treatment option for 'more time'. However, clinicians understood that any individual patient could be part of this spectrum and sometimes this could only become apparent as fatigue worsened and the illness progressed.

> *CI04, Page 7 – So I've recently had a patient who would have prioritised survival over absolutely every aspect of quality of life, that any, all of us were looking at her thinking this would be not acceptable to me. But to her survival was the only thing she really wanted to work for. And there are other women who are completely the other end, and say, you know, this is, you know, I want good quality of life, I don't, I don't want to be messed around any more than that.*

Although all clinicians mentioned they had cared for patients who had prioritised survival over severe levels of fatigue, they differed on how often this occurred in clinical practice. Clinicians who cared for patients predominantly with chemo-insensitive disease felt it was common for patients to tolerate severe levels of fatigue for modest gains in treatment. However, other clinicians, particularly those treating chemo-sensitive disease, felt it was rare to encounter similar patients. A few felt that a patient's psychological need to have treatment could dampen the perception of worsening fatigue and the realisation in the patient may only occur later when treatment had stopped.

> *CI07, Page 8 – And it's that, that need for treatment, and putting up with stuff, just sort of seems to outweigh the fatigue aspect of it. (…) And I think there is evidence in the literature that patients are prepared to put up with a huge amount of toxicity (fatigue) for relatively modest gains in treatment. And that's certainly the case with the cancers that I treat. I would say the gains are incredibly modest, but you know, I think patients will put up with that. I don't think perhaps at the time that they sign up they realise the costs, but they don't have another one of them to compare themselves to, do they? And I think that gets lost, doesn't it.*

Some clinicians talked about attempting to rebalance a patient's goal of treatment when they believed fatigue was becoming too onerous and burdensome on quality of life. This occurred when they felt there was a possible disconnect between the clinician's goals of treatment and the patient's goals of treatment. A few clinicians, particularly those who primarily cared for chemo-insensitive diseases, mentioned about reflecting on the goals of palliative treatment with patients and exploring how fatigue might be interfering with quality of life.

> *CI01, Page 14 – I'm always very keen to emphasise to the patients that the purpose of the treatment for that is to preserve their quality of life, and so if their, if their side effects are getting in the way of doing things that are important to them, and that includes fatigue, then those are things we need to think about, we need to think about the sense of continuing with the chemotherapy, or continuing with it as it is, if that's the case. And sometimes when we're talking about these symptoms, about how tired people have been, I do sort of say well, you know, let's talk about why we're giving you this treatment. Because again there's that disconnect*

> *between us saying well the purpose of the treatment is to help with your symptoms, quality of life. It may add time, but that's sort of almost a secondary importance, because that's not the only reason.*

In general, clinicians offered palliative treatments to patients with fatigue when they felt it was reasonable to do so and patients had the autonomy to decide on whether this had implications for their quality of life. In other words, if the patient with fatigue was deemed to be fit enough for treatment, the patient had the choice of commencing or continuing with treatment. Therefore, individual patients who might tolerate levels of fatigue that a clinician deemed to be interfering with quality of life but not with fitness for treatment could proceed as to their preferred goals of care.

> *CI04, Page 8 – But if there are treatments available, and that's what a patient wants to have, I don't think it's my job to say no, that quality of life (fatigue) for you is unacceptable to me. I think breast cancer is unusual in cancer treatments, in that we've got so many lines of therapy, that discussing when you come to an end, in patients who are fit enough to make that decision, you know, it does sort of happen.*

6.3.2.3. ***Negotiating treatment changes because of fatigue***

Negotiating treatment changes because of fatigue identified how cancer treatments were adjusted to lessen the burden of fatigue. All clinicians mentioned that it was common in their clinical practice to reduce, adjust or withdraw palliative cancer treatments for reasons related to fatigue. Some outlined the strategies that they used in their clinical practice to prepare patients in advance for this review of treatment discussions and to help gain agreement. A few mentioned vaguely introducing the idea that the treatment dose or schedule may alter in the future to get the best balance of quality of life, with energy to do family and social activities, and disease control. Others appeared to be more forthright with patients about how worsening and disabling fatigue would lead to treatment cessation.

> *CI09 Page 17 – So what I normally say to patients who are starting, if they're not 100%, is look, we'll give you the treatment, but you have to either be better or the same each time you come. If you're getting worse, despite the treatment, it's to stop. So fatigue is now disabling, you're unable to function, it's not worth it.*

Clinicians had different views and experiences on how they adjusted chemotherapy doses when fatigue was negatively affecting quality of life or causing a deterioration in functional ability. Some clinicians reduced the chemotherapy drugs in the treatment regimens. Others preferred to adjust the treatment schedule by omitting a treatment dose to allow more time to recover between treatment cycles. A few clinicians believed that patients felt obliged to continue with treatment and needed permission to reduce which was sometimes met with relief.

> *CI07, Page 13 – And I think patients need to be given permission, and so I give them permission to have a week or two off, to allow them to experience what it's like to be off treatment, to see if they can regain back a bit of reserve. And then I can say to them look, you know, you're now feeling a lot stronger again. And what I tend to do is modify the schedule rather than the dose. I might say look, you know, rather than having three weeks and one week off, you could have three weeks and two weeks off, or you know, kind of, I make it up a little bit, you know. But in a way I'm trying to juggle that thing for them.*

However, when a patient was on a clinical trial, the clinician generally had less flexibility to alter the treatment regimen when fatigue was deemed to be affecting quality of life. Most clinical trial protocols restricted an alteration in the treatment dose or schedule until fatigue interfered with fitness for treatment.

> *CI08, Page 6 – For most of our (clinical trial) protocols, unless they had grade three fatigue, which is pretty limiting, i.e. spend most of the time probably on the couch or in bed, then you're not, you're unlikely to reduce the dose on that basis.*

Most clinicians regularly recalled examples of patients resisting their recommendations for reducing treatment for fatigue because of relayed concerns about how this would interfere with treatment effect on survival. Some felt that achieving agreement for treatment dose reduction was much easier when there was additional clinical evidence, such as a low white cell count or platelets, to indicate this treatment decision was necessary. Several clinicians regularly gave reassurance that reducing treatment would not lessen treatment effectiveness and one often quoted supportive research evidence.

> *CI05, Page 9 – They quite often say that (survival is more important), but I often quote, so Mandy Birch is one of the medical oncologists who does lots of chemotherapy research, and she (..) published a paper looking at a big cohort of, they'd done all the adjuvant colon trials. And they looked at those that were dose reduced versus those that hadn't been dose reduced, and they did equally as well. So I often quote that to patients, to say listen, in those who genuinely need a dose reduction for a symptom, they don't do any less well, so please don't feel worried about reducing a dose. Because they quite often are worried about that.*

Some clinicians mentioned how treatment decisions for fatigue, particularly for treatment cessation, were often agreed over several clinic visits. Sometimes there was uncertainty about the cause of the fatigue but severe functional impairment meant treatment could not be safely continued. A strategy that some clinicians used was to outline how fatigue may improve off treatment and therefore add a potential positive outcome to an otherwise negative discussion. If persistent resistance to treatment cessation was encountered, one clinician would explain that further treatment would shorten life rather than prolong it.

> *CI01, Page 22 – He was very tired, very fatigued, as in, he's one of those ones that say oh yeah, yeah, I'm fine. But he'd lost an awful lot of weight, still losing weight, and his wife was like no you're not! He'd been sleeping all the time at home. And I said look, I can't tell whether you're tired because the cancer or tired because of the chemotherapy, and it could be either. But I said you're not well enough for me to give you chemotherapy anyway, and taking away the chemotherapy, it often makes people feel better anyway, because we're no longer poisoning you, and actually a surprising number of people do feel better when we stop their chemotherapy, at least initially.*

6.3.3 Fatigue challenges the role of the cancer doctor

Fatigue challenges the role of the cancer doctor represented the difficulty and disappointment that clinicians perceived about managing fatigue in clinical practice. This theme comprised of: feeling unsure about giving advice for fatigue; resigned to limited treatments for fatigue; and facilitating the normalisation of fatigue. Nearly all clinicians described feeling somewhat subdued or constricted when patients they cared for were fatigued. It was common for clinicians to feel uncertain about giving advice for fatigue and this centred around the general nature of this advice and whether doctors were best placed to give it. Clinicians often described the limited treatment options for fatigue in comparison to other cancer symptoms and a lack of support services to signpost patients. In general, clinicians talked about how they routinely normalised fatigue with patients as they expected fatigue to occur on treatment and as the disease progressed.

6.3.3.1. Feeling unsure about giving advice for fatigue

Feeling unsure about giving advice for fatigue was defined as clinicians feeling hesitant about giving advice for fatigue. Some clinicians mentioned they regularly gave advice for fatigue but felt somewhat uncertain about the credence and benefits of this advice. A few suggested the scientific evidence to support exercise for fatigue in the adjuvant setting but found it was difficult to transfer this to practice. They felt it was even more challenging to transfer this to the palliative setting as exercise was felt to be too burdensome. Sometimes clinicians substituted advice on exercise for social activity that benefited quality of life and encouraged patients to do an activity that was balanced to their fatigue pattern and energy levels. A few recalled giving advice on conserving energy and adapting to new physical self while also encouraging self-management. However, it was common for clinicians to feel unsure about giving advice for fatigue.

> *CI01, Page 20 – We tell them gentle exercise helps (..) The fantastically unhelpful advice of gentle exercise is helpful, but try not to do too much, without defining what too much is. Because often people describe where they're quite active one day, wake up, think oh, I feel really good today, do loads of stuff. And the next day they feel like they've been hit by a truck, because they've kind of done too much. But we can't, but we don't define what too much is, because we can't, because it's very different. And so yeah, so we often tell patients this advice, and even when I'm saying it I'm thinking this is not particularly helpful.*

A few clinicians described feeling less confident about giving advice for fatigue and believed other healthcare professionals were better placed to do this. Physiotherapists or occupational therapists were often viewed as more suitable for giving advice on exercise and explaining adaptive behaviours for fatigue. A few perceived their role as providing expertise on cancer treatments and screening for reversible causes of fatigue but not for providing a holistic assessment or giving advice which could best be given by another healthcare professional.

> *CI03, Page 4 – if it's (fatigue) related to either multifactorial, for things that you can't treat, or mild anaemia, mild whatever else it is, there's not really a lot of options we can do, other than treat them with steroids to see if they improve, or try and give them some kind of holistic advice, which I wouldn't say as a clinician I'm particularly good at. I might refer them on to other people, like the OTs or physios, to give them advice, but I wouldn't say I'm particularly good at doing that, in terms of how they manage their fatigue, how they cope with their fatigue.*

The uncertainty around how to define and manage fatigue was viewed by some clinicians as reasons to believe that other healthcare professionals might be better at giving advice for fatigue. Some clinicians identified themselves as problem solvers and revealed they struggled to manage fatigue when contributory causes were indeterminable or unfixable. Fatigue was perceived by some as an ambiguous symptom with no set formula or simplified process to manage or advise which made it difficult to address in a busy cancer clinic environment.

> *CI04, Page 14 – On the whole, I think nurses would be better placed to do that (give advice for fatigue). I hesitate to say they're nicer, but they are probably. I suspect that doctors… Doctors like to know what a problem is, what caused the problem, and what to do to make it better. And in anything which is as woolly as fatigue, I think doctors don't like that, I think we tend, you know, if we can't even blame it on a virus we particularly don't like it, and if we can't blame it on a virus we quite like to blame it on the patient. And so I think with the kind of very soft woolly things, of course there are doctors who can do it brilliantly. On the whole, in pressurised clinics, I think probably that's not something that we're going to do very well. Unless it's very set advice.*

Some clinicians felt that even if there were some specific set advice for fatigue, that might involve some training, they would still struggle due to time constraints and oversubscribed clinics. They felt outpatient appointments were concerned with reviewing the tolerability and effectiveness of cancer treatments while also screening for symptoms that assessed the stage of the disease.

> *CI07, Page 28 – I just can't see how we would (give set advice for fatigue), even if we really wanted to do it, I don't see how we would actually be able to deliver it in a 20 minute consultation, which predominantly focuses around chemotherapy and, plus general screening. That's I think pretty much what I do, is general screening for issues and then signposting to the right place. And I can't see how we could do that.*

*6.3.3.2. **Resigned to limited treatments for fatigue***

Resigned to limited treatments for fatigue identified that clinicians felt there was very little they could do for fatigue in comparison to other common cancer symptoms. Clinicians approached fatigue by assessing for potential reversible causes; however, they felt this was more difficult to turn around in advanced disease. They believed the treatment options for fatigue were very limited once there was less scope to adjust or administer cancer treatments. In general, they listed the treatments as a transfusion for anaemia and a single drug treatment option. Practical strategies for fatigue were not viewed as treatments per se and were more akin to general advice. Sometimes fatigue was contrasted with other symptoms, such as pain or nausea, where identifying a definitive cause might be easier and more effective drug treatment options existed.

> *CI09, Page 7 – I think one of the difficulties with fatigue it's a multifactorial, there's lots of different components to it. (..) And suddenly you end up with a situation where it's actually quite complex to pick out the thing you can treat. Now in those situations you often end up with either giving a blood transfusion or steroids. But there isn't anything else. You know, stimulants and stuff like that don't make much difference. So you're kind of in that situation, so the treatments are just rubbish, and that's one of the problems of fatigue. But it's also really complex, so it isn't just that, you know, unlike nausea which you might say well actually if it's chemo related you just chuck a nausea drug in. There aren't those types of drugs for fatigue available that I'm aware of.*

Most clinicians considered a short trial of steroids as the only drug treatment option for fatigue but clinical experience and practice varied. A few clinicians recalled drug treatment options that they previously used with some limited success (i.e. Megestrol, Melatonin and Modafinil) and a sentiment of regret was expressed that research proved these drugs to be ineffective. Some clinicians rarely prescribed steroids solely for fatigue but in conjunction with other symptoms including poor appetite. Steroids were mostly viewed as a short-term treatment due to concerns of harmful side effects such as proximal myopathy.

> *CI07, Page 21 – I tend not to use steroids as a way of trying to boost energy. Yet for some people it can do that. And I always have concerns about steroids, the long-term use and the problems with myopathy and things, and that can develop quite quickly. I'm just not sure that that intervention is worth it sometimes. At a stage when the patient is reasonably fit… is still functioning and not resting all the time, it would be a shame to wipe them out with steroid myopathy. And I've seen it, some pretty awful cases of that.*

In general, clinicians found fatigue more problematic when they perceived it to be untreatable and this was often associated with hopelessness. Many felt more at ease by being able to do something, such as recommending or prescribing a drug treatment. Moreover, one clinician felt patients were expectant of this role from their doctor and were therefore only interested in drug therapies for fatigue. However, fatigue deemed untreatable created a sense of inaction and this led to frustration or resignation in some clinicians. This resulted in clinicians focusing on issues and symptoms other than fatigue which they felt could be addressed more successfully.

> *CI05, Page 15 – If you've got somebody who comes to see you and you've got 10 minutes to assess them, you're going to ask about the things that you can change. So you ask about sickness, you ask about neuropathy, you ask about things that you can manage, or symptoms that you can manage. You know, have you got any bleeding? Because I can fix those things. But if I can't fix fatigue I'm not going to spend a large proportion of my short clinic asking about it, because you know, if I don't have any good reversible things, then… Yeah, I don't. So I think if we did know more about how to fix it, or how to manage it or assess it, whatever, then it might go higher up on the list of priorities, totally.*

Many clinicians felt that fatigue contrasted with other symptoms as there were limited signposting options to support the patient with fatigue and this enhanced the sense that nothing could be done for fatigue. Most believed this was unlikely to change in the foreseeable future due to limited personnel resources in oncology care. One clinician was sceptical that a patient he referred to specialist palliative care services for end-of-life care would receive anything other than a trial of steroids. Although one clinician talked about the possibility of referring to other services, many did not feel such services were available or suitable for patients with fatigue.

> *CI03, Page 11 – And actually pain is a good example, that we can do very basic things, and if we struggle with that we've either got the palliative care team… to manage it at a higher level, or we've got the pain team to manage it. Fatigue, we don't really have anything that we could at the moment really do. We can maybe send them to Maggie's or we can maybe send a few physios, but there's no kind of set things of this is what you can do for it.*

6.3.3.3. Facilitating the normalisation of fatigue

Facilitating the normalisation of fatigue was defined as clinicians seeing their role as providing reassurance to patients that fatigue is a normal and acceptable experience on palliative cancer treatments. Many clinicians explained how they usually normalised fatigue during treatment decision discussions by mentioning how it was the commonest side effect of cancer treatments during the consent process. In the adjuvant setting, fatigue that limited function was sometimes deliberately normalised with the aim of increasing tolerability and acceptability. However, in the palliative setting, some clinicians were explicit in how they both normalised and problematised fatigue. They sought an equilibrium where fatigue did not impede on quality of life for the entire duration of the chemotherapy cycle, with 'more good days than bad days'. Some also normalised fatigue by sharing first-hand accounts from other patients which possibly encouraged the acceptance of fatigue.

> *CI07, Page 7 – It's constantly reported by my patients that they get fatigue for 24, 48 hours after each intravenous dose, which is on a weekly basis. So yes I do prepare patients for that. You know, that the likelihood is that their fatigue might, might worsen on chemo. And that there's also cumulative effect of it. So there's*

> *the short term effect, 48… 24, 48 hours, but as the weeks and months go by that can build up. But I also say to patients that surprisingly a lot of my patients seem to accept it and get on with it, because they've weighed up the pros and cons of having treatment.*

Most clinicians believed normalising fatigue related to treatment and cancer could offer reassurance to patients who might otherwise be concerned or worried about it. Normalising fatigue was closely linked by some with giving permission to patients to listen to their bodies, resting when necessary and being active when able. It was also deemed helpful when discordance occurred between the patient and family about how to manage fatigue, whether the family was being overprotective or overburdening.

> *CI02, Page 5 – And I think with patients (..) to say that fatigue is so variable, and it could be day-to-day. Because I think part of the frustration is they come and they go well I was really well yesterday and now I'm not well, and it's really worrying, because yesterday I felt I could do anything and I had lots of energy, and today I can't. And just saying well you will, you will have days like that, that's perfectly normal, you know, there will be some days that you won't feel like doing anything, and just, you know, use the good days to do the things you want to do and just allow yourself to rest on the days that aren't so good. And unfortunately we can't tell you when they'll be! But it's normal, and I think knowing that it's normal is helpful as much as anything else. (..) Because otherwise people panic, because they have a bad day, think oh no, it's getting worse, the cancer's getting worse.*

Several clinicians mentioned a range of contributory causes for fatigue other than cancer and treatments which helped them to facilitate the normalisation of fatigue. A few clinicians routinely explained to patients that the treatments had aged them over a shorter length of time than would otherwise have been expected and this required adjustment to their new normal. This was particularly evident in disease groups where treatments pre-maturely induced sex hormone depletion. Other contributory causes for fatigue included frequent visits to the hospital for appointments and treatments coupled with typical busy family life. One clinician felt that fatigue was expected with increasing age and adjusted patient expectations.

> *CI03, Page 9 – I mean some of the fatigue… particularly with the prostate group… because of their age and the fact they're getting older, and also some of it is about the fact that as we get older we don't sleep as much as we do when we're younger, and some of it is these men with prostate cancer are troubled by waking up in the night to go for a pee. So to a certain extent the fatigue that they feel in the day is related by and large to age, as well as… things that happen to them because of their cancer… I think it's having those kind of conversations with them about what their expectation of fatigue or tiredness is, because… they just have to adapt their lifestyle as they get older anyway, or they have to accept that certain things are going to happen to them.*

A few clinicians mentioned how they routinely normalised progressive fatigue in end-of-life discussions with patients to offer reassurance about the dying process. Many associated constant extreme fatigue as a pre-terminal sign in patients no longer fit enough for cancer treatments and some felt this could lead to end-of-life discussions.

> *CI05, Page 25 – They often say so what's going to happen (at the end-of-life)? And I'll say well usually it's just you getting gradually more t… Well I always use the word tired, but tired. So one week you'll just be having a sleep for two hours in the afternoon, then the next week actually you'll have a sleep in the morning, and the next week you'll spend a bit more of the time in bed, and then you won't be able to get out of bed, and then… (..) And I'll say well actually that's what's likely to happen before you die, is you'll just get more and more tired, until you can't do things for yourself.*

6.4 Chapter summary

This chapter has presented the findings from the clinician interview study. One overarching theme was identified from the interview data: fatigue is perceived as different. The overarching theme comprised three themes: fatigue is challenging to assess; the interaction of fatigue with treatment decisions; and fatigue challenges the role of the cancer doctor.

The theme 'fatigue is challenging to assess', highlighted the difficulties clinicians had in assessing fatigue, in comparison to other symptoms, in patients with advanced cancer. This theme consisted of three sub-themes. The first sub-theme was 'Fatigue is individual and subjective', and this presented how clinicians found the experience of fatigue so variable between patients and sometimes unique to the individual. Closely related to this, the second sub-theme was 'Fatigue is hard to articulate', and this described the communication difficulties clinicians had in defining fatigue and examining the individual experience of fatigue. The third sub-theme was 'Fatigue is complex to unravel and understand', which outlined the common belief that it was difficult to fully comprehend and decipher the numerous contributory causes of fatigue in the individual patient.

The second theme was 'The interaction of fatigue with treatment decisions', and this related to fatigue being closely connected to treatment decisions in clinician's day to day clinical practice. This theme comprised three sub-themes. The first sub-theme 'adjusting fatigue approach to treatment goals and disease response' described how clinicians altered their behaviour to fatigue in a palliative setting and in cancer groups deemed to be less responsive to cancer treatments. 'Balancing fatigue with the patient's priority for survival' was the second sub-theme and was concerned with clinicians maintaining the goals of care in patients with fatigue on treatment. The third sub-theme was 'Negotiating treatment changes because of fatigue', and this described how clinicians altered cancer treatments when fatigue was interfering with fitness for treatment and quality of life.

The third and final theme presented was 'Fatigue challenges the role of the cancer doctor', which highlighted how fatigue could affect the emotions and behaviours of the clinician who might usually be accustomed to solving the patient's problem. This theme consisted of three sub-themes. The first sub-theme was 'Feeling unsure about giving advice for fatigue' and described a lack of surety and confidence that doctors had in giving advice for fatigue. This was also associated with some thoughts that other healthcare professionals were better at dealing with fatigue in advanced disease. The second sub-theme was 'Resigned to limited treatments for fatigue' and this related to the lack of treatment and signposting options for fatigue that was felt by clinicians. Finally, the third sub-theme was 'Facilitating the normalisation of fatigue', and this reflected the clinician's expectation of fatigue occurring and routinely normalising the experience with patients.

Chapter 7: Discussion and conclusions

7.1 Introduction to chapter

This doctoral research aimed to explore how patients and doctors approach fatigue in advanced cancer and how they communicate this symptom in oncology care.

The overarching research questions were:

1. What talk connected with fatigue occurs in advanced cancer care consultations and how do participants talk about it?
2. How do patients with advanced cancer deal with fatigue?
3. How do oncologists approach fatigue in those with advanced cancer?

Chapter 4 presented the findings from the examination of oncology care consultation which aimed to understand what talk in relation to fatigue occurred in the data and how it was discussed and approached by participants. Chapter 5 presented the findings from the patient interview study which explored how patients deal and cope with clinically meaningful fatigue. Chapter 6 presented the findings from the clinician interview study which explored how oncologists approach and manage fatigue in advanced cancer care. The present chapter will address these research questions in relation to the main findings from this PhD study. The strengths and limitations of this PhD will also be discussed. The final section of this chapter will present the conclusions of this doctorate, outline the possible implications for clinical practice and policy, and suggest recommendations for future research.

7.2 Discussion

The key findings from this research and what this PhD adds to the field of knowledge are discussed in this section. This PhD was divided into three parts and each dataset contributed to aspects of the research questions as outlined above. This section integrates the findings from the three datasets and discusses the novel contributions of this research to the understanding of fatigue in advanced cancer care.

7.2.1. Key findings

7.2.1.1 Fatigue is difficult to define and communicate

This study has shown through the integration of the analysis from all three data sets that the experience of fatigue was difficult to articulate. When patients voluntarily reported fatigue to the doctor, their language varied considerably, with 20 separate terms used for fatigue and in only one case was the word fatigue used (see Chapter 4, p.96). This finding suggests fatigue was not the term patients routinely used to describe their experience. Further reasons to explain the variety of descriptors used by patients were suggested in the overarching themes of ‘Fatigue is perceived as different’ and ‘The interconnectedness of fatigue’ (see Chapter 5). Patient participants expressed how fatigue was different from the usual experience of tiredness and how it could be hard to comprehend unless experienced. Perhaps this uniqueness of fatigue and the need to contrast it with usual tiredness was reflected by the variety of descriptors used for fatigue in the data. In the clinician interviews, the theme ‘Fatigue is challenging to assess’ demonstrated a perceived difficulty in assessing fatigue partly because of the language used by patients and some adapted their screening of fatigue so that they communicated more effectively with patients (see Chapter 6). This finding could have implications for clinical practice and research. If patients do not routinely use the term fatigue in their language then clinicians need to be informed of this to help in their assessment of fatigue. Similarly, researchers measuring and examining fatigue need to incorporate this finding into their research study design.

Other cancer care research has suggested that fatigue is difficult to articulate but the methods used in this study provided greater insights into this phenomenon. In Chapter 2 (p. 24), the frequent use of descriptors, euphemisms, colloquial language and metaphors for fatigue was found from the analysis of patient qualitative interviews (Barsevick et al., 2001; Magnusson et al., 1999; Messias et al., 1997; Porock & Juenger, 2004; Ream & Richardson, 1997). There are, however, few communication studies in the literature that reported on the language used for fatigue in doctor-patient interactions. Tang et al. (2018) found various descriptors for fatigue were used by patients and their companions in 29 recorded palliative oncology consultations but no data was presented. Hence, this PhD study provided a more detailed account of the language used by patients in their reporting of fatigue to clinicians and a forensic examination of how they communicated this symptom. Finally, fatigue is commonly experienced with illnesses other than cancer and it is possible the findings from this study about the difficulty in articulating fatigue may resonate in these healthcare settings.

The micro-analysis of talk provided some further evidence to support that fatigue was difficult to communicate. There were many cases in the data where there was hesitancy as patients articulated fatigue, suggesting some difficulty in the relaying of their experience to the doctor. These pauses in talk may have reflected participants thinking carefully about the language and terms to describe their experience of fatigue. Hesitancy in the reporting of fatigue was commonly associated with the action of hedging in the data. This may have been participants attempting to show themselves to the oncologist that they were ‘reasonable patients’ accurately monitoring their bodies and providing relevant information to the cancer clinician (Halkowski, 2006, p.60). Moreover, it could have displayed stoicism with fatigue being a bearable and acceptable symptom while receiving cancer treatment. However, this observed behaviour could also have represented a reluctance to report fatigue as a problem that needs to be addressed by the oncologist through the adjustment of cancer treatments which was not desired by the patient. This is covered in more detail later in this chapter. To summarise, the experience of fatigue was often difficult to articulate and usually the reporting of fatigue was carefully communicated to the doctor, in part to avoid treatment decision discussions.

Other reasons to explain the observations of hesitancy and hedging in the interaction data are provided from the analysis of the patient interviews. Some participants described the nature of fatigue itself could limit their capacity to engage with clinicians and the effect fatigue had on cognition made it difficult to communicate fluently. Others recounted feeling apathetic with fatigue and having a lack of motivation. These feelings resonated sometimes with a portrayal of being lazy as viewed by themselves and others. Further evidence to support these hypotheses were suggested by patient companions intervening and assisting in the communication of fatigue while patients displayed difficulty in the reporting of fatigue to the doctor. In several cases, patient companions relayed their perspective to the clinician that the reduced activity levels of the patient were not attributable to laziness. The cognitive effects of fatigue have been described in many studies (see Chapter 2, p.26), resulting in an inability to think and concentrate, and limiting the engagement and interaction with others (Barsevick et al., 2001; Glaus et al., 1996; Messias et al., 1997; Porock et al., 2004).

Therefore, clinicians should be mindful that the nature of fatigue itself and how it could be misconstrued as laziness may hinder the communication of this symptom.

From the clinician's perspective, fatigue could be difficult to define, understand and communicate. There were two examples in the data where the clinician displayed difficulty in understanding the terminology for fatigue uttered by patients and this delayed the assessment of the symptom. In these cases, the accurate assessment of fatigue was important because it informed treatment decision discussions. In their interviews, the oncologists routinely perceived difficulty in assessing fatigue in their day to day practice. Some relayed how they could use different terminology for fatigue to communicate more effectively when assessing fatigue. However, others appeared to have adapted their routine approach to assessing fatigue perhaps because it was difficult to define and communicate. These clinicians suggested they focused their assessment of fatigue by examining activity levels. This meant the severity of fatigue was measured through performances status or ECOG PS and hence, fitness for cancer treatment. When doctors screened for fatigue in the data, half used the term 'energy levels' (13/26) rather than tiredness and/or fatigue (13/26). The term 'energy levels' could be perceived by the patient as closely related to activity and these were follow up questions by clinicians. Therefore, because fatigue was difficult to define and communicate, it was suggested that clinicians adapted their approach to assessing fatigue to the most important denominator as perceived by them, whether the patient remained fit enough for palliative cancer treatments.

The PhD has shown that fatigue was difficult to define and communicate, for both patients and clinicians. These findings were supported by the observational and interview data. In this study, fatigue-talk was often sequentially linked with treatment decision discussions. Hence, an accurate assessment of fatigue could be important to ensure fatigue was manageable in those receiving palliative cancer treatments. Because any potential misunderstandings between the patient and the doctor about the severity of fatigue could have an influence on the outcome of such discussions or indeed, whether they occur.

7.2.1.2 Patient companions have a role in the communication and assessment of fatigue

Patient companions often engaged in talk connected to fatigue and this is the first study that used some of the concepts and tools of CA, to demonstrate how they influenced the communication of fatigue in oncology care consultations. They were present in 73% of consultations and shared their perspective of fatigue in 32% (see Chapter 4). The perspectives of patients and their companions sometimes aligned and this helped in the communication and assessment of fatigue. However, patient companions occasionally took different perspectives on the impact of fatigue on function and quality of life. Most often, this divergence in views occurred as the patient companion perceived fatigue was more severe than the patient. In these instances, the clinician managed the discordance by clarifying with the patient the effect of fatigue on functional ability and this frequently led to treatment decision discussions. Therefore, this study has highlighted the potential role of patient companions in the communication and assessment of fatigue in palliative oncology clinics and these findings are relevant to clinicians.

In comparison to other observational studies with much larger samples of patients with advanced cancer, patient companions or informal caregivers were similarly present in 73% of recorded consultations (Clayton et al., 2007; Epstein et al., 2017). Tang et al. (2018) used content analysis to describe the symptoms reported by patients in palliative oncology visits and suggested some caregivers occasionally shared their perspective of being anxious about fatigue and the detrimental effect it had on quality of life for the couple. However, this method of inquiry did not adequately investigate how caregivers raised their concerns about fatigue and how it was received by patients or doctors. CA is considered an empirical method of enquiry as the findings are transparent and validated through the next turn (Peräkylä, 2011). Hence, this study provides more detailed and meaningful findings of the role of patient companions in the communication and assessment of fatigue in palliative oncology consultations. These findings suggest that patient companions are a resource for clinicians during the screening or reporting of fatigue, especially when the communication of fatigue is difficult. Furthermore, where there was disagreement between the patient and their companion on the impact of fatigue on functional ability and quality of life, this usually resulted in treatment decision discussions related to fatigue.

In patients with clinically relevant fatigue, the perspectives of patient companions matter because they are commonly akin to informal caregivers. The theme 'support' described how patients often relied on the practical support of family and friends when they experienced fatigue (see Chapter 5, p.158). This researcher's observations from the outpatient clinic and the interviews provided further evidence that patient companions were often informal caregivers for patients with clinically relevant fatigue. They could, therefore, provide a first hand account of how fatigue interfered with the patient's functional ability and quality of life. Other research undertaken in palliative oncology clinics has shown that increasing severity of fatigue in patients was associated with a rising consequential burden on their informal caregivers (Peters et al., 2015; Wadhwa et al., 2013). Thus, patients with clinically relevant fatigue attending palliative oncology clinics commonly rely on patient companions as informal caregivers. In addition, clinicians may not only need to consider the burden of worsening fatigue on the patient but also the consequential burden on their caregiver.

As seen in this study, patient companions can often provide added insights to the clinician on the impact of fatigue on the patient's functional ability and daily life. Moreover, when patient companions reported fatigue as a concern or upgraded the patient's complaint of fatigue, this usually resulted in treatment decision discussions. This suggests that when patient companions share their perspectives of fatigue in palliative oncology clinics, this can be an important prompt for clinicians to evaluate fatigue and review cancer treatments.

The findings from the micro-analysis of talk and patient interviews are further supported by the analysis of the clinician interviews. A few clinicians described an occasional reliance on patient companions in their assessment of fatigue, to ensure they were understood and an accurate account of fatigue was given (see Chapter 6, p.195). Examples of disagreements between patients and their companions were recalled, usually where patients had mitigated fatigue and their companions provided a more accurate account of the functional impact of fatigue that informed fitness for treatment and led to adjustments of cancer treatments to alleviate fatigue. Hence, patient companions are proposed to be a medium in the communication and assessment of fatigue. They can be utilised as a resource by cancer clinicians in obtaining an accurate assessment of fatigue and should be encouraged by clinicians to share their perspectives of fatigue in palliative oncology consultations.

7.2.1.3 Fatigue was integral to cancer treatment decisions and end of life discussions

In this study, fatigue-talk was connected and often central to cancer treatment decision discussions in nearly a third of cases (See Chapter 4, p.122). Fatigue was the sole or a contributory reason for the reduction of chemotherapy drugs, the lengthening of treatment cycles and the pausing or withdrawal treatment. Talk connected with fatigue was sequentially linked with goals of treatment and end of life discussions. In treatment decision discussions concerning patients with clinically meaningful fatigue, the goals of palliative cancer treatments were regularly referred to by clinicians and worsening fatigue was often synonymous with bad quality of life. As future treatment options became more limited for progressive disease and severe disabling fatigue resulted in deteriorating performance status, the outlining of goals of treatment was usually accompanied by end of life conversations.

The finding that fatigue was connected and integral to many cancer treatment decisions and end of life discussions was important because it has not been clearly shown in previous observational studies undertaken in oncology clinics. These studies have limited detail on whether fatigue was connected to cancer treatment decisions because fatigue was not a primary focus and there were limitations within the methods used for analysis (Clayton et al., 2007; Epstein et al., 2017; Rodriguez et al., 2010; Setmar et al., 2002; Takeuchi et al., 2011). Previous studies have used content analysis to examine what was discussed rather than how it was discussed, therefore the relevant detail and context of fatigue-talk was missing. Tang et al. (2018) described treatment decision discussions related to fatigue in palliative oncology visits and similarly used content analysis. They reported cases where oncologists discussed adjusting treatments for fatigue and patients questioned the need to continue with treatment but it was uncertain how these conversations were initiated and constructed by participants (Tang et al., 2018). In this PhD study, the primary aim was to examine talk connected with fatigue and CA provided an in-depth understanding of how it occurred in the data. This research has illuminated how talk connected with fatigue can be a central component in palliative oncology visits.

An adequate assessment of fatigue in palliative oncology clinics would appear to be important as fatigue was commonly associated with cancer treatment decisions, goals of treatment, quality of life, and end of life discussions. Yet, all clinicians in this study described how fatigue was routinely challenging to assess in day to day clinical practice. The micro-analysis of talk regularly showed hesitancy and hedging when patients communicated fatigue. This linked with the theme ‘Fatigue is difficult to define and communicate’ and the subtheme ‘Fatigue is offset by the will to live’ from the patient interviews. Therefore, if the clinician were to underestimate the severity of fatigue and its’ potential to impede on fitness for treatment then cancer treatment decision discussions may be influenced towards the patient’s preference or indeed these may not occur at all within the consultation. Thus, the assessment of fatigue informs cancer treatment dosing and fitness for treatment, which means this assessment needs to be accurately made by clinicians.

7.2.1.4 Fatigue is an acceptable consequence of treatment for the benefit of survival

Fatigue that resulted from the side effects of cancer treatments was routinely accepted by patients, patient companions and doctors. This was supported from the micro-analysis of talk with the frequent occurrence of action, such as hedging, minimising and normalising, uttered by all participants. Moreover, these actions in talk were often associated with implicit or explicit acceptance of fatigue (see Chapter 4 p.108). Notably, in over half of those who reported clinically relevant fatigue, there were similar actions that reflected acceptance. The normalising of fatigue by patients and clinicians could also be associated with alternative explanations for fatigue which encouraged acceptance. Coping mechanisms could also be volunteered by patients which implied they were managing fatigue satisfactorily. Utterances confirming the acceptance of fatigue were clearly observed in participants with clinically relevant fatigue who resisted treatment recommendations to adjust or withdraw chemotherapy because of fatigue. These findings suggest that in palliative oncology care, the impact of clinically relevant fatigue on quality of life was often an acceptable consequence of cancer treatments for patients, their families and clinicians. However, this study also highlights that patients and doctors sometimes disagree when fatigue becomes problematic and interferes with fitness for treatment. In the data, some patients receiving cancer treatment found severe disabling fatigue acceptable and wished to continue with their treatment regimen unaltered. Hence, when clinicians perceive that the burden of fatigue is unacceptable, they should be prepared for patients disagreeing with their assessment.

The finding from the micro-analysis of talk that fatigue can be acceptable to patients and their companions has not been clearly shown in previous interactional research. In Chapter 2 (p.48), interactional evidence that showed oncologists hedging and normalising fatigue was described but the published data did not illustrate this behaviour in patients and caregivers (Greenhalgh et al., 2013). Nevertheless, some research may have alluded to the acceptability of fatigue in patients receiving palliative cancer treatments. A survey of patients with advanced cancer who received palliative chemotherapy indicated 90% experienced some fatigue and only 3% responded that they would not repeat chemotherapy (Mende et al., 2013). A separate longitudinal study of patients receiving palliative cancer treatments showed 19% reported severe fatigue at each time point which suggested the impact of severe fatigue on quality of life was not a barrier for some patients to continue with cancer treatment (Peters et al., 2016). Although previous studies may have insinuated that patients put up with fatigue for the potential benefits of cancer treatment, the observed findings from palliative oncology clinic visits in this PhD study clearly highlighted the acceptability of fatigue through the action in talk by patients. Importantly, this study has also illustrated that some patients will accept the detrimental effects of severe fatigue on function by expressing a clear preference to continue with cancer treatments.

Patients routinely accepted fatigue as a trade-off for the perceived benefit of cancer treatments controlling the disease and this was supported in the data. In their interviews, patients described the strategies they used to facilitate the acceptance of fatigue and this provided further insights into the CA findings. In Chapter 5, the theme ‘psychological strategies for enduring fatigue’ described how many patient participants claimed fatigue was acceptable because of the perceived benefits of cancer treatments and it was an expected side effect of treatment. The experience of fatigue was offset by the hope for a prolonged life and an imagined future life with less fatigue after completing cancer treatments. Several qualitative studies have reported similar findings of patients willing to accept worsening fatigue because they felt positive about palliative cancer treatments and either perceived or assumed treatments were effective at prolonging life (Bergqvist & Strang, 2017; Potgieter & Maree, 2018; Westerman et al., 2007). In addition, fatigue attributed to cancer treatments could provide reassurance because it was normal and fatigue attributed mainly to cancer burden could lead to end of life discussions (Bergqvist & Strang, 2017). Importantly, this PhD has examined treatment decision discussions in patients with clinically meaningful fatigue and these illustrated how fatigue could be an acceptable trade-off for the control of cancer. Perhaps the observed resistance to treatment changes for fatigue suggested that continuing with cancer treatment was perceived as living and not having treatment equated to dying.

The acceptance of fatigue was also enhanced by and sometimes dependent on other factors. The theme 'practical strategies for fatigue' outlined how patients managed and accepted chronic fatigue by adapting their daily lives and reframing their life to a new normal (see Chapter 5, p.175). Similarly, the perception of fatigue or reference point could change over time as individuals adapted to a new normal life and this has previously been identified as a recalibration response shift in those experiencing fatigue (Westerman et al., 2007). Thus, the data suggested that patients could shift their limits of tolerability of fatigue over time and could recalibrate their perception of fatigue. The theme 'complex nature of self and fatigue' revealed other aspects related fatigue, the individual, the illness and life experience which could either enhance or counter the acceptance of fatigue. Clinicians, in their interviews, described how the perception of fatigue was subjective and relative to the individual which reflected the themes identified from the patient interviews. Therefore, how fatigue was accepted and tolerated by an individual depended on an array of interconnected strategies and influences.

This section has outlined how clinically relevant fatigue could be an acceptable trade-off for the control of cancer by all participants in palliative oncology visits. This study suggests that the tolerability and acceptability of fatigue as perceived by patients could change over time. In the data, patients and clinicians sometimes differed on their interpretations of acceptable levels of fatigue and took opposite stances. The next section illustrates how patients and doctors talk can be constructed when doctors perceive the level of fatigue is unacceptable but patients perceive it remains acceptable.

7.2.1.5 Patients with clinically relevant fatigue resisted cancer treatment changes

The frequent occurrence of misalignment in talk which concerned resistance in actions connected with fatigue was a key finding in this thesis (see Chapter 4). Misalignment in this context referred to the ways in which participants at given moments 'steer their interaction in diverging directions' and resistance occurred in actions of talk (Voutilainen et al., 2011). In the main, the opposing affiliations of doctors and patients to the perceived burden of fatigue and benefit of palliative cancer treatments on survival lead to this observed resistance in talk. Misalignment became evident from the patient's resistance to cancer treatment recommendations that were construed by the oncologist with the explicit intention of limiting the burden of fatigue on quality of life. This resistance was mostly passive but occasionally it was active. As mentioned previously, patients resisted because they accepted the effects of fatigue on quality of life as a trade-off for the perceived benefits of cancer treatments prolonging of life. Moreover, they may have found fatigue more tolerable over time because they adapted to it. Resistance was observed in those who reported moderate and severe fatigue both on measured intensity and functional questionnaires. Importantly, resistance was observed at different time points in the trajectory of cancer treatments and illness, seen during first-line palliative treatments and in those nearing the end of their lives. This suggested that some patients with severe disabling fatigue in palliative oncology clinics could prefer to continue with cancer treatments and cancer clinicians need to be aware of this.

The findings from this doctorate suggested that when misalignment occurred, the outcomes of these cancer treatment decision discussions were dependent on the formulations of the treatment recommendations for fatigue and the strategies used to gain agreement. When treatment recommendations for fatigue were first initiated, they were usually formulated as proposals and therefore presented as a joint decision to make. Proposals invited the collaboration or endorsement of the patient and are generally characterised by a speculative nature, meaning the decision has not yet been made (Stivers et al., 2018). After encountering resistance, oncologists attempted to gain agreement by reformulating the treatment recommendations for fatigue and this was usually with stronger or more authoritative forms of treatment recommendations in the pursuit of agreement. When these treatment recommendations were modified or reformulated as a combination of proposals and pronouncements, the outcome of the cancer treatment decision discussion veered towards the oncologist's preference which was the reduction or withdrawal of cancer treatments. Pronouncements more strongly encouraged acceptance of treatment changes and placed more responsibility on oncologists who essentially determined the decision (Stivers et al., 2018). Hence, oncologists may need to take more responsibility in the decision-making process when patients resist their treatment recommendations to lessen the burden of fatigue on palliative cancer treatments.

Promoting patient choice in treatment recommendations for fatigue may result in patients with clinically relevant fatigue continuing with palliative cancer treatments unaltered and result in worsening severe fatigue. In the data, when treatment recommendations for fatigue were modified or reformulated as a combination of proposals and suggestions, the outcome of the cancer treatment decision discussion veered towards the patient's preference which regularly was to continue treatment unchanged. Suggestions recommended treatment changes that were optional, placing more responsibility on patients as the decision was broadly left for them to make (Stivers et al., 2018). Therefore, when patients resisted treatment recommendations for fatigue, providing them with more choice and responsibility in the decision-making process meant treatment was continued as scheduled. There was evidence from some interactions and interviews to suggest these decisions were perceived by patients as life and death decisions when survival for them was paramount. Hence, oncologists may need to be aware that by offering patients with clinically relevant fatigue more autonomy in the decision-making process while receiving palliative cancer treatments, this could lead to disabling fatigue and potentially impede on fitness for treatment.

Other communication studies have described the occurrence of misalignment in medical consultations and patients resisting within their own experiential expertise (Monzoni et al., 2011; Thompson, 2013). Thompson (2013) identified that patients frequently resisted treatment formulations for psychiatric drugs that were designed as proposals and offers and this resistance was expressed overtly. Patients resisted by orientating to their own expertise and referred to the physical side effects of medications experienced which suggested an inability to comply with the proposal or offer (Thompson, 2013). It was also noted that psychiatrists often framed their proposals and offers delicately which may have suggested a form of anticipated contingency planning (Thompson, 2013). When resistance or misalignment occurred, the medication was often not prescribed by the psychiatrist (Thompson, 2013). Similarly, Monzoni et al. (2011) found patterns of interactional resistance expressed overtly but also passively in neurology settings. Resistance was most obvious when topics were within the patient's own 'epistemic remit' and in discussions concerning the aetiology of symptoms and treatment recommendations (Monzoni, 2011).

The relevance for this research, the experience of fatigue was within the patient's own 'epistemic remit' and resistance was observed in discussions about the impact of fatigue on quality of life and cancer treatment recommendations for fatigue. Moreover, it was possible that oncologists may have routinely anticipated resistance because cancer treatment recommendations for fatigue were often introduced or framed tentatively. However, in contrast to the studies mentioned that described misalignment, this PhD study included qualitative interviews of participants which allowed for possible explanations to emerge as to why and how misalignment might have occurred (Monzoni et al., 2011; Thompson, 2013). Findings from the interaction and interview data suggested oncologists gave patients less agency in the decision-making process when they felt the level of fatigue clearly meant the patient was not fit for palliative cancer treatments. In their interviews, oncologists described quality of life as within the domain of the patient. Perhaps then if fatigue was deemed by the oncologist to only interfere with quality of life, patients were autonomous over this. Therefore, patients may have routinely resisted treatment recommendations for fatigue as the effects of fatigue on quality of life were deemed to be within their epistemic remit and oncologists may have made concessions as they understood this. However, when oncologists believed fitness for treatment was in question, perhaps it was within their epistemic remit to alter or withdraw palliative cancer treatments.

Although patients with clinically relevant fatigue frequently resisted changes to palliative cancer treatment to lessen the burden of fatigue (24%, 9/37), agreement was maintained through the actions of participants. In the cases of misalignment, oncologists were observed to use several strategies during their attempts to gain agreement with their treatment recommendations for fatigue. These strategies were numerous and some included aligning with the patient's agenda for cancer treatment by suggesting the scheduled treatment could be completed at a reduced dose or maintaining hope by introducing the possibility of alternative future cancer treatments when fatigue had lessened. Other strategies included oncologists depersonalising the decision to reduce or withdraw palliative cancer treatments when fitness for treatment was questioned and not placing the reason for the decision solely on themselves. For example, oncologists placed less personal responsibility for the decision by broadening the agency of the decision-making to include external factors such as hospital chemotherapy protocols and national guidelines citing patient safety concerns. These strategies appeared to be important when active resistance occurred as doctors maintained agreement and hence the therapeutic alliance. These strategies could be useful for cancer clinicians to be aware of as resistance to cancer treatment changes for fatigue appear to occur commonly in palliative oncology clinics.

This section has highlighted that patients with clinically relevant fatigue resisted changes to palliative cancer treatments recommended by oncologists with the aim of lessening the burden of fatigue. It is suggested that how recommended actions are formulated by the physician may be an important factor as to whether the patient agrees to the treatment recommendations for fatigue or not. The next section illustrates how oncologists may have judged whether to make concessions to the resistance encountered from patients with clinically relevant fatigue.

7.2.1.6 Oncologists modified palliative chemotherapy for fatigue until fitness for treatment was impeded

This research has shown that clinicians offered and continued palliative cancer treatments in patients with clinically relevant fatigue until it corresponded with a deterioration in ECOG PS that hindered fitness for treatment. The observational data contained many examples of the adjustment of palliative chemotherapy specifically for clinically relevant fatigue, with the stated aim by clinicians of lessening the burden of fatigue and the probability of it impeding on fitness for treatment. When new palliative cancer treatments were offered by clinicians, it was sometimes stated that treatment doses were reduced because of fatigue and further adjustments to treatments were forecasted should fatigue worsen. For patients who developed worsening fatigue mid-treatment, clinicians routinely proposed to modify the doses of chemotherapy and alter the treatment schedule to lessen the burden of fatigue. When these proposals were resisted by patients, sometimes clinicians forecasted adjustments in treatment should fatigue correspond with a stated deterioration in ECOG PS. Lastly, when the clinician deemed that fitness for treatment was clearly impeded because of fatigue, palliative cancer treatments were withdrawn. Therefore, cytotoxic cancer treatments were offered and continued by clinicians, unless and until fatigue was deemed to impede fitness for treatment.

In the data, when new palliative cancer treatments were offered to patients with clinically relevant fatigue, clinicians could take more authority in the decision-making regarding the modification of chemotherapy because of fatigue. Although the treatment recommendations for new palliative cancer treatments could be proposals or offers, within these actions the decision to reduce the dose or the interval of chemotherapy because of fatigue could be the sole responsibility of the oncologist and not the patient. Therefore, physicians exerted their epistemic authority by outlining their scientific and clinical knowledge that the full dose of chemotherapy would not be tolerable due to the level of fatigue experienced. This suggested that patients with clinically relevant fatigue had agency over the decision to have new palliative treatment options or not, but did not have agency over the dose of chemotherapy. Therefore, clinicians could use their learned scientific and clinical knowledge to decide on the optimal dose when initiating a new palliative treatment for the individual patient with fatigue.

The micro-analysis of talk revealed that oncologists could differentiate between recommendation actions related to fatigue and this appeared to depend on whether they judged fatigue to impede fitness for treatment. In patients with clinically relevant fatigue, doctors demonstrated different orientations to patient participation and thus patient agency depending on how they measured fatigue to interfere solely with quality of life or more definitively with fitness for treatment. During a treatment cycle, treatment recommendations related to fatigue could be designed as a proposal or offer when fatigue was adjudged by the clinician to primarily interfere with quality of life rather than fitness for treatment. These recommendation actions promoted patient participation in the decision-making process and sometimes patients had full agency which facilitated patient choice. As mentioned in the previous section, doctors sometimes made concessions when resistance occurred from patients. However, if the physician deemed that fatigue convincingly interfered with fitness for treatment, they could take more responsibility for the decision-making process and assert more authority in recommendation actions with the use of pronouncements. Hence, the results from this PhD have suggested that patients could be autonomous over the impact of fatigue on quality of life until the oncologist was certain that fatigue hindered fitness for treatment.

Other cancer care communication research has similarly shown a differentiation in the agency of the decision-making process but none has primarily focused on treatment recommendations related to fatigue. The data from Tate's (2018) PhD study showed that patients routinely participated and had more agency in recommendations for new cancer treatments with the majority designed as proposals and suggestions. However, during treatment cycles or mid-course treatment recommendations, oncologists usually deployed more agency and were more authoritative in recommendations for changes to cancer treatments with the use of pronouncements (Tate, 2018). The context of these mid-course treatment recommendations for changes to cancer treatments was described as medical issues related to the cancer or cancer treatments but none were specifically related to fatigue (Tate, 2018). The examples of pronouncements in the data highlighted the addition of new cancer treatments for ineffective control of cancer and the weaning of steroid therapy while cancer treatment is beginning to take effect (Tate, 2018). In this PhD, mid-course treatment recommendations for changes to cancer treatments for fatigue could be designed so that patients retained agency in the decision-making to continue with treatment at the current dose or accept a dose reduction, often preferred by the clinician. However, once fitness for treatment was in question, the agency was usually transferred from the patient to the physician and the modification of treatment became the responsibility of the physician. Therefore, this research adds more nuanced insights into the differentiation in agency of the decision-making process in palliative oncology care clinics than previously known.

The observational findings in this doctorate were supported from the clinician interview findings, in the theme, 'Fatigue interacting with treatment decisions' which examined how fatigue routinely influenced and effected palliative cancer treatment decisions (see Chapter 6, p.187). Clinicians described how they often managed the burden of fatigue through the adjustment of palliative cancer treatments. Fatigue was for clinicians, synonymous with quality of life and patients were viewed as the arbitrators of this. Although clinicians may have viewed the interference of fatigue on quality of life unacceptable to them and outlined the goals of palliative treatment, ultimately, patients were deemed to have autonomy over their quality of life. However, once fatigue resulted in functional impairment that potentially hindered fitness for treatment, clinicians were more assertive about how they adjusted or withdrew cancer treatments. Hence, this perhaps explains why, in the observations, clinicians routinely gave more agency to patients with fatigue in the decision-making process regarding new and mid-course palliative treatment decisions, when fatigue was adjudged to solely affect quality of life rather than fitness for treatment.

In their interviews, oncologists described how they relied on the ECOG PS to assess fatigue and this meant the assessment of fatigue was centred around fitness for treatment. The theme, 'Fatigue is challenging to assess', revealed how the individual nature and language of fatigue, regularly made it difficult to assess in clinical practice (see Chapter 6, p.192). Because of these unique qualities, clinicians described how they usually interpreted the severity of fatigue through the measuring of the ECOG PS. This could mean the assessment of fatigue was routinely centred around the fitness for treatment and the ECOG PS then informed treatment decisions related to fatigue. Therefore, clinicians may have been reluctant to exert more authority in the decision-making process, unless they were more certain that fatigue was potentially threatening fitness for treatment. The clinician's reliance on ECOG PS for assessing fatigue may also suggest why, in the observational findings, they gave more agency to patients in the decision-making process until they perceived fatigue to interfere with fitness for treatment rather than solely with quality of life.

Other research has similarly suggested that oncologists found fatigue difficult to assess and it was measured based on fitness for treatment with ECOG PS. Strang & Bergqvist (2017) found that fatigue was perceived as difficult to evaluate in advanced disease and it was mentioned interchangeably with quality of life and ECOG PS. This implied that fatigue was synonymous with quality of life and was measured with respect to fitness for treatment. Thus, it would be important for oncologists to accurately measure ECOG PS if routinely used to assess the burden of fatigue in patients receiving palliative cancer treatments. However, several studies have reported that oncologists have tended to better grade the ECOG PS of patients receiving palliative chemotherapy compared to nurses, palliative care physicians and even patients themselves (Ando et al., 2001; Dajczman et al., 2008; Kim et al., 2015; Zimmerman et al., 2010). The interpretations of ECOG PS could have significance because if oncologists were to routinely overestimate ECOG PS in patients with fatigue this could lead to two plausible outcomes. First, the adjustments of cancer treatments to lessen the burden the fatigue may not occur which could delay or avoid the onset of severe disabling fatigue. Second, some unfit patients could receive palliative chemotherapy which could worsen disabling fatigue and limit survival (Bachelot et al., 2000; Glare et al., 2008; Oken at al., 1982; Swetz & Smith, 2010). Therefore, in clinical practice, an accurate measurement of ECOG PS might be crucial in order to best manage fatigue levels through the adjustments of cancer treatments.

From an oncologist's perspective, controlling the disease could be a significant goal even in late-lines palliative treatments when fatigue was expected to become more burdensome and omnipresent (Strang & Bergqvist, 2017). Providing chemotherapy may be construed as part of the role and identity of oncologists as suggested from this research (see Chapter 6). Therefore, it is conceivable that an oncologist could be more optimistic about ECOG PS when fatigue was ambiguous or difficult to measure, especially when confronted by a patient describing fatigue as tolerable and quite keen to continue with treatment unchanged. Furthermore, fatigue could be an invisible symptom within a time-pressed outpatient visit and some patients liked to present a positive front to their oncologist as seen in this research (see Chapters 4 & 5). Other research has suggested that positivity from patients about cancer treatments can make it more difficult for physicians to observe signs of fatigue and it facilitated fulfillment in the cancer specialists' role of providing cancer treatment (Maree & Potgieter, 2018). Thus, the interplay between the role of the cancer specialist to control the cancer and the over compliant behaviour of the patient with fatigue could have important consequences. The effect could lead to the accidental underestimation of fatigue and the unconscious acceptability of disabling fatigue on palliative cancer treatments from both patients and clinicians.

7.2.1.7 Advice giving for fatigue and the practical strategies used by patients

Although advice giving for fatigue occurred infrequently (8%, 5/60) in the data, how this advice was received was a novel finding in this study. Advice giving occurred when fatigue was reported as a concern by patients and viewed as problematic. Passive or active resistance to advice giving was observed in three cases and this has not been reported previously in CA research that examined advanced cancer care interactions. It is important to understand why resistance to advice giving might have occurred as this could help and optimise advice giving for fatigue in advanced cancer care.

In two cases of misalignment, both patients were experiencing fatigue that was constant and progressively worsening. One patient was receiving chemotherapy with the intensity of fatigue increasing and the other patient experienced severe disabling fatigue near the end of life as he died several weeks later. Reasons to explain this resistance to advice giving might be gleaned from the patient interview findings. The theme 'navigating fatigue through practical strategies' outlined the practical strategies that helped manage fatigue and examined how or when these strategies were most effective (see Chapter 5). Exercise or goal setting was described as the most effective strategy when the trajectory and intensity of fatigue related to cancer treatments was naturally beginning to improve once treatments had finished. However, these strategies were deemed ineffective by participants when fatigue was constant and the trajectory was worsening. Thus, when might be the most appropriate moment to offer exercise as a strategy for fatigue might be relevant to clinicians and researchers. It is suggested from this research that exercise as advice giving for fatigue might be best considered when the trajectory of fatigue is expected to improve and not worsen further.

It was difficult to ascertain the frequency of advice giving reported in palliative oncology care studies because they have generally relied on the recollections of patients but some reported receiving no advice to manage fatigue from cancer clinicians (Spichiger et al., 2012). Fatigue has also been reported by patients as the most common perceived barrier to complying with the advice of physical activity (Fisher et al., 2016). Several conversation analytic studies of healthcare encounters have described resistance to advice giving in other clinical settings including: health visitors giving advice to new mothers, and; nurses giving advice to patients being tested for HIV (Heritage & Sefi, 1992; Silverman, 1997). However, resistance to advice giving for fatigue in cancer care was not identified in a review of the literature.

In this study, doctors occasionally endorsed of the patient's reported use of practical strategies for fatigue occasionally occurred (8%, 5/60). This may have suggested that patients were managing fatigue through self-management or reflected advice that was previously given from cancer clinicians. In their interviews, patients often revealed the source of how they learned the practical strategies for fatigue and some learned through self-management (see Chapter 5). However, these self-care strategies were sometimes only partially effective for fatigue and participants sought more support from cancer clinicians regarding practical strategies for fatigue but some felt this was lacking. Similar findings have been reported by patients with advanced cancer in other studies (Richardson & Ream, 1997; Spichiger et al., 2012). Hence, some patients in this research identified a need for more support in managing fatigue from cancer clinicians and these unmet needs should be considered.

Findings from the clinician interviews might explain why some patients felt their need for advice on managing fatigue went unaddressed in the oncology clinic. In Chapter 6, the theme 'fatigue challenges the role of the cancer doctor', described how clinicians felt uncertain about giving advice for fatigue and were resigned to limited supportive treatments for it. For some, the lack of evidence and the nature of the advice itself did not fit their role and identity as a cancer specialist which meant they preferred others to deliver such advice. Many also felt the short appointment visits and the time pressures in the clinic environment were a barrier to advice giving. This perception was reflected in the interviews of some patients and has been reported in the literature (Spichiger et al., 2012). These findings are important as they have not been identified in the literature previously. This research suggests that some oncologists may need training to encourage them to deliver advice giving for managing fatigue. Moreover, oncology clinics may need better access to physiotherapists and occupational therapists, to ensure that patients with fatigue receive sufficient support in managing fatigue.

7.2.1.8 Summary of findings

A summary of the findings from this thesis has been used to articulate a provisional framework for cancer clinicians to utilise in clinical practice and is outlined in Table 7.1. This provisional framework is intended for cancer clinicians in palliative oncology clinics and is also based on the findings from the literature review in this thesis. However, it should be noted that cancer clinicians and people with lived experience of fatigue have not yet been consulted on this provisional framework.

Figure 7.1: Summary of findings and provisional framework for clinical practice

On commencing palliative cancer treatments:

- Reflect on whether the starting dose of treatment should be adjusted for fatigue
- Advise the patient that fatigue is an expected side effect with cancer treatments
- Explain what normal or abnormal levels of fatigue would be
- Mention that it is common for palliative cancer treatments to be adjusted (e.g. the dose and schedule) as the cycles of treatment progress with the aim of alleviating the burden of fatigue on treatment and reassure this is normal clinical practice
- Reassure that any adjustments in cancer treatments will not interfere with effectiveness at controlling the disease and could facilitate the treatment to continue for longer
- Consider discussing the goals of palliative cancer treatments, check for patient understanding and explore their goals for treatment. Patients may overestimate the potential benefit to survival and therefore endure severe fatigue for this reason

The experience of fatigue is complex and individual:

- Individual patients may need more support to cope with fatigue especially when sudden changes in intensity occur and in those who enjoy being physically active
- Individual patients may tolerate severe disabling fatigue while receiving palliative treatment and may not recognise that this could impede on fitness for treatment

Screening and assessing fatigue:

- “Fatigue” is a medical term and may be understood differently by patients
- “Tiredness” may not equate to the experience of fatigue
- Patients can use many terms for what doctors refer to as fatigue
- Screening for fatigue using the term “energy levels” may be helpful
- Patient companions may help in the communication and assessment of fatigue
- If ECOG PS changes, this could be used to assess the effect of fatigue on function

- Consider that some patients may minimise the effects of severe disabling fatigue on quality of life and function as they understand this could lead to reductions in palliative treatment which would reduce survival length

Managing fatigue by adjusting or withdrawing cancer treatments:

- Consider the contributory causes for fatigue and assess for simple reversible causes
- Consider adjusting the dose or schedule of cancer treatments to lessen the burden of fatigue and projected fatigue
- Expect that patients may be concerned and worry about treatment adjustments because they understand this might reduce survival length
- Reassure patients that adjusting treatment will not limit treatment effectiveness and the best response to cancer treatments is seen in the first few cycles
- Consider preparing patients in advance to expect that if fatigue levels continue to worsen then fitness for treatment could be impeded
- Try to avoid placing sole responsibility for decision making on the patient and aim for joint decision-making process
- If fitness for treatment is in question and patients resist treatment changes, then clinicians may need to be more authoritative in the decision-making process while seeking agreement from the patient
- Patients may resist the withdrawal of treatment as they equate having cancer treatments as living and the withdrawal of cancer treatments as dying
- It may be appropriate to maintain hope through the potential offer of future palliative cancer treatments

Managing fatigue through supportive treatments:

- Pacing and conserving, having an awareness of energy levels and resting/sleeping are all practical strategies for fatigue. Patients may benefit from these being explained to them
- Gentle activity or exercise could be helpful to improve fatigue but best to recommend when the trajectory of fatigue is expected to improve and not worsen
- If fatigue is chronic and/or irreversible, consider helping patients to adapt and come to terms with their new baseline physical condition

- Provide Macmillan information booklet: Coping with tiredness (fatigue)
- Consider whether nutritional supplements might have a role (e.g. malabsorption in Upper Gastrointestinal cancers)

- Consider referral to allied healthcare professionals, palliative care clinicians or psychological services for patients when these services are available to support patients with fatigue

Talking about fatigue and quality of life can lead to end of life discussions

- Fatigue can be central to quality of life and end of life discussions
- Patients may understand that worsening constant fatigue after the cessation of cancer treatments is related to progressive cancer and this may lead to end of life discussions
- Talking about worsening severe fatigue at the end of life can be reassuring for patients but they need to understand the help and support they will need with disabling fatigue
-

7.2.2. Limitations

This PhD had several limitations, and these are considered in this section. The challenges that arose in each study are explored and the lessons that were learned are suggested.

7.2.2.1. Sample size and study participants

This PhD consisted of three studies and the limitations within each study are detailed here.

Consultation study

In comparison to some other medical interactional studies, the sample size was modest and therefore the results warrant caution. As outlined in Chapter 3, the study design was based on similar studies but the projected recruitment phase did not take into account the frail population studied, the unpredictable scheduling of future appointments and the demands on a sole researcher also undertaking research interviews. Although a consecutive sampling strategy was performed, clinicians may have selected preferred potential patient participants and this could have influenced the data collected. Moreover, patients were asked to give consent and those who consented may differ from those who declined participation. In addition, it is conceivable that some of those who declined felt too fatigued to consent and were possibly aware that cancer treatments were to be withdrawn with a change of focus in clinical care. The researcher’s observations during the recruitment phase appeared to support this hypothesis. Therefore, it is possible that missing data could potentially have yielded important findings. Most of the data collected came from one NHS Trust and the sample of patient participants was predominantly from an older white British population with a confined range of cancer of diagnoses. Hence, the patient sample observed may not be a representative sample of patients with fatigue attending palliative oncology clinics and findings cannot be transferable or generalisable in other settings.

A wide number of oncologists took part in this study and those with more clinical experience generally had more consultations recorded. However, these clinician participants may have contrasted with other oncologists who may have declined to take part. For example, communication styles and practices could differ as well as their approaches to fatigue in advanced cancer care. The cancer clinicians observed may not be a representative group of UK cancer clinicians therefore the data and findings cannot be transferable or generalisable in other settings. Furthermore, it should also be noted that both clinician and patient participants could have intentionally modified their behaviour with the awareness of being observed (Coleman, 2000). The data and findings from the observed interactions may therefore not reflect real-world communication in palliative oncology clinics which limits the reliability of this research.

Although there are many strengths to the design of the consultation study, combining quantitative (coding) and qualitative (CA) approaches, there are also some limitations which are considered here. The coding framework as described in Chapter 3, coded the utterances of talk related to fatigue or fatigue-talk. This coding framework was adapted from a published study, discussed in supervisory team meetings and underwent pilot-testing. However, the coding framework has not undergone sufficient reliability testing from other researchers and therefore cannot be viewed as a reliable method (Murphy et al., 1998). Therefore, the reliability and validity of the findings from the coding data are questionable. The CA findings outlined observed phenomena in the data collected only because the sample was too small to perform any statistical analysis. In addition, there was no possibility to explore a correlation inquiry as to what approaches taken by oncologists lead to certain outcomes. For example, were different formulations of treatment proposals related to fatigue associated with the preferred outcomes of clinicians? Therefore, this PhD was not an applied project in cancer care research as statistical associations and outcomes are usually demanded. The CA findings in this study are not generalisable because no statistical techniques were utilised and hence their interpretation warrant caution.

Patient interview study

Although all the participants in the patient interview study had experienced clinically relevant fatigue, they were not a homogenous group. There were differences amongst the group as to the: pattern and trajectory of fatigue experienced; potential disease response to treatment; and, prognosis. The sample size was too small to explore the differences between these subgroups and therefore the findings are not generalisable to subgroup populations. In addition, the intensity and level of fatigue experienced at the consultation clinic were not always reported as the same at the patient interview. Frequently patient interviews occurred some days or weeks after the recorded consultation and this was a result of many factors, mostly relating to the preferences of the patient and the availability of the researcher. Repeating the fatigue measurements at the interview might have further helped to clarify the level of fatigue experienced and perhaps stratify the patients into subgroups. Patients were asked to give consent for the interview study and those who consented may differ from the ten who declined participation. Lastly, the researcher excluded three potential participants because they attributed fatigue to medical conditions other than cancer or cancer treatments. Hence, the patient sample interviewed may not be a representative sample of patients with fatigue attending palliative oncology clinics and the findings cannot be transferable or generalisable in other settings.

Clinician interview study

Most clinicians who participated in the consultation study were invited for interview many months after recruitment had ceased in their outpatient clinic. This decision was made by the researcher as the preliminary analysis of the consultations and patient interviews took considerably longer than expected. The delay in inviting clinicians for interview contributed to the low number of clinicians interviewed as evidenced by the four that were missed. The clinician participants may have contrasted with those that were missed and the other oncologists that declined to take part. The small sample size in the clinician interview study is significant and this may limit the reliability of findings (Murphy et al., 1998). Although the themes were broadly represented in every clinician participant, it was not possible to conclude that data saturation had been reached due to the sample size. However, it should be noted that the researcher's observations of clinicians during the recruitment of participants for the observational study appeared to resonate with the findings. In conclusion, the clinician sample interviewed are not a representative sample of oncologists from palliative oncology clinics and therefore the findings cannot be transferable or generalisable to other settings.

The framework for practice was informed from the findings of the three qualitative studies, the literature review and the dual role of the researcher. However, as discussed above the limitations in each study affected the reliability and generalisability of the data and findings. In addition, it is possible that the dual role of the researcher affected the validity of the findings and this will be discussed further in the next section. Neither cancer clinicians who took part in the research project nor independent from this research project were consulted about the framework for practice and this limits the validity of these findings. Nonetheless, the framework may provide a prompt for cancer clinicians to reflect on and consider in how they usually approach fatigue in clinical practice.

Finally, this was a significant PhD project with three separate data sets and this type of communication research is labour-intensive. Although the focus of the analysis was on the primary component, the observational study in palliative oncology clinics, the supplementary components, provided important complementary findings and provided a more comprehensive examination of the research problem. However, it was not possible to present the entire study findings in this thesis as it was necessarily constrained. This meant that the findings presented in this thesis resulted in the exclusion of other topics of interest and therefore it may not represent the full extent to which fatigue was approached by participants. For example, oncologists assessed fatigue in several ways and it may have been relevant to highlight this more in detail.

7.2.2.2 Dual role and identity of the researcher

This researcher had a dual role and identity, that of a doctoral research student and a palliative medicine trainee doctor. It is possible that this dual role could have influenced the findings of this study and this will be discussed in detail in this section.

As described in Chapter 3, at the outset of the study, clinicians were contacted to provide input into the design of the study and to gain permission for access to research participants. These clinicians were fully aware of my dual role and some recognised me from my previous role as a specialty trainee registrar during previous clinical attachments at the hospital sites. During the recruitment process, more clinicians enrolled in the study and inevitably all became aware of my dual role as it was impossible to conceal this from them. However, many patient participants were possibly unaware of my dual role unless the clinician had mentioned this while introducing the study or they asked directed questions about my clinical background which I answered truthfully.

The relative disadvantages of being an 'insider' or having a dual role are considered here. It is possible that my shared connection with clinicians, my clinical practitioner experience in an allied medical specialty and providing palliative care to cancer patients, may have introduced bias to the sample recruited, data collected and findings (Allen, 2004; Anderson & Taylor, 2006). During the recruitment phase, my dual role was sometimes introduced by clinicians to potential patient participants and this may have influenced the patient sample recruited. Occasionally patient-participants referred to my dual identity in their interviews and this could have introduced bias to the data collected when questions exploring how doctors dealt with fatigue were asked. Other patient participants may have assumed I was an 'insider' as I was dressed similarly to clinicians and appeared comfortable in this clinical setting. In a few of the clinician interviews, my dual role was explicitly referred to by participants and this could have had a bearing on the data collected. A conversation between healthcare professionals could have occurred which conceivably, could have biased the data collected. It is also possible that the 'insider' status led to an over-familiarity with the research topic and the data collected which could have distorted the interpretation of the ethnographic accounts in the consultation and interview studies (Borbasi and Jackson, 2005; Patton, 2002). Therefore, the dual role of the researcher could have negatively influenced the validity of the findings of this PhD.

There are relative advantages to researching a familiar setting or culture and these 'insider' privileges are explored. It is likely that the dual role helped this researcher gain access to research participants and provided a platform to develop a rapport with clinician participants (Gerrish, 2003). This may have placed this researcher in a unique and privileged position with access to a research world which may not have been readily available to other researchers. Some ethnographic healthcare researchers argue that having insider knowledge and experience can lead to the provision of an accurate and realistic account, thereby limiting bias (Allen, 2004). Moreover, having an in-depth understanding of the setting, palliative cancer care, and a familiarity with the culture of clinician participants could be viewed as advantageous (Bonner and Tolhurst, 2002). Unique adequacy is a concept derived from ethnomethodological researchers which suggests that researchers observing and reporting on social norms, such as palliative oncology clinics, should be as skilled in understanding the research setting as the participants being observed (Wakefield, 2000). Drawing on this insider knowledge about the setting puts the researcher in a 'uniquely adequate' position to explain what is going in the research arena but this should also be tempered by the researcher not imposing their own standards or values on the data

(Wakefield, 2000). Other researchers take the position that a rapport with participants enhances the quality of the data collected through the opportunities awarded to the researcher within the research setting (Shah, 2004). Therefore, the dual role of the researcher could have also positively influenced the validity of the findings of this PhD.

Research has suggested that having a dual identity can be difficult for some to separate the role of researcher from that of healthcare professional (Fowler, 1988). This is important to consider as the researcher sees the participant as an informer but the healthcare professional views the participant as a patient (Holloway and Wheeler 2002). By adopting a reflexive approach, this researcher attempted to mitigate against this dual role and identity throughout the PhD study. A reflexive diary was kept and field notes were routinely completed during the recruitment phase. However, despite these efforts, it was not always possible for this researcher to detach himself from his role as a palliative care doctor and this is recognised in the literature (Holloway and Wheeler, 2002; Gerrish, 2003; Hesse-Biber and Leavy, 2005). For example, a few patient-participants became emotional when talking about the impact of cancer and fatigue on their lives with end of life issues openly discussed. In these sensitive situations, it was sometimes difficult to maintain clear boundaries within the research interview and not inadvertently veer into a therapeutic encounter with patient participants. A research interview can have similarities to a therapy interview, particularly when there is listening, interpreting and making sense of the participant’s experience (Hart & Crawford- Wright, 1999). However, there is an important difference and this is reflected by the contrasting power dynamic in the research interview, where the participant is helping the researcher (Hart & Crawford- Wright, 1999).

Nonetheless, despite these limitations, this thesis provided an in-depth understanding of how fatigue was talked about in advanced cancer care and how it was managed by participants. Novel findings have been presented which warrant further exploration through research and in the concluding section, recommendations for future research will be suggested.

7.3. Conclusions

This PhD showed how fatigue is a complex phenomenon in advanced cancer care and how it can be integral to the decision-making surrounding palliative cancer treatments. This piece of research has advanced the field of knowledge in this area as it is the first to specifically observe the communication of fatigue and combine it with the views of participants. There are complimentary but important differences in the perspectives of patients and doctors with respect to fatigue in advanced cancer care. These became apparent from the in-depth analysis of talk and the exploration of how fatigue was dealt with by patients and approached by oncologists.

Patients and oncologists in this study identified fatigue as a complex phenomenon that was hard to define and articulate. Patients felt that fatigue was different from tiredness and the symptom was difficult to fully comprehend until it was experienced. This accounted for the varied language and terminology used to describe fatigue in the interaction data. Moreover, the nature of fatigue itself could have a detrimental effect on the patients' cognitive ability to communicate clearly with the doctor. Consequently, when cancer clinicians screen and assess for fatigue, they may need to consider the term fatigue better reflects medical terminology rather than the language used by patients and the symptom could interfere with conversation. Physicians found the subjective and individual nature of fatigue was a factor in it being difficult to define and assess. Fatigue could also be an invisible symptom in the clinic unless signs of weakness were noticeable. Hence, this appeared to be a reason why they routinely measured the severity of fatigue by determining the level of daily activity and judging fatigue against fitness for cancer treatment. Therefore, some cancer clinicians may have adapted their screening of fatigue to focus more on activity levels and it was uncertain whether the term 'energy levels' may have better provided for this. Fatigue was perceived as a complex phenomenon by both sets of participants and observed behaviours in the interaction data provided further insights into this.

This research has also shown that patient companions had an important role in the communication and assessment of fatigue in palliative oncology clinics. The relevance of patient companions in relation to fatigue was not previously known in cancer care communication research. They shared their perspectives of the burden of fatigue in a third of consultations and these did not always align with the patient's perspective which prompted further evaluation by the oncologist. The contribution of patient companions often aided in the communication of fatigue and therefore this helped the clinician to assess fatigue more accurately. Thus, cancer clinicians should be mindful that patient companions could provide a useful perspective on the effect of fatigue on daily living, especially when some patients could tolerate severe levels of fatigue on treatment. Therefore, encouraging the participation of patient companions in palliative oncology clinics could provide for better screening and assessment of fatigue.

The micro-analysis of 60 purposively selected palliative oncology consultations has illustrated how fatigue can be central to cancer treatment decision-making in palliative oncology clinics. In the data, talk connected with fatigue was often sequentially linked with discussions surrounding cancer treatment decisions, goals of treatment, quality of life, and end of life issues. This finding has not been previously shown in cancer care communication research. Physicians expected fatigue to occur with palliative cancer treatments and believed it would progressively worsen as the disease progressed until the end of life. Frequently, they were observed to reflect on the goals of palliative cancer treatments with patients and fatigue was a surrogate marker for quality of life. When fatigue began to interfere with fitness for treatment, this could lead to end of life discussions that were initiated by either patients or clinicians. In addition, patients may have understood that the reporting of fatigue as a problem to the oncologist would lead to cancer treatment decision discussions which may not have been desirable. Hence, this may be a reason why the reporting of fatigue was often associated with actions that mitigated and indicated acceptance of fatigue. Overall, this study highlighted how fatigue-talk transcended symptom-talk and was crucially important in the decision-making process related to cancer treatment decisions in palliative oncology clinics. Hence, this finding further illustrated the need to effectively communicate and accurately assess fatigue in palliative oncology clinics because of fatigue’s integral role in cancer treatment decisions.

The findings from this study suggested that fatigue was an acceptable trade-off for the potential benefit of disease control from palliative cancer treatments. Generally, there were utterances from patients, patient companions and clinicians that implied fatigue was acceptable on treatment. And notably, over half of the patients with clinically relevant fatigue voiced to the oncologist how fatigue was acceptable them. Patients coped with fatigue by maintaining hope that cancer treatments would prolong their lives and believing it would lessen after completion of treatments. However, this meant some patients tolerated disabling fatigue by prioritising the pursuit of cancer treatments over and above the impact of worsening disabling fatigue on daily living. This was observed in the data when disagreements occurred between the patient and the oncologist about the effect of fatigue on quality of life and/or fitness for treatment. This finding is relevant because a patient who has a higher tolerability of disabling fatigue could relate to a misunderstanding of the primary goal of palliative chemotherapy which is to preserve quality of life rather than attempt to prolong life at all costs. It could also suggest that some patients may not be able to comprehend worsening disabling fatigue until it is experienced and therefore oncologists may need to communicate the impact of severe disabling fatigue more clearly. Hence, this research suggests that oncologists should regularly reflect on the goals of palliative chemotherapy with patients and explain clearly the impact of disabling fatigue on daily life and how it leads to cancer treatment decisions.

The resistance observed from patients with clinically relevant fatigue to cancer treatment changes proposed by oncologists to lessen the burden of fatigue was a key finding in this thesis. As mentioned, some patients were willing to put up with severe disabling fatigue for the perceived benefits of palliative chemotherapy. Moreover, it was possible some thought it was a life or death decision because receiving cancer treatment confirmed living with the cancer controlled and not receiving treatment confirmed the inevitability of death. The findings proposed that when resistance to treatment recommendations for fatigue occurred and patients were then given more agency in the decision-making process this led to the continuation of cancer treatments unchanged. Perhaps another reason for why resistance was routinely observed may have been because oncologists usually supported patient choice and autonomy in their treatment recommendations for new and mid-course palliative cancer treatments. Therefore, oncologists were naturally inclined to promote shared decision making as they were observed “to work together” and proposed to reach “a mutual agreement on the best course of action” (Coulter & Collins, 2011, page 2). Thus, patient participation was routinely encouraged which facilitated the patient to outline their acceptability of fatigue and preference to continue with treatment unchanged.

How oncologists managed the resistance to treatment recommendations to limit the burden of fatigue was relevant for clinical practice. Oncologists usually offered and continued palliative cancer treatments in patients with clinically relevant fatigue until it corresponded with a deterioration in ECOG PS that hindered fitness for treatment. Thus, fatigue that interfered with quality of life was the remit of patients and fatigue that interfered with fitness for treatment was the remit of clinicians. When the oncologist perceived that fatigue interfered with quality of life, they were observed to cede more agency to patients in treatment recommendations for fatigue when they encountered resistance. However, when the oncologist perceived that fatigue convincingly interfered with fitness for treatment, they were observed to deploy more agency and be more authoritative in their treatment recommendations when they encountered resistance. In addition, some oncologists voiced a delay in deploying more agency in treatment recommendations for fatigue until there was more certainty that fatigue interfered with fitness for treatment. Even though the oncologist may have projected fatigue to worsen based on clinical experience, when faced with resistance, they sometimes facilitated patient autonomy to continue with palliative cancer treatments unchanged. Clinicians may have felt these actions were necessary in order to maintain agreement and preserve the therapeutic alliance.

When oncologists encounter resistance, this research suggests they can then deploy more agency in treatment recommendations for fatigue while maintaining agreement and preserving the therapeutic alliance. In the data, oncologists were observed to manage passive and active resistance to treatment recommendations for fatigue by deploying more agency and being more authoritative in treatment recommendations while seeking agreement. In the process, they could use several strategies to reach an agreement and maintain the therapeutic relationship. Oncologists generally aimed to control the disease with cancer treatments but felt this was finely balanced with the need to manage fatigue levels through adjustments of treatment doses or schedule. Although oncologists believed patients had remit over quality of life perhaps this should be considered against a patient’s overly optimistic belief about the benefits to survival with cancer treatments and a difficulty in comprehending clinically relevant fatigue. Hence, some patients may need more direction and help from oncologists in the decision-making process regarding cancer treatment decisions, especially when fatigue is projected to worsen. Otherwise, a strong focus on patient autonomy and stressing the importance of the patients’ choice could be problematic with increased risk of harm (Entwistle et al., 2010). Thus, by clinicians deploying more agency in treatment recommendations for fatigue, this could potentially reduce the risk of patients unnecessarily experiencing disabling fatigue. Moreover, clinicians may feel more confident about being more authoritative in treatment recommendations if they understood that the therapeutic alliance could be maintained. These findings could be useful to cancer clinicians and therefore could have implications for clinical practice.

Finally, this research offered further insights into how patients dealt with fatigue and these findings are relevant to cancer clinicians. It was proposed that how fatigue was managed and tolerated by patients was dependent on an array of interconnected strategies, influences and individual factors. Therefore, some patients may need more support from clinicians to help manage fatigue and others may need less support. Perhaps this partly explained why fatigue was perceived by oncologists as a subjective and individual symptom. Patient participants may have learned practical strategies to manage fatigue through self-management or from cancer clinicians in the oncology clinic or chemotherapy day treatment unit. However, oncologists in this study appeared reluctant to offer advice for fatigue because they felt less qualified to do so. There were examples in the data of patients resisting advice from oncologists, and the reason for this may be that the specific advice given was not the most appropriate for the individual. It was suggested that exercise for constant severe fatigue may be less helpful advice to patients unless the trajectory of fatigue was expected to improve. Thus, it could be important to understand when to offer the most appropriate practical strategy for the individual patient with fatigue. This research may have identified training needs in oncologists that should be considered. Furthermore, patients with fatigue may need better access to physiotherapists and occupational therapists who perhaps could provide a more individualised assessment and better support those with disabling fatigue.

Integrating the observed talk and behaviour in clinical encounters with the complementary insights of both patients and clinicians in this study, provided a comprehensive exploration of fatigue in advanced cancer care. The findings of this thesis have several important implications for policy, practice and guidance for future research. These will be discussed in the following section.

7.3.1. Implications for policy and practice

This study has shown that fatigue is difficult to define and articulate for patients with clinically relevant fatigue and oncologists in palliative oncology clinics. The term fatigue was seldom used by patients in their language and they felt the experience of fatigue was different from tiredness. This accounted for the varied language and terminology used by patients to describe their experience of fatigue to the oncologist. Thus, cancer clinicians need to be aware that the term fatigue may represent medical language when they screen for fatigue and assess it in clinical practice. Moreover, clinicians should make attempts to speak the same language as patients or else this could potentially lead to misunderstandings about the level of fatigue experienced. In this study, fatigue-talk was often closely associated with cancer treatment decision discussions and this further highlights the importance of accurately assessing fatigue in palliative oncology clinics. If fatigue is not assessed accurately then it cannot be effectively managed through the adjustment of palliative cancer treatments. The findings of this study could help cancer clinicians to assess fatigue better in clinical practice.

This research also suggested that clinically relevant fatigue was difficult for patients to communicate and report in palliative oncology clinics. This was illustrated by frequent actions of hesitancy and hedging observed when patients reported fatigue. The nature of fatigue meant it could limit cognitive ability to engage and communicate clearly. Moreover, fatigue was an expected side effect of cancer treatments and was viewed as an acceptable trade-off for disease control. Therefore, some patients may feel obliged to remain stoic and put up with fatigue. Alternatively, some may be reluctant to report fatigue for fear it could lead to cancer treatment decision discussions. In the data, when patient participants identified fatigue as a problem this usually led to oncologists proposing adjustments to cancer treatments to lessen the burden of fatigue. Therefore, patients could deliberately minimise fatigue so as to avoid alterations to cancer treatments. In palliative oncology clinics, fatigue can be an invisible symptom to the oncologist unless signs of physical weakness are noticeable. If the patient has difficulty communicating fatigue and/or is reluctant to report it, this could mean fatigue is not accurately assessed and perhaps not effectively managed. Thus, cancer clinicians should be careful in their assessments of fatigue. Cancer clinicians in this study routinely measured the severity of fatigue by determining ECOG PS and therefore judged it against fitness for cancer treatment. This suggests the importance of properly and cautiously grading ECOG PS in order to limit the burden of fatigue in palliative oncology clinics.

A key characteristic of shared decision-making includes the sharing of information that concerns the balancing of benefits of treatments against the risks and costs and also avoiding harm (Charles et al., 1997; Stiggelbout et al., 2012). Although fatigue may have been tolerable to patients, the clinical experience of doctors meant they had more understanding that disabling severe fatigue could occur with the accumulation of cancer treatments. In addition, it was suggested that patients and their companions were concerned that treatments could be less effective at controlling the disease if treatments were adjusted for fatigue. Research has shown that patients frequently overestimate their survival chance with palliative cancer treatments and this influences their decision-making for continuing with cancer treatments (Gramling et al., 2016; Weeks at al., 1998). Moreover, oncology clinical trial data has indicated that palliative cancer treatments could be stopped and restarted at a later date without compromising survival benefit whilst limiting the burden of fatigue on quality of life (Maughan et al., 2003). This suggests that oncologists may need to exert their epistemic authority by outlining their scientific knowledge in their treatment recommendations for fatigue (Stevanovic & Svennevig, 2015). Therefore, it could be helpful for oncologists to consistently reassure patients and their families that the survival benefit would not be compromised when palliative cancer treatments were adjusted with the aim of relieving the burden of fatigue. Perhaps this could better inform patients and prepare them in advance that palliative cancer treatments were routinely adjusted for fatigue so as to promote patient agreement for treatment proposals. Furthermore, by limiting the burden of fatigue from cancer treatments that interfered with ECOG PS and fitness for treatment, then perhaps patients could avail of future treatments and possibly live longer.

The micro-analysis of talk revealed many strategies that were used by oncologists to strengthen their treatment recommendations for fatigue in the pursuit of an agreement. Furthermore, the therapeutic relationship was maintained even when active resistance was encountered to treatment recommendations for fatigue and when end of life issues needed to be explored. This research also confirmed that fatigue was often sequentially linked with discussions around goals of care and end of life issues. These data could be important in the training of oncology doctors as they seldom get to see how experienced senior clinicians attempt to manage fatigue in advanced cancer care and the interactional consequences of alternative communicative selections. Illustrating these strategies to cancer clinicians could mean they more consciously consider their actions with patients and encourage reflective practice (Drew et al., 2001). The findings from the micro-analysis of talk in naturally occurring clinical encounters have been utilized as a method for training communication skills as an alternative to simulated role-play which attempts to mimic actual events (Stokoe, 2014). It is possible that further examination of the data combined with data from other studies examining palliative oncology clinics could inform future communication skills training of cancer clinicians.

The findings from the interviews with patients provided a comprehensive insight into the psychological and practical strategies that were utilised to manage clinically relevant fatigue. For example, this research suggested a better understanding of when active strategies for fatigue were likely to be more effective and appropriate to advise which could benefit patients and clinicians. Knowledge of these simple strategies could assist in the self-management of fatigue and could help clinicians to feel more confident in giving advice for fatigue. Certain qualities in fatigue, such as the rate of change in intensity, and characteristics in the individual, such as their preference for activity, were identified that could either facilitate or inhibit the management of fatigue. This has implications for clinical practice as some individual patients may require more attention and enhanced support to help them learn to adjust and cope with fatigue. Sharing of this knowledge gained from patients. Finally, the knowledge gained from patients about the strategies used for fatigue could be summarised for cancer clinicians and help them share this knowledge with other patients in palliative oncology clinics.

Policy-makers may be interested to know that oncology clinics might not be sufficiently resourced to manage the needs of palliative patients with clinically relevant fatigue. This was implied in the interviews of both sets of participants as time-limited appointments were perceived as a barrier to address fatigue and this has been reported elsewhere (Spichiger et al., 2012). Although the combined incidence of all cancers is projected to rise by 2% within the UK by 2035, there will likely be a more significant increase in the prevalence of patients living with advanced cancer and the effects of fatigue from palliative cancer treatments

(Italiano et al., 2008; Smittenaar et al., 2016). Clinicians perceived this increasing demand in clinical practice but policy was suggested to concentrate more investment in resources on survivorship from cancer (NHS England, 2015). NHS cancer policy aims to provide access to a holistic needs assessment at the end of each treatment and as progressive disease occurs or on request of the patient, with self-management promoted and more GPs involved in care (NHS England, 2017). The findings of this thesis could contribute to understanding self-management and be helpful for GPs. In addition, other healthcare professionals or providers, such as Maggie's Centres or hospices, could be explored as to whether they could continue to or, do more to address these unmet needs of patients living with cancer and fatigue.

7.3.2. Recommendations for future research

This thesis makes an important contribution to the field of fatigue in advanced cancer care and also generates a number of questions for future research.

This was a moderate sized study sample and one important future direction would be to collect more data from palliative oncology care consultations, to develop the findings from this thesis. This would ensure that the research was reflective of how fatigue was approached by patients and oncologists in advanced cancer care. Furthermore, additional insights could be revealed that were not apparent within the sample and the remit of this PhD. For example, this research illustrated how fatigue could be difficult to communicate and define for patients and doctors. Fatigue was different from tiredness and this contributed to the variety of euphemisms used for fatigue. It was uncertain whether there were communication practices initiated by doctors that provided some interactional evidence to suggest that fatigue was better assessed and addressed. For instance, some clinicians routinely screened for fatigue by enquiring about energy levels and this often resulted in the patient describing the functional impact of fatigue which was the information the doctor was seeking to inform fitness for treatment. Furthermore, if oncologists wished for patients to fully comprehend the risk of severe disabling fatigue as a consequence of continuing cancer treatments, it was uncertain whether the use of the descriptor tiredness facilitated or hindered this. There were however, insufficient numbers of these episodes in the corpus of data to explore these questions further so they remain as yet unanswered. It was also possible that some analytic themes remain unaddressed in the data as certain decisions had to be made during the course of this PhD.

A longitudinal study design and collection of consecutive oncology care consultations may provide further insights. It was suggested from the interaction data and the clinician interview data that treatment decisions for fatigue may have occurred over several outpatient visits. In some cases of misalignment, the agency of the decision-making supported patient autonomy and the cancer treatment remained unchanged. However, the clinician occasionally projected future treatment recommendations for fatigue where the oncologist deployed more agency and was authoritative in recommendations for changes to cancer treatment should fatigue continue to worsen. Recording and analysing consecutive consultations would be practically difficult but could address how decision-making occurred over time and whether resistance to treatment recommendations for fatigue persisted.

Similarly, a longitudinal interview study with a larger number of patient participants experiencing clinically relevant fatigue might reveal strategies that were more effective at different intensities and trajectories of fatigue. This research contained subgroups of patients and it seemed likely that different strategies were used at various trajectories of fatigue and the illness. For example, those who experienced chronic disabling fatigue, used normalising and adaptive strategies for fatigue which appeared to help with the perception and tolerability of fatigue. Perhaps these findings could then help in the development of an individualised supportive intervention for fatigue in patients with advanced cancer and clinically relevant fatigue. Furthermore, the design of the study could include and improve the selection and stratification of patients to an appropriate intervention for the fatigue experienced.

Finally, all clinicians in this study identified a need to signpost or refer patients with clinically relevant fatigue to services who could better support some patients. The results from this thesis, in combination with other research, could inform an individualised supportive intervention for fatigue which could include a holistic needs assessment delivered by a palliative care clinician and/or an allied healthcare specialist. The findings of this study could better inform and provide evidence for the delivery of early palliative care in oncology care clinics. It is suggested that this intervention could be more acceptable when provided in a variety of settings as it could then better suit the needs of potential participants with clinically relevant fatigue. It is proposed that the intervention could be delivered in: the oncology clinic, the chemotherapy day treatment unit, through information and communications technology and through day services in a hospice.

Bibliography

Adamsen, L., Midtgaard, J., Andersen, C., Quist, M., Moeller, T., & Roerth, M. (2004). Transforming the nature of fatigue through exercise: qualitative findings from a multidimensional exercise programme in cancer patients undergoing chemotherapy. *European Journal of Cancer Care, 13*(4), 362-370.

Addington-Hall, J. (2007). Introduction. In J. Addington-Hall, E. Bruera, I. Higginson, & S. Payne (Eds.), *Research Methods in Palliative Care* (pp. 1-9). Oxford: Oxford University Press.

Allen, D. (2004). Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of health care settings. *Nursing Enquiry*, *11*(1), 14-24.

Anderson, M. L., & Taylor, H. F. (2006). *Sociology: the Essentials.* USA: Thomson Wadsworth.

Ando, M., Ando, Y., Hasegawa, Y., Shimokata, K., Minami, H., Wakai, K., Ohno, Y., & Sakai, S. (2001). Prognostic value of performance status assessed by patients themselves, nurses, and oncologists in advanced non-small cell lung cancer. *British Journal of Cancer*, *85*(11), 1634-1639.

Antaki, C., Billig, M., Edwards, D., & Potter, J. (2003). Discourse analysis means doing analysis: A critique of six analytic shortcomings.

Arber, A. (2006). Reflexivity: a challenge for the researcher as practitioner? *Journal of Research in Nursing*, *11*(2), 147-157.

Asch, D. A., Jedrziewski, M. K., & Christakis, N. A. (1997). Response rates to mail surveys published in medical journals. *Journal of Clinical Epidemiology*, *50*(10), 1129-1136.

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology*, *8*(1), 21.

Auret, K. A., Schug, S. A., Bremner, A. P., & Bulsara, M. (2009). A randomized, double-blind, placebo-controlled trial assessing the impact of dexamphetamine on fatigue in patients with advanced cancer. *Journal of Pain and Symptom Management*, *37*(4), 613-621.

Bachelot, T., Ray-Coquard, I., Catimel, G., Ardiet, C., Guastalla, J. P., Dumortier, A., Chauvin, F., Droz, J. P., & Clavel, M. (2000). Multivariable analysis of prognostic factors for toxicity and survival for patients enrolled in phase I clinical trials. *Annals of Oncology*, *11*(2), 151-156.

Bakshi, R. (2003). Fatigue associated with multiple sclerosis: diagnosis, impact and management. *Multiple Sclerosis Journal*, 9(3), 219-227.

Barnes, R. (2005). Conversation analysis: a practical resource in the health care setting. *Medical Education*, 39(1), 113-115.

Barsevick, A. M., Whitmer, K., & Walker, L. (2001). In their own words: using the common sense model to analyze patient descriptions of cancer-related fatigue. *Oncology Nursing Forum*, *28*(9), 1363-9.

Bergqvist, J., & Strang, P. (2017). The will to live–breast cancer patients perceptions' of palliative chemotherapy. *Acta Oncologica*, *56*(9), 1168-1174.

Bonner, A., & Tolhurst, G. (2002). Insider-outsider perspectives of participant observation. *Nurse Researcher*, *9*(4), 7.

Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: positionality, practicalities and predicaments. *Journal of Advanced Nursing*, *51*(5), 493-501.

Boulton, M. (2009) Research Ethics. In J. Neale (Ed.), *Research Methods for Health and Social Care* (pp. 31-45). Basingstoke: Palgrave Macmillan.

Bower, J. E., & Lamkin, D. M. (2013). Inflammation and cancer-related fatigue: mechanisms, contributing factors, and treatment implications. *Brain, Behavior, and Immunity*, *30*, S48-S57.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Braun, V., Clarke, V., & Terry, G. (2014). Thematic Analysis. In P. Rohleder, & A. Lyons (Eds.), *Qualitative Research Clinical Health Psychology* (pp. 95-114). Basingstoke: Palgrave MacMillan.

Britten, N. (2006). Qualitative interviews. In C. Pope, & M. Mays (Eds.), *Qualitative Research in Health Care* (3rd ed., pp. 12-20). Malden, WA: Blackwell.

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, *7*(4), 209-215.

Brown, L. F., & Kroenke, K. (2009). Cancer-related fatigue and its associations with depression and anxiety: a systematic review. *Psychosomatics*, *50*(5), 440-447.

Bruera, E., & Yennurajalingam, S. (2010). Challenge of managing cancer-related fatigue. *Journal of Clinical Oncology, 8*(23), 3671-3671.

Bruera, E., El Osta, B., Valero, V., Driver, L. C., Pei, B. L., Shen, L., Poulter, V. A., & Palmer, J. L. (2007). Donepezil for cancer fatigue: a double-blind, randomized, placebo-controlled trial. *Journal of Clinical Oncology*, *25*(23), 3475-3481.

Bruera, E., Kuehn, N., Miller, M. J., Selmser, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care*, *7*(2), 6-9.

Bruera, E., Valero, V., Driver, L., Shen, L., Willey, J., Zhang, T., & Palmer, J. L. (2006). Patient controlled methylphenidate for cancer fatigue: a double-blind, randomized, placebo-controlled trial. *Journal of Clinical Oncology*, *24*(13), 2073-2078.

Bruera, E., Yennurajalingam, S., Palmer, J. L., Perez-Cruz, P. E., Frisbee-Hume, S., Allo, J. A., Williams, J. L., & Cohen, M. Z. (2013). Methylphenidate and/or a nursing telephone intervention for fatigue in patients with advanced cancer: a randomized, placebo-controlled, phase II trial. *Journal of Clinical Oncology*, *31*(19), 2421-2427.

Bryman, A. (2006). Integrating quantitative and qualitative research: how is it done? *Qualitative Research*, *6*(1), 97-113.

Byrne, A., Ellershaw, J., Holcombe, C., & Salmon, P. (2002). Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Education and Counseling*, *48*(1), 15-21.

Cancer Research UK (CRUK), (2018) (2013-2015). Cancer Research United Kingdom, Retrieved from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival#heading-Four

Carpenter, L. J., & Merkel, W. T. (1988). The effects of three methods of observation on couples in interactional research. *American Journal of Family Therapy*, *16*(2), 144-157.

Cassidy, J., Clarke, S., Díaz-Rubio, E., Scheithauer, W., Figer, A., Wong, R., Koski, S., Lichinitser, M., Yang, T., Rivera, F., Couture, F., Sirzén, F., & Saltz, L. (2008). Randomized phase III study of capecitabine plus oxaliplatin compared with fluorouracil/folinic acid plus oxaliplatin as first-line therapy for metastatic colorectal cancer. *Journal of Clinical Oncology, 26*(12), 2006-2012.

Cella, D. (1997). The Functional Assessment of Cancer Therapy-Anemia (FACT-An) Scale: a new tool for the assessment of outcomes in cancer anemia and fatigue. *Seminars in Haematology, 34*(3, Suppl 2), 13-19.

Cella, D., Lai, J. S., Chang, C. H., Peterman, A., & Slavin, M. (2002). Fatigue in cancer patients compared with fatigue in the general United States population. *Cancer, 94*(2), 528-538.

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S., Winicour, P., Brannon, J., Eckberg, K., Lloyd, S., Purl, S., Blendowski, C., Goodman, M., Barnicle, M., Stewart, I., McHale, M., Bonomi, P., Kaplan, E., Taylor, S., Thomas, C.R., & Harris, J. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology, 11*(3), 570-579.

Chan, R. J., Yates, P., & McCarthy, A. L. (2016). Fatigue self-management behaviors in patients with advanced cancer: A prospective longitudinal survey. *Oncology Nursing Forum*, *43*(6), 762-771.

Charalambous, A., & Kouta, C. (2016). Cancer related fatigue and quality of life in patients with advanced prostate cancer undergoing chemotherapy. *BioMed Research International*, *2016*(11), 1-11.

Cheville, A. L., Kollasch, J., Vandenberg, J., Shen, T., Grothey, A., Gamble, G., & Basford, J. R. (2013). A home-based exercise program to improve function, fatigue, and sleep quality in patients with Stage IV lung and colorectal cancer: a randomized controlled trial. *Journal of pain and symptom management, 45*(5), 811-821.

Clarke, G., Johnston, S., Corrie, P., Kuhn, I., & Barclay, S. (2015). Withdrawal of anticancer therapy in advanced disease: a systematic literature review. BMC cancer, 15(1), 892.

Clayton, J. M., Butow, P. N., Tattersall, M. H., Devine, R. J., Simpson, J. M., Aggarwal, G., Clark, K. J.,Currow, D. C., Elliot, L. M., Lacey, J., Lee, P. G., & Noel, M. A. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, *25*(6), 715-723.

Cleeland, C. S., Bennett, G. J., Dantzer, R., Dougherty, P. M., Dunn, A. J., Meyers, C. A., Miller, A. H., Payne, R., Rueben, J. M., Want, X. S., & Lee, B. N. (2003). Are the symptoms of cancer and cancer treatment due to a shared biologic mechanism? A cytokine-immunologic model of cancer symptoms. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *97*(11), 2919-2925.

Cleeland, C. S., Mendoza, T. R., Wang, X. S., Chou, C., Harle, M. T., Morrissey, M., &

Engstrom, M. C. (2000). Assessing symptom distress in cancer patients: the MD Anderson Symptom Inventory. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *89*(7), 1634-1646.

Clift, R. (2001). Meaning in interaction: The case of actually. *Language*, *77*(2), 245-291.

Coleman, T. (2000). Using video-recorded consultations for research in primary care: Advantages and limitations. *Family Practice*, *17*(5), 422–427.

Collins, S., de Vogel-Voogt, E., Visser, A., & van der Heide, A. (2008). Presence, communication and treatment of fatigue and pain complaints in incurable cancer patients. *Patient Education and Counseling*, *72*(1), 102-108.

Conroy, T., Desseigne, F., Ychou, M., Bouché, O., Guimbaud, R., Bécouarn, Y., Adenis, A., Raoul, J.L., Gourgou-Bourgade, S., de la Fouchardière, C., Bennouna, J., Bachet, J.B., Khemissa-Akouz, F., Péré-Vergé, D., Delbaldo, C., Assenat, E., Chauffert, B., Michel, P., Montoto-Grillot, C., & Ducreux, M. (2011). FOLFIRINOX versus gemcitabine for metastatic pancreatic cancer. *New England Journal of Medicine, 364*(19), 1817-1825.

Coulter, A., & Collins, A. (2011). *Making Shared Decision-Making a Reality: No Decision about Me, without Me.* London: King's Fund.

Cramp, F., & Byron-Daniel, J. (2012). Exercise for the management of cancer-related fatigue in adults. *Cochrane database of systematic reviews, (11).*

Creswell, J. W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (3rd Ed.). Sage publications.

Creswell, J. W., & Creswell, J. D. (2017). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (5th Ed.). Sage publications.

Crombie, I. K., & Harvey, B. J. (1997). The pocket guide to critical appraisal: a handbook for health care professionals. *Canadian Medical Association Journal, 157*(4), 448.

Cunningham, D., Starling, N., Rao, S., Iveson, T., Nicolson, M., Coxon, F., Middleton, G., Daniel, F., Oates, J., & Norman, A. R. (2008). Capecitabine and oxaliplatin for advanced esophagogastric cancer. *New England Journal of Medicine, 358*(1), 36-46.

Curtisa, J. R., Patrick, D. L., Caldwell, E., Greenlee, H., & Collier, A. C. (1999). The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians. *Aids, 13*(9), 1123-1131.

Dajczman, E., Kasymjanova, G., Kreisman, H., Swinton, N., Pepe, C., & Small, D. (2008). Should patient-rated performance status affect treatment decisions in advanced lung cancer? *Journal of Thoracic Oncology, 3*(10), 1133-1136.

Daveson, B. A., de Wolf-Linder, S., Witt, J., Newson, K., Morris, C., Higginson, I. J., & Evans, C. J. (2015). Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine*, *29*(10), 939-949.

Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N. K. (2002). Health related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA*, *288*(23), 3027-3034.

Dhillon, H. M., Bell, M. L., van der Ploeg, H. P., Turner, J. D., Kabourakis, M., Spencer, L., C. Lewis, C., Hui, R., Blinman, P., Clarke, S. J., Boyer, M. J., Vardy, J. L. (2017). Impact of physical activity on fatigue and quality of life in people with advanced lung cancer: a randomized controlled trial. *Annals of Oncology*, 28(8), 1889-1897.

Dillon, E., & Kelly, J. (2003). The status of cancer fatigue on the island of Ireland: AIFC professional and interim patient surveys. *The Oncologist*, *8*(Suppl. 1), 22-26.

Donovan, H. S., Hartenbach, E. M., & Method, M. W. (2005). Patient–provider communication and perceived control for women experiencing multiple symptoms associated with ovarian cancer. *Gynecologic oncology*, 99(2), 404-411.

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open, 2016*(6), e011458.

Downe-Wamboldt, B. (1992). Content analysis: method, applications, and issues. *Health Care for Women International, 13*(3), 313-321.

Drew, P. (2006). Misalignments in" after-hours" calls to a British GP's practice: a study in telephone medicine. *Studies in International Sociolinguistics*, *20*, 416-444.

Drew, P., Chatwin, J., & Collins, S. (2001). Conversation analysis: a method for research into interactions between patients and health-care professionals. *Health Expectations*, 4(1), 58-70.

Drew, P., & Holt, E. (1995). The role of idioms in the organisation of topic in conversation. *Idioms: Structural and psychological perspectives*, *1*, 17-31.

Elkington, H., White, P., Addington-Hall, J., Higgs, R., & Edmonds, P. (2005). The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*, 19(6), 485-491.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107-115.

Entwistle, V. A., Carter, S. M., Cribb, A., & McCaffery, K. (2010). Supporting patient autonomy: the importance of clinician-patient relationships. *Journal of General Internal Medicine, 25*(7), 741-745.

Epstein, R. M., Duberstein, P. R., Fenton, J. J., Fiscella, K., Hoerger, M., Tancredi, D. J., Xing, G., Gramling, R., Mohile, S., Franks, P., Kaesberg, P., Plu, S., Cipri, C. S., Street, R. L., Shields, C. G., Back, A. L., Butow, P., Walczak, A., Tattersall, M., Venuti, A., Sullivan, P., Robinson, M., Hoh, B., Lewis, L, & Kravitz, R. L. (2017). Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: the VOICE randomized clinical trial. *JAMA Oncology*, *3*(1), 92-100.

Fearon, K., Strasser, F., Anker, S. D., Bosaeus, I., Bruera, E., Fainsinger, R. L., Jatoi, A., Loprinzi C., MacDonald, N., Mantovani G., Davis, M., Muscarotoli M., Ottery, F., Radburch, L., Ravasco, P., Walsh, D., Wilcock, A., Kaasa, S., & Baracos, V. E. (2011). Definition and classification of cancer cachexia: an international consensus. *The Lancet Oncology*, *12*(5), 489-495.

Feilzer, M. Y. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of Mixed Methods Research, 4*(1), 6-16.

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), 80-92.

Fisher, A., Williams, K., Beeken, R., & Wardle, J. (2015). Recall of physical activity advice was associated with higher levels of physical activity in colorectal cancer patients. *BMJ Open, 5*(4), e006853.

Fisher, A., Wardle, J., Beeken, R. J., Croker, H., Williams, K., & Grimmett, C. (2016). Perceived barriers and benefits to physical activity in colorectal cancer patients. Supportive Care in Cancer, 24(2), 903-910.

Fowler, M. (1988). Ethical Issues in Nursing Research: Issues in Qualitative Research. *Western Journal of Nursing Research, 10*, 109-111.

Gerrish, K. (2003). Self and Others: The rigour and ethics of insider ethnography. In J. Latimer (Ed.), *Advanced Qualitative Research for Nursing* (pp. 77-92). Oxford: Blackwell Publishing.

George, G. C., Iwuanyanwu, E. C., Anderson, K. O., Yusuf, A., Zinner, R. G., Piha-Paul, S. A., Tsimberidou, A. M., Naing, A., Fu, S., Janku, F., Subbiah, V., Cleenland, C. S., Mendoza, T. R., & Hong, D. S. (2016). Sleep quality and its association with fatigue, symptom burden, and mood in patients with advanced cancer in a clinic for early-phase oncology clinical trials. *Cancer*, *122*(21), 3401-3409.

Ghoshal, A., Salins, N., Deodhar, J., Damani, A., & Muckaden, M. (2017). Impact of symptom control on fatigue improvement in patients with advanced cancer: A prospective observational study. *Progress in Palliative Care*, *25*(2), 63-74.

Glare, P., Sinclair, C., Downing, M., Stone, P., Maltoni, M., & Vigano, A. (2008). Predicting survival in patients with advanced disease. *European Journal of Cancer, 44*(8), 1146-1156.

Glaus, A., Crow, R., & Hammond, S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. *Supportive Care in Cancer*, *4*(2), 82-96.

Goodlin, S. J. (2009). Palliative care in congestive heart failure. *Journal of the American College of Cardiology*, 54(5), 386-396.

Gramling, R., Fiscella, K., Xing, G., Hoerger, M., Duberstein, P., Plumb, S., Mohile, S., Fenton, J.J., Tancredi, D.J., Kravitz, R.L., & Epstein, R. M. (2016). Determinants of patient-oncologist prognostic discordance in advanced cancer. JAMA oncology, 2(11), 1421-1426.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105-112.

Greenhalgh, J., Abhyankar, P., McCluskey, S., Takeuchi, E., & Velikova, G. (2013). How do doctors refer to patient-reported outcome measures (PROMS) in oncology consultations? *Quality of Life Research, 22*(5), 939-950.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Ectj*, 29(2), 75.

Gysels, M., Shipman, C., & Higginson, I. J. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics, 9*(1), 7.

Halkowski, T. (2006). Realizing the illness: patients' narratives of symptom discovery. Studies in Interactional Sociolinguistics, 20, 86.

Hargreaves, P. N., & Peppiatt, R. (2001). Is videotaping of consultations acceptable to patients attending a hospice day centre? *Palliative Medicine, 15*(1), 49-54.

Hart, N., & Crawford-Wright, A. (1999). Research as therapy, therapy as research: Ethical dilemmas in new-paradigm research. *British Journal of Guidance and Counselling, 27*(2), 205-214.

Heath, C., Hindmarsh, J., & Luff, P. (2010). *Video in Qualitative Research*. Sage Publications.

Hennink, M., Hutter, I., & Bailey, A. (2010). *Qualitative Research Methods*. Sage Publications.

Hepburn, A., & Bolden, G. B. (2013). The conversation analytic approach to transcription. *The handbook of conversation analysis*, 57-76.

Heritage, J. (2015). Well-prefaced turns in English conversation: A conversation analytic perspective. *Journal of Pragmatics*, *88*(October), 88-104.

Heritage, J., & Clayman, S. E. (2010). *Talk in action: Interactions, Identities and Institutions.* Oxford: Blackwell Wiley.

Heritage, J., & Maynard, D. W. (2006). Introduction: Analyzing interaction between doctors and patients in primary care encounters. In J. Heritage & D. W. Maynard (Eds.), *Communication in medical care: Interaction between primary care physicians and patients* (Vol. 20, pp. 1-21). Cambridge: Cambridge University Press.

Heritage, J., & Sefi, S. (1992). Dilemmas of advice: Aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. In P. Drew, & J. Heritage (Eds.), *Talk at Work: Interaction in Institutional Settings* (pp. 359-419). Cambridge: Cambridge University Press.

Heritage, J., Robinson, J. D., Elliott, M. N., Beckett, M., & Wilkes, M. (2007). Reducing patients' unmet concerns in primary care: the difference one word can make. *Journal of General Internal Medicine*, *22*(10), 1429-1433.

Herzmark, G. (1985). Reactions of patients to video recording of consultations in general practice. *British Medical Journal, 291*(6491), 315-317.

Hesse-Biber, S. (2010). Qualitative approaches to mixed methods practice. *Qualitative Inquiry, 16*(6), 455-468.

Hesse-Biber, S., & Leavy, P. (2005). *The Practice of Qualitative Research*. London: Sage.

Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative Research*, *3*(3), 345-357.

Holloway, I., & Wheeler, S. (2002). *Qualitative Research in Nursing*. Great Britain: Blackwell Publishing.

Holt, E. (1996). Reporting on talk: The use of direct reported speech in conversation. *Research on Language and Social Interaction*, *29*(3), 219-245.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

Hui, D., Glitza, I., Chisholm, G., Yennu, S., & Bruera, E. (2013). Attrition rates, reasons, and predictive factors in supportive care and palliative oncology clinical trials. *Cancer*, *119*(5), 1098-1105.

Hwang, S. S., Chang, V. T., Cogswell, J., & Kasimis, B. S. (2002). Clinical relevance of fatigue levels in cancer patients at a Veterans Administration Medical Center. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *94*(9), 2481-2489.

Italiano, A., Massard, C., Bahleda, R., Vataire, A. L., Deutsch, E., Magne, N., Pignon, J. P., Vassal, G., Armand, J. P., & Soria, J. C. (2007). Treatment outcome and survival in participants of phase I oncology trials carried out from 2003 to 2006 at Institut Gustave Roussy. *Annals of Oncology*, *19*(4), 787-792.

Jackson, M. (2008). Content Analysis. In J. Neale (Ed.), *Research Methods for Health and Social Care* (pp. 78-91). Palgrave Macmillan, 2008.

James, S., Wright, P., Scarlett, C., Young, T., Jamal, H., & Verma, R. (2015). Cancer-related fatigue: results from patient experience surveys undertaken in a UK regional cancer centre. *Supportive Care in Cancer*, *23*(7), 2089-2095.

Jefferson, G. (1988). On the sequential organization of troubles-talk in ordinary conversation. *Social Problems*, *35*(4), 418-441.

Jefferson, G. (2004). Glossary of transcript symbols with an introduction. *Pragmatics and Beyond New Series*, 125, 13-34.

Jenkins, L., Cosgrove, J., Ekberg, K., Kheder, A., Sokhi, D., & Reuber, M. (2015). A brief conversation analytic communication intervention can change history-taking in the seizure clinic. *Epilepsy & Behavior, 52*(Pt A), 62-67.

Jiménez, A., Madero, R., Alonso, A., Martínez-Marín, V., Vilches, Y., Martínez, B., Feliu, M., Diaz, L., Espinosa, E., & Feliu J. (2011). Symptom clusters in advanced cancer. *Journal of Pain and Symptom Management*, *42*(1), 24-31.

Johnsen, A. T., Petersen, M. A., Pedersen, L., & Groenvold, M. (2009). Symptoms and problems in a nationally representative sample of advanced cancer patients. *Palliative Medicine*, *23*(6), 491-501.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14-26.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112-133.

Kerr, R. S., Love, S., Segelov, E., Johnstone, E., Falcon, B., Hewett, P., Weaver, A., Church D., Scudder, C., Pearson, S., Julier P., Pezzella, F., Tomlinson, I., Domingo, E., & Kerr, P. (2016). Adjuvant capecitabine plus bevacizumab versus capecitabine alone in patients with colorectal cancer (QUASAR 2): an open-label, randomised phase 3 trial. *The Lancet Oncology*, *17*(11), 1543-1557.

Kim, Y. J., Hui, D., Zhang, Y., Park, J. C., Chisholm, G., Williams, J., & Bruera, E. (2015). Differences in performance status assessment among palliative care specialists, nurses, and medical oncologists. *Journal of Pain and Symptom Management, 49*(6), 1050-1058.

Kirshbaum, M. N., Olson, K., Pongthavornkamol, K., & Graffigna, G. (2013). Understanding the meaning of fatigue at the end of life: An ethnoscience approach. *European Journal of Oncology Nursing*, *17*(2), 146-153.

Krishnasamy, M. (2000). Fatigue in advanced cancer—meaning before measurement? *International Journal of Nursing Studies*, *37*(5), 401-414.

Kwak, S. M., Choi, Y. S., Yoon, H. M., Kim, D. G., Song, S. H., Lee, Y. J., Yeom, C. H., Koh, S. J., Lee, M. A., & Suh, S. Y. (2012). The relationship between interleukin-6, tumor necrosis factor-α, and fatigue in terminally ill cancer patients. *Palliative Medicine*, *26*(3), 275-282.

Land, V., Parry, R., & Seymour, J. (2017). Communication practices that encourage and constrain shared decision making in health-care encounters: Systematic review of conversation analytic research. *Health Expectations, 20*(6), 1228-1247.

Lis, C. G., Rodeghier, M., Grutsch, J. F., & Gupta, D. (2009). Distribution and determinants of patient satisfaction in oncology with a focus on health related quality of life. *BMC Health Services Research*, 9(1), 190.

Lutfey, K., & Maynard, D. W. (1998). Bad news in oncology: How physician and patient talk about death and dying without using those words. *Social Psychology Quarterly*, *61*, 321-341.

Macmillan Cancer Support. (2017). *Statistics Fact Sheet.* Retrieved from: https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf

Maddams, J., Utley, M., & Møller, H. (2012). Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*, *107*(7), 1195.

Madsen, U. R., Groenvold, M., Petersen, M. A., & Johnsen, A. T. (2015). Comparing three different approaches to the measurement of needs concerning fatigue in patients with advanced cancer. *Quality of Life Research*, *24*(9), 2231-2238.

Magnusson, K., Möller, A., Ekman, T., & Wallgren, A. (1999). A qualitative study to explore the experience of fatigue in cancer patients. *European Journal of Cancer Care*, *8*(4), 224-232.

Maree, J. E., & Potgieter, T. (2018). Palliative chemotherapy: The perspectives and experiences of south african nurses. *Asia-Pacific Journal of Oncology Nursing, 5*(1), 77.

Maughan, T. S., James, R. D., Kerr, D. J., Ledermann, J. A., Seymour, M. T., Topham, C., McArdle, C., Cain, D., Stephens, R.J. Medical Research Council Colorectal Cancer Group. (2003). Comparison of intermittent and continuous palliative chemotherapy for advanced colorectal cancer: a multicentre randomised trial. The Lancet, 361(9356), 457-464.

Maynard, D. W. (2003). *Bad News, Good News: Conversational Order in Everyday Talk and Clinical Settings*. US: University of Chicago Press.

Maynard, D. W., & Frankel, R. M. (2006). On diagnostic rationality: bad news, good news, and the symptom residue. In J. Heritage & D. W. Maynard (Eds.), *Communication in Medical Care: Interaction between Physicians and Patients*. Cambridge: Cambridge University Press.

Maynard, D. W., Cortez, D., & Campbell, T. C. (2016). 'End of life' conversations, appreciation sequences, and the interaction order in cancer clinics. *Patient Education and Counseling*, *99*(1), 92-100.

McCosker, H., Barnard, A., & Gerber, R. (2001). Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research 2*(1), article 22.

Mende, M., Trautmann, K., Rentsch, A., Hornemann, B., Schuler, U. S., Ehninger, G., & Folprecht, G. (2013). Patients' perspectives on palliative chemotherapy of colorectal and non-colorectal cancer: a prospective study in a chemotherapy-experienced population. *BMC Cancer*, *13*(1), 66.

Messias, D. K. H., Yeager, K. A., Dibble, S. L., & Dodd, M. J. (1997). Patients' perspectives of fatigue while undergoing chemotherapy. *Oncology Nursing Forum, 24*(1), 43-50.

Minton, O., & Stone, P. (2008). A systematic review of the scales used for the measurement of cancer-related fatigue (CRF). *Annals of Oncology, 20*(1), 17-25.

Minton, O., Richardson, A., Sharpe, M., Hotopf, M., & Stone, P. (2010). Drug therapy for the management of cancer-related fatigue. *Cochrane Database of Systematic Reviews 2010,* 7.

Minton, O., Strasser, F., Radbruch, L., & Stone, P. (2012). Identification of factors associated with fatigue in advanced cancer: a subset analysis of the European palliative care research collaborative computerized symptom assessment data set. *Journal of Pain and Symptom Management*, *43*(2), 226-235.

Monzoni, C. M., Duncan, R., Grünewald, R., & Reuber, M. (2011). Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient Education and Counseling*, *85*(3), e189-e200.

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research, 6*(1), 45-59.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research, 1*(1), 48-76.

Morrow, G. R., Hickok, J. T., Roscoe, J. A., Raubertas, R. F., Andrews, P. L., Flynn, P. J., Hynes, H. E., Banerjee, T. K., Krishner, J. J., & King, D. K. (2003). Differential effects of paroxetine on fatigue and depression: a randomized, double-blind trial from the University of Rochester Cancer Center Community Clinical Oncology Program. *Journal of Clinical Oncology*, *21*(24), 4635-4641.

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3-5.

Morse, J. M. (2010). Simultaneous and sequential qualitative mixed method designs. *Qualitative Inquiry, 16*(6), 483-491.

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25*(9), 1212-1222.

Morse, J. M., & Niehaus, L. (2009). *Mixed Methods Design: Principles and Procedures*. USA: Left Coast Press.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), 13-22.

Mücke, M., Cuhls, H., Peuckmann-Post, V., Minton, O., Stone, P., & Radbruch, L. (2015). Pharmacological treatments for fatigue associated with palliative care. *Cochrane Database Systematic Reviews 2015,* 5.

Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: a review of the literature.

Murtagh, G. M., Furber, L., & Thomas, A. L. (2013). Patient-initiated questions: How can doctors encourage them and improve the consultation process? A qualitative study. *BMJ Open, 3*(10), e003112.

National Cancer Intelligence Network and Cancer Research UK. Routes to diagnosis of cancer by stage, 2012-2013 workbook. London: NCIN; 2016. Retrieved from: http://www.ncin.org.uk/publications/routes_to_diagnosis

NCIN (National Cancer Intelligence Network) (2016). Stage Breakdown by CCG 2014. London: NCI. Retrieved from: http://www.ncin.org.uk/publications/survival_by_stage

NCRAS (National Cancer Registration & Analysis Service and Cancer Research UK) (2017a): "Chemotherapy, Radiotherapy and Tumour Resections in England: 2013-2014" workbook. London. Retrieved from: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments

NCRAS (National Cancer Registration & Analysis Service and Cancer Research UK) (2017b): Retrieved from: http://www.ncin.org.uk/about_ncin/releases

National Comprehensive Cancer Network, (2014). *NCCN Guidelines® & Clinical Resources*. London: NCCN. Retrieved from: https://www.nccn.org/professionals/physician_gls/default.aspx#supportive

NHS England (2015). *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020.* Retrieved from: https://www.cancerresearchuk.org/sites/default/files/achieving_world class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

NHS England (2016). *Achieving World-Class Cancer Outcomes: Taking the strategy forward*. Retrieved from: https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf

NHS England (2017). *Achieving world class cancer outcomes: A Strategy for England 2015-2020 Progress Report 2016-17*. Retrieved from: https://www.england.nhs.uk/publication/achieving-world-class-cancer-outcomes/

NICR (Northern Ireland Cancer Registry) (2016). Queens University Belfast, Incidence by stage 2010-2014. Belfast. Retrieved from: http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/

O'Cathain, A., Murphy, E., & Nicholl, J. (2007). Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. *BMC Health Services Research, 7*(1), 1.

Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T., & Mc Fadden, E. T. (1982). Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology, 5*(6), 649-55.

Oldenmenger, W. H., Pleun, J., de Klerk, C., & van der Rijt, C. C. (2013). Cut points on 0–10 numeric rating scales for symptoms included in the Edmonton Symptom Assessment Scale in cancer patients: a systematic review. *Journal of Pain and Symptom Management*, *45*(6), 1083-1093.

Oldervoll, L. M., Loge, J. H., Lydersen, S., Paltiel, H., Asp, M. B., Nygaard, U. V., Oredalen, E., Frantzen, T. L., Lesteberg, I., Amundsen, L., Hjermstad, M. J., Haugen, D. F., Paulsen, Ø., & Kaasa, S. (2011). Physical exercise for cancer patients with advanced disease: a randomized controlled trial. *The Oncologist, 16*(11), 1649-1657.

Olson, K., Krawchuk, A., & Quddusi, T. (2007). Fatigue in individuals with advanced cancer in active treatment and palliative settings. *Cancer Nursing*, *30*(4), E1-E10.

O'Regan, P., & Hegarty, J. (2017). The importance of self-care for fatigue amongst patients undergoing chemotherapy for primary cancer. *European Journal of Oncology Nursing*, *28*, 47-55.

Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., Currow, D., Ghershi, D., Glare, P., Hagerty, R., & Tattersall, M. H. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of Pain and Symptom Management*, *34*(1), 81-93.

Parry, R. (2010). Video-based conversation analysis. In I. Bourgeault, R. Dingwall, & R. de Vries (Eds.), *The SAGE Handbook of Qualitative Methods in Health Research* (pp. 373-396). London: Sage.

Parry, R., Land, V., & Seymour, J. (2014). How to communicate with patients about future illness progression and end of life: a systematic review. *BMJ Supportive and Palliative Care, 4*(4), 331-341.

Parry, R., Pino, M., Faull, C., & Feathers, L. (2016). Acceptability and design of video-based research on healthcare communication: Evidence and recommendations. *Patient Education and Counseling, 99*(8), 1271-1284.

Passik, S. D., Kirsh, K. L., Donaghy, K., Holtsclaw, E., Theobald, D., Cella, D., & Breitbart, W. (2002). Patient-related barriers to fatigue communication: initial validation of the fatigue management barriers questionnaire. *Journal of Pain and Symptom Management*, 24(5), 481-493.

Patton, M. (2002). *Qualitative Research and Evaluation Methods*. USA: Sage.

Penner, L. A., Orom, H., Albrecht, T. L., Franks, M. M., Foster, T. S., & Ruckdeschel, J. C. (2007). Camera-related behaviors during video recorded medical interactions. *Journal of Nonverbal Behavior, 31*(2), 99-117.

Peräkylä, A. (1997). Conversation analysis: a new model of research in doctor–patient communication. *Journal of the Royal Society of Medicine, 90*(4), 205-208.

Peräkylä, A. (2011). Validity in research on naturally occurring social interaction. In D. Silverman (Ed.), *Qualitative Research* (3rd ed., pp.365-382). London: Sage.

Pertl, M. M., Quigley, J., & Hevey, D. (2014). 'I'm not complaining because I'm alive': barriers to the emergence of a discourse of cancer-related fatigue. *Psychology & Health*, 29(2), 141-161.

Peters, M. E., Goedendorp, M. M., Verhagen, S. A., Smilde, T. J., Bleijenberg, G., & van der Graaf, W. T. (2015). A prospective analysis on fatigue and experienced burden in informal caregivers of cancer patients during cancer treatment in the palliative phase. *Acta Oncologica*, *54*(4), 500-506.

Peters, M. E., Goedendorp, M. M., Verhagen, C. A., Bleijenberg, G., & van der Graaf, W. T. (2016). Fatigue and its associated psychosocial factors in cancer patients on active palliative treatment measured over time. *Supportive Care in Cancer*, *24*(3), 1349-1355.

Peuckmann-Post, V., Elsner, F., Krumm, N., Trottenberg, P., & Radbruch, L. (2010). Pharmacological treatments for fatigue associated with palliative care. *Cochrane Database of Systematic Reviews 2010,* 11.

Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research synthesis methods*, 5(4), 371-385.

Pino, M., & Parry, R. (2018). How and when do patients request life-expectancy estimates? Evidence from hospice medical consultations and insights for practice. *Patient Education and Counseling.* Retrieved from: https://doi.org/10.1016/j.pec.2018.03.026

Pino, M., Parry, R., Land, V., Faull, C., Feathers, L., & Seymour, J. (2016). Engaging terminally ill patients in end of life talk: How experienced palliative medicine doctors navigate the dilemma of promoting discussions about dying. *PloS One*, *11*(5), e0156174.

Pino, M., Parry, R., Feathers, L., & Faull, C. (2017). Is it acceptable to video-record palliative care consultations for research and training purposes? A qualitative interview study exploring the views of hospice patients, carers and clinical staff. *Palliative Medicine, 31*(8), 707-715.

Pomerantz, A. (1984). Agreeing and disagreeing with assessments: Some features of preferred/dispreferred turn shaped. In J. M. Atkinson, & J. Heritage (Eds.), *Structures of Social Action* (pp. 57-101). Cambridge: Cambridge University Press.

Poort, H., Peters, M., Bleijenberg, G., Gielissen, M. F., Goedendorp, M. M., Jacobsen, P., Verhagen, S., & Knoop, H. (2017). Psychosocial interventions for fatigue during cancer treatment with palliative intent. *Cochrane Database of Systematic Reviews 2017,* 7. Retrieved from: DOI: 10.1002/14651858.CD012030.pub2.

Porock, D., & Juenger, J. A. (2004). Just go with the flow: a qualitative study of fatigue in biotherapy. *European Journal of Cancer Care, 13*(4), 356-361.

Potter, J. (2004). Fatigue experience in advanced cancer: a phenomenological approach. *International Journal of Palliative Nursing*, *10*(1), 15-23.

Potter, J., & Hepburn, A. (2005). Qualitative interviews in psychology: Problems and possibilities. *Qualitative research in Psychology*, 2(4), 281-307.

Poulson, M. J. (2001). Not just tired. *Journal of Clinical Oncology*: official journal of the American Society of Clinical Oncology, 19(21), 4180.

Preston, N. J., Fayers, P., Walters, S. J., Pilling, M., Grande, G. E., Short, V., Owen-Jones, E., Evans, C. J., Benalia, H., Higginson, I. J., & Todd, C. J. (2013). Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: part of the MORECare research method guidance on statistical issues. *Palliative Medicine*, *27*(10), 899-907.

Price, D. D., McGrath, P. A., Rafii, A., & Buckingham, B. (1983). The validation of visual analogue scales as ratio scale measures for chronic and experimental pain. Pain, 17(1), 45-56.

Pyszora, A., Budzyński, J., Wójcik, A., Prokop, A., & Krajnik, M. (2017). Physiotherapy programme reduces fatigue in patients with advanced cancer receiving palliative care: randomized controlled trial. Supportive Care in Cancer, 25(9), 2899-2908.

Quaresma, M., Coleman, M. P., & Rachet, B. (2015). 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: a population-based study. *The Lancet*, 385(9974), 1206-1218.

de Raaf, P. J., Sleijfer, S., Lamers, C. H. J., Jager, A., Gratama, J. W., & van der Rijt, C. C. D. (2012). Inflammation and fatigue dimensions in advanced cancer patients and cancer survivors: an explorative study. *Cancer*, *118*(23), 6005-6011.

Radbruch, L., Strasser, F., Elsner, F., Gonçalves, J. F., Løge, J., Kaasa, S., Nauck, F., Stone, P., & Research Steering Committee of the European Association for Palliative Care (EAPC). (2008). Fatigue in palliative care patients—an EAPC approach. *Palliative Medicine, 22*(1), 13-32.

de Raeve, L. (1994). Ethical issues in palliative care research. *Palliative Medicine 8*(4), 298-305.

Rapley, T. (2012). The (extra) ordinary practices of qualitative interviewing. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research: The Complexity of the Craft* (2nd ed., pp. 541-555). SAGE.

Raudonis, B. M. (1992). Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research*, *2*(2), 238-249.

Ream, E., & Richardson, A. (1997). Fatigue in patients with cancer and chronic obstructive airways disease: a phenomenological enquiry. *International Journal of Nursing Studies*, *34*(1), 44-53.

Richardson, A., & Ream, E. (1996). The experience of fatigue and other symptoms in patients receiving chemotherapy. *European Journal of Cancer Care*, *5*, 24-30.

Richardson, A., & Ream, E. K. (1997). Self-care behaviours initiated by chemotherapy patients in response to fatigue. *International Journal of Nursing Studies*, *34*(1), 35-43.

Rivas, C. (2011). Coding and Analysing Qualitative Data. In C. Seale (Ed.), *Researching Society and Culture* (3rd ed., pp. 368-382). California: SAGE.

Robinson, J. D., & Heritage, J. (2006). Physicians' opening questions and patients' satisfaction. *Patient Education and Counseling*, *60*(3), 279-285.

Robinson, J. D., & Heritage, J. (2014). Intervening with conversation analysis: The case of medicine. *Research on Language and Social Interaction, 47*(3), 201-218.

Rodrigues, A. R., Trufelli, D. C., Fonseca, F., de Paula, L. C., & Giglio, A. D. (2016). Fatigue in patients with advanced terminal cancer correlates with inflammation, poor quality of life and sleep, and anxiety/depression. *American Journal of Hospice and Palliative Medicine*, *33*(10), 942-947.

Rodriguez, K. L., Bayliss, N., Alexander, S. C., Jeffreys, A. S., Olsen, M. K., Pollak, K. I., Kennifer, S. L., Tulsky, J. A., & Arnold, R. M. (2010). How oncologists and their patients with advanced cancer communicate about health-related quality of life. *Psycho-Oncology*, *19*(5), 490-499.

Roscoe, J. A., Kaufman, M. E., Matteson-Rusby, S. E., Palesh, O. G., Ryan, J. L., Kohli, S., Perlis, M. L., & Morrow, G. R. (2007). Cancer-related fatigue and sleep disorders. *The Oncologist*, *12*(Supplement 1), 35-42.

Roscoe, J. A., Morrow, G. R., Hickok, J. T., Mustian, K. M., Griggs, J. J., Matteson, S. E., Bushunow, P., Qazi, R., & Smith, B. (2005). Effect of paroxetine hydrochloride (Paxil®) on fatigue and depression in breast cancer patients receiving chemotherapy. *Breast Cancer Research and Treatment*, *89*(3), 243-249.

Roter, D., & Larson, S. (2002). The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Education and Counseling, 46*(4), 243-251.

Rushmer, R., Themessel-Huber, M., Coyle, J., Humphris, G., Dowell, J., & Williams, B. (2011). Is the routine recording of primary care consultations possible… and desirable? Lessons for researchers from a consultation with multiple stakeholders. *Patient Education and Counseling*, *82*(2), 247-253.

Ryan, J. L., Carroll, J. K., Ryan, E. P., Mustian, K. M., Fiscella, K., & Morrow, G. R. (2007). Mechanisms of cancer-related fatigue. *The Oncologist*, *12*(Supplement 1), 22-34.

Sacks, H. (1987). On the preferences for agreement and contiguity in sequences in conversation. *Talk and Social Organisation*, 54-69.

Saligan, L. N., & Kim, H. S. (2012). A systematic review of the association between immunogenomic markers and cancer-related fatigue. *Brain, Behavior, and Immunity*, *26*(6), 830-848.

Saligan, L. N., Olson, K., Filler, K., Larkin, D., Cramp, F., Sriram, Y., Escalante, C. P., del Giglio, A., Kovber, K. M., Kamath, J., Palesh, O., Mustian, K., & Multinational Association of Supportive Care in Cancer Fatigue Study Group – Biomarker Working Group. (2015). The biology of cancer-related fatigue: a review of the literature. *Supportive Care in Cancer*, *23*(8), 2461-2478.

Schegloff, E. A. (2007). *Sequence Organization in Interaction: A Primer in Conversation Analysis (Vol. 1)*. Cambridge: Cambridge University Press.

Seale, C., Chaplin, R., Lelliott, P., & Quirk, A. (2007). Antipsychotic medication, sedation and mental clouding: an observational study of psychiatric consultations. *Social Science & Medicine*, *65*(4), 698-711.

Selby, D., Cascella, A., Gardiner, K., Do, R., Moravan, V., Myers, J., & Chow, E. (2010). A single set of numerical cutpoints to define moderate and severe symptoms for the Edmonton Symptom Assessment System. *Journal of Pain and Symptom Management*, *39*(2), 241-249.

Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative care: the World Health Organization's global perspective. *Journal of Pain and Symptom Management, 24*(2), 91-96.

Shah, S. (2004). The researcher/interviewer in intercultural context: A social intruder. *British Educational Research Journal. 30*(4) , 549-577.

Sharpe, M., Walker, J., Hansen, C. H., Martin, P., Symeonides, S., Gourley, C., Wall, L., Weller, D., Murray, G. (2014). Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial. The Lancet, 384(9948), 1099-1108.

Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology, 7*(3), 233-243.

Shaw, R., & Reuber, M. (2013). Initiating decision-making in neurology consultations: ‘recommending’ versus ‘option-listing’ and the implications for medical authority. *Sociology of Health & Illness*, *35*(6), 873-890.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63-75.

Siegel, K., Lekas, H. M., & Maheshwari, D. (2012). Causal attributions for fatigue by older adults with advanced cancer. *Journal of Pain and Symptom Management*, *44*(1), 52-63.

Silverman, D. (1996). *Discourses of Counselling: HIV Counselling as Social Interaction*. London: Sage.

Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: Sage.

Silverman, D. (2013). *Doing Qualitative Research: A Practical Handbook* (4th ed.). SAGE Publications Limited.

Simon, M. S., Du, W., Flaherty, L., Philip, P. A., Lorusso, P., Miree, C., Smith, D., & Brown, D. R. (2004). Factors associated with breast cancer clinical trials participation and enrollment at a large academic medical center. *Journal of Clinical Oncology, 22*(11), 2046-2052.

Singh, S., Cortez, D., Maynard, D., Cleary, J. F., DuBenske, L., & Campbell, T. C. (2017). Characterizing the nature of scan results discussions: insights into why patients misunderstand their prognosis. *Journal of Oncology Practice*, *13*(3), e231-e239.

Slamon, D. J., Leyland-Jones, B., Shak, S., Fuchs, H., Paton, V., Bajamonde, A., Fleming, T., Eiermann, W., Wolter, J., Pegram, M., Baselga, J., & Norton, L. (2001). Use of chemotherapy plus a monoclonal antibody against HER2 for metastatic breast cancer that overexpresses HER2. *New England Journal of Medicine, 344*(11), 783-792.

Smith, J. A. & Osborn, M. (2007). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 51-80). London: Sage.

Smittenaar, C. R., Petersen, K. A., Stewart, K., & Moitt, N. (2016). Cancer incidence and mortality projections in the UK until 2035. *British Journal of Cancer, 115*(9), 1147.

Spathis, A., Fife, K., Blackhall, F., Dutton, S., Bahadori, R., Wharton, R., O'Brien, M., Stone, P., Benepal, T., Bates, N., & Wee, B. (2014). Modafinil for the treatment of fatigue in lung cancer: results of a placebo-controlled, double-blind, randomized trial. *Journal of Clinical Oncology, 32*(18), 1882-1888.

Spichiger, E., Rieder, E., Müller-Fröhlich, C., & Kesselring, A. (2012). Fatigue in patients undergoing chemotherapy, their self-care and the role of health professionals: a qualitative study. *European Journal of Oncology Nursing*, *16*(2), 165-171.

Stevanovic, M., & Svennevig, J. (2015). Introduction: Epistemics and deontics in conversational directives. *Journal of Pragmatics*, *78*, 1-6.

Stiggelbout, A. M., van der Weijden, T., de Wit, M. P., Frosch, D., Légaré, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: really putting patients at the centre of healthcare. *British Medical Journal, 344*, e256.

Stivers, T., Heritage, J., Barnes, R. K., McCabe, R., Thompson, L., & Toerien, M. (2018). Treatment recommendations as actions. *Health Communication*, *33*(11), 1335-1344.

Stokoe, E. (2014). The Conversation Analytic Role-play Method (CARM): A method for training communication skills as an alternative to simulated role-play. *Research on Language and Social Interaction, 47*(3), 255-265.

Stone, P., Ream, E., Richardson, A., Thomas, H., Andrews, P., Campbell, P., Dawson, T., Edwards, J., Goldie, T., Hammick, M., Kearney, N., Lean M., Rapley, D., Smith A. G., Teague, C., & Young, A. (2003). Cancer-related fatigue–a difference of opinion? Results of a multicentre survey of healthcare professionals, patients and caregivers. *European Journal of Cancer Care*, *12*(1), 20-27.

Stone, P., Richards, M., Ahern, R., & Hardy, J. (2000). A study to investigate the prevalence, severity and correlates of fatigue among patients with cancer in comparison with a control group of volunteers without cancer. *Annals of Oncology*, *11*(5), 561-567.

Storey, D. J., Waters, R. A., Hibberd, C. J., Rush, R. W., Cargill, A. T., Wall, L. R., Fallon, M.T., Strong, V.A., Walker, J., & Sharpe, M. (2007). Clinically relevant fatigue in cancer outpatients: the Edinburgh Cancer Centre symptom study. *Annals of Oncology*, *18*(11), 1861-1869.

Strang, P., & Bergqvist, J. (2017). Does palliative chemotherapy provide a palliative effect on symptoms in late palliative stages? An interview study with oncologists. *Acta Oncologica*, *56*(10), 1258-1264.

Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling*, 74(3), 295-301.

Swetz, K. M., & Smith, T. J. (2010). Palliative chemotherapy: when is it worth it and when is it not? *The Cancer Journal, 16*(5), 467-472.

Takeuchi, E. E., Keding, A., Awad, N., Hofmann, U., Campbell, L. J., Selby, P. J., Brown, J. M., & Velikova, G. (2011). Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *Journal of Clinical Oncology*, *29*(21), 2910-2917.

Tang, C. C., Draucker, C., Tejani, M. A., & Von Ah, D. (2018). Patterns of interactions among patients with advanced pancreatic cancer, their caregivers, and healthcare providers during symptom discussions. *Supportive Care in Cancer*, *26*(10), 3479-3506.

Tang, C. C., Draucker, C., Tejani, M. A., & Von Ah, D. (2018). Symptom experiences in patients with advanced pancreatic cancer as reported during healthcare encounters. *European Journal of Cancer Care*, *27*(3), e12838.

Tate, A. (2018a). The Interactional Negotiation of Complex Treatment: Physician Authority and Patient Agency in Cancer Care (Doctoral dissertation, UCLA).

Tate, A. (2018b). Treatment Recommendations in Oncology Visits: Implications for Patient Agency and Physician Authority. *Health Communication*, *33*(12), 1-11.

Terry, W., Olson, L. G., Ravenscroft, P., Wilss, L., & Boulton-Lewis, G. (2006). Hospice patients' views on research in palliative care. *Internal Medicine Journal*, *36*(7), 406-413.

Teunissen, S. C., Wesker, W., Kruitwagen, C., de Haes, H. C., Voest, E. E., & de Graeff, A. (2007). Symptom prevalence in patients with incurable cancer: a systematic review. *Journal of Pain and Symptom Management*, *34*(1), 94-104.

Themessl-Huber, M., Humphris, G., Dowell, J., Macgillivray, S., Rushmer, R., & Williams, B. (2008). Audio-visual recording of patient–GP consultations for research purposes: A literature review on recruiting rates and strategies. *Patient Education and Counseling*, *71*(2), 157-168.

Thompson, L. (2013). *" So you feel a bit anxious?": psychiatrist-patient communication and treatment adherence in schizophrenia*. Doctoral dissertation, Queen Mary, University of London.

Todd, A. M., Laird, B. J., Boyle, D., Boyd, A. C., Colvin, L. A., & Fallon, M. T. (2009). A systematic review examining the literature on attitudes of patients with advanced cancer toward research. *Journal of Pain and Symptom Management*, *37*(6), 1078-1085.

Toerien, M., Shaw, R., Duncan, R., & Reuber, M. (2011). Offering patients choices: A pilot study of interactions in the seizure clinic. *Epilepsy & Behavior*, *20*(2), 312-320.

Toerien, M., Shaw, R., & Reuber, M. (2013). Initiating decision-making in neurology consultations: 'recommending' versus 'option-listing' and the implications for medical authority. *Sociology of Health & Illness*, *35*(6), 873-890.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357.

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences, 15*(3), 398-405.

Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., & Selby, P. J. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *Journal of Clinical Oncology*, *22*(4), 714-724.

Vogelzang, N. J., Breitbart, W., Cella, D., Curt, G. A., Groopman, J. E., Horning, S. J., Itri, L. M., Johnson, D. H., Scherr, S. L., & Portenoy, R. K. (1997). Patient, caregiver, and oncologist perceptions of cancer-related fatigue: results of a tripart assessment survey. The Fatigue Coalition. *Seminars in Hematology, 34*(3 Suppl. 2), 4-12).

Voutilainen, L., Peräkylä, A., & Ruusuvuori, J. (2011). Therapeutic change in interaction: Conversation analysis of a transforming sequence. *Psychotherapy Research, 21*(3), 348-365.

Wadhwa, D., Burman, D., Swami, N., Rodin, G., Lo, C., & Zimmermann, C. (2013). Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psycho-Oncology*, *22*(2), 403-410.

Wakefield, A. (2000). Ethnomethodology-The problems of unique adequacy. NT Research, 5(1), 46-53.

Walling, A. M., Weeks, J. C., Kahn, K. L., Tisnado, D., Keating, N. L., Dy, S. M., Arora, N. K., Mack, J. W.,Pantoja, P. M., & Malin, J. L. (2015). Symptom prevalence in lung and colorectal cancer patients. *Journal of Pain and Symptom Management*, *49*(2), 192-202.

Wang, X. S., Zhao, F., Fisch, M. J., O'Mara, A. M., Cella, D., Mendoza, T. R., & Cleeland, C. S. (2014). Prevalence and characteristics of moderate to severe fatigue: a multicenter study in cancer patients and survivors. *Cancer*, *120*(3), 425-432.

Weaver, A., Love, S. B., Larsen, M., Shanyinde, M., Waters, R., Grainger, L., Shearwood, V., Brooks, C., Gibson, O., Young, A.M., & Tarassenko, L. (2014). A pilot study: dose adaptation of capecitabine using mobile phone toxicity monitoring—supporting patients in their homes. *Supportive Care in Cancer*, *22*(10), 2677-2685.

Weeks, J. C., Catalano, P. J., Cronin, A., Finkelman, M. D., Mack, J. W., Keating, N. L., &

Schrag, D. (2012). Patients' expectations about effects of chemotherapy for advanced cancer. *New England Journal of Medicine*, 367(17), 1616-1625.

Weeks, J. C., Cook, E. F., O'Day, S. J., Peterson, L. M., Wenger, N., Reding, D., Harrell, F.E., Kussin, P., Dawson, N.V., Connors, J.R., & Philips, R.S. (1998). Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA, 279*(21), 1709-1714.

Westerman, M. J., The, A. M., Sprangers, M. A., Groen, H. J., van der Wal, G., & Hak, T. (2007). Small-cell lung cancer patients are just ‘a little bit’ tired: response shift and self-presentation in the measurement of fatigue. *Quality of Life Research*, *16*(5), 853-861.

White, C., & Hardy, J. (2010). What do palliative care patients and their relatives think about research in palliative care?—a systematic review. *Supportive Care in Cancer*, *18*(8), 905-911.

Williams, L. A., Bohac, C., Hunter, S., & Cella, D. (2016). Patient and health care provider perceptions of cancer-related fatigue and pain. *Supportive Care in Cancer*, *24*(10), 4357-4363.

Wright, A. A., Zhang, B., Keating, N. L., Weeks, J. C., & Prigerson, H. G. (2014). Associations between palliative chemotherapy and adult cancer patients’ end of life care and place of death: prospective cohort study. *BMJ*, 348, g1219.

Wu, H. S., & McSweeney, M. (2007). Cancer-related fatigue: “It's so much more than just being tired”. *European Journal of Oncology Nursing*, *11*(2), 117-125.

Yellen, S. B., Cella, D. F., Webster, K., Blendowski, C., & Kaplan, E. (1997). Measuring fatigue and other anemia-related symptoms with the Functional Assessment of Cancer Therapy (FACT) measurement system. *Journal of Pain and Symptom Management, 13*(2), 63-74.

Yennu, S., Urbauer, D. L., & Bruera, E. (2012). Factors associated with the severity and improvement of fatigue in patients with advanced cancer presenting to an outpatient palliative care clinic. *BMC Palliative Care*, *11*(1), 16.

Yennurajalingam, S., Frisbee-Hume, S., Palmer, J. L., Delgado-Guay, M. O., Bull, J., Phan, A. T., Tannir, N. M., Litton, J. K., Reddy, A., Hui, D., Dalal, S., Massie, L., Reddy, S. K., & Bruera, E. (2013). Reduction of cancer-related fatigue with dexamethasone: a double-blind, randomized, placebo-controlled trial in patients with advanced cancer. *Journal of Clinical Oncology, 31*(25), 3076-3082.

Yennurajalingam, S., Palmer, J. L., Zhang, T., Poulter, V., & Bruera, E. (2008). Association between fatigue and other cancer-related symptoms in patients with advanced cancer. *Supportive Care in Cancer*, *16*(10), 1125-1130.

Zeng, L., Koo, K., Zhang, L., Jon, F., Dennis, K., Holden, L., Nguyen, J., Tsao, M., Barnes, E., Danjoux, C., Sahgal, A., & Chow, E. (2012). Fatigue in advanced cancer patients attending an outpatient palliative radiotherapy clinic as screened by the Edmonton Symptom Assessment System. *Supportive Care in Cancer*, *20*(5), 1037-1042.

Zimmermann, C., Burman, D., Bandukwala, S., Seccareccia, D., Kaya, E., Bryson, J., Bryson, J., Rodin, G., & Lo, C. (2010). Nurse and physician inter-rater agreement of three performance status measures in palliative care outpatients. *Supportive Care in Cancer, 18*(5), 609-616.

Appendix 3.1 Letter of ethics approval from FREC

Oxford Brookes University

Faculty of Health and Life Sciences

Decision on application for ethics approval

The Departmental Research Ethics Officer (DREO) / Faculty Research Ethics Committee (FREC) has considered the application for ethics approval for the following project:

Project Title: A mixed methods study exploring patients' and doctors' attitudes to fatigue in advanced cancer and chronic heart failure and how they communicate this symptom

FREC Study Number: 2013/16

Name of Applicant: Dr John Curtin

Name of Supervisor: Dr Helen Walthall

Please tick one box

1. The Faculty Research Ethics Committee gives ethical approval for the research project. ☐

   Please note that the research protocol as laid down in the application and hereby approved must not be changed without the approval of the DREO / FREC

2. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project, subject to the following: ☐

3. The Departmental Research Officer / Faculty Research Ethics Committee cannot give ethical approval for the research project. The reasons for this and the action required are as follows: ☐

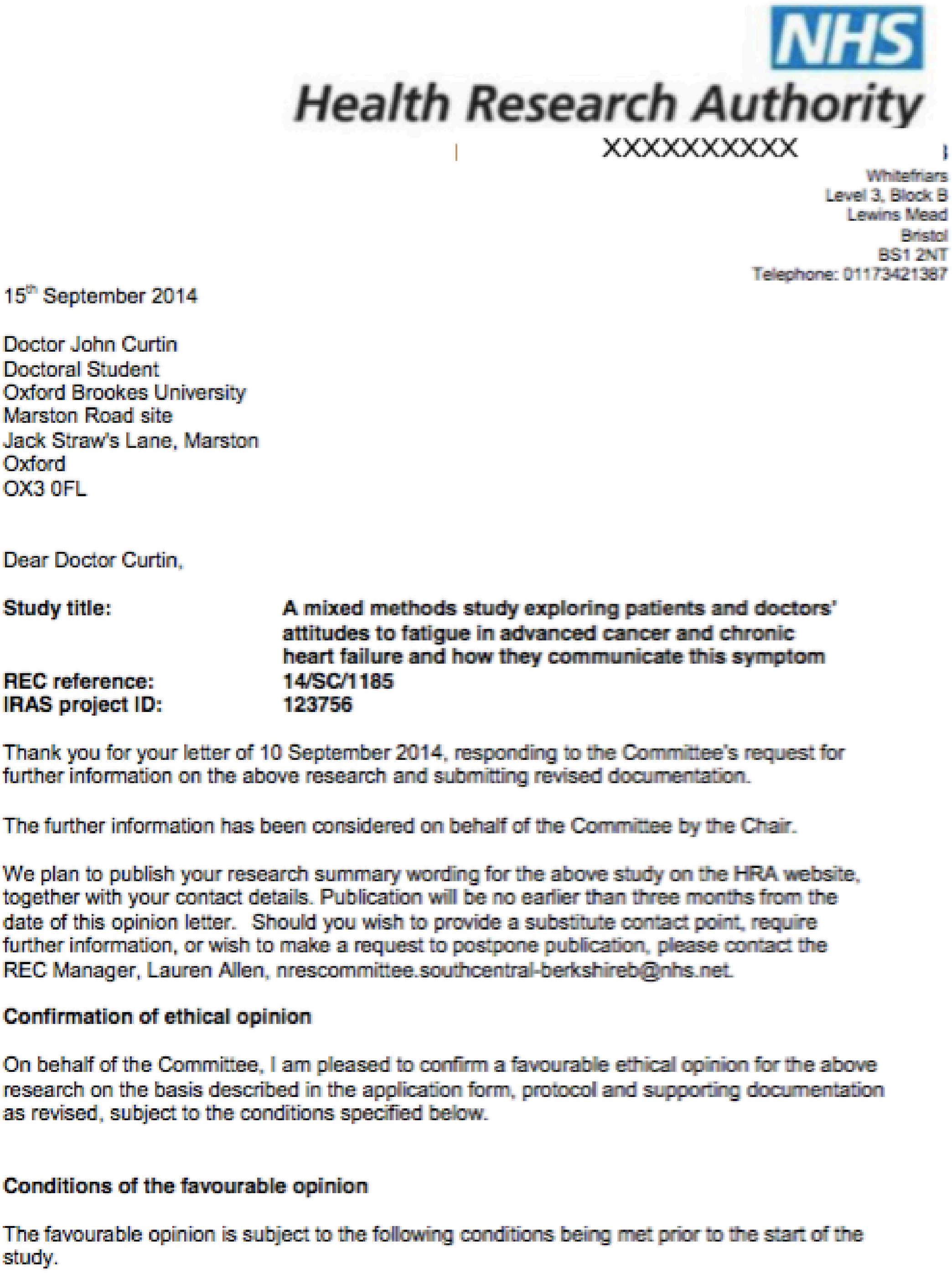
Signed: …Hazel Abbott … ……………………… Approval Date: ………2nd May 2014………

Designation: Departmental Research Ethics Officer

(Signed on behalf of the Faculty Research Ethics Committee)

Date when application reviewed (*office use only*): 25th February 2014 ………………………………

Appendix 3.2 Letter of ethics approval from NRES



NHS

Health Research Authority

XXXXXXXXXX

Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT
Telephone: 01173421387

15th September 2014

Doctor John Curtin
Doctoral Student
Oxford Brookes University
Marston Road site
Jack Straw's Lane, Marston
Oxford
OX3 0FL

Dear Doctor Curtin,

Study title:	**A mixed methods study exploring patients and doctors' attitudes to fatigue in advanced cancer and chronic heart failure and how they communicate this symptom**
REC reference:	**14/SC/1185**
IRAS project ID:	**123756**

Thank you for your letter of 10 September 2014, 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.

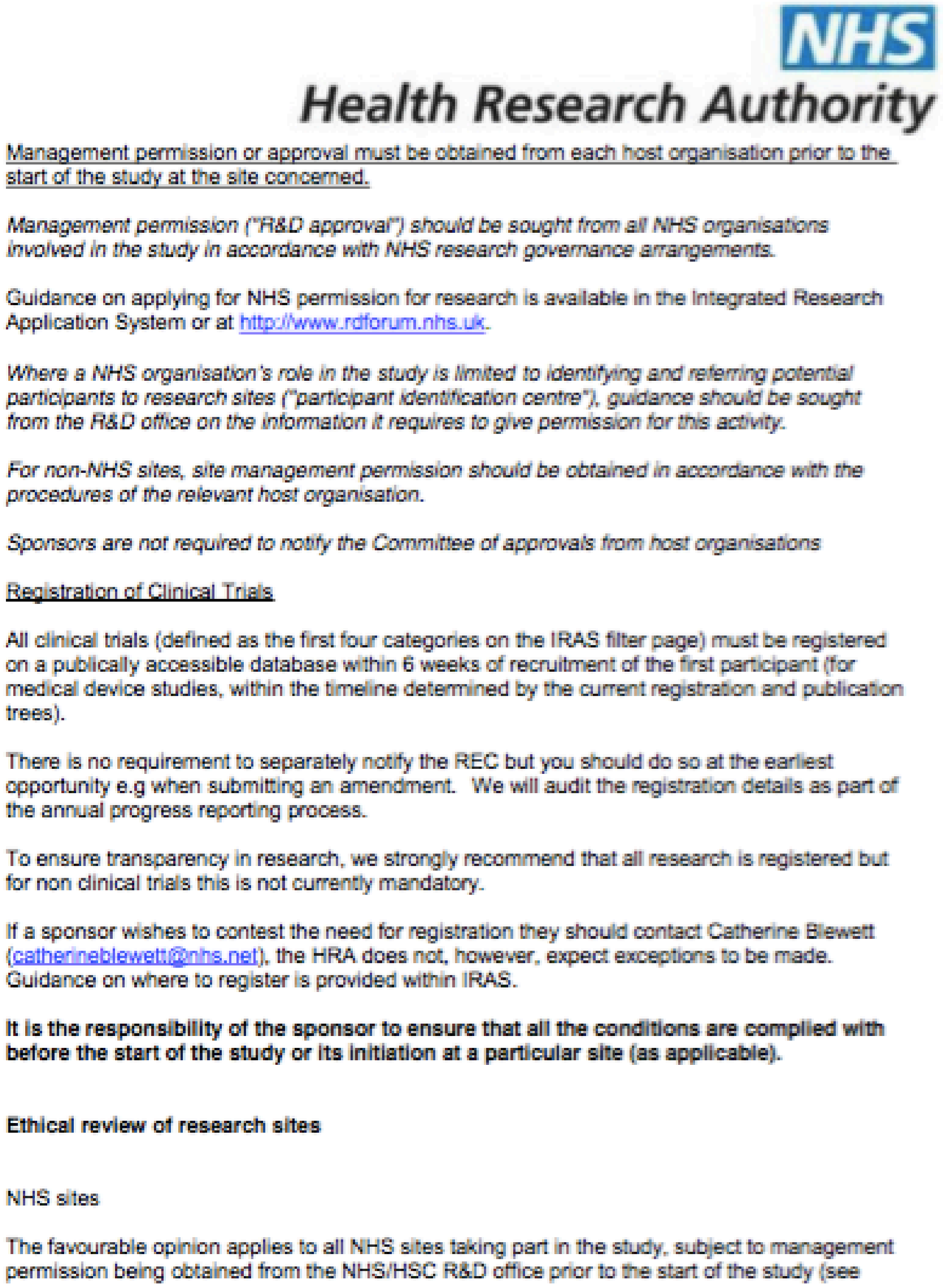
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Lauren Allen, nrescommittee.southcentral-berkshireb@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.

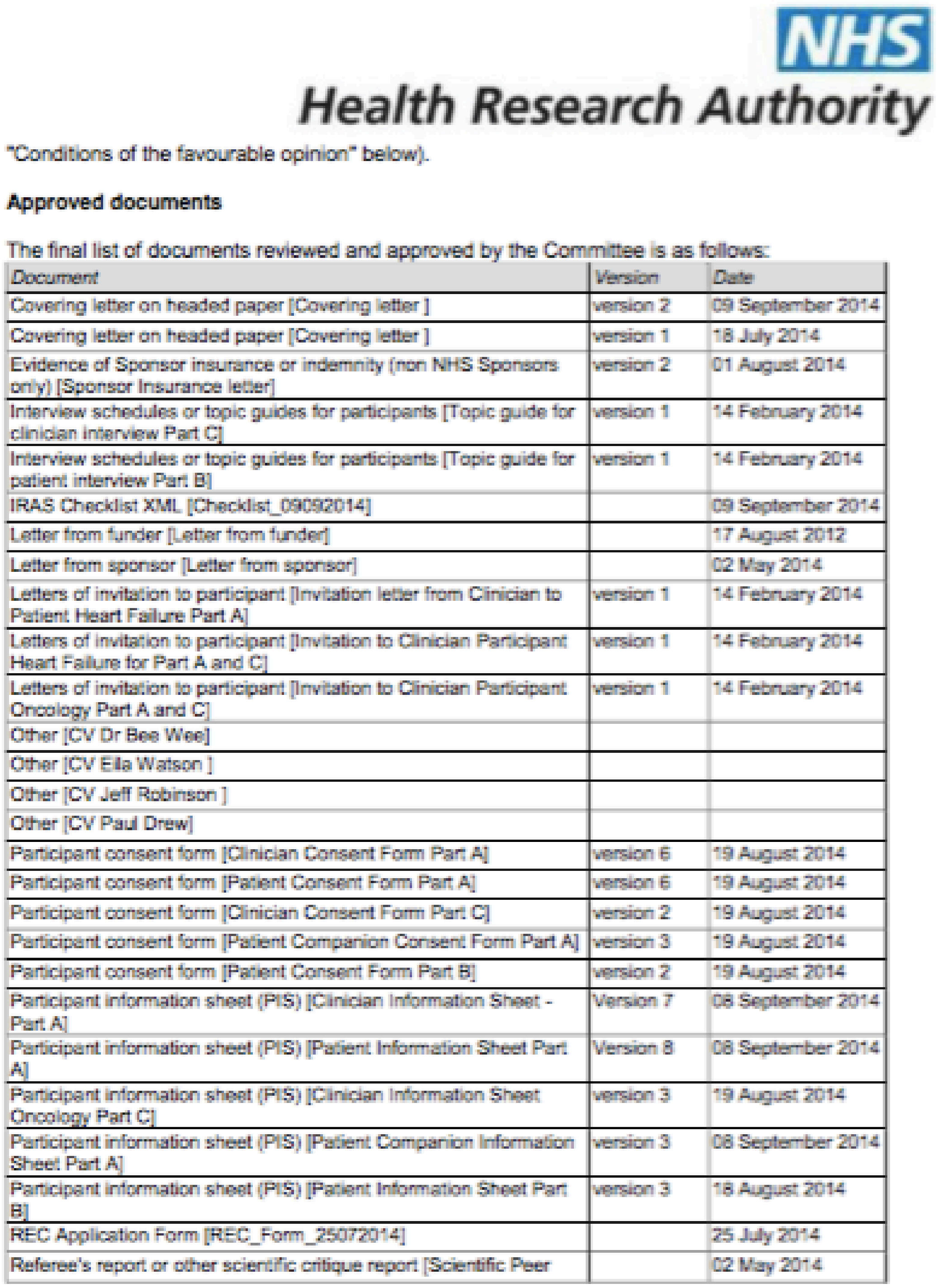
If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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



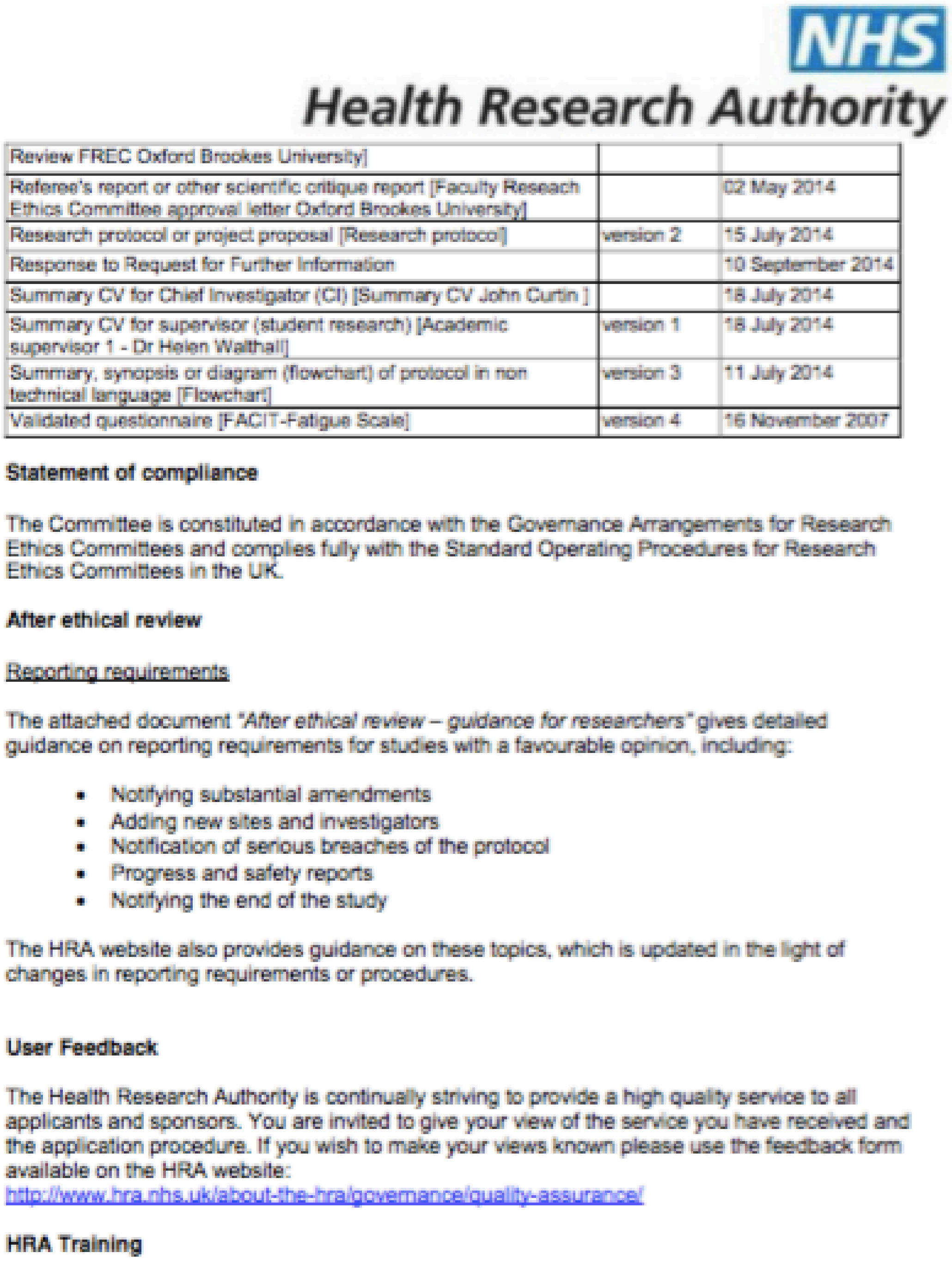
NHS
Health Research Authority

"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 [Covering letter]	version 2	09 September 2014
Covering letter on headed paper [Covering letter]	version 1	18 July 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance letter]	version 2	01 August 2014
Interview schedules or topic guides for participants [Topic guide for clinician interview Part C]	version 1	14 February 2014
Interview schedules or topic guides for participants [Topic guide for patient interview Part B]	version 1	14 February 2014
IRAS Checklist XML [Checklist_09092014]		09 September 2014
Letter from funder [Letter from funder]		17 August 2012
Letter from sponsor [Letter from sponsor]		02 May 2014
Letters of invitation to participant [Invitation letter from Clinician to Patient Heart Failure Part A]	version 1	14 February 2014
Letters of invitation to participant [Invitation to Clinician Participant Heart Failure for Part A and C]	version 1	14 February 2014
Letters of invitation to participant [Invitation to Clinician Participant Oncology Part A and C]	version 1	14 February 2014
Other [CV Dr Bee Wee]		
Other [CV Ella Watson]		
Other [CV Jeff Robinson]		
Other [CV Paul Drew]		
Participant consent form [Clinician Consent Form Part A]	version 6	19 August 2014
Participant consent form [Patient Consent Form Part A]	version 6	19 August 2014
Participant consent form [Clinician Consent Form Part C]	version 2	19 August 2014
Participant consent form [Patient Companion Consent Form Part A]	version 3	19 August 2014
Participant consent form [Patient Consent Form Part B]	version 2	19 August 2014
Participant information sheet (PIS) [Clinician Information Sheet - Part A]	Version 7	08 September 2014
Participant information sheet (PIS) [Patient Information Sheet Part A]	Version 8	08 September 2014
Participant information sheet (PIS) [Clinician Information Sheet Oncology Part C]	version 3	19 August 2014
Participant information sheet (PIS) [Patient Companion Information Sheet Part A]	version 3	08 September 2014
Participant information sheet (PIS) [Patient Information Sheet Part B]	version 3	18 August 2014
REC Application Form [REC_Form_25072014]		25 July 2014
Referee's report or other scientific critique report [Scientific Peer		02 May 2014



Review FREC Oxford Brookes University]		
Referee's report or other scientific critique report [Faculty Reseach Ethics Committee approval letter Oxford Brookes University]		02 May 2014
Research protocol or project proposal [Research protocol]	version 2	15 July 2014
Response to Request for Further Information		10 September 2014
Summary CV for Chief Investigator (CI) [Summary CV John Curtin]		18 July 2014
Summary CV for supervisor (student research) [Academic supervisor 1 - Dr Helen Walthall]	version 1	18 July 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart]	version 3	11 July 2014
Validated questionnaire [FACIT-Fatigue Scale]	version 4	16 November 2007

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, including:

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

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

NHS
Health Research Authority

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

14/SC/1185	**Please quote this number on all correspondence**

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

Yours sincerely,

PP S Payne.

Dr John Sheridan
Chair

Appendix 3.3 Clinician Information Sheet – Part A

Clinician Information Sheet

A study of communication about symptoms in Outpatient Clinics

My name is John Curtin and I am a PhD student at Oxford Brookes University. I am also a specialist trainee in palliative medicine on approved out of programme research experience from the XXXXXXXX Deanery.

In association with the Oncology and Heart Failure clinical teams at XXXXXXXXXXX NHS Trust, we are conducting a research study about outpatient consultations in the hospital. This research study will contribute towards my PhD thesis.

Thank you for considering taking part in this study.

We want to understand what happens within the consultation between the patient and the doctor, specifically surrounding the communication of cancer or heart failure symptoms (e.g. breathlessness, fatigue or pain) and how they are addressed by doctors. Some patient surveys suggest that some symptoms which are important to patients, such as fatigue, are sometimes not addressed within the consultation. We want to understand what is important to patients and see if we can identify ways to improve communication between doctors and patients. This can be best explored by videoing consultations and separately interviewing patients and doctors. The study **will not** evaluate individual job performance.

The **first part** of the study will involve video-recording 60 - 100 consultations between doctors and patients, at a number of oncology and heart failure outpatient clinics in several hospitals.

If you take part in this study, your appointments with patients who give consent during the study period will be audio and video recorded. Patients will be asked to arrive 10 minutes early for their appointment and the consent process should not delay their scheduled appointment. The patient's companion(s), any person(s) who attends the consultation with the patient, are considered participants in this study and will also sign a consent form.

The camcorder and audio recorder are very discreet and research has shown that this should not interfere with the consultation. I will set up the equipment prior to the appointment and start the recording when you are ready. I will not be present when you see the patient. The camcorder will not record physical examination and the lens can be covered with a screen if necessary. I will show you how to do this.

I will show all participants how to turn off the camcorder in case any participant wishes to stop the recording at any time and for any reason. After the consultation, I will ask you all if you are happy for your recording to be used in the research study. If any participant is unhappy with it, I will delete the recording immediately.

Why are appointments being video-recorded?

We need to record appointments in order to capture the details of what is said and how it is said. It is impossible to do this just by observing and making notes or by asking cardiologists about their work. We want to video-record in particular, because it helps us to record both verbal and non-verbal communication.

The **second part** of the study involves interviewing patients and doctors separately some days to weeks after the recorded consultation. Patients with fatigue, as measured by a validated assessment tool, will be interviewed in their own home. Consultant oncologists or cardiologists, including specialist trainees with at least 2 years' experience, will be interviewed at a convenient place and time. The semi-structured interview will last between 20 and 40 minutes. We hope to interview 30 to 40 clinicians.

If you wish to hear more about the study or wish to take part, please contact me on the details at the end of this information sheet. If you agree to take part, I will ask you to sign a consent form at a time that is convenient, prior to your outpatient clinic. Consent will last for the duration of the study, which we expect will be for 12 months.

What are the possible benefits of taking part?

We hope the study may help to improve the assessment and management of symptoms in patients with cancer or heart failure. Subject to each participant's consent, it is possible that your recordings could be used for the training and teaching of students and healthcare professionals. If you wish, the findings of the study will be fed back to you in written form and where possible, will be presented at departmental or network research meetings.

What are the possible disadvantages of taking part?

We do not foresee any risks to doctors taking part, other than it will take up some of your time. The recordings of consultations will be used only for the purposes of this research. You should also be aware that I am a registered doctor with the General Medical Council and I am bound by the professional duties of a doctor by this professional body. If something of concern is observed or reported during the research study then the researcher has a duty to report this.

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

You are free to withdraw from the study at any time. Any information collected during the time that you took part will be destroyed and your confidentiality will continue to be protected.

What will be done with the information collected in the study?

The recordings will be analysed by researchers at Oxford Brookes University, Loughborough University and Portland State University. Subject to consent, the findings will be published in scientific journals, presented at conferences and in training workshops. All quotes will be anonymous and your name will never be included in any paper or presentation.

Will my taking part in the study be confidential?

All information that is collected about you (video and audio recordings and transcripts) will be handled and kept strictly confidential, and any information about you will have your name removed so that you cannot be recognised. Once the data has been collected, code numbers or false names will be used in place of real names. Your data can only remain confidential within the limitations of the law. All members of the research and transcribing teams have a duty to protect your confidentiality. Audio recordings only will be sent to a professional transcribing team. Nothing that could reveal your identity will be disclosed beyond these teams.

Transcripts of your recordings and consent forms will be kept by the research team (John Curtin and Dr Helen Walthall) and stored securely in locked cupboards in a locked office at Oxford Brookes University. Your recordings will be stored on a password protected computer and access will be restricted to named research team members. Your recordings may be shared outside of the European Economic Area (EEA), as one of the research team (Dr Jeffrey Robinson) is based in Portland State University, USA. No patient identifying details will accompany your recordings. Dr Robinson is bound by the National Institute for Health in the USA, to adhere to excellent data protection standards and so all data will remain confidential.

All information that is collected about you will be kept for 20 years for the purposes of writing up the study's findings for publication and in order that the data can be reanalysed. After 20 years, all your information will be destroyed. No individual participants will be identified when the results of the study are published.

With your permission, we may show small clips from your audio or video recordings to other researchers at meetings, or use them for teaching or in the training of clinicians. If we play any clips from the recordings at meetings they will be very short, typically less than a minute. With your permission, we may use your recordings for other research projects or share with other research teams. Your confidentiality will be protected at all times.

Oxford Brookes University will act as data controller of the study and the data collected is for research purposes only. The University has no intention of causing harm or distress to any participant in this study.

Who is organising and funding the study?

The research is funded by Oxford Brookes University. The research team includes researchers from Oxford Brookes University and Loughborough University. The study has been approved by both the Oxford Brookes University Faculty Research Ethics Committee and the XXXXXXXXXXX NHS Research Ethics Committee.

If you have any **questions** about the study, please don't hesitate to contact:

Dr John Curtin, PhD student, Faculty of Health and Life Sciences, Oxford Brookes University

Telephone: 01865 485278 or email: john.curtin-2013@brookes.ac.uk

If you wish to raise questions about how the research is being conducted or **complain** formally, you can contact:

Hazel Abbott, Departmental Research Ethics Officer, Faculty of Health and Life Sciences

Telephone: 01865 482639 or email: heabbott@brookes.ac.uk

Research and academic supervisory team from Oxford Brookes University includes:

Dr Helen Walthall, Principal Lecturer, Faculty of Health and Life Sciences

Prof Eila Watson, Professor in Supportive Cancer Care, Department of Clinical Health Care

Dr Bee Wee, Consultant and Senior Lecturer in Palliative Medicine, Sobell House,
Oxford University Hospitals NHS Trust

Research and academic team from Loughborough University includes:

Prof Paul Drew, Professor of Conversational Analysis, Department of Social Sciences

Research and academic team from Portland State University, Oregon, USA includes:

Dr Jeffrey Robinson, Professor of Communication, Department of Communication

Many thanks for your time in reading this leaflet and considering taking part

Appendix 3.4 Patient Information Sheet – Part A

Patient Information Sheet

A study of communication about symptoms in Outpatient Clinics

Introduction and invitation

Insert Photo of Student

My name is John Curtin and I am a PhD student at Oxford Brookes University. In association with the Cancer and Heart Failure clinical teams at XXXXXXXXXXXXX NHS Trust, we are conducting a research study about patient-doctor consultations, in the outpatient clinic of the hospital. This research study will contribute towards my PhD thesis.

Thank you for considering taking part in this study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

This information sheet tells you about the study. Please read it carefully and ask me if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part. Many thanks for reading this.

What is the purpose of this study?

We want to understand what happens within the consultation, the interaction between a patient and doctor in a hospital appointment, specifically surrounding the communication of cancer or heart failure symptoms (e.g. breathlessness, fatigue or pain) and how they are addressed by doctors. Research has shown that some symptoms that are important to patients, such as fatigue (tiredness, exhaustion or low energy levels), are sometimes not discussed in the consultation. We want to understand what is important to patients and see if we can identify ways to improve communication between doctors and patients.

Why have I been invited?

This research study includes patients with a diagnosis of cancer or heart failure. You have been invited to take part because you have an appointment with a cancer or heart specialist who has agreed to take part in this study. We hope that around 60 - 100 patients who attend the cancer or heart failure clinics at the hospital will take part in this study.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide whether you want to take part and we are happy to answer any questions you may have. If you wish to hear more about the study, please complete and return the reply slip at the end of this information sheet. I would then meet with you before your next appointment to explain the study further. This request for further information would not commit you to take part in the study. **Even if you were to opt in, you would be free to leave at any time**. A decision to leave the study or to decline to be involved would not affect the standard of care you receive from the clinical team.

What will happen to me if I take part?

If you would like to hear more about the study, please complete and return the reply slip in the stamped addressed envelope provided. I will meet you in the waiting area of the outpatient clinic after you have checked in with the receptionist. Please come 10 minutes early for your appointment. I will describe the study and go over the information sheet with you and ask if you have any questions. When you think I have answered all your questions and if you agree to continue, I will ask you to sign a consent form. You are free to change your mind at any time.

After this, you will have your consultation with the specialist which will be just like normal except that I will audio and video record it. The recording equipment will be set up before the appointment so that I will not be present while you talk with the doctor. This gives you privacy. The camcorder and audio recorder are very discreet and most people forget they are being recorded. Apart from the recording, your appointment will be no different to what would have happened with the specialist if you were not taking part in the study. The camcorder will be left on throughout your appointment and will record the conversation between you and your doctor. The camcorder will not record physical examination and the lens can be covered with a screen if necessary.

I will show you how to turn off the camcorder in case you wish to stop the recording at any time and for any reason. After the consultation, I will ask you if you still agree for your recording to be used in the research study. If you are unhappy with it, I will delete the recording immediately.

After the consultation I will ask you to fill in a questionnaire that will take less than 10 minutes to complete. You are free to not answer any question. I will also ask you less than 5 questions about your general activity and symptoms (breathlessness and fatigue) in the preceding week.

There is a second part of this study, an interview study with some of the patients who had their consultation recorded. You might or might not be invited to this follow-up interview study after your appointment with the doctor. Further information will be provided to you at this point.

Why are appointments being recorded?

We would like to see how doctors and patients communicate during a consultation and how common symptoms are discussed and managed. Video-recording provides us with the opportunity to observe what is discussed without being present and is therefore less intrusive for both the patient and doctor. It also helps us to know, for example, what is happening in silences during the consultation (e.g. did someone nod or smile or shake their head).

What will I have to do?

If you decide to take part, you will be asked to sign a consent form. After your appointment I will ask you to complete a short questionnaire and ask you a few questions, that in total will take less than 10 minutes.

What are the possible benefits of taking part?

The study may not have any direct benefits for you but it is hoped that the findings will help doctors to provide better support for patients in the future. The findings of the study may help doctors to improve the assessment and management of symptoms in cancer or heart failure.

What are the possible disadvantages of taking part?

There is a small chance that you might feel uncomfortable about having your appointment video-recorded. At any time, you are free to turn off the camcorder or ask for the recording to be stopped. There is also a small chance that you might find some questions difficult to answer in the questionnaire. In this case you are free not to answer a question.

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

You can withdraw from the study at any time without your standard of care being affected in any way. Any information collected during the time that you took part will be destroyed and your confidentiality will continue to be protected. This means that the video-recording of the consultation will be deleted and your questionnaire responses will be shredded. In addition, where possible, your data that has been destroyed will be confirmed in writing.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (on phone number 01865 485278). If you remain unhappy and wish to raise questions about how the research is being conducted, you can contact Hazel Abbott, Departmental Research Ethics Officer, Faculty of Health and Life Sciences on 01865 482639. If you remain unhappy and wish to complain formally, you may also follow the normal NHS complaints procedure. Please see: www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx for more information.

What will be done with the information collected in the study?

The recordings and the questionnaire responses will be examined by researchers at Oxford Brookes University, Loughborough University and Portland State University. The findings will be used to develop guidelines on how best to assess symptoms in the clinic. The findings will also be published in scientific journals and presented at conferences and in training workshops. With your permission, we may use direct quotes from your appointment with the specialist in these papers, presentations and workshops. However, the quotes will be anonymous and your name will never be included in any paper or presentation. If you wish, we will send you a summary of the findings at the end of the study. This will be in about two years' time.

Will my taking part in the study be confidential?

All information that is collected about you (video and audio recordings, transcripts and questionnaires) will be handled and kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. Once the data has been collected, code numbers or false names will be used in place of real names. Your data can only remain confidential within the limitations of the law. All members of the research and transcribing teams have a duty to protect your confidentiality. Audio recordings only will be sent to a professional transcribing team. Nothing that could reveal your identity will be disclosed beyond these teams.

Transcripts of your recordings, questionnaires and consent forms will be kept by the research team (John Curtin and Dr Helen Walthall) and stored securely in locked cupboards in a locked office at Oxford Brookes University. Your recordings will be stored on a password protected computer and access will be restricted to named research team members. Your recordings may be shared outside of the European Economic Area (EEA), as one of the research team (Dr Jeffrey Robinson) is based in Portland State University, USA. No patient identifying details will accompany your recordings. Dr Robinson is bound by the National Institute for Health in the USA, to adhere to excellent data protection standards and so all data will remain confidential.

All information that is collected about you will be kept for 20 years for the purposes of writing up the study's findings for publication and in order that the data can be reanalysed. After 20 years, all your information will be destroyed. No individual participants will be identified when the results of the study are published.

With your permission, we may show small clips from your audio or video recordings to other researchers at meetings, or use them for teaching or in the training of clinicians. If we play any clips from the recordings at meetings they will be very short, typically less than a minute. With your permission, we may use your recordings for other research projects or share with other research teams. Your confidentiality will be protected at all times.

Oxford Brookes University will act as data controller of the study and the data collected is for research purposes only. The University has no intention of causing harm or distress to any participant in this study.

Who is organising and funding the study?

The research is funded by Oxford Brookes University. The research team includes researchers from Oxford Brookes University, Loughborough University and Portland State University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been approved by both the Oxford Brookes University Faculty Research Ethics Committee and the XXXXXXXXXX NHS Research Ethics Committee.

Who should I contact with questions?

If you have any questions about the study, please don't hesitate to contact:

John Curtin, PhD student, Faculty of Health and Life Sciences, Oxford Brookes University

Telephone: 01865 485278 or email: john.curtin-2013@brookes.ac.uk

Research and supervisory team from Oxford Brookes University includes:

Dr Helen Walthall, Principal Lecturer, Faculty of Health and Life Sciences

Prof Eila Watson, Professor in Supportive Cancer Care, Department of Clinical Health Care

Dr Bee Wee, Consultant and Senior Lecturer in Palliative Medicine, Sobell House,
Oxford University Hospitals NHS Trust

Research and academic team from Loughborough University includes:

Prof Paul Drew, Professor of Conversational Analysis, Department of Social Sciences

Research and academic team from Portland State University, Oregon, USA includes:

Dr Jeffrey Robinson, Professor of Communication, Department of Communication

Many thanks for your time in reading this leaflet and considering taking part

Appendix 3.5 Correspondence from FREC officer

From: Hazel Abbott <heabbott@brookes.ac.uk>
Subject: Re: Update of experience of recruitment with study: FREC 2013/16; REC 14/SC/1185
Date: 4 December 2014 at 11:43:09 GMT
To: John Curtin <john.curtin-2013@brookes.ac.uk>

Dear John,

Many thanks for this update. Yes, I think that this approach falls within the boundaries of your ethics approval and good practice. You have emphasised the consensual nature of taking part to potential participants and taken steps to ensure they have time to consider and then re-consider participation. If the approach proposed is at the potential participant's request and makes responding easier for them I am happy that this is the method adopted.

Best wishes,

Hazel

On 1 December 2014 at 15:17, John Curtin <john.curtin-2013@brookes.ac.uk> wrote:
Dear Hazel,

I just wanted to update you on my experiences of recruiting patient participants for my study in order to ensure that I am staying within best ethical practice and the ethical boundaries of my FREC/ NRES approval.

I informed you recently that some patients prefer to give me their contact details and want to be contacted by me prior to their appointment. They give their information voluntarily (as they would on the Reply Slip if they posted it back to me). I understand ethically this is fine as participants are directing the researcher.

Some patients are very keen to partake in the study and direct me that they wish to meet me at their next appointment. I then suggest that they need to read the PIS form carefully and think about it etc. These patients frequently direct me to complete the Reply Slip with me in the clinic rather than post it back to me as this is too much of a burden. I want to ask if ethically this similar to our earlier discussion and that they are similarly directing the researcher?

When we complete the Reply Slip together, I emphasise that it is completely optional that they give me their contact details. If they wish to give me their contact details, then I suggest the reasons why this might be helpful so that I could contact them before their appointment to ensure that they are still happy to meet with me or well enough to partake in the study or well enough to attend the clinic.

I always emphasise that just by agreeing to meet me does not mean they have to

Appendix 3.6 Patient Companion Information Sheet – Part A

Patient's Companion Information Sheet

A study of communication about symptoms in Outpatient Clinics

Introduction and invitation

Insert Photo of Student

My name is John Curtin and I am a PhD student at Oxford Brookes University. In association with the Cancer and Heart Failure clinical teams at XXXXXXXXXX NHS Trust, we are conducting a research study about patient-doctor consultations, in the outpatient clinic of the hospital. This research study will contribute towards my PhD thesis.

Thank you for considering taking part in this study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

This information sheet tells you about the study. Please read it carefully and ask me if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part. Many thanks for reading this.

What is the purpose of this study?

We want to understand what happens within the consultation, the interaction between a patient and doctor in a hospital appointment, specifically surrounding the communication of cancer or heart failure symptoms (e.g. breathlessness, fatigue or pain) and how they are addressed by doctors. Research has shown that some symptoms that are important to patients, such as fatigue (tiredness, exhaustion or low energy levels), are sometimes not discussed in the consultation. We want to understand what is important to patients and see if we can identify ways to improve communication between doctors and patients.

Why have I been invited?

We have invited you to take part because you will be accompanying the patient to an appointment with a cancer or heart specialist who has agreed to take part in this study. We hope that around 60 - 100 patients who attend the cancer or heart failure clinics will take part in this study.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide whether you want to take part and we are happy to answer any questions you may have. If you wish to hear more about the study, please complete and return the reply slip at the end of this information sheet. I would then meet with you and the patient before their next appointment to explain the study further. This request for further information would not commit you to take part in the study. **Even if you were to opt in, you would be free to leave at any time**. A decision to leave the study or to decline to be involved would not affect the standard of care that the patient receives from the clinical team.

What will happen to me if I take part?

If you would like to hear more about the study, please complete and return the reply slip in the stamped addressed envelope provided. I will meet you and the patient in the waiting area of the outpatient clinic after you have checked in with the receptionist. Please come 10 minutes early for the appointment. I will describe the study and go over the information sheet with both of you and ask if you have any questions. When you think I have answered all your questions and if you agree to continue, I will ask both of you to sign a consent form. You are free to change your mind at any time.

After this, the patient will have their consultation with the specialist which will be just like normal except that I will audio and video record it. The recording equipment will be set up before the appointment so that I will not be present while both of you talk with the doctor. This gives you privacy. The camcorder and audio recorder are very discreet and most people forget they are being recorded. Apart from the recording, the appointment will be no different to what would have happened with the specialist if you were not taking part in the study. The camcorder will be left on throughout the appointment and will record the conversation between you and the doctor. The camcorder will not record physical examination and the lens can be covered with a screen if necessary.

I will show both of you how to turn off the camcorder in case you wish to stop the recording at any time and for any reason. After the consultation, I will ask you if you still agree for your recording to be used in the research study. If you are unhappy with it, I will delete the recording immediately.

After the consultation I will ask the patient to fill in a questionnaire that will take less than 10 minutes to complete. The patient is free to not answer any question. I will also ask the patient less than 5 questions about their general activity and symptoms (breathlessness and fatigue) in the preceding week.

There is a second part of this study, an interview study with some of the patients who had their consultation recorded. The patient might or might not be invited to this follow-up interview study after the appointment with the doctor. Further information will be provided to the patient at this point.

Why are appointments being recorded?

We would like to see how doctors and patients communicate during a consultation and how common symptoms are discussed and managed. Video-recording provides us with the opportunity to observe what is discussed without being present and is therefore less intrusive for both the patient and doctor. It also helps us to know, for example, what is happening in silences during the consultation (e.g. did someone nod or smile or shake their head).

What will I have to do?

If you decide to take part, you will be asked to sign a consent form. After the patient's appointment, I will ask the patient to complete a short questionnaire and ask them a few questions that in total will take less than 10 minutes.

What are the possible benefits of taking part?

The study may not have any direct benefits for the patient but it is hoped that the findings will help doctors to provide better support for patients in the future. The findings of the study may help doctors to improve the assessment and management of symptoms in patients with cancer or heart failure.

What are the possible disadvantages of taking part?

There is a small chance that you or the patient might feel uncomfortable about having the appointment video-recorded. At any time, you or the patient are free to turn off the camcorder or ask for the recording to be stopped.

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

You can withdraw from the study at any time without the standard of care of the patient being affected in any way. Any information collected during the time that you took part will be destroyed and your confidentiality will continue to be protected. This means that the video-recording of the consultation will be deleted. In addition, where possible, your data that has been destroyed will be confirmed in writing.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (on phone number 01865 485278). If you remain unhappy and wish to raise questions about how the research is being conducted, you can contact Hazel Abbott, Departmental Research Ethics Officer, Faculty of Health and Life Sciences on 01865 482639. If you remain unhappy and wish to complain formally, you may also follow the normal NHS complaints procedure. Please see: www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx for more information.

What will be done with the information collected in the study?

The recordings and the questionnaire responses will be examined by researchers at Oxford Brookes University, Loughborough University and Portland State University. The findings will be used to develop guidelines on how best to assess symptoms in the clinic. The findings will also be published in scientific journals and presented at conferences and in training workshops. With your permission, we may use direct quotes from the patient's appointment with the specialist in these papers, presentations and workshops. However, the quotes will be anonymous and your name will never be included in any paper or presentation. If you wish, we will send you a summary of the findings at the end of the study. This will be in about two years' time.

Will my taking part in the study be confidential?

All information that is collected about you (video and audio recordings and transcripts) will be handled and kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. Once the data has been collected, code numbers or false names will be used in place of real names. Your data can only remain confidential within the limitations of the law. All members of the research and transcribing teams have a duty to protect your confidentiality. Audio recordings only will be sent to a professional transcribing team. Nothing that could reveal your identity will be disclosed beyond these teams.

Transcripts of your recordings and consent forms will be kept by the research team (John Curtin and Dr Helen Walthall) and stored securely in locked cupboards in a locked office at Oxford Brookes University. Your recordings will be stored on a password protected computer and access will be restricted to named research team members. Your recordings may be shared outside of the European Economic Area (EEA), as one of the research team (Dr Jeffrey Robinson) is based in Portland State University, USA. No patient identifying details will accompany your recordings. Dr Robinson is bound by the National Institute for Health in the USA, to adhere to excellent data protection standards and so all data will remain confidential.

All information that is collected about you will be kept for 20 years for the purposes of writing up the study's findings for publication and in order that the data can be reanalysed. After 20 years, all your information will be destroyed. No individual participants will be identified when the results of the study are published.

With your permission, we may show small clips from your audio or video recordings to other researchers at meetings, or use them for teaching or in the training of clinicians. If we play any clips from the recordings at meetings they will be very short, typically less than a minute. With your permission, we may use your recordings for other research projects or share with other research teams. Your confidentiality will be protected at all times.

Oxford Brookes University will act as data controller of the study and the data collected is for research purposes only. The University has no intention of causing harm or distress to any participant in this study.

Who is organising and funding the study?

The research is funded by Oxford Brookes University. The research team includes researchers from Oxford Brookes University, Loughborough University and Portland State University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been approved by both the Oxford Brookes University Faculty Research Ethics Committee and the XXXXXXXXXXXX NHS Research Ethics Committee.

Who should I contact with questions?

If you have any questions about the study, please don't hesitate to contact:

John Curtin, PhD student, Faculty of Health and Life Sciences, Oxford Brookes University

Telephone: 01865 485278 or email: john.curtin-2013@brookes.ac.uk

Research and supervisory team from Oxford Brookes University includes:

Dr Helen Walthall, Principal Lecturer, Faculty of Health and Life Sciences

Prof Eila Watson, Professor in Supportive Cancer Care, Department of Clinical Health Care

Dr Bee Wee, Consultant and Senior Lecturer in Palliative Medicine, Sobell House,
Oxford University Hospitals NHS Trust

Research team from Loughborough University includes:

Prof Paul Drew, Professor of Conversational Analysis, Department of Social Sciences

Research and academic team from Portland State University, Oregon, USA includes:

Dr Jeffrey Robinson, **Professor of Communication, Department of Communication**

Many thanks for your time in reading this leaflet and considering taking part

Appendix 3.7 Consent form

Patient Consent Form

A study of communication about symptoms in Outpatient Clinics

Please write your initials in the relevant boxes:
(only initial those boxes where you agree to what is being asked)

1. I confirm that I have read and understand the information sheet for the above study, that I have had the opportunity to ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐

3. I agree to my consultation with the specialist being video and audio recorded. ☐

4. I agree to complete the questionnaire on the understanding that I can choose not to answer some questions. ☐

5. I understand that by taking part, I am agreeing that the research team can obtain information from my Consultant in relation to the diagnosis and treatment plan of my illness. ☐

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

7. I understand that by taking part, I am agreeing that the researchers may use anonymous extracts from the transcripts of my audio/video -recordings and information from my completed questionnaires in publications and ☐

8. I agree that anonymous extracts from the transcripts of my audio/video-recordings can be used for training and teaching students and healthcare professionals. ☐

9. I agree that the researchers can use clips from my audio recording for the teaching and training of students or healthcare professionals. I understand that all identifying details (e.g. names, place names) will be deleted before the clips are played and my name will not be used. ☐

10. I agree that the researchers can use clips from my video recording for the teaching and training of students or healthcare professionals. I understand that all identifying details (e.g. names, place names) will be deleted before the clips are played and my name will not be used. ☐

11. I agree that my data gathered in this study may be stored (after it has been anonymised) in Oxford Brookes University and may be used for future research. ☐

12. I give consent for the research team to share anonymised written, video and audio material collected in this study with other researchers. ☐

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

Name (please print): ____

Signature: ____

Name of researcher
taking Consent: ____

Signature of reseacher
taking Consent:____

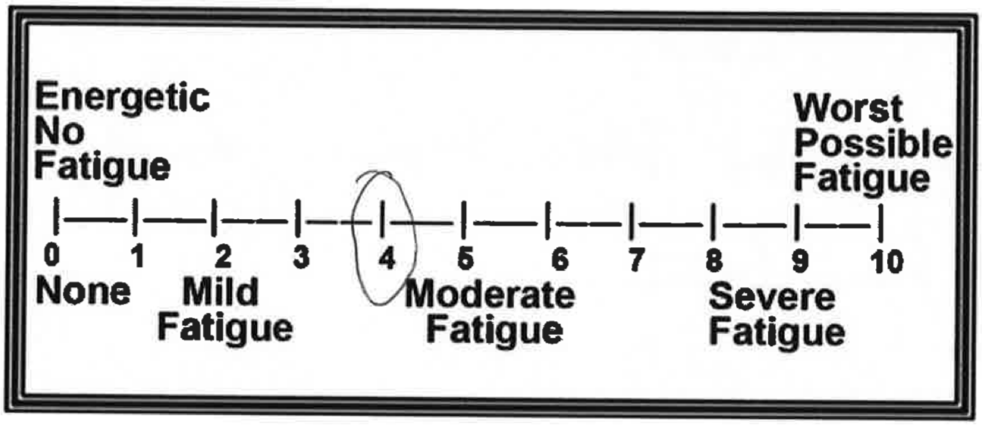
Date:____

Appendix 3.8 Fatigue Visual Analogue Scale (VAS)

Fatigue-VAS with clinically relevant fatigue on numerical rating scale (NRS) ≥4. (adapted from Bruera et al, 1991 & Oldenmenger et al., 2013).

Question:

On a Scale of 0 – 10, how would you rate your level of fatigue?



Appendix 3.9 Fatigue subscale FACIT

FACIT Fatigue Scale (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
HI7	I feel fatigued	0	1	2	3	4
HI12	I feel weak all over	0	1	2	3	4
An1	I feel listless ("washed out")	0	1	2	3	4
An2	I feel tired	0	1	2	3	4
An3	I have trouble starting things because I am tired	0	1	2	3	4
An4	I have trouble finishing things because I am tired	0	1	2	3	4
An5	I have energy	0	1	2	3	4
An7	I am able to do my usual activities	0	1	2	3	4
An8	I need to sleep during the day	0	1	2	3	4
An12	I am too tired to eat	0	1	2	3	4
An14	I need help doing my usual activities	0	1	2	3	4
An15	I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
An16	I have to limit my social activity because I am tired	0	1	2	3	4

English (Universal)

16 November 2007

Appendix 3.10 CA Transcription Symbols

These are the main transcription symbols used for CA analyses (adapted from Jefferson, 2004 and Hepburn and Bolden, 2013).

(.)	Micro-pause – less than a tenth of a second
(0.2), (2.6)	Examples of timed pauses (in seconds)
↑word	Onset of noticeable pitch rise
↓word	Onset of noticeable pitch fall
A: wor[d B: [word	Square brackets aligned across adjacent lines denote the start of overlapping speech
.	Falling vocal pitch
?	Rising vocal pitch
.hhh	In-breath
hhh	Out-breath
wo(h)rd	Within-speech aspirations
wor-	A sharp cut-off
wo:rd	Colons show that the speaker has stretched the preceding sound
(words)	A guess at what might have been said if unclear
A: word= B: =word	The equals sign shows that there is no discernible pause between two speakers’ turns
word	Vocal emphasis
WORD	Talk pronounced loudly in comparison with surrounding talk
°word°	Talk between ‘‘degree signs’’ is quieter than surrounding talk
>word word<	Talk between inward arrows is delivered faster than surrounding talk
<word word>	Talk between outward arrows is delivered slower than surrounding talk
((sniff))	Transcriber’s effort at representing something difficult, or impossible, to write phonetically

Appendix 3.11 Patient Information Sheet – Part B

Patient Information Sheet

Understanding fatigue in patients with cancer or heart failure

Invitation

Thank you for taking part in the first stage of our research study and we would like to invite you to take part in the **second stage**. This is a PhD student project towards the thesis of John Curtin. This information sheet tells you about this. Please read it carefully and ask me if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part. Many thanks for reading this.

What is the purpose of this study?

We want to understand how fatigue (tiredness, exhaustion or low energy levels) affects the quality of life, the ability to undertake activities of everyday living and physical activity in patients living with cancer or heart failure. We also want patients to reflect on how they felt their doctor addressed their symptoms, in particular fatigue, in a recent hospital appointment. We want to understand what symptoms are important to patients and see if we can identify ways to improve communication between doctors and patients.

Why have I been invited?

You have been invited to take part because you have had your appointment with the doctor video-recorded and you experience fatigue. We hope that around 30 - 40 patients will complete the second part of the study.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide whether you want to take part and we are happy to answer any questions you may have. You are free to withdraw at any time, without giving a reason. A decision to leave the study or to decline to be involved would not affect the standard of care you receive from the clinical team.

What will happen to me if I take part?

If you agree to take part, I will agree a convenient time for you to be interviewed in your own home. I will ask you to sign a consent form before the interview. This interview will be no longer that one hour long and it will be a discussion with you about your experience of living with cancer. Particularly how fatigue affects your daily life and what impact this has on your family. You are

What are the possible benefits of taking part?

The study may not have any direct benefits for you but it is hoped that the findings will help doctors to provide better support for patients in the future. The findings of the study may help doctors to improve the assessment and management of symptoms in patients with cancer or heart failure.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (on phone number 01865 485278). If you remain unhappy and wish to raise questions about how the research is being conducted, you can contact Hazel Abbott, Departmental Research Ethics Officer, Faculty of Health and Life Sciences on 01865 482639.

Will what I say in this study be kept confidential?

All information that is collected about you will be handled and kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. Your data can only remain confidential within the limitations of the law. Audio recordings will be sent to a professional transcribing team who have a duty to protect your confidentiality. All information (transcripts and consent forms) will be kept by the research team (John Curtin and Dr Helen Walthall) and stored securely in locked cupboards in a locked office at Oxford Brookes University. This information will be kept for 20 years for the purposes of writing up the study's findings for publication and in order that the data can be reanalysed. After 20 years, all your information will be destroyed. This data will not have any identifying details.

What should I do if I want to take part?

I will ask for your permission to contact you in a few days time, in order to give you time to decide if you want to take part in this study. Alternatively, if you prefer, you can contact me by telephone or email. Please see the contact details at the end of this information sheet.

What will be done with the information collected in the study?

The findings will be published in scientific journals and presented at conferences and in training workshops. With your permission, we may use direct quotes from your interview in these papers, presentations and workshops. However, the quotes will be anonymous and your name will never be included in any paper or presentation. If you wish, we will send you a summary of the findings at the end of the study. This will be in about two years' time.

Who is organising and funding the study?

Oxford Brookes University

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been approved by both the Oxford Brookes University Faculty Research Ethics Committee and the XXXXXXXXXX NHS Research Ethics Committee.

Who should I contact with questions?

If you have any questions about the study, please don't hesitate to contact:

John Curtin, PhD student, Faculty of Health & Life Sciences, Oxford Brookes University

Telephone: 01865 485278 or email: john.curtin-2013@brookes.ac.uk

Research and supervisory team from Oxford Brookes University includes:

Dr Helen Walthall, Principal Lecturer, Faculty of Health and Life Sciences

Prof Eila Watson, Professor in Supportive Cancer Care, Department of Clinical Health Care

Dr Bee Wee, Consultant and Senior Lecturer in Palliative Medicine, Sobell House,
Oxford University Hospitals NHS Trust

Many thanks for your time in reading this leaflet and considering taking part

Appendix 3.12. Patient interview topic guide

Study title – Exploration of fatigue in advanced cancer and chronic heart failure

Topic guide for patient interview

1. Open with general inquiry on history of illness and impact on life
2. Experience of fatigue
3. Feelings of fatigue
4. Causes of fatigue - meaning of fatigue to patient
5. Coping strategies
6. Impact of fatigue on family and carers
7. Communication of fatigue with family and carers
8. Communication of fatigue with healthcare professionals
9. Management of fatigue by healthcare professionals

Appendix 3.13 Clinician Information Sheet – Part C

Clinician Information Sheet

Exploring fatigue in advanced cancer or chronic heart failure

My name is John Curtin and I am a PhD student at Oxford Brookes University. I am also a specialist trainee in palliative medicine on approved out of programme research experience from the XXXXXXXXXX Deanery.

In association with the Oncology and Heart Failure clinical teams at XXXXXXXXXXX NHS Trust, we are conducting a research study about fatigue in advanced cancer or chronic heart failure. This research study will contribute towards my PhD thesis.

Thank you for considering taking part in the **second part** of this study.

Fatigue is a common and complex symptom in advanced cancer or chronic heart failure. Recent published systematic reviews reveal that there are few pharmacotherapy options that are potentially beneficial in these patient groups. This suggests that fatigue may be a difficult symptom for clinicians to manage in their patients. We want to explore what doctors feel are the challenges in the assessment and management of fatigue in patients with advanced cancer or chronic heart failure.

The **first part** of the study involves the video-recording of patient-doctor consultations in oncology or heart failure clinics in several hospitals. The **second part** of the study involves interviewing patients and doctors.

You have been invited because you are either a consultant cardiologist or oncologist, or a specialist trainee with at least 2 years' experience. We would like to interview 30 to 40 clinicians in this study.

It is up to you to decide to join the study. If you wish to hear more about the study or wish to take part please contact me by telephone or email, using my details at the end of this information sheet. You are free to withdraw at any time, without giving any reason.

If you agree to take part, I will agree a convenient time for you to be interviewed in a place of your choosing. I will ask you to sign a consent form before the interview. The interview will last for approximately 30 minutes and with your permission, will be audio-recorded. It will be a discussion on your experiences and views on the assessment and management of fatigue in patients with advanced cancer or chronic heart failure. You are free to stop the interview at any time and for any reason.

We hope the study may help to improve the assessment and management of symptoms in patients with advanced cancer or chronic heart failure. We do not foresee any risks to doctors

The findings will be published in scientific journals and presented at conferences and in training workshops. With your permission, we may use direct quotes from your interview in these papers, presentations and workshops. However, the quotes will be anonymous and your name will never be included in any paper or presentation. If you wish, the findings of the study will be fed back to you in written form and where possible, will be presented at departmental or network research meetings.

All information that is collected about you will be handled and kept strictly confidential, and any information about you will have your name removed so that you cannot be recognised. Your data can only remain confidential within the limitations of the law. Audio recordings will be sent to a professional transcribing team who have a duty to protect your confidentiality. All information will be kept by the research team (John Curtin and Dr Helen Walthall) and stored securely in locked cupboards in a locked office at Oxford Brookes University. This information will be kept for 20 years for the purposes of writing up the study's findings for publication and in order that the data can be reanalysed. After 20 years, all your information will be destroyed. This data will not have any identifying details.

The research is funded by Oxford Brookes University. The study has been approved by both the Oxford Brookes University Faculty Research Ethics Committee and the XXXXXXXXXX NHS Research Ethics Committee.

If you have any **questions** about the study, please don't hesitate to contact:

Dr John Curtin, PhD student, Faculty of Health & Life Sciences, Oxford Brookes University
Telephone: 01865 485278 or email: john.curtin-2013@brookes.ac.uk

If you wish to raise questions about how the research is being conducted or **complain** formally, you can contact:

Hazel Abbott, Departmental Research Ethics Officer, Faculty of Health & Life Sciences, OBU
Telephone: 01865 482639 or email: heabbott@brookes.ac.uk

Research and supervisor team from Oxford Brookes University includes:

- Dr Helen Walthall, Principal Lecturer, Faculty of Health & Life Sciences
- Prof Eila Watson, Professor in Supportive Cancer Care, Department of Clinical Health Care
- Dr Bee Wee, Consultant and Senior Lecturer in Palliative Medicine, Sobell House, Oxford University Hospitals NHS Trust

Many thanks for your time in reading this leaflet and considering taking part

Appendix 3.14. Clinician interview topic guide

Study title – Exploration of fatigue in advanced cancer and chronic heart failure

Topic guide for doctor interview

1. Open with general inquiry on clinician's experience and usual patient population
2. Fatigue in patient population
3. Assessment of fatigue
4. Communication of fatigue
5. Interventions for fatigue
6. Role of doctor

Appendix 14.1 Pen portraits of participants in Part B

Sharon

Sharon was a retired widow and lives alone. She retired to care for her husband with Motor Neuron Disease who died several years previously at home. She enjoyed daily exercise and was house proud. She was diagnosed with bowel cancer after presenting to hospital with bowel obstruction and then had curative surgery followed by a short trial of adjuvant oral chemotherapy. About 8 months later, she was diagnosed with metastatic cancer and started palliative chemotherapy, planned 8 cycles, with the possibility of surgical liver resection. The interview took place several days after her 5th cycle of treatment. She described transient physical fatigue which lasted several days post chemotherapy.

Stephen

Stephen lived with his second wife and young daughter. He was self-employed and his wife worked part-time. He was diagnosed with metastatic colon cancer and underwent surgical excision of the primary tumour followed by palliative systemic chemotherapy about 2 years previously. He received almost continuous chemotherapy in the intervening period due to disease progression whenever treatment was withdrawn. His maintenance cancer treatment regimen contributed to gradually progressive fatigue over the previous 6-12 months. At recent clinic review, the Oncologist temporarily stopped his oral chemotherapy to facilitate recovery from a viral illness and help fatigue. He was interviewed several weeks after a pause in oral chemotherapy. He described constant severe physical and mental fatigue.

Cecil

Cecil lived with his wife and she performed all the household tasks. He had a strong faith and believed in the power of prayer. He had radical surgery for prostate cancer about 10 years ago and he felt fatigue gradually started after this. Ever since then, on medical advice, he had a daily afternoon nap which he found helpful. He was diagnosed with colorectal cancer 2 years ago, with emergency surgery followed by adjuvant chemotherapy. Metastatic liver disease was confirmed over a year later and since then, he has received 2 lines of palliative chemotherapy treatment. His most recent treatment dose was reduced by the Oncologist due fatigue and he was interviewed about 5 days after his final cycle. He described transient severe physical fatigue. He died around 6 months later.

Michael

Michael was single and had always lived with his parents. His father had dementia with poor short term memory and he helped his mother with maintaining the household. He had always thought that he would be looking after them in old age until their death. He enjoyed sport and had always been an active person, walking twice daily. About a year ago, he was diagnosed with metastatic colorectal cancer with liver disease after presenting with abdominal pain. He was on his second line of palliative systemic chemotherapy with alterations in his treatment schedule due to bone marrow suppression. The day before the interview, his chemotherapy was cancelled for this very reason. He felt he could do only half of what he could do previously. He died within a year of the interview.

Conor

Conor lived with his wife, step-son, daughter-in-law and baby grandchild. He had retired within the last year when he was diagnosed with cancer. He had always been an active person and enjoyed exercising. He was diagnosed with metastatic colorectal cancer with lung disease after a delayed presentation with rectal bleeding. He had a palliative colostomy followed by downsizing chemo-radiotherapy which the disease progressed on. He was receiving second line palliative chemotherapy and was hopeful for a surgical stoma reversal if he responded to treatment. He was interviewed after his 4th cycle of chemotherapy and his wife was present throughout the interview. He described constant physical and mental fatigue. He died within a year of the interview.

Gordon

Gordon was married and lived with his wife. He worked as a self-employed contractor in the same factory as his wife. He absence was difficult for them financially and in the workplace. He was diagnosed with inoperable pancreatic cancer after presenting with diabetes mellitus and obstructive jaundice about 4 months previously. He was receiving palliative chemotherapy with the possibility of 12 scheduled cycles. The interview occurred after his 5th cycle of treatment. Because of treatment related side effects which included severe fatigue, the chemotherapy dose was reduced on several occasions. He described severe transient physical and mental fatigue lasting for around 5 days after each cycle. He died within a year of the interview.

Brian

Brian was single, lived alone and his sister lived nearby. He was diagnosed with inoperable pancreatic cancer nearly 4 years previously. Initially, he had a clinical trial cancer treatment, followed by systemic palliative chemotherapy and then chemo-radiotherapy. He was scheduled for a re-challenge of treatment with the possibility of 12 cycles scheduled. He was interviewed after his 3rd cycle. Because of treatment related side effects which included severe fatigue, the chemotherapy dose was reduced and the dose interval between cycles was increased to 3 weekly. He described severe transient physical and mental fatigue lasting around 7 days after each cycle followed by constant moderate fatigue. Since this treatment began, he very much depended on his sister and her husband. He died within 6 months of the interview.

Clive

Clive was married and lived with his wife. He retired at the age of 75 years. He was diagnosed with a sigmoid tumour with metastatic lung disease about 3 years previously and then received palliative chemotherapy. Almost 1 year ago he underwent a palliative surgical ileostomy followed by pelvic radiotherapy. Recently he started a new line of palliative systemic chemotherapy treatment and was interviewed after the 2nd cycle. He described constant moderate physical fatigue which he felt had improved since the commencement of treatment. He died within 6 months of the interview.

Eileen

Eileen was single and lived in a residential care home for some years. She was a retired teacher and over the years her activity levels had declined. She was diagnosed with a rectal tumour after presenting with rectal bleeding about 9 months ago. She received downsizing radiotherapy but disease progressed and she metastatic lung disease was confirmed. She was then commenced on reduced dose oral palliative chemotherapy and recent scans confirmed stable disease. She described constant moderate physical fatigue which worsened on treatment. She died within 6 months of the interview.

Shay

Shay was married and lived with his wife and son. He was a retired painter decorator. He presented almost 3 years previously with a rectal tumour and declined surgery, preferring radical chemo-radiotherapy instead. Following this he had further chemotherapy followed by surgical excision of tumour with stoma formation. Restaging scans one year later confirmed local recurrence and metastatic lung disease. He received a further re-challenge of palliative systemic chemotherapy and was on surveillance follow up at the oncology clinic. He was interviewed 3 months after completing treatment. Overall his physical ability had deteriorated over the preceding 3 years but he was able to do some gardening.

Claire

Claire was married and lived at home with her husband who had Parkinson’s disease. They were both retired and had 3 grown up boys together. She had a colonic carcinoid tumour excised 4 years ago and lung nodules were then confirmed on re-staging scans 2 years later. Surgical excision of lung nodules confirmed lung cancer and she received adjuvant chemotherapy. Recurrent lung disease was confirmed several months later and she completed a further course of palliative systemic chemotherapy. Recent clinic review and investigations confirmed stable disease. She was interviewed 6 months after finishing treatment and in the company of her husband. She described constant severe fatigue.

Sonya

Sonya was widow and lived alone. She was a retired teacher and had lost her daughter the year previously due to a long illness with Multiple Sclerosis. She was club captain in her golf club and tried to keep up with her commitments. She presented with metastatic colorectal cancer with liver disease about 15 months previously. In the interim she had 2 lines of palliative systemic chemotherapy. She was interviewed about 3 weeks after completing the final cycle of chemotherapy scheduled. She described constant moderate fatigue.

Daniel

Daniel was married and lived at home with his wife. He was a retired management consultant and practiced management by objectives. For many years, he had a daily exercise routine devised by the Canadian Air Force and was quite active. He was diagnosed with mesothelioma around 6 months previously after presenting with breathlessness and a pleural effusion. He received palliative systemic chemotherapy and his treatment dose was reduced due to severe fatigue. At recent clinic review, disease progression was confirmed and treatment was stopped. He was interviewed about 5 weeks after stopping treatment and was awaiting to be seen in the phase 1 clinical trials unit.

Larry

Larry was married and lived at home with his wife. He was a retired heavy goods vehicle driver and had multiple co-morbidities with continuous home oxygen in place. He was a keen gardener and previously managed 3 allotments in the past. He was diagnosed with metastatic lung cancer after a fall resulted in a fractured neck of femur which required surgical repair about 8 months previously. In the interim he had palliative radiotherapy to his femur and lung. He was not fit enough for palliative chemotherapy and his symptoms were monitored in the clinic. At recent clinic review, he was treated for an infective exacerbation of chronic obstructive pulmonary disease. He was interviewed in the company of his wife. He described constant moderate fatigue.

Tom

Tom lived with his wife in an apartment in an independent shared living retirement complex. He was a retired fireman and previously enjoyed being active. He was diagnosed with metastatic oesophageal cancer with liver disease 4 months ago. He then commenced on palliative systemic chemotherapy with a projected schedule of 6 cycles. He was interviewed a couple of weeks after his 5th cycle and his wife was present throughout. He described severe transient fatigue which was modestly improving at the time of the interview. He died within a year of the interview.

Pandora

Pandora was married and lived with her husband. She worked part-time as an administrator, while he was retired from finance and they had 3 adult children together. She presented with symptomatic anaemia nearly 2 years previously and had emergency surgery for a colonic tumour followed by adjuvant chemotherapy. Relapse disease was confirmed about 1 year later and in the interim she completed 11 cycles out of a scheduled 12. She was interviewed over 2 months after completing this treatment and her constant moderate fatigue had improved considerably. She died within a year of the interview.

Jane

Jane was divorced and lived alone in a flat. She was a retired housekeeper and had one daughter who lived a distance away. She was diagnosed with breast cancer and had a mastectomy 8 years previously. Staging scans confirmed extensive metastatic bone disease and she then completed a course of palliative systemic chemotherapy. In the intervening period, she had several different hormone blockade therapies and more recently a trial of oral chemotherapy. At the clinic review, the Consultant stopped her oral chemotherapy due to deteriorating performance status and end of life discussions took place. She described constant severe fatigue. She died within 2 months of the interview.

Chloe

Chloe was married and lived with her husband. She was retired from paid work and was close to her 2 adult children who lived nearby. She had abdominal surgery to repair a hernia about a year previously and to avail of surgery, she was obliged to significantly alter her lifestyle by losing weight and exercising daily. Several months later, she was diagnosed with metastatic breast cancer with nodal and lung disease, after presenting with breathlessness related to pulmonary emboli. She was scheduled for 6 cycles of palliative systemic chemotherapy and was interviewed several days after her final cycle. She described severe transient fatigue.

Clodagh

Clodagh was a single mother and lived on her own. She worked as an English teacher in a school for children with special needs and her daughter was attending college. She was diagnosed with metastatic breast cancer with extensive bone disease nearly 5 months previously and was scheduled to complete 6 cycles of palliative systemic chemotherapy. She was interviewed several days after her final cycle. She described moderate constant fatigue.

Peggy

Peggy was divorced and lived on her own. She was a retired historian and artist. She enjoyed spending time with her 2 remaining children and several grandchildren. She was diagnosed with breast cancer around 18 years ago and had a mastectomy followed by adjuvant chemotherapy. Relapse metastatic bone and lung disease was confirmed several years ago. In the intervening period, she had hormone blockade therapy and more recently was commenced on a clinical trial with combination oral hormone blockade and targeted therapy. Cancer treatment was paused after she developed pneumonia and was admitted to hospital. She was interviewed several weeks after discharge. She described moderate constant fatigue.

Gloria

Gloria was married and lived with her husband. She was a retired healthcare professional. She was diagnosed with breast cancer around 15 years ago and had surgery followed by adjuvant hormone blockade therapy. Relapse metastatic liver and bone disease was confirmed one year ago, after she presented with cauda equina syndrome. She initially had palliative systemic chemotherapy but this was stopped after 2 cycles due to severe side effects. In the intervening period, she had hormone blockade therapy and more recently was commenced on palliative systemic chemotherapy. Cancer treatment was paused after she developed pneumonia and was admitted to hospital. She was interviewed over a month after discharge. She described constant severe fatigue. She died around 6 months after the interview.

Mary

Mary was single and lived in a shared living space with her sister and her family. She was a retired office worker and had a long history of mental health illness including anxiety and depression. She was diagnosed with inflammatory breast cancer 1 year previously and underwent neo-adjuvant chemotherapy prior to surgery which was then followed by adjuvant radiotherapy. She was diagnosed relapsed metastatic skin and bone disease some months later. She was commenced on oral chemotherapy with a projected schedule of 6 cycles. She was interviewed after her 4th cycle. She described constant moderate fatigue.