

**Pre-operative treatment for oesophageal cancer:  
perspectives and experiences**

**Kirsten Stewart-Knight**

A thesis submitted in partial fulfilment of the requirements of the  
University of East London for the degree of Professional Doctorate  
in Clinical Psychology

July 2016

## **ABSTRACT**

The relationship between cancer and psychological distress is widely recognised and reflected by the large and growing body of psycho-oncology research. Oesophageal cancer is an aggressive malignant disease which is most frequently diagnosed once too advanced for curative treatment. For a small proportion of patients, a risky and invasive oesophagectomy operation can attempt to remove the cancer. The treatment process is physically and emotionally gruelling, yet little research has focused on the experience for patients. The majority of existing research has used quantitative methods.

This study aimed to increase understanding of how people with oesophageal cancer experience the pre-operative treatment process and the approaching, yet uncertain, surgery. Qualitative semi-structured interviews were carried out with seven patients and eight members of their cancer centre's multidisciplinary team. This intended to increase insight into patients' personal experiences and staff's accounts of diverse patients with whom they have worked. Analysis was conducted using a critical realist epistemology and thematic analysis.

Three overarching patient themes were identified of 'fear and the unknown', 'treatment brings hope and uncertainty' and 'committing to getting through treatment'. Patient participants described determinedly following medical advice whilst feeling fearful about surgery and its aftermath. Staff spoke more directly about the risks, dilemmas and often harrowing effects of treatment, as well as their efforts to support patients with this. Two main staff themes were developed of 'between the devil and the deep blue sea' and 'predicting the unpredictable'.

The findings suggest a need to consider decision-making in this particular context. In clinical practice, healthcare professionals must facilitate careful consideration of the subjective complexity central to treatment decisions. Further research should examine the transmission of information about the risks and potential consequences of surgery, the psychological processes involved in patients' decisions and methods for improving psychological preparation for surgery.

## Table of Contents

1. INTRODUCTION .....	11
1.1 Background .....	11
1.2 Cancer .....	12
1.2.1 Prevalence and policy .....	12
1.2.2 Emotional effects of cancer .....	14
1.2.3 Health-Related Quality of Life .....	17
1.3 Oesophageal Cancer.....	17
1.3.1 Multidisciplinary treatment pathway.....	20
1.4 Systematic Literature Searches.....	22
1.4.1 Search strategy.....	22
1.4.2 Inclusion criteria.....	23
1.4.3 Exclusion criteria.....	23
1.4.4 Search results.....	23
1.5 Critical appraisal of core papers.....	24
1.5.1 Review papers.....	24
1.5.2 Relationship between HR-QOL and oesophagectomy.....	26
1.5.2.1 HR-QOL post-surgery.....	26
1.5.2.2 Prospective studies.....	29
1.5.3 Patients' experiences of oesophagectomy.....	33
1.5.4 Critical evaluation.....	39
1.6 Rationale.....	40
1.6.1 Aims.....	41
1.6.2 Research questions.....	42
2. METHODS.....	43
2.1 Overview.....	43
2.2 Epistemology.....	43

2.3 Design.....	44
2.4 Ethics.....	45
2.5 Recruitment and research procedure.....	47
2.5.1 Patient inclusion criteria and procedure.....	47
2.5.2 Staff inclusion criteria and procedure.....	48
2.6 Interviews and Transcription.....	49
2.7 Analysis.....	49
3. ANALYSIS.....	52
3.1 Overview.....	52
3.2 Patient Analysis.....	52
3.2.1 Setting the context.....	52
3.3 Patient Thematic Analysis.....	52
3.4 Staff Thematic Analysis.....	70
3.4.1 Setting the context.....	71
4. DISCUSSION.....	83
4.1 Overview.....	83
4.2 Contextualising the Analysis.....	83
4.3 Summary of Findings.....	84
4.3.1 Patient analysis.....	84
4.3.2 Staff analysis.....	84
4.4 Connections Between Patient and Staff Themes.....	86
4.5 Contribution Towards Understanding of Patients' Experiences.....	88
4.5.1 Engagement with treatment.....	89
4.5.2 Gender.....	92
4.5.3 Decision-making and consent.....	93
4.5.4 Shared and unique features.....	97
4.6 Implications.....	95
4.6.1 Clinical practice.....	95

4.6.2 Research.....	101
4.7 Critical Evaluation.....	102
4.7.1 Quality assessment.....	104
4.8 Reflection.....	106
7. REFERENCES.....	108
8. APPENDICES.....	129

## **LIST OF TABLES**

**Table 1.** Patient participants: demographic information

**Table 2.** Patient analysis themes

**Table 3.** Staff analysis themes

## **LIST OF FIGURES**

**Figure 1.** Typical oesophageal cancer care pathway

**Figure 2.** Oesophagectomy pre-habilitation pathway

**Figure 3.** Overview of search process

**Figure 4.** Diagram of themes

## **LIST OF APPENDICES**

**APPENDIX A:** Literature review table 1

**APPENDIX B:** Literature review table 2

**APPENDIX C:** Literature review table 3

**APPENDIX D:** Literature review table 4

**APPENDIX E:** Literature review table 5

**APPENDIX F:** NRES Committee Ethical Approval

**APPENDIX G:** University of East London Ethical Approval

**APPENDIX H:** Change in Title

**APPENDIX I:** Patient information sheet and consent form

**APPENDIX J:** Staff information sheet and consent form

**APPENDIX K:** Patient interview schedule

**APPENDIX L:** Staff interview schedule

**APPENDIX M:** Transcription key, Parker (2005)

**APPENDIX N:** Example of transcript with initial observations

**APPENDIX O:** Initial patient codebook

**APPENDIX P:** Initial staff codebook

**APPENDIX Q:** Extract from coding tables

**APPENDIX R:** Examples of thematic maps



## **ACKNOWLEDGEMENTS**

There are many people I would like to express my thanks and gratitude to for making this thesis possible and for journeying with me through this long process.

Firstly to my participants: this could never have been written without your honesty and generosity. Thank you for changing my perspective in ways that will have long-lasting effects on me.

My supervisor Dr Ken Gannon: you have been so patient and precise. I have benefitted greatly from your wealth of knowledge and you have offered calm in the storm! I am very grateful to have been supervised by you.

My field supervisor Dr Alex King: life changed for me when we first met in 2012 at St. Thomas! Thank you for all of your support since then - your expert knowledge, helpful advice and sense of humour have all been invaluable. Thank you for the opportunity to do this project with you and the team.

To my parents, grandparents and friends: thank you for your support and for listening to me speak incessantly about cancer, ethics and psychology! You inspired me to keep going even when the challenges felt immense.

A special thank you to Dr Anna Janssen for immeasurable support, gourmet dinners and for sharing your incredible mind and insightful revisions. I have loved our conversations of all kinds throughout this process and will always be grateful.

## **DEDICATION**

Pour Cristina. Merci pour tout.

“À vaillant cœur rien d'impossible.”

# 1. INTRODUCTION

## 1.1 Background

This research focuses on exploring patients'<sup>1</sup> experiences of pre-operative treatment for oesophageal cancer (O.C.) from the perspective of both patients and staff. I<sup>2</sup> begin the introduction by describing the context of cancer drawing on relevant literature, policy and practice guidelines, considering implications for clinical practice. The specific features of potentially curative treatment for O.C. will then be described, highlighting the characteristics and challenges of this disease and treatment pathway. Finally, I will outline the findings of a systematic literature review which gave rise to the study's aims and research questions.

Both those who encourage and critique qualitative approaches acknowledge the influence of researchers' assumptions and interpretations on the process and analysis (Harper, 2012). I have therefore aimed to become aware of assumptions influencing my decisions throughout this thesis. During my first experience of working in oncology and palliative care in 2010, I became interested in the idiosyncratic responses of individuals with varied sociocultural contexts who encounter the challenges of cancer and its treatment. I believe that a life-threatening cancer diagnosis interacts with other challenges and social inequalities and developing a contextualised understanding is therefore necessary, in order to consider how staff and systems can help.

My belief is that it is crucial to question taken-for-granted 'truths'. In line with this, my aim is that this thesis can create the possibility for further insight into patients' experiences of pre-operative treatment for O.C. I hope that hearing directly from staff and patients during the challenging pre-operative period will

---

<sup>1</sup> This term will be used to refer to people with cancer in line with conventions, but with the acknowledgement of its problematic hierarchical connotations.

<sup>2</sup> I have written this thesis in the first person to reflect that this is one interpretation, inextricably influenced by my own position and experiences, rather than a reflection of a reality.

enable us to learn how patients themselves conceptualise their experiences (which may differ from the dominant narratives about generic cancer experiences), with the opportunity to focus on this very specific treatment context.

## **1.2 Cancer**

### 1.2.1 Prevalence and policy

Unprecedented numbers of people receive cancer diagnoses each year and it is anticipated that by the end of 2016 more than one thousand people will be diagnosed with cancer daily in the United Kingdom (UK; Macmillan, 2015). Improved diagnostics, public health initiatives, screening and awareness are key contributors to this. In addition, work is being done to change cultural attitudes about cancer, particularly by organisations like Macmillan. This aims to reduce negative and hopeless ideas about the disease, increasing awareness and consequently improving access to screening (Macmillan, 2013).

Over the past 15 years, medical advances have led not only to more curative outcomes, but also to significantly higher numbers of people surviving and living with cancer (Cancer Research UK; CRUK, 2014). Increases in cancer 'survivorship' have primarily been linked with the aging population in the UK and more successful treatments, as well as earlier diagnoses (Macmillan, 2013). Maddams, Utley and Møller (2012) projected that numbers of cancer survivors in the UK will continue to grow by approximately one million every decade, doubling from two million in 2010 to four million in 2030. In 2015, this figure was reportedly two and a half million (Macmillan, 2015). This reflects great changes in outlook for many people with cancer, which is a disease that has historically been perceived as a 'death sentence' (Macmillan, 2012).

Increases in cancer survivorship, whilst providing hope, also create concern about the challenges this presents to the National Health Service's (NHS)

resources. Vast developments in medical science are increasing the chances of cure and survival and the resource-stretched NHS is therefore caring for and monitoring the growing numbers of people living with cancer and the effects of treatment (Macmillan, 2013). Although many people who have cancer will return to their pre-diagnostic levels of wellbeing and functioning, a significant number will continue to experience long-term distressing difficulties (Macmillan, 2013). The National Cancer Survivorship Initiative (NCSI, 2013) report *‘Living with and Beyond Cancer: Taking Action to Improve Outcomes’* asked commissioners and service providers to develop and commission care pathways that would work to minimise the consequences of cancer and its treatments. Macmillan argues that self-management (which has been emphasised in recent policy initiatives; Macmillan, 2009) is not sufficient without the health service taking responsibility for supporting the significant proportion of cancer patients managing long-term effects of the disease and treatment. From a health economic perspective, the NCSI report (2013; chapter 4) highlights the cost to the NHS and wider economy of failing to meet the needs of these people, due to the high costs following the end of treatment when needs are not met. For example, patients and carers’ ability to work is commonly impacted by cancer.

The UK government have identified cancer as a national priority and *Improving Outcomes: A Strategy for Cancer* (Department of Health; DoH, 2014) outlined the challenges for the NHS of meeting the growing number of patients’ needs, coupled with current requirements for services to make savings. In the accompanying document to this, the government reported considerable progress in survival rates and patient experiences of cancer care in the UK since the *Cancer plan* (DoH, 2000) and *Cancer Reform Strategy* (DoH, 2007). However, these rates remain lower than in comparable countries (De Angelis et al., 2014).

Wilkinson and Pickett’s (2009) *The Spirit Level* provides powerful evidence for a relationship between inequalities and health, where areas with the largest income gaps (including the UK and United States of America; U.S.A.) report greatest health problems. Cancer Research UK (2004) found a cancer

'socioeconomic gradient' with wealthier people more likely to have greater knowledge of cancer risks, leading to widespread inequalities. Evidence also suggests that there are higher rates of some cancers in people from minority ethnic groups (e.g. prostate cancer and black men; Ben-Shlomo et al., 2008) which is likely to relate to inter-group differences in lifestyle-based risk factors, diagnosis and access to treatment including lower income, educational opportunity and racism, as well as genetics. People from subjugated groups are also less likely to attend health screening (e.g. Baker & Middlerton; Rankow & Tessaro, 1998). Alongside this, people who described themselves as from an ethnic or sexual minority or as having a disability reported less positive experiences of cancer care in the patient experience survey (DOH, 2010). The Department of Health (2011) also highlight the continuing impact of social inequalities in cancer services. This evidence demonstrates that as with many health conditions, intersectional inequalities have a bidirectional relationship with cancer (Rowlingson, 2011). Therefore, I would suggest increasing understanding of cancer embedded in the complicated realities of people's dynamic and intersecting contexts, is central to the pursuit of patient-centred care at all levels.

### 1.2.2 Emotional effects of cancer

Cancer continues to cause immense suffering for patients and carers, eliciting a diverse range of emotional responses and social consequences (Han et al., 2014). Although progress in medical oncology has provided increased hope, pervasive ideas about cancer as a 'death sentence' remain influential. In 1978, Susan Sontag's classic work *Illness as Metaphor* powerfully illuminated the ways in which societal ideas about cancer influence individuals' experiences, with the argument that in order to make sense of our experiences, we draw on the ideas available within society.

People's experiences of cancer and the emotions it evokes are unique and individual, shaped by these societal narratives, multiple intersecting contexts and wide variation in the disease itself. A large and growing body of psychosocial literature reflects the increasing focus in western cancer care on

emotional and holistic support, in which HCPs work to enhance all aspects of wellbeing and health related-quality of life (HR-QOL). In comparison, historically, the focus was almost entirely on the physical consequences of illness. The effects of cancer and its treatments are at best unpleasant and at worst devastating. For a considerable proportion of people this leads to far-reaching changes in every area of life and identity. That said, the changes that cancer provokes are not always negative, as the large body of literature on the concept of 'post-traumatic growth' suggests (Parkes, 1971).

Distress and fear for cancer patients has been described as the 'sixth vital sign'<sup>3</sup> by Bultz and Carlson (2005) and studies using systematic screening tools have found that 33%-45% of cancer patients reported 'significant distress' (Carlson & Bultz, 2003; p.403). The appropriate and understandable response of fear and distress when facing cancer is eloquently articulated by Brennan (2001; p. 2): 'It<sup>4</sup> seems highly arguable whether psychological turmoil provoked by a severe life event should be regarded as morbid or part of an adaptive process'.

However, as the literature review for this study later exemplifies, a considerable proportion of psychosocial research in cancer has viewed distress through the lens of psychiatric diagnosis, portraying psychological distress in isolation rather than in context (Brennan, 2004). This is despite the well-established relationship between context and wellbeing, extensively supported by research evidence and included in national and international policies (DOH, 2003; World Health Organisation, 2009). The ethos of supportive and palliative care is also based upon principles of 'person-centred care' which aim to understand the person and the meaning of their experiences in the context of their individual history, current circumstances and values (Jeffrey, 2003).

The uncertainty associated with cancer often makes it particularly psychologically challenging. The construct of locus of control developed by Rotter (1954) can be applied to make sense of why unpredictability is so

---

<sup>3</sup> A reference to the five vital signs of nursing usually considered to be: pain, respiratory rate, temperature, heart rate and blood pressure (Berry et al., 2001).

<sup>4</sup> Single quotation marks will be used to indicate quotations from academic texts and reports, double quotation marks will be used for direct quotes from interviews.

difficult. This theory has been highly influential across health research and practice, and suggests that when people believe that what happens to them is related to their own actions (internal reinforcement) or rather due to powerful outside forces (external reinforcement), it impacts on their capacity to adapt to illness. Internal health locus of control has consistently been associated with better health outcomes, when focused on having control in the future, but is related to more distress if this is focused on perceptions of control in the past (Mystakidou et al., 2015). However, Christensen, Howren and Rosenthal (2010) found that strong internal locus of control is related to positive adjustment to illness solely where control is 'realistic'. They suggest that it may conversely be harmful where there are insurmountable barriers to utilising personal control. In a cancer context, this is particularly complicated, as overall personal control may be limited, for example despite adhering to medical advice, the effectiveness of treatment itself may be outside of patients' control. Oppressive social circumstances may exacerbate this.

Understanding how people adapt to such threatening events and how to support them with this, is central to clinical practice with people with cancer. Brennan's (2001) influential social-cognitive transition model of adjustment proposes that the highly shocking demands of cancer require a fundamental re-adjustment of the mental maps through which we predict and make sense of our experiences and the world. The experience of violation of our expectations of safety by a cancer diagnosis leads the world to feel uncertain and unsafe until more coherent mental maps can be developed. These processes of adjustment through re-organising our beliefs often lead to distress (Brennan, 2004).

Much research has investigated variables that influence patients' experiences of cancer. This has included factors such as speed of diagnosis (Thomas et al., 2001), age (Brennan, 2004), gender (Moynihan, 2002) and attitudes of 'fighting spirit' or optimism which have been proposed as associated with better coping (Watson, Greer & Rowden et al., 1991; Carver et al., 1993). Brennan (2004), however, highlights that research on attitudes is individualising and implies universality, rather than acknowledging that a variety of styles are likely to be



helpful at different time points or in combination, depending on circumstances. He proposes that the strongest evidence suggests that 'active' styles of coping, where patients participate and engage with their circumstances and healthcare, are associated with positive adjustment (e.g. Rodrigue, Behen & Tumlin, 1994).

### 1.2.3 Health-Related Quality of Life

The concept of HR-QOL, a dominant construct in the cancer literature (Abitbol, 2014), can be defined as a subjective sense of satisfaction with life and wellbeing (Schumacher, Olschewski & Schulgen, 1991). Cancer and its treatment affects people's HR-QOL in individual and varied ways depending on individual circumstances (Macmillan, 2014a). Götze et al.'s (2014) multi-site longitudinal survey study of heterogeneous cancer patients post-treatment found that emotional, role and social domains of HR-QOL were most negatively affected by cancer, above physical symptoms.

Macmillan (2013; p.3) highlight that it is important to note that 'not dying' is not the same as 'being well'. Similarly the idea of HR-QOL not being about how long you live, but rather a subjective sense of wellbeing is often used in definitions of supportive and palliative care (Payne, Seymour & Ingleton, 2008). Calman's classic paper (1984; p. 124) emphasised that HR-QOL '...can only be described by the individual, and must take into account many aspects of life'. However, Rapley (2003) highlighted the problematic use of this construct in measures which attempt to quantify HR-QOL. The effects of this can be seen in the literature review presented later in this chapter.

## **1.3 Oesophageal Cancer**

While cancers share a basic biological process of the uncontrolled replication of cells, there is much variation in unique presentation and the impact it has on an individual's experiences in a particular context (Vickery, Latchford, Bellew &

Feber, 2003). I think it is therefore important to put the challenges faced by specific patient groups in context (Clarke, McCorry & Dempster, 2011).

Oesophageal cancer (O.C.) is an aggressive malignant disease, most often diagnosed at an advanced stage (Hodgson, 2006). It is internationally the eighth most common form of cancer for males and thirteenth most common for females (CRUK, 2016c). In 2012 it was found by Cancer Research UK to be the fourth most common cause of cancer death for men in the UK and the sixth most common cause of cancer death overall. Since the late 1970s rates of O.C. diagnoses have increased by 43% in the UK (CRUK, 2016c). The UK's incidence rates for O.C. are the highest in Europe for females and second highest for males, although the reasons are unclear (CRUK, 2016c). There are differences in O.C. mortality rates across the UK with higher rates in the north and lowest rates in the south and east (CRUK, 2012). O.C. is most common in socioeconomically deprived areas (Price, Sikora & Illidge, 2008).

Patients with O.C. usually experience symptoms of dysphagia (difficulty swallowing), weight loss and pain. Due to the oesophagus' expandable nature, there is often a delay before these symptoms are noticed and in most cases the cancer is only identified once too advanced for curative treatment (Andreassen & Randers et al., 2006). Lagergren's (2010) review found that up to 75% of patients with O.C. are not treated with curative intent, usually due to advanced cancer stage or insufficient fitness for surgery. As with most other major resections for cancer, the number of patients for whom surgery is deemed plausible declines as age increases (National Cancer Intelligence Network, 2014).

Overall most people with advanced O.C. live on average for 3-12 months post-diagnosis (CRUK, 2016b). Where potentially curative treatment is feasible, there is a good chance of survival (Lagergren, 2010) and the National Oesophago-Gastric Cancer Audit (2014) found a reduction in deaths within 90 days of surgery from 5.7% in 2010 to 4.4% in 2014. Approximately 14% of people underwent major resection surgery between 2006 and 2010 in England (CRUK, 2016c) which intends to remove the cancer surgically with the aim of

cure. This 'oesophagectomy' surgery is an invasive and complicated procedure which offers potentially curative treatment, with a long and arduous recovery process. However, this is only viable when the disease is identified at an early and localised stage. Cancer Research UK (2016b) reports that 30-40% of people with localised O.C. would be eligible for this treatment.

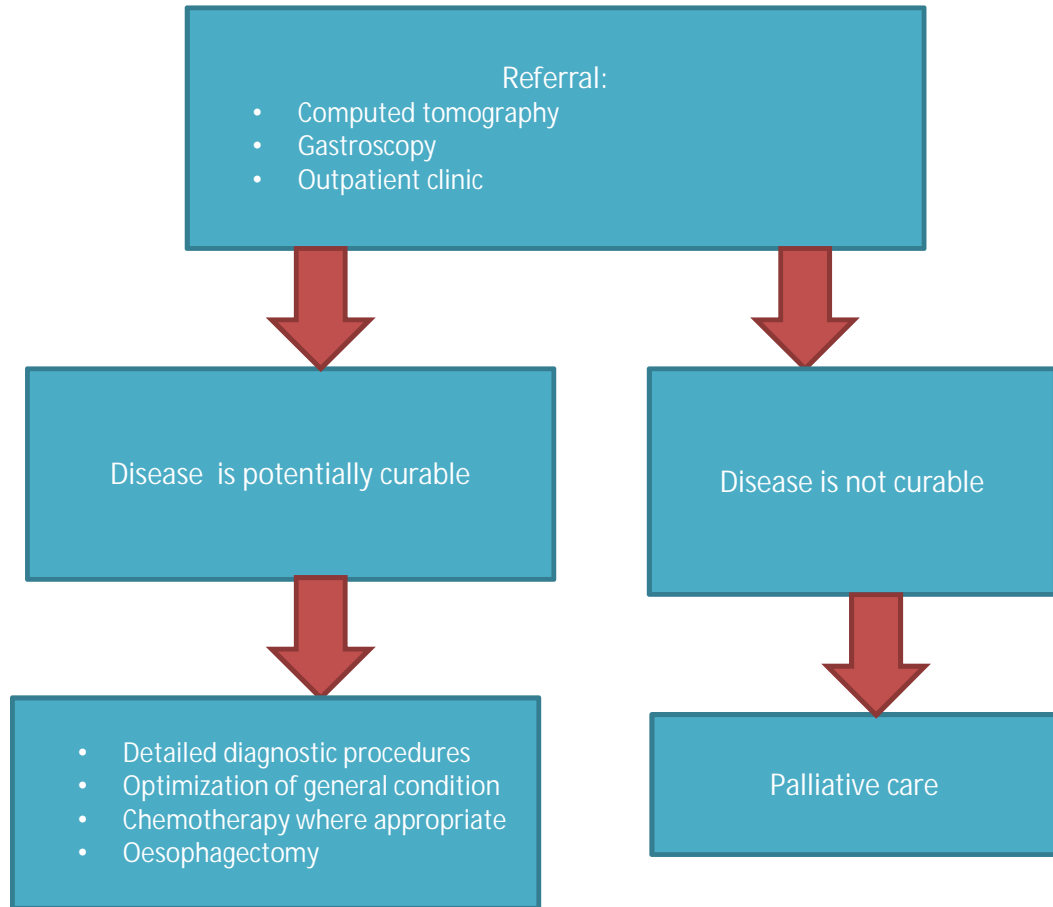
However, even after curatively intended oesophagectomy, five-year survival figures have been reported as 30% (Rouvelas, Zeng, Lindblad et al., 2005). In contrast, five-year survival rates for breast and prostate cancers in the UK have been reported as 78% and 84% respectively, with testicular cancer's 10-year survival rate of 98% (CRUK, 2016a). Oesophagectomy provides hope of a cure, but has the highest mortality rates of any planned surgery. It has been described as 'perhaps the most traumatic general surgical procedure' (Tatematsu, Hasegawa, Tanaka, Sakai & Tsuboyama, 2013; p. 309) and long-term effects include nutritional and gastrointestinal difficulties. At the point of diagnosis patients deemed suitable begin intensive treatment in preparation for surgery, often including chemotherapy (Lagergren, 2010).

The emotional demands of O.C. in particular have been acknowledged in the literature as posing a significant threat to HR-QOL (Verschuur et. al., 2006). The pre-operative treatment process can be especially gruelling, as treatment and physical optimisation begin soon after diagnosis and are crucial preparation for the operation (Djarv & Lagergren, 2012). It is widely acknowledged that patients who have oesophagectomy operations face great challenges physically and psychologically and so it is perhaps unsurprising that the process is usually associated with a negative impact on HR-QOL and daily living, persisting during the long recovery period (e.g. Malmstrom, Klefsgård, Ivarsson et al., 2015). Malmstrom, Ivarsson, Johansson & Klefsgård (2013a) highlight that outcome of oesophagectomy has mainly been reported through quantitative measures such as survival, hospital stays and medical complications (e.g. Blazeby et al., 2000; Viklund et al., 2006a). Although important, this fails to capture patients' lived experiences or to acknowledge other aspects of a successful outcome.

While much has been written about the impact of cancer on HR-QOL, little research has focused on this unique treatment context. I would argue that the

experience of this type of treatment is likely to differ significantly from the experience of the more common types of treatment for O.C. (e.g. palliative symptom control). The below figure depicts typical care pathways for patients with O.C. (adapted from Viklund & Lagergren, 2007).

*Figure 1: Typical oesophageal cancer care pathway*



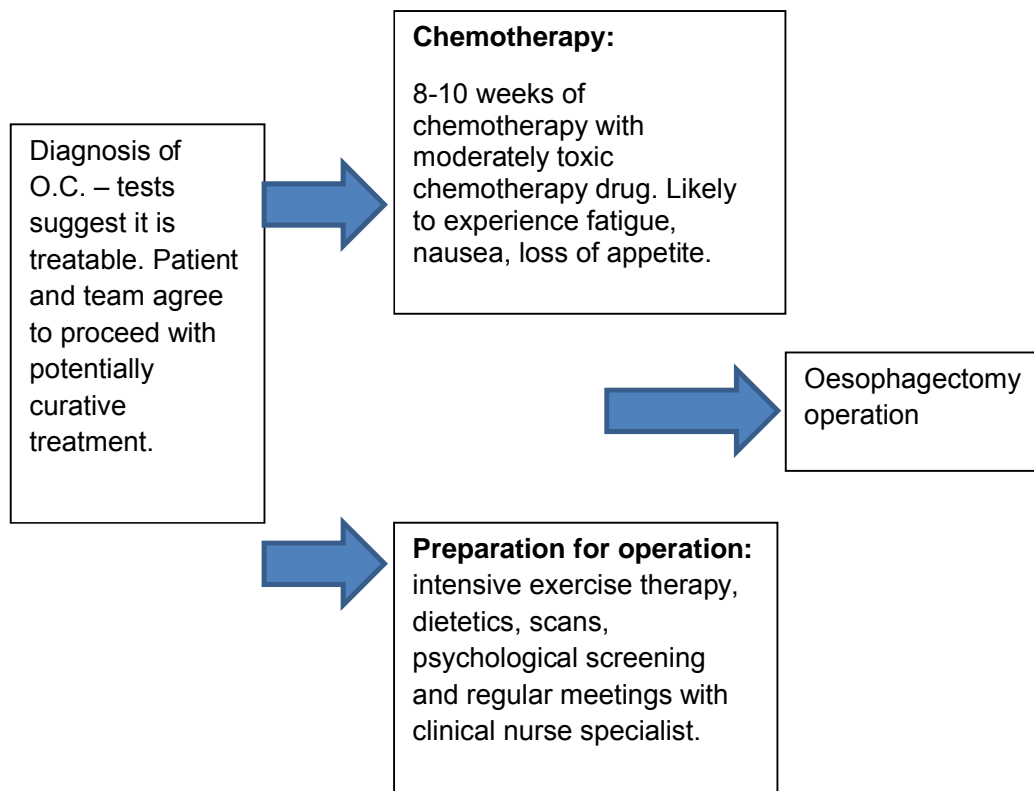
In addition to the widely-accepted sequence of treatments (Lagergren, 2010) the importance of a well-co-ordinated pathway for patients having this treatment has been documented extensively in the literature (Viklund, Wengstrom & Lagergren, 2006b; Viklund & Lagergren, 2007).

### 1.3.1 Multidisciplinary treatment pathway

Some treatment centres have developed specialist treatment pathways to support patients during this process.

Intensive pre-operative pathways known as ‘pre-habilitation care pathways’ have been shown to improve physical and emotional outcomes (Silver & Baima, 2013). It is common for pre-habilitation care pathways to involve intensive multidisciplinary support alongside direct medical treatment. At the London cancer centre where this study was carried out, there is a specific pre-habilitation care pathway for those patients with O.C. who are medically suitable for treatment with curative intent. This pathway was introduced in 2014 to prepare patients for oesophagectomy surgery. The pathway which is this study’s focus entails additional medical and dietetic consultations, intensive exercise therapy and specialist nurse support throughout the pre-operative process where patients frequently also have chemotherapy. It has a holistic approach, emphasising both personalised care and standardisation, aiming to offer equity and efficiency to all patients. This new pathway is showing promise and is likely to be expanded to other cancers in the near future. The following figure depicts the pre-habilitation pathway for patients at this cancer centre.

*Figure 2: oesophagectomy pre-habilitation pathway*



During the pre-operative treatment period, patients usually receive multidisciplinary pre-operative support through specialist nurses, doctors, dieticians, physiothererapists and psychologists whose interventions aim to physically and psychologically prepare patients for surgery, whilst supporting them during pre-operative treatment. There is much variation in patients' physical symptoms and responses to treatment, meaning that there is a wide range of treatment pathways and experiences. For example, at the point of diagnosis and during the pre-operative treatment process some patients have very few physical symptoms while others experience extreme dysphagia obstructing eating and drinking, which may lead to rapid weight loss and necessitate a feeding tube.

The recommended medical treatment typically includes patients undergoing approximately nine weeks of neoadjuvant chemotherapy, followed by a scan to check the response to chemotherapy and confirm eligibility for surgery. When patients are eligible, after a break of four to six weeks following chemotherapy, potentially curative surgery can take place. Where patients experience adverse effects to chemotherapy (particularly toxicity), chemotherapy will be discontinued and the timing of surgery will at times be accelerated. However where the scan indicates tumour progression, surgery would not be possible and would be removed as a treatment option.

#### **1.4 Systematic literature searches**

Systematic literature searches were carried out in November 2014-March 2016 to set the empirical context for the study.

##### **1.4.1 Search strategy**

The following questions guided the literature review:

- How is the relationship between oesophagectomy and HR-QOL conceptualised?
- How do patients describe their experiences of the process leading up to and following potentially curative oesophagectomy surgery?

The following databases were searched: Psychinfo, PsychArticles, CINAHL Plus and Science Direct, with no limits on date or country.

The search terminology used in varied combinations was: (\*esophagectomy OR \*esophageal cancer) AND (experience\* OR health related-quality of life OR mood OR distress).

#### 1.4.2 Inclusion criteria

Qualitative and quantitative articles published in the English language in a peer-reviewed journal, describing research where a significant focus was the experience or HR-QOL of patients who were having or had surgery for O.C. with curative intent.

#### 1.4.3 Exclusion criteria

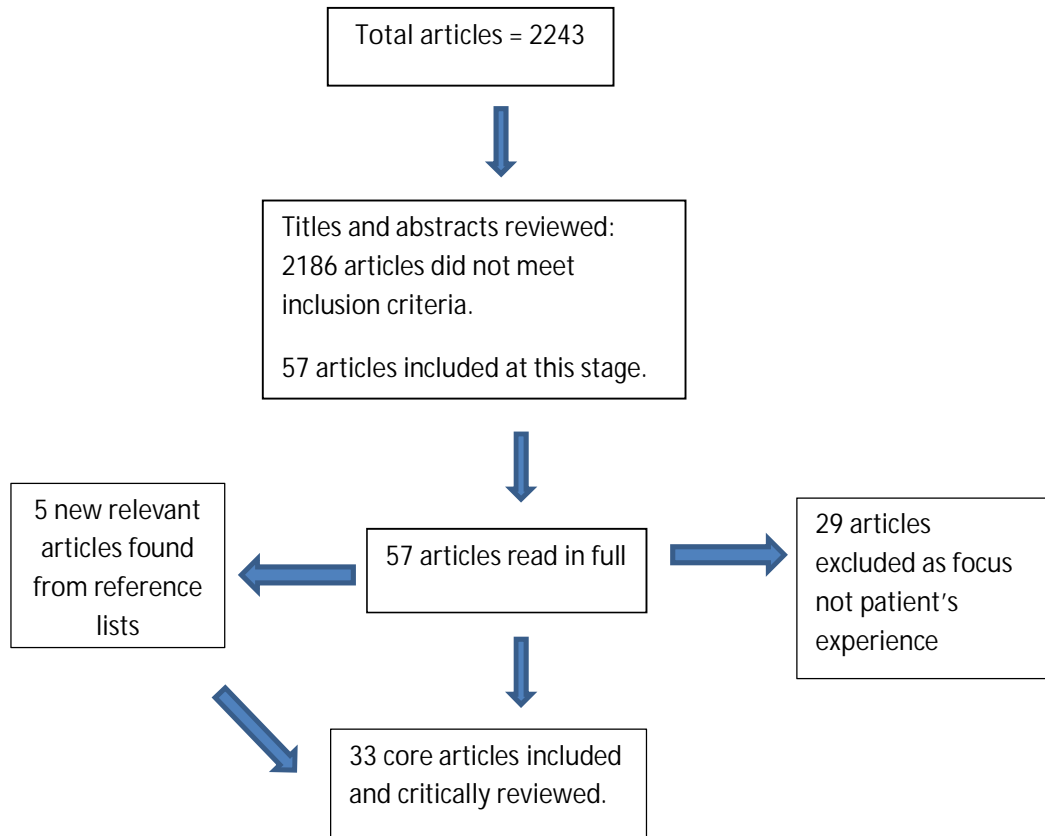
Papers not written in English, where the focus was not on the psychological experience for patients who were due to have or have had oesophagectomy. Papers where HR-QOL was mentioned but where the focus was on surgical or treatment techniques were excluded.

#### 1.4.4 Search results

The search strategy initially identified a total of 2243 publications (170 from *PsychInfo*, 3 from *PsychArticles*, 1367 from *CINAHL Plus*, 703 from *Science Direct*). These searches, along with a search of the Cochrane library of systematic reviews using the search terms 'oesophageal cancer' and 'experience' and 'HR-QOL' revealed that no similar systematic reviews had been published under these terms. The below figure depicts the process of initial searches, followed by manually reviewing the titles, abstracts and then full texts. In the case of uncertainty over the inclusion of a paper, the methodology and results section were also reviewed and on occasion, decisions were discussed with my supervisory team. Manual searching of the reference lists of relevant publications revealed a further five publications for screening. The final

step of retrieving and reviewing these 62 papers in full identified a total of 33 publications which fulfilled the inclusion criteria for review. A narrative review of the identified articles follows, with further details in Appendices A-E.

**Figure 3: overview of search process**



### 1.5 Critical appraisal of core papers

The quality of all papers meeting inclusion criteria was assessed. Most of the articles found were quantitative studies with a proportion of qualitative, as well as review articles. The review papers will be discussed first. Papers focusing on HR-QOL and oesophagectomy will then be considered, followed by papers which attend to elements of patients' experiences of oesophagectomy.

#### 1.5.1 Review papers

Wikman, Smedfors and Lagergren's (2013) review suggested that there has been limited investigation of emotional distress and O.C., despite available



evidence demonstrating that these patients tend to experience significant distress in the short- and long-term. They state that it is difficult to draw conclusions from the current literature, as studies are mainly cross-sectional and have inconsistent assessment points with small and heterogeneous samples of patients with different treatment pathways and stages. The authors suggest further research is essential to look at the prevalence of distress and risk factors for this, and to further consider carers' roles in emotional distress. Whilst I agree that further research is important, I would argue that research that contextualises distress, rather than considering it detached from meaning and social context, is crucial.

In a meta-analysis of 15 papers, Jacobs et al. (2014) found that deterioration on social (role functioning) domains of HR-QOL questionnaires was particularly striking and correlated with physical symptoms. They concluded that participants experienced a long-lasting deterioration in HR-QOL following oesophagectomy, although this frequently improved 9-12 months post-surgery. The authors invite further qualitative research to explore in more detail how patients conceptualise their experiences and HR-QOL.

A review paper by Djärv and Lagergren (2012) aimed to assess the empirical evidence on HR-QOL post-oesophagectomy. They described the importance of HR-QOL as a concept within oncology and palliative care that emphasises patients' subjective and individual experiences (rather than symptom checklists that reflect HCPs' priorities). This paper recommends that all patients should be assessed for HR-QOL and strongly communicates a view that this improves every consultation. However, although this principle is appealing, I think that it is problematic to assume that improvement will be a definite consequence of assessment regardless of the approach taken.

Jacobs et al.'s (2013) systematic review of studies reporting HR-QOL post-oesophagectomy concluded that the quality of most studies evaluating HR-QOL following surgery is poor and limited in ability to inform practice. They highlight

three robust studies, which they describe as ‘well designed and well reported’ (Zhang, et al., 2011; de Boer et al., 2004; Lagergren et al., 2007). Only one of these is included in this review as the other two studies were excluded due to the focus on different medical techniques. Given the quality of the Lagergren et al. (2007) study, it seems important to highlight their finding that patients who survive three years post-oesophagectomy report a good HR-QOL.

### 1.5.2 Relationship between HR-QOL and oesophagectomy

#### Quantitative

Fourteen of the included papers investigated HR-QOL quantitatively, using questionnaires. The majority of papers adopted a narrow conceptualisation of HR-QOL and despite the value of reporting the findings of tools used in clinical practice; they often fail to acknowledge alternative dimensions and the context-specific meaning of this concept. These quantitative studies also tend to measure HR-QOL without a theoretical basis or clearly described conceptualisation of the meaning of this for participants.

#### *1.5.2.1 HR-QOL post-surgery*

Many studies reported HR-QOL measured at one time point, with others examining the trajectory of scores at multiple intervals. I will now give an analytical summary of the overarching findings (see Appendix A for study details).

Viklund et al. (2006a) found HR-QOL to be significantly lower for people six-months post-oesophagectomy than for both a general population reference group and a group of heterogeneous cancer patients. Given the typically long recovery period following oesophagectomy (at least 12 months), continuing physical symptoms and the risks and magnitude of surgery, it is perhaps unsurprising that HR-QOL scores would be comparatively low at 6 months. These scores are comparable to those for patients with a palliative diagnosis (reported by Homs et al., 2004). The authors argue that the findings provide

evidence against oesophagectomy for palliative patients and that it should only be used with curative intent because of the impact on HR-QOL. They recommend providing clear and detailed information to inform patients' expectations, as well as contact with a specialist nurse. They also highlight the implication that if detailed and honest information is provided, this may influence patients' willingness to agree to surgery, stating that 'patients should be informed of postoperative problems that often occur also since this might influence their approval to accept the surgical treatment' (p.1412). This makes an important ethical point about informed consent necessitating realistic information. The authors caution against overselling this highly risky surgery.

Akkerman et al. (2015) found that one year post-surgery, global HR-QOL was comparable to a general population group. Hallas et al. (2001) also found that the majority of participants had HR-QOL scores comparable to the general population group at five years post-oesophagectomy. However, in both these studies participants generally reported low HR-QOL on physical functioning, reflecting persisting symptoms long after surgery. These authors suggest that for the small proportion of patients who had lower global HR-QOL this was associated with continuing pain and fatigue. In addition Derogar et al. (2012) reported that five years post-oesophagectomy, post-operative complications predicted reduced post-surgery HR-QOL. They recommend careful screening for symptoms at follow-up appointments and the offer of rehabilitation interventions. This supports Hallas et al.'s (2001) suggestion of an association between physical trajectory and HR-QOL longitudinal scores.

Wu et al.'s (2015) investigation of symptom distress and HR-QOL in patients undergoing postoperative chemotherapy also found that symptom impact and HR-QOL were negatively related. They report that participants who worked and had lower anxiety often reported lower symptom distress and HR-QOL. The active coping strategy of 'confrontation' was positively correlated with symptom impact. The authors suggest that while confrontation could be considered to be an active style (as opposed to avoidance), one coping strategy is not sufficient for adapting to O.C. and treatment, as coping is situationally specific and its

effects are dynamic (Lazarus and Folkman, 1984). They propose that “appropriate avoidance” may be more adaptive for some patients, as confronting O.C. may cause overwhelming anxiety and distress. This corresponds with Brennan’s (2004) suggestion that a single coping style (such as ‘fighting spirit’ which has long been associated with better psychological wellbeing in people with cancer; Watson et al., 1991) is unlikely to be effective for all situations.

Derogar and Lagergren (2012) found that the majority of patient’s HR-QOL was rated as stable or improved over time since surgery, though a section of participants had substantially lower HR-QOL than the general population. The majority of participants scored comparably to the general population group at five years post surgery. The authors recommend that in order to be able to tailor interventions for improved long-term HR-QOL, more research is needed to identify which factors negatively impact on oesophagectomy survivors’ wellbeing. They suggest that multidisciplinary interventions including dietetics, psychological support, and physiotherapy could be protective of HR-QOL. This support could be tailored to individuals’ unique needs as in the pre-habilitation care pathway. The flexible and person-centred nature of these recommendations seems compatible with the subjectivity of HR-QOL proposed by Calman (1984).

Conversely, Hellstadius et al. (2015) found that almost half of patients reported anxiety, worry and low mood at six months, which for most persisted at five years. They also found participants who were living alone were less likely to report tension, which is contrary to previous research which found cancer patients living alone to report more symptoms of depression than those cohabiting (Parker et al. 2003) and seems counterintuitive. The authors highlight that information about relationship quality for co-habiting participants could aid understanding. They also found patients with lower education reported more problems with anxiety at six months. They recommend further research examining relationships between education and emotional distress to consider whether job and sick leave arrangements, for example, may play a role in this.

This study points to the effects of social context and relationships, raising further questions about how these influence patients' experiences of treatment and why the results of this study contrast to previous findings.

Malmstrom et al. (2015) focused on how HR-QOL fluctuated during the first year following surgery, suggesting that this would inform understanding of when the most support should be timed. They found that HR-QOL was negatively affected throughout the first year following surgery, with the lowest point at two months post-surgery. They suggest that additional support at two months could be helpful in meeting patients' needs. The authors recommend proactive care programmes, discharge preparation meetings and nurse-led telephone calls in the year following surgery. Reflecting on the literature as a whole, the authors emphasise the importance of multidisciplinary support and co-ordination as a buffer to the challenges these patients face.

Overall these quantitative studies gave patients questionnaires post-operatively and found HR-QOL to be reported as significantly lower for people who have had oesophagectomy than for the general population and patients with heterogeneous cancer diagnoses. In line with what we might expect, several studies make links between physical symptoms and reduced HR-QOL. All studies found HR-QOL to be lowest soon after surgery with some reporting HR-QOL improved at 12 months and by five years appeared unaffected. However, one study found that reduced HR-QOL persisted at five-years post-oesophagectomy. Across studies there was little theoretical basis to understanding the meaning of HR-QOL to these patients.

#### *1.5.2.2 Prospective studies*

Six studies reported prospective designs with measures both prior to and following surgery (see Appendix B). Sweed et al. (2002) in a small pilot study found little change in HR-QOL, although in support of previous findings, a significant inverse association was found between symptom intensity and global HR-QOL. While the authors emphasise caution as this is a small study, these

findings are replicated in larger studies. For example, Tatematsu et al. (2013) focused on oesophagectomy and HR-QOL and physical fitness. Comparing pre- and post-surgery HR-QOL scores, they found that physical, role, cognitive and social HR-QOL and physical fitness scores decreased significantly post-surgery.

Chang et al. (2014) found that overall function and global HR-QOL fell below baseline at one month following surgery, improving at six months but not to the pre-surgery levels. This echoes the findings of Viklund et al. (2006a) that at six months oesophagectomy survivors scored lower than comparison groups. Chang and colleagues found greater financial and social function difficulties for younger patients, which they suggest may relate to their working age. Younger age has also been associated with more distress in multiple studies (e.g. Avis et al., 2012; Van't Spijker, Trijsburg & Duivenvoorden, 1997). Also exploring the influence of age, Cavallin et al. (2015) found that change in HR-QOL pre- and post-surgery was comparable for both younger and older age groups. They argue that this is evidence that age itself should not be seen as exclusionary for oesophagectomy decision-making.

Lagergren et al.'s (2007) study (described as 'well designed' by Jacobs et al., 2013) found that postoperative increases in symptoms and deterioration in HR-QOL function usually improved within 6-12 months post-surgery. They concluded that patients who survive beyond three years usually reported a good HR-QOL. The authors hypothesise that at the point of diagnosis patients often struggle emotionally, becoming more confident after surgery. This fits with literature about post-traumatic-growth following cancer (e.g. Jim & Jacobsen, 2008). Interestingly, although emotional functioning improved between before surgery and three years post-surgery, some physical symptoms worsened and global HR-QOL was lower at three years post-surgery than pre-operatively.

Verschuur et al. (2006) explored patients' self-reported needs (questionnaire) and expectations (interview) during the year following surgery. Reflecting other

findings (e.g. Malmstrom et al. 2013a), most patients described concerns of fatigue, food-related problems and gastrointestinal difficulties. Verschuur and colleagues found that patients reported expecting HCPs' help for physical concerns, but that for psychological or social concerns they would look to friends and family. This raises concern about patients who do not have this social support and the relationship between this and sociocultural expectations about the role of HCPs and potential stigma attached to seeking emotional support. Notably, in this study they asked patients to evaluate their own health on a scale of 0-100 (with 100 indicating optimal health). On average, patients chose 70, despite multiple difficult physical symptoms, which seems surprising. However, the authors suggest that perhaps this relates to the poor prognosis for O.C. and patients' willingness to accept postoperative physical difficulties.

These prospective studies also tended to find that HR-QOL increased with time following oesophagectomy. As Lagergren et al. (2007) highlight that the initial score is described as a 'baseline', when a true baseline which could provide valuable information, would be prior to diagnosis (despite being beyond the limits of possibility). As with the papers described in the previous section, all of the quantitative studies seem to lack a theoretical basis for the work, for example they do not draw on health psychology theoretical frameworks to inform the measured variables. Few acknowledged the narrow conceptualisation of HR-QOL provided by quantitative questionnaires.

### Qualitative

A minority of the retrieved articles reported studies using qualitative methods. These will now be discussed (Appendix C contains further details).

Malmstrom et al. (2013a, 2013b) carried out focus groups with patients following surgery and wrote two papers where qualitative content analysis was used to analyse participants' reported experiences. The first paper (2013a) focused on patients' experiences of HR-QOL and emotional responses after surgery. The authors describe that it is well-known that such surgery has a

significant impact on HR-QOL but few studies have considered patients' perspectives on this, as the majority of quantitative research imposes particular constructions of HR-QOL. This study aimed to address this. They found that symptoms continued to have a long-lasting impact on patients after surgery (particularly nutritional problems and diarrhoea) which not only affected patients from a physical perspective but also on a social and emotional level. For example loss of pleasure in eating had a detrimental impact on socialising. The authors argue that the study shows coping with the symptoms which can negatively impact on HR-QOL depends on patients' ability to 'take control' of their new life situation and learn to live with symptoms instead of the symptoms constraining their HR-QOL and controlling them. This study provides useful information from patients' perspectives. However, the idea of patients' ability to take control of their life is an individualised concept. This could be seen as placing responsibility with the patient to 'take control', evoking connotations of effort and competence, without acknowledging the key role of HCPs and social context, for example the impact of social support and financial resources. However, the authors' second paper which I will now describe, addresses many of these issues.

Malmstrom et al. (2013b) focuses on supportive care needs. They found that patients said 'honest information' was necessary in order to develop 'realistic expectations' and that in line with other studies, HCPs underestimate patients' needs for information (e.g. Andreassen et al., 2006; Wittmann et al., 2011; p. 25). Bringing this focus to the relationship between HCPs and patients' responses places patients' needs in context. Access to a specialist nurse is also highlighted as being of central importance to improving co-ordination. This finding has been reported across research and fits with the aims the pre-habilitation pathway described above (Viklund et al., 2006b; Viklund & Lagergren, 2007). The authors recommended indirect support to patients in maintaining contact with friends and involving relatives where possible, as participants suggested that this would be helpful. They advocate that these findings support a great need for tailored programmes of supportive care, focussing on HR-QOL. They conclude that following oesophagectomy patients are faced with an unknown and frightening new life situation which will have



unique meanings for all and therefore patients require a 'guiding light' and tailored supportive care. This emphasises patients' subjective experience in a way that most of the O.C. literature seems to omit.

Hodgson (2006) focused on improving nursing care for patient's post-oesophagectomy, describing this surgery as 'a major life-changing event'. From a small specially developed questionnaire study, with patients and partners, three themes are summarised: '*food*', '*activity*' and '*positivity*'. In this article Hodgson highlights that the psychological articles on this topic usually do not apply their findings to nursing practice, despite nurses' primary role in psychological support within cancer care (Macmillan, 2014b). This article acknowledges the context in which patients experience this treatment and the role of HCPs.

These qualitative studies illuminate the complexity of patients' unique experiences and the idiosyncratic contextual influences on their responses to the same treatment. I agree with Malmstrom et al. (2013b) that understanding patients' experiences is a precursor to improving supportive care.

### 1.5.3 Patients' experiences of oesophagectomy

#### Quantitative

The following papers consider patients' experiences of oesophagectomy (see Appendix D for further details). These papers seem to contain more theoretical foundations than the studies described to this point.

Andreassen et al.'s (2007) questionnaire pilot study asked patients, family members and HCPs about their experiences of information following a diagnosis of O.C. They found that HCPs rated information needs lower than

patients and family members. Patients generally reported being more satisfied with information provided than family members. As this was a quantitative study, the authors recommend qualitative research aiming to understand this further. Wittmann, Beaton and Lewis et al. (2011) replicated this with junior doctors who rated information needs significantly lower than patients. This raises questions about how information is experienced by patients. Further enquiry into factors (such as emotion) which might influence how information is mediated and processed by patients seems important, as well as tailoring information to meet patients' preferences.

Dempster et al. (2011) drawing on Leventhal et al.'s (1980) self-regulatory model, examined patient-carer illness perceptions and psychological distress. Interestingly they did not find any significant differences in anxiety and depression for the participants without a carer. Carers reported significantly higher anxiety scores than survivors and rated the consequences of the disease more severely than survivors rated it. This fits with Andreassen et al.'s (2006) findings of differences in patients and carers' experiences. Dempster and colleagues also found that carers' beliefs and perception of O.C. had a large impact on the patient's psychological wellbeing. They report that this study shows that illness perceptions and coping styles contribute to variance in psychological distress. For example, survivors were likely to report better psychological health when they perceived less severe consequences of the condition, perceived more personal control and believed they understood their condition. Patients who believed their O.C. was caused by stress reported higher psychological distress.

In another study using Leventhal et al.'s self-regulatory model (1980), Dempster et al. (2010) found that the anxiety and depression scores for O.C. survivors were comparable to findings for patients with head and neck cancers, but higher than for those with prostate, bronchial, gastrointestinal and breast cancers. Some parallels can be drawn between O.C. and some head and neck cancers, particularly the impact on eating and the serious losses associated with surgery, which for both cancer groups often impact on social confidence. Their findings

suggest that changes in illness perceptions are associated with changes in psychological well-being over time. They recommend that increasing control beliefs may improve the psychological wellbeing of O.C. survivors.

Wikman et al. (2014) found that 15.3% of the sample had accessed some form of psychiatric care prior to diagnosis and 35.8% of the whole sample, who had previously not accessed psychiatric care, did so following oesophagectomy. This may reflect the highly stressful impact of O.C. The authors infer 'psychiatric morbidity' from accessing psychiatric care data, which they admit is problematic as many patients who are struggling are unlikely to access support. Despite the widely recognised critiques of psychiatric diagnosis as pathologising distress (Rapley, Moncrieff & Dillon, 2011), anxiety, adjustment disorders and depression diagnoses are commonly utilised and measured in oncology (Brennan, 2004).

### Qualitative

The following diverse qualitative studies explore patients' relationships with self and others, the importance of eating, impact on carers and information-giving. For further details see Appendix E.

Clarke, McCorry & Dempster (2011) used semi-structured interviews and Interpretive Phenomenological Analysis, arguing that understanding the meaning of patients' experiences is an important precursor for meeting their needs. They found that patients gave highly detailed, contextualised accounts of their experiences which always included a sense of 'change' from before O.C. This was described as having an impact on their 'self-concept'. For some participants this was linked with loss but others described stories of personal growth and positive consequences from coping with challenges.

The study found that readjusting to a changed relationship with food was a key challenge, which included a sense of loss for many, as well as changed social roles. Patients also described navigating tensions between former and new identities (and at times negotiating this with family members). Particular to this disease, the authors suggest that eating was the most obvious reminder of the cancer. Participants reported similar experiences in relation to identity as those described by cancer patients' more broadly, for example a wish to be viewed as their nuanced and unique selves rather than as defined by cancer.

Clarke, McCorry & Dempster (2011) highlight that during the analysis of interviews, the concept of identity became particularly salient in participants' assigning of meaning to their experiences. Participants described feeling depersonalised, particularly during early stages of the illness. Personalised relationships with HCPs are highlighted as a crucial antidote to this. Another theme was the value of hearing from peers early in the process, particularly those who had survived O.C. for several years. Participants described thinking that peers could provide reassurance, hope and normalising in ways that could enable talking in a more personal way about their fears and experiences. The authors link this with a need to develop a shared identity. They also emphasise the importance of preparation for these changes, through pre-operative information and the power of HCPs to reduce depersonalisation which in turn nurtures patients' sense of self and provides opportunities for positively contributing to patients' experience of the illness process. The study took a contextualising approach highlighting the individual impact of this disease. It seems to capture the nuances of patients' experiences in a way that a quantitative measure alone is unable to.

Wainwright et al. (2007) focus on 'remapping the body' which they describe as socially adapting to physical changes post-oesophagectomy. They suggest that it is impossible to separate physiological and psychological consequences of surgery. Thematic analysis of semi-structured interviews led to three key themes: the meaning of weight loss and physical change, remapping the body, and eating as a social activity: stigma and embarrassment. This study

demonstrates the potentially far-reaching effects of eating difficulties for people after oesophagectomy. Eating is an activity that most people find pleasurable, sociable and satisfying. However, post-oesophagectomy it often becomes a chore which is replaced by unpleasant symptoms like diarrhoea, nausea and embarrassment, leading patients to avoid eating with others. The authors highlight that although oesophagectomy is a physical procedure, it has great consequences for patients' sense of self and social identity. For this reason they emphasise the importance of integrated physical and psychosocial care and the impossibility of separating nutritional support from psychosocial support.

Jaromahum and Fowler (2010) also looked at experiences of eating after oesophagectomy, using a phenomenological approach. During interviews between the first and third meals post-operatively, three major themes were identified: physical, psychosocial, and psychological, with key subthemes of gastrointestinal problems, fear of going home, and positive feelings toward eating. The authors describe nurses and patients as sharing a role in achieving optimal eating post-oesophagectomy. They also emphasise the importance of holistic care through understanding the meaning of eating for patients, for example through acknowledging the significance for many of eating for the first time following surgery. They suggest turning this event into a 'celebration of life' (p. 100).

McCorry et al. (2009) focused on patients' and carers' adjustment post-oesophagectomy using focus groups and thematic analysis. Participants ranged from seven months to 17 years since oesophagectomy. The range in time since the surgery is likely to have brought high variability in stage of recovery. Patients talked about hearing the diagnosis and immediately thinking about death and feeling surprised that there were treatment options. Both carers and patients emphasised the benefits of peer support. In line with Clarke, McCorry and Dempster (2011) participants also talked about challenges in negotiating changes in role (for example being unable to work or care). This study is helpful in emphasising the value of patients and carers' perspectives. The findings of this study fit with those of Wainwright et al. (2007) who described the process of

'remapping the body' and learning to eat again after surgery for O.C., in a similar way to learning to walk again after lower leg amputation. McCorry et al. state that the study provides evidence to show that ongoing person-centred, holistic support is necessary for these patients as they adjust to physical, social and emotional changes after surgery.

Andreassen et al. (2006) capture themes of patients' experiences of investigations, diagnosis and treatment using qualitative content analysis of interviews. Most participants described that when hearing the diagnosis, they did not know anything about O.C. The authors therefore emphasise the role of information-giving, as patients are reliant on HCPs to provide information. The findings of this study suggest that patients perceive their partners to be more psychologically affected than they are themselves, finding that caregivers suffered higher levels of recurrence fears.

Henselmans et al. (2011) adopted an open focus in their study of patients' views on communication and patient participation barriers and facilitators through qualitative interviews analysed by content analysis. In line with Verschuur et al's. (2006) findings, they found that patients did not tend to expect HCPs to meet psychosocial needs. They found that patients' needs and requests for information were often related to symptoms like dysphagia, inability to do specific activities, the likely course of symptoms and how to respond to them, as well as the cause of symptoms or rationale for tests and medication. The majority of patients emphasised the importance of the outcome of surgery and keenness to know about the results and the risks of recurrence. They identified 16 barriers that obstruct patients' influence on medical consultations. The authors described being able to categorise these into 'values' and 'hindering beliefs' or 'lack of skills', however noted that emotions are not reported by patients as hindering communication in consultations. They also found some participants highlighted HCP characteristics as barriers or facilitators to communication (see Appendix E). This article particularly emphasised wide variation in patients' responses and the importance of HCPs tailoring support to patients' needs, acknowledging individual meanings,

contexts and differences, in a way that is missed in much of the quantitative research in this area.

Mills and Sullivan (2000) qualitatively interviewed patients retrospectively about their experiences of treatment with curative intent for O.C. Key findings using thematic analysis were that while participants reported overall feeling well-informed, they valued staff providing honest information and saying explicitly if they did not know the answer to questions. They also highlighted perceiving staff who gave their time to sit down and speak with them as showing interest and worry about them as a person. Participants reported that in contrast, staff appearing too busy or inaccessible negatively impacted on their experience. Patients were keen to convey the importance of a specialist nurse in clarifying, reassuring and informing them about what to expect. This provides further evidence for the value of specialist nurses and tailored support.

#### 1.5.4 Critical evaluation

These papers demonstrate that although this is a growing area of research, many studies have so far adopted a narrow and often reductionist conceptualisation of HR-QOL, rendering other aspects of patients' experiences invisible. Although identifying proportions of patients with high scores on HR-QOL screening tools may be important, it is crucial to acknowledge that these tools screen patients for factors defined by professionals as relevant to HR-QOL. This is counter to the original assumptions of HR-QOL as subjective and self-defined (Calman, 1984; Rapley, 2003). While studies have spanned a diverse range of topics, few have explored the experience from patients' perspectives. Several studies have highlighted differences between HCPs' assessment and patients' reported experience (e.g. Malmstrom et al., 2013b; Andreassen et al., 2006; Wittmann et al., 2011).

As highlighted by Clarke, McCorry & Dempster (2011), in recent years, patients' descriptions of their experiences have taken a more valued position in research along with an increasing acknowledgement of the importance of understanding

their perspective. This fits with NHS aims of identifying and meeting patients' needs through the development of services, as well as by understanding the relationship between professional, cultural and societal responses to cancer (Crouch & McKenzie, 2000). It also corresponds with a general rise in appreciation for qualitative health research findings (Sandelowski, 2004). However, when compared with breast cancer, where there is a high level of public awareness and discussion, O.C. is not widely known or understood by the public (Kaiser, 2008). Clarke, McCorry and Dempster (2011) suggested that this makes such patients 'a somewhat marginalized group' (p.100). Research with people with potentially curable O.C. is especially challenging because of the comparatively small numbers, rapid progression and high morbidity.

Studies that have focused on patients' experiences and individual conceptualisations of the impact of treatment for O.C. and how they navigate this, have brought rich findings. For example, the impact on changing roles, identity and distressing symptoms. This seems to bring forth nuanced descriptions of experience that are made invisible if we do not acknowledge the limitations of quantitative measures such as HR-QOL questionnaires. Such questionnaires can clearly have great value when used alongside methods of understanding patients' individual concerns and experiences. However, to enrich understanding and inform clinical practice, qualitative research to explore the meaning of patients' experiences is required.

## **1.6 Rationale**

This chapter has demonstrated that treatment for potentially curable O.C. has unusual characteristics, most notably the highly risky surgery, long pre-operative preparation and great uncertainty and potential losses. The current evidence tends to focus on patients post-operatively, primarily using symptom-focused questionnaires with an absence of attention paid to how patients describe their experiences and adjustment whilst going through treatment and the meaning of this. However, it seems important to understand patients'



experiences of the period of intensive preparation in order to inform optimal support for patients in this unique context. Although this pre-habilitation treatment pathway offering intensive support is currently novel and unique, it is likely to become more widely used soon. The relative homogeneity provided by studying patients on the same treatment pathway at one cancer centre will offer more consistency than much of the previous research as highlighted by Wikman, Smedfors and Lagergren's (2013).

My aim is that this study will make a novel contribution to the literature through hearing patients' descriptions of their experiences during interviews. With the hope of increasing understanding of patients' experience, I also plan to interview staff who can describe their knowledge of patients' experiences. Staff will uniquely be able to base their descriptions on their experiences with multiple and varied patients, including those who would be unlikely to participate in research. Staff are a crucial part of the system, offering a valuable observer perspective on patients' experiences of the pre-operative treatment process. Given that the approach to gathering data influences the data itself, I hope that this will offer a method that goes beyond an individualising and universalising approach. I also hope that this will provide opportunities to understand parallels and differences between the contrasting perspectives.

#### 1.6.1 Aims

This study aims to inform understanding of patients' experiences of this treatment from the perspectives of patients themselves and multidisciplinary staff. Findings from this study will aim to influence research-driven approaches for supporting patients. The proposed study will explore this by:

- Qualitatively interviewing patients with O.C. who are undergoing pre-operative treatment in order to explore their experiences of treatment and what has influenced this.
- Qualitatively interviewing multidisciplinary staff working with patients on the same treatment pathway about their observations of a range of

patients' experiences of pre-operative treatment and what they think influences this.

### 1.6.2 Research questions

A qualitative design will address the following research questions through interviews with patients and multidisciplinary staff:

- What are patients' experiences of pre-operative treatment for oesophageal cancer?
- What do patients describe as helpful and unhelpful during the pre-operative treatment process?

## **2. METHODS**

### **2.1 Overview**

In this chapter, I will first articulate the critical realist stance of the study and the relationship between this and the methodology and research questions. Following this, I will describe the procedures of carrying out this research, including ethical approval, design and data collection processes. I will then outline the approach to analysis.

### **2.2 Epistemology**

Epistemology can be defined as the philosophy of knowledge (Barker, Pistrang & Elliot, 2003). I take the position that the epistemological assumptions underpinning any research are important to make explicit in order to situate the foundations upon which knowledge is sought (Willig, 2008).

Research considered to be scientific, which makes essentialist claims, has commonly been taken to hold the dominant epistemological stance and top hierarchical position for evidence across healthcare. Examples of this include randomised controlled trials and experimental designs which claim to yield 'scientific truths'. Such approaches are based on the realist assumption that it is possible, through 'objective' science, to prove reality (Clarke, MacIntyre & Cruickshank, 2007). Healthcare research which meets criteria for evidence-based practice has tended to fit with this paradigm, in line with the idea that treatments and approaches must be proven to be safe and effective in order to be concordant with professional and ethical duties. Despite the infallible and objective appearance of 'scientific evidence', Marks (2009) has highlighted that all evidence is subsumed by value-laden, context-specific and subjective assumptions. Psychological screening measures can be used to demonstrate this as they are based on assumptions about both what is important to measure and the meanings of concepts. This often implies an assumption of universality,

yet many psychological phenomena vary between cultures and languages (Cooper & Denner, 1998). Social constructionism argues that the search for facts is flawed, because there are multiple realities and research findings will always be mediated by context (Burr, 1985).

Critical realism was developed in response to the perceived shortcomings of both realism and social constructionism, aiming to take elements of both approaches. Critical realism therefore views reality to exist, but as highlighted by Bhaskar (1989), our perception of human sciences is steeped in social structures and values, and research findings may be influenced by unobservable events. As articulated by Pilgrim (2013; p.158) critical realism works on the premise that 'the map is not the territory. The territory does exist; it is just very challenging to investigate'.

Marks (2009) suggested that in healthcare there is a large and growing discrepancy between research and what is important to patients. This study's design intends to address questions about patients' experiences that are closely relevant to patients, healthcare professionals, organisations and commissioners. I am approaching this with a critical realist stance. For example, accepting that while realities such as cancer exist, the frameworks through which we understand these realities are informed by subjective assumptions and biases, mediated through language, which in turn shapes experience. This stance rejects the positivist suggestion that objective facts can be searched for and found or proven, without taking these assumptions and biases into account (Mackay & Petocz, 2011). For example, the meaning of cancer is idiosyncratic and culturally specific and experiences of cancer are influenced by wider discourses, which also determine which constructs are seen as worthy of measurement within research and clinical practice.

### **2.3 Design**

In order to address the research questions, I chose a qualitative design to explore patients' experiences through the openness of semi-structured

interviews with both staff and patients. This multiperspective approach aimed to maximise the scope of the research to contribute to understanding. The qualitative design aimed to adopt an exploratory stance as this specific area has received little research (Kimble, 1984). The approach to analysis of thematic analysis was chosen because of its flexibility and theoretical openness. As it is not aligned with a particular paradigm, it is compatible with the critical realist position and our hope to provide a contextualised account (Braun & Clarke, 2006).

## **2.4 Ethics**

Ethical approval for components of the study involving patients was granted by a Research Ethics Committee (Appendix F) and the University of East London's (UEL) Ethics Committee (Appendix G). For the staff component of the study, approval was granted by the UEL Ethics Committee (Appendix G). Approval was also sought and granted for all aspects of the study from the local Research and Development Department at the recruiting Trust.

All participants gave written consent (Appendices I & J) and verbal and written information was provided to all potential participants aiming to ensure informed consent. I emphasised all participants' right to decline, or if giving consent, to withdraw at any time without providing a reason and with no disadvantage or implications for them, their medical care (for patients) or their employment (for staff). Confidentiality and exceptions to this were also explained.

I considered the sensitivity of this research topic at all stages of the research. However, I agreed with my supervisor that discussing cancer with patients and staff during this treatment was unlikely to increase distress, particularly as this was a topic they were frequently talking about as part of the intensive treatment pathway. However, as highlighted by Brinkmann and Kvale (2008), the meaning of talking with a researcher is likely to be individual to each person and ethical

research goes beyond simply following rules. My intention was that participants would not only be protected from harm during the process but also that I maximised the potential for them benefiting from the experience.

I took a cautious approach during interviews, continually monitoring distress levels and offering to pause or stop the interview when these seemed to be high. I hoped that the opportunity to talk about experiences would offer participants a potentially helpful expressive space. Many participants told me that they had found the interview an “enjoyable” experience which in some cases helped them to make sense of their experiences. Staff also told me that the interview was helpful to their self-esteem, as through describing their experiences to me they noticed how much they had learnt about supporting patients.

A debrief was offered after the interview with the possibility for participants to speak about any issues raised. All participants were given my contact details and I emphasised that they could contact me afterwards should they wish to discuss the research. Patient participants were reminded of the Trust’s psycho-oncology service and told that their Clinical Nurse Specialist (CNS) could offer advice and support to access this if necessary. With staff participants the possibility for support from supervisors and line managers was discussed.

To ensure anonymity all confidential information was stored on password protected files (using participant numbers and pseudonyms) and in accordance with NHS policy. I was the only person who had access to identifiable transcripts and recordings, which will be destroyed 12 months after the study’s completion.

## 2.5 Recruitment and research procedure

### 2.5.1 Patient inclusion criteria and procedure

Patients on the treatment pathway (described in chapter one), where the multidisciplinary HCP deemed it clinically appropriate and where the person was towards the end of chemotherapy treatment, spoke fluent English and had capacity to consent to the interview. Staff were asked to invite patients meeting this criterion to take part by giving them an information sheet (Appendix I). Staff then asked potential participants for their permission to be contacted. Where patients said yes and met criteria for the study, the team member passed me their details and I contacted them by telephone. I introduced myself and explained the study, answering any questions they had. Where they agreed to proceed, we arranged a time to meet at a private location of their choice.

The full consent procedure (outlined in section 2.4) was then carried out before audiorecording and the interview commenced. During the recruiting period (October 2015-February 2016), the aim was to recruit six to eight patient participants. Ultimately seven patient participants gave their consent and were interviewed.

Table 1 summarises key demographic information concerning the seven patient participants<sup>5</sup>. The sample approximately reflected the gender, age and ethnicity ratio of O.C. patients in the UK (CRUK, 2016a). Four of the participants chose to be interviewed on the hospital site, with three selecting to be interviewed at home. All patient participants were at least one month into the pre-operative treatment pathway. However, due to individualised treatments it was not possible to interview patients at exactly the same point. While the standard chemotherapy treatment is nine weeks Audrey's treatment had been paused due her being too unwell to continue. Conversely Joe and Matthew reported few side effects or physical difficulties. Carole, Abdul, Peter and David all described

---

<sup>5</sup> All names are pseudonyms.

finding chemotherapy side effects challenging but reported that having completed several cycles, they had learnt what to expect.

*Table 1: patient participants: demographic information*

	Age	Gender	Ethnicity	Place of interview
Joe	58	Male	White British	Hospital
Audrey	61	Female	Black Caribbean	Home
David	60	Male	White British	Hospital
Matthew	69	Male	White Irish	Hospital
Abdul	65	Male	Indian	Home
Peter	71	Male	White British	Home
Carole	52	Female	White British	Hospital

### 2.5.2 Staff inclusion criteria and procedure

For the staff part of the study, members of the multidisciplinary team (MDT) working on the care pathway described in chapter one, have been consulted in planning the research. I contacted each member of the team to explain the process and to invite them to take part. Where they said they were willing to be interviewed, I sought their permission to meet and audio record the interview. On the agreed date, I followed the consent procedure described in section 2.4. and audio recording began.

I aimed to recruit six to eight staff participants and ultimately eight members of the staff team consented and participated. The following staff participants were interviewed:

- Sean
- Josh
- Emma
- Lucy
- Jay
- Olivia



- Sarah
- Cathy

They were multidisciplinary team members whose specialties included: surgery, exercise therapy, internal medicine, dietetics, specialist nursing and project management. To retain confidentiality and anonymity, the roles of each participant will not be stated, as although pseudonyms are used throughout, revealing the speaker's role would make them identifiable to those familiar with this small specialism.

## **2.6 Interviews and transcription**

Semi-structured interviews were guided by the interview schedules (Appendix K & L), from which questions were used flexibly. Questions were intended to be neutral, open and curious, encouraging participants to speak freely. The questions were guided by the key area of patients' experiences of treatment and any factors that influenced, helped or hindered this. However, I followed topics patients raised, aiming to facilitate the conversation rather than impose particular types of descriptions upon them.

I semantically transcribed recordings verbatim which Willig (2008) describes as a 'translation of spoken word'. I used conventions described by Parker (2005; Appendix M), removing all identifiable information. I then repeatedly checked anonymity and accuracy of transcription through listening to the recording multiple times (Gibbs, 2007). One perspective is that this form of transcription limits information on the interactional nature of interviews (Parker, 2005). However, I felt it was sufficient for the current analysis.

## **2.7 Analysis**

The qualitative data were analysed using inductive thematic analysis in order to identify patterns and themes in the data. As there were two groups of data, with staff and patients speaking from different perspectives, I decided to analyse each group separately. Guided by the stages recommended by Braun & Clarke (2006), I undertook the following steps of analysis for each group:

1. I considered transcription to be the beginning of the analytic process (Braun & Clarke, 2013).
2. I read each transcript several times to familiarise myself with the data, making notes on anything that struck me from the text. I selected and highlighted areas of potential interest (Appendix N). I also re-read the field notes I made following each interview. During this process I wrote down thoughts and observations, which later usefully informed my thoughts about the analysis.
3. I then took one interview at a time and coded the text, initially using pens and paper to connect with the participants' narrative. I then used a table to record each code and corresponding quotes (Appendix Q). I aimed to code extensively in line with Braun and Clarke's (2013) recommendations. Many extracts therefore had multiple codes. I aimed to code from the text, being careful to acknowledge and challenge my own assumptions. Repeated reading helped to make these explicit. I kept in mind the research questions but also stayed open to anything participants raised and I avoided imposing theoretical constructs on the data at this stage. This process produced 76 codes across the seven patient interviews and 156 across eight staff interviews (Appendices O & P).
4. After all interviews had been coded I began connecting codes together. There was some overlap between codes and I was able to reduce the number of codes whilst retaining the semantic level of analysis.
5. I then used mind maps to begin to map potential themes by identifying recurring commonalities within the codes, considering possible overarching concepts (Appendix R). This was also informed by the notes I had made during the familiarisation and coding processes.
6. Once I had candidate themes, I re-read all transcripts and considered the coherence of the themes and how they fitted with the whole data set. This led to some revisions of the initial map (Appendix R).
7. I then worked to define and write summaries of each theme and subtheme and continued to try different names that seemed to best capture their content.
8. Once I began writing to produce the report, I continued to take an analytical position, aiming to finesse and tweak the analysis.

This was an iterative process which was repeated for the staff analysis once the patient analysis was complete.

### **3. ANALYSIS**

#### **3.1 Overview**

This chapter presents the findings of the analysis, firstly for the patient group and then for the staff group.

#### **3.2 Patient Analysis**

##### *3.2.1 Setting the context*

The interview schedule invited participants to describe their experiences with O.C. and they all told their story from the point of experiencing first signs and presenting to a GP. Many patients talked about long and difficult processes leading up to diagnosis. Some participants felt that their local hospital moved too slowly, whilst others described feeling regret that they presented after a delay. They described a radical change in pace from pre-diagnostic tests at local hospital to the speed of the specialist cancer centre. One participant described this as “going from slow motion to warp drive” (David).

#### **3.3 Patient Thematic Analysis**

After completing the stages of analysis described in chapter two, I developed three main themes and six subthemes, as depicted in table 2. The subthemes are named using participant quotes.

Table 2: patient analysis themes

THEME	SUB THEMES
<b>Fear and the unknown</b>	“Life changes with surgery”
	“Up and down”
<b>Treatment brings hope and uncertainty</b>	“Surgery means survival”
	“Cancer takes over”
<b>Committing to getting through treatment</b>	“I'm doing what I can”
	“Not letting cancer take over”

### **THEME ONE: FEAR AND THE UNKNOWN**

The first overarching theme concerned participants’ descriptions of the unfamiliarity of O.C. and their fears in relation to the anticipated surgery. They all expressed that worries about surgery felt greater than fears about any other aspect of treatment. The situation in which they found themselves was characterised by the new and frightening nature of a life-threatening diagnosis, while participating in the pre-operative preparation programme. Participants described this experience in diverse ways.

#### ***Subtheme 1: “Life changes with surgery”***

The goal of pre-operative treatment is optimising the patient physically and preparing for surgery. Patients without exception referred to the surgery as both “life-changing” and “frightening”. In the following quote Peter describes an awareness of surgery throughout the pre-operative process:

Peter: You know your life changes at that point. At the moment I feel no different than I've ever felt. I've been aware of it all the way through () that you know once you have this operation () your life changes...my actual thing has been 'let's string this out as long as possible'. You know the operation is the only thing I've got any fear of... it's not just the operation, it's 10 days in ITU. You know your life changes at that point. At the moment I feel no different than I've ever felt.

Interviewer: How has it been to have that awareness all the way through this?

Peter: Sanguine is the answer. It's better than the other option. That's what I say if my wife says 'how do you feel'; the other option is not being here. You know being dead, so you know being not exactly whatever I was before, mentally I'll be the same I'm sure, I might lose some weight, it might be good for me you never know.

There was a recurrent sense in all interviews that the surgery was a defining point in participants' lives where their life could be saved, but at great risk and with irreversible consequences. However, after referring to his fear of surgery, Peter seemed to revert rapidly to a rational rather than emotional focus. For example, he refers to the losses he expects to encounter but then describes his feelings as "sanguine". He reflects on the positives and divides the options into a dichotomy between surgery and death. Peter refers to some anticipated physical effects in the aftermath of surgery, but turns the negative nutritional effects of "losing weight" into a potentially good thing. His assertion that he will be the same "mentally" also builds a sense of impervious strength which seems counter to the fear he describes about surgery.

At times, participants touched on worries about the imagined consequences of surgery, as demonstrated by Matthew and Carole:

Matthew: The only thing I don't like about it is the after effects of this operation, loss of weight, no strength, not being able to carry on...That's if I'm alive and I come through it. If I don't come through it I don't give a shit about it. It's a long drawn out project, not something you're going to achieve overnight, anybody who thinks it will is kidding themselves.

Carole: I shed a tear [when I found out about the operation] and said to the CNS I am scared about that, what kind of happens, how do you eat. To me it's still a horrible idea () and she said apparently you can have a relatively normal life after the surgery, she has explained to me how they'll link one part of the body to another and that you'll have to have smaller meals you know and initially there may be problems but eventually it should be relatively OK. So that was a bit () to be told () getting that information and they were clear from day one () they were clear about what needed to happen.

Whilst dread of the surgery or its effects was unanimous, there were differences in how participants conceptualised time with some speaking with urgency and others with avoidance. The above quote from Peter (p. 54) depicts this, as he described wanting the surgery to be delayed for as long as possible. The following quotes from David, Matthew and Joe demonstrate the variation in attitudes to the timing of the surgery:

David: I suppose it is a long wait but it has to be because of the timeframe for the chemotherapy to be out of your system. So yes it has been quite a long time...I said today I wish it could be tomorrow. Even at the time I felt like I'd rather have it today () to get it over with.

Joe: ...then you see, I don't want to have the operation () so you know if they said we're not going to do it for another four years. That would be fine I'd go 'ok good', because () you know my life is going to be much worse for a period of time because of having the operation. Because I've got no symptoms except for catching the food...apart from saving my life

the operation's just going to be bad news for me. Apart from saving my life. So I'm not stupid enough to think I shouldn't do it, but I don't want it to happen because it's going to be a whole pile of unpleasant for quite a lot of time.

Matthew: It's worse waiting for it...I want to get it over and done with and see what kind of a skeleton is going to be left.

From David there's a sense of wanting to get the cancer removed as soon as possible, while rationally outlining that there are reasons for the timescale to be as it is. From Joe there is a feeling of wanting to delay the surgery and the associated losses for as long as possible, though stating that it would be "stupid" to not have the surgery. Matthew's description is shocking, as on the one hand he describes in pragmatic terms wanting to get the surgery "over and done with..." and yet, he uses emotive language to describe an image of his future self as a "skeleton". To me, this evokes imagery of the walking dead, someone only half alive, and even concentration camps. This could be seen as a macho way of talking which masks feelings of distress and fear, however, the use of language implies that strong feelings are likely to be present. Perhaps gendered influences render such feelings hidden. This could also be a hypothesis in relation to the strength Peter conveys (p. 54). These quotes demonstrate a strong sense from patients that the operation was hanging over them and while they feared it and dreaded the potential consequences, they believed it would keep them alive. This leads to a tension between rational and emotional responses.

### ***Subtheme 2: "Up and down"***

This subtheme reflects patients' repeated descriptions of experiencing the period of pre-operative treatment as highly unpredictable and unfamiliar. There seemed to be three distinct components of this: lack of knowledge about O.C., unfamiliarity with treatment and the alien experience of unknown procedures in a disorienting new system. These all exacerbated feelings of disorientation and unfamiliarity for patients going through this treatment.



Firstly, many participants talked about never having heard of O.C. previously:

Interviewer: Did they explain to you what this type of cancer meant?

Audrey: I'd never heard of oesophageal cancer before, I heard about breast cancer and all sorts of cancer () but oesophagus, I never knew you could have it where your food's going down.

Abdul: ...I went on Google to find out why am I suffering from these symptoms, if that was like a stomach cancer, I didn't know about the food pipe cancer tumour () I just was thinking I had something like a stomach cancer.

These examples from Audrey and Abdul reflect a strong sense from many participants that O.C. was far less familiar to them than other cancers, which heightened a sense of unknown. The following extract from David articulates this unknown quality of both O.C. and treatment. He also suggests a connection between knowledge and feeling prepared for treatment.

Interviewer: What were your ideas about chemotherapy before you started?

David: Of course at that time I had almost no knowledge about the whole cancer subject or chemotherapy. In my mind () and I think in most people's minds actually chemotherapy, you have generic knowledge and because you don't know. I had no idea that chemotherapy's so different for everyone. I had no idea... I think with the first round I didn't have any understanding. It was tough... I was absolutely not prepared for the effect it would have on me and how I felt afterwards. People can tell you you'll feel wobbly or you'll feel unwell () but I was just not ready. That's

nobody's fault as such, I just had no idea of the impact that the chemotherapy would have.

This extract from David highlights differences between expectations and lived experience which were described by many participants. I think that this reflects the generic understanding many people have of cancer, without realising the great differences between specific cancers. In many ways this adds to the unpredictable nature of this experience, where patients are required to adapt to great uncertainty as well as their experience differing from expectations. This extract suggests that not knowing what to expect added to how "tough" the process was for David initially.

Throughout this unfamiliar pre-operative treatment process, patient participants talked about the "up and down" of hope and disappointment as treatment decisions were made by the medical team. Joe described the experience of uncertainty, firstly about whether he had cancer and then whether he would need to have chemotherapy treatment.

Joe: And the worst bit of the whole process has been the up and down of information of 'yes you have', 'no you haven't', 'yes you have', 'no you haven't'. And I understand that nobody's in any position to do anything...once I know what the deal is it's easy enough to deal with it, it's the process of having hopes raised and then lowered that is a bit harder to deal with. Certainly each time that happened, I had a crash of mood about it and had to pull myself back out.

The disappointment and hope Joe articulates fits with numerous other examples from patient participants of trying to adapt to great uncertainty with potentially grave consequences which was highly stressful. I was struck by Joe's description that this was the "worst bit of the whole process". Knowing that he had encountered physical complications during chemotherapy that led him to be hospitalised repeatedly (p. 62), contextualises his report that the psychological

effect of hopes raised, then dashed, was most difficult. This fits with David's (p. 57) description that not knowing made the experience of treatment more difficult.

Many participants described arriving for treatment at the beginning and feeling confused and unsure of what was expected of them. They described feelings of disorientation in this unknown healthcare system, compounded by them feeling that it was assumed they knew what to do. Peter described that along with the novelty and unfamiliarity of every aspect of this treatment, his perception that it was assumed he would know what to do was particularly difficult:

Peter: It's this funny thing, it's not unkindness or anything it's just people assuming that you've been there before and you know it and you haven't.

At this time of high emotion and uncertainty, patient participants described going through a process of "catching up" and getting to be familiar with the systems during pre-operative treatment. The following extracts from Audrey and Abdul depict these processes in relation to where to go and how to get there, but also in expectations of how they would feel with chemotherapy.

Interviewer: What was having chemotherapy like for you?

Abdul: That was very new to me [chemotherapy] and it was very hard. First 10 days, all the time, whenever I get up or whatever I'm going to do I was dizzy all of the time, and after 10 days I'm getting used to it and getting normal but my taste buds are tired and I can't feel hungry, for 10 days () very hard... It's OK I'm getting used to it you know. It was hard but I had to.

Audrey: To be honest with you the first time you go to the hospital you don't know A from B, and the more you go there the more you get used

to it. You don't know what department this is, what bus to take, what train to take, but the more you go there the more you get used to it.

This subtheme illustrates that initially patients experienced all aspects of this process as new and unfamiliar. While experiencing threat we particularly crave certainty and safety, and yet patients perceived an expectation that they must participate in their treatment and become familiar with this foreign world in order to adhere to the treatment programme. Many participants began from a point of knowing little about O.C. which compounded feelings of fear and uncertainty.

## **THEME TWO: TREATMENT BRINGS HOPE AND UNCERTAINTY**

I identified this theme as all participants talked about a tension between surgery offering hope and the only chance of cure, whilst also bringing life-changing and uncertain consequences. I noticed that no participant directly spoke about surgery as a difficult decision; rather, they showed a belief that surgery would save their life. They were all very clear and certain about it being the obvious decision for them to have surgery, despite occasional acknowledgement of the risks that they may not survive (Matthew, p. 55) and that if they did; there would likely be negative consequences (Joe, p.p 55-56).

### ***Sub-theme 1: "Surgery means survival"***

This subtheme relates to participants' portrayal of treatment as an opportunity for survival. Participants spoke about the choice to have surgery as a 'no-brainer' as it offered the chance of cure. David demonstrated that life-saving treatment was the priority above all else.

David: ...you get this feeling of muted elation you know [when offered the surgery] and ok it's good news in the way that they're now saying that we're going to operate to remove it but they're tempering it with () and of course the medical profession are ultra-conservative, they've got to downplay it and I get that...Not being treated for it was not going to be an

option, instantly () that's not going to happen, so what's the best form of treatment with the best outcomes... They said, 'well what do you want? Do you want to go away and think about it?' and 'No? Good, OK you can start the chemotherapy tomorrow'. For me there was no decision to be made, go away and die in six months or start the chemotherapy.

David's comment that "the medical profession are ultra-conservative" implies that he thinks they may be downplaying the odds of success, which could be a way to reduce uncertainty and protect his hopeful outlook that treatment will indeed lead to cure. Patients also described thinking that the option of surgery indicated professionals' belief that a good outcome was likely, reflected in the quote below from Carole:

Carole: I kind of think erm () they wouldn't be offering me the operation was the outcome not going to be worthwhile. So you know because obviously there is a cost, so I kind of think you wouldn't be put forward for surgery if people didn't genuinely believe there could be a good outcome so you know you can't think any other way () I've got an opportunity even though it's a scary one.

Both of these examples demonstrate treatment representing hope of cure. However, I interpret Carole's statement that "you can't think any other way" to imply that she is purposefully controlling cognitions, as though to ensure her thinking remains positive and hopeful rather than veering towards the fear she feels.

### ***Sub-theme 2: "Cancer takes over"***

This sub-theme captures participants' recurrent descriptions of the impact of O.C. on relationships, normal routines and basic activities like eating. The following extract depicts the interruptions pre-operative treatment causes to

daily life. As demonstrated by Joe, there seemed to be a contrast between predictable, scheduled treatments and the unexpected and unpredictable events such as being hospitalised.

Joe: Once you get the structure of it () going to and from the hospital every day for half-an-hour's treatment 23 days...and then at the weekends I was in bloody hospital every time. You have to go to A&E if your temperature goes up above 47.5 for 2 hours or 48 once because you get this thing called neutropenic. It happened the first weekend...so I went into A&E and they put me on a drip and tested me...Then the next weekend I collapsed and just slept for the whole weekend and then the next weekend I was back in because my temperature was high again... The weekend after my treatment finished I was admitted again and they kept me in for four days... So I was going there for A&E every weekend and then going here to the cancer hospital every day.

The impact on relationships was also great and Joe went on to describe that his relationship with his wife had "broken down" a few days before the interview and he described this as precipitated by her worries about the possibility of his death and also her response to him not seeking her support:

Joe: So () so () I think she's frightened about what might happen with me () whether I'm going to die or not. I have a 13-year-old daughter. Scared I'll die on the table. Scared I'll die afterwards. Scared I'll die. Erm () But also, I think the concept that I got cancer and didn't collapse into her arms seeking her support all of the time, I just got on and dealt with it and part of her constant belief is that I don't need her (). Is it partially true on a day to day, I don't really need support from people?

Joe's description could also relate to gender, as a reluctance to discuss cancer would fit with the traditional ideas of masculinity which will be discussed in relation to hegemonic masculinity in chapter four. This paradigm can also be applied to participants' descriptions of worrying about the impact of O.C. on their loved ones as demonstrated by the following extracts:

Peter: [My wife] she's really worried about me you know. She's my guardian angel she makes me do my exercises, she comes out with me to do my exercises and it's good, but the strain shows. And I worry about/ it's good I've got something better to worry about than a tumour in my oesophagus. We're very close you know. She's been brilliant.

Carole: It is kind of horrible because you know sometimes you also worry about other people and how the impact of you being ill is going to affect them psychologically <tearful> sorry. Oh yeah. You know I've got an elderly mum and so it was quite hard for her to digest that news, I'm still not 100% sure that she fully understands or wants to believe, I think she would still like to think that it's not the diagnosis that I've got, but it is.

These extracts demonstrate an interesting contrast, with Peter's wife seeming to take responsibility for his health while Carole speaks as a carer concerned about her mother's wellbeing, trying to help her to understand. While both extracts depict participants' concern for their relatives, Carole positions herself as a carer and Peter as cared-*for* by his wife. This fits with traditional gender roles.

The impact of treatment was also discussed in relation to the physical effects of chemotherapy, which were varied. Some participants described being less affected than they had anticipated and others described fatigue that made life difficult. Only one participant had a feeding tube, due to the quick progression of dysphagic symptoms. She described the immense loss she felt of being unable to eat and the ways this led her to feel excluded:

Audrey: It feels a big loss to me to be honest to not be able to eat, to have this tube inside of me instead. Food is important to everybody, every animal, even butterflies, bees, food is a very essential thing. If we don't have a mouth to eat we starve to death and food is very essential. I mean I am jealous, if I see you eating right now I would be looking in your food and watching you putting it in your mouth, it is very hard I'm telling you. Even the advertisement on the television I have to turn over. And walking down the street seeing shops and people eating and

sometimes I look in their plates and sometimes I feel so bad I have to turn my head, like I'm starving. It is bad it's a bad feeling.

This moving account of the loss Audrey is experiencing fits with the idea of eating as a primal process, which gives us nourishment, social connection and inclusion. To be unable to eat has far-reaching circumstances. Although Audrey was in unique circumstances amongst this group of participants as she had a feeding tube, notably other aspects of her reported experience were consistent with others in the sample.

Another way that participants described the impact of treatment was through speaking of control being out of their hands, rather located with professionals and other factors including luck. Abdul described feeling relieved when following diagnosis he arrived at the cancer centre.

Interviewer: You described that hearing the diagnosis understandably was very emotional and difficult, in the week between having the diagnosis and then going to the cancer centre (). Did it stay the same or different?

Abdul: Then I feel a bit different, then I'm going to the professionals' hands you know () they can sort it out. I feel less bad than before.

Interviewer: Would you say a bit more about being in the professionals' hands and what impact that had emotionally?

Abdul: That relieved me more you know.



Whilst loss of control can often be construed as negative, the above extract shows the relief that being “in professionals’ hands” brought to Abdul, which led me to consider the reassurance expertise can provide at times of illness. This was also the time when death was spoken about by participants.

David: ...so you put yourself in their hands and what you then want to see is they are doing it as fast as they can. And they were... You take the anaesthetic and you know nothing more about it, you either wake up or you don't.

Participants also frequently spoke about luck, both in relation to getting O.C. in the first place (as depicted in the below quote from Audrey) and in relation to the success of surgery (as described by Abdul).

Audrey: I was talking in my lunch break to an old lady 85 who's been smoking since she was 15 and they don't have no cancer so it all depends you know, some people are lucky, some people aren't, it's just one of those things...I would say to be truthful we're all born with cancer but it all depends on how things comes out of your body.

Abdul: That's what the surgeon said to me, that definitely, he said 'we've got everything here these days but at the end of the day I've got my fingers crossed' ( ) that's what he said.

There is a strong sense from both Audrey and Abdul that chance is a central component in the outcome of this treatment. This emphasises the uncertainty of the situation they are in. Regardless of the precision of the description of the surgeon's words (“I've got my fingers crossed”) Abdul's description depicts the fatalism and profound sense of chance about the outcome of this treatment.

### **THEME THREE: COMMITTING TO GETTING THROUGH TREATMENT**

This theme refers to the underpinning assertion from all patients that they were committed to getting through treatment. They described varied methods that they employed to adapt to O.C.

#### ***Subtheme 1: "I'm doing what I can"***

Through taking power and control participants spoke about trying to reduce the power the disease had over them, whilst preparing for surgery. There was a strong sense of participants wanting to do their 'part', as well as the belief that their behaviour prior to surgery would have implications for the outcome. There was an idea of reciprocity from patients, that while they acknowledged that many aspects of this were beyond their control, they spoke about exercise as the element that was in their power.

Peter: ...he says [the surgeon] you know that's my part of the bargain getting really as fit as I can and I'm doing that...

Some patients also talked about taking responsibility through expressing regret for their own actions that may have increased their risk of O.C. (for example smoking, drinking and being overweight):

Audrey: To be honest when they told me it's near to me throat, because I'm a smoker and I was drinking. Because I started smoking when I was 21. I have tried to give up cigarettes before but it's very very hard. I give up cigarettes now because I have cancer in my throat, so it's not a good reason for me to give up but I should have give up () because I was smoking 20 cigarettes a day and before I had cancer I was smoking 15

roll ups a day so the drink and the cigarettes have some part. It could have.

Joe: I'm at least 5 stone () overweight yeah so erm () really I'm taking the piss and I don't do any exercise. I have no right to be as healthy as I am. I have poured a significant amount of alcohol down my throat over the years especially when I was younger, I smoked 30 a day for much of my life. I've put other stuff in me that may or may not have had an effect, I don't blame myself for the cancer, I recognised it could happen, but I also recognise that probably if I had lived a different lifestyle, I might have reduced the chances of it happening.

Hearing these self-critical descriptions was poignant in the context of participants' current situation. However, Joe's comments contained interesting contradictory sentiments as he reflected on feelings of responsibility for increasing the risk of O.C., but then said "I don't blame myself". This suggests that there are limits to taking responsibility or perhaps this was a way of softening difficult emotions.

Another aspect of taking responsibility was conveyed through participants speaking about relying on themselves during this process as articulated by Matthew. His description in the following extract is also consistent with hegemonic masculinity.

Matthew: And when they said the biopsy () it's cancer you kind of go <sharp intake of breath> even though you know it and then it knocks you for a certain amount of time and then you get over it.

Interviewer: How did you cope with that, when it knocked you?

Matthew: No problem, you just get on with it. Like you hear so much bad things about cancer, it's everybody's fear and everybody's ready and if you hear somebody's got cancer, in fact I was a bit like it myself, if you came up to me and told me you've got cancer here or cancer there you

don't quite know how to speak to them. And I've found this myself that some people they just don't know how to handle, that's kind of a general thing and that's the thing in general. It's not difficult, it knocked my confidence for a week or more alright because you're thinking of everything of what you're going to do and what's going to be done you know, and then after a while it just all disappears and you just carry on. You just carry on. I was always a happy go lucky guy anyway. What's to be is what's to be and that's it...Nothing you can do for me to make me feel better. I'm as good as I'm going to feel. There's nothing you or anybody else can do to make me feel better. You can be sympathetic or you can say get on with it, it's happening every day of the week. You can go plan a or plan b.

While describing the way the diagnosis “knocked” him, Matthew quickly moved to describing “carrying on” and that it “disappears”. It struck me that the move from being “knocked” to “carrying on” seemed like a quick shift from one fixed position to another, as though there were two available options of “plan a” or “plan b”, rather than a continuum or spectrum of emotions that patients may oscillate between. This is representative of how participants generally spoke about their feelings and I wondered whether the necessity of getting through treatment engendered this attitude of “carrying on” in order to cope. He also described the responses of others, connecting with how he responded to people with cancer in the past. One plausible contributory factor to relying on oneself could relate to negative or isolating responses from others. He also described a fatalistic approach (“what's to be...”) which may relate to him acknowledging a loss of control.

### ***Sub-theme 2: “Not letting cancer take-over”***

This sub-theme refers to patients' descriptions of different ways of trying to prevent cancer from dominating their thoughts and identity through remaining connected to things and people that they valued. In the following extract Carole articulated techniques she has used to stop cancer from “ruling”:

Interviewer: During this experience as a whole, what's been the most difficult part of it?

Carole: To be honest, I think...desperately what I'm trying to do, like I said before is I don't want cancer ruling my life. I want to carry on as if I hadn't got cancer () so it's kind of just trying to make my life normal () as normal as I can . I don't want to be miserable because if I'm honest I don't feel too bad at all and as long as I'm feeling OK, then I must focus on you know carrying on, staying in touch with people, erm not kind of becoming isolated, so getting the diagnosis was horrible but the battle is to make sure you've got a, you know, a happy life and that you're not allowing the kind of cancer to swamp your mind so that all you think about is cancer, the operation and chemotherapy. Don't want to.

Carole's description is representative of numerous other examples where patients spoke about a conscious effort to prevent cancer from taking over their life and thoughts. Many participants spoke about trying to think positively and "get on with it", trying not to think about cancer too much. In contrast to Matthew's descriptions (pp. 67-68), however, Carole depicts an ongoing struggle between despair and hope, as well as emphasising the importance of staying connected to others. Audrey describes her approach to this in the following extract.

Interviewer: What is the most difficult part of all of this?

Audrey: Well you can't eat, that's part of it. I think having cancer is difficult. But it's how you cope with it is harder. Just ignore it the best you can, you know, don't think about it too much don't let it play on your mind because once it's playing on your mind you're going to feel miserable, feel sorry for yourself, want to lock up in your house and don't want to socialise with anybody. Don't feel sorry for yourself still do what you have

to do. Well try and read as well, make sure that your mind is functioning and then look at the television and I go for a walk...if there's a friend nearby just go and have a little chat with her. Sometimes other people are too helpful, sometimes I don't want them to come to my house sometimes they phone too often but I think it's because they care. Because even my work colleagues came and visit me on Saturday and I get phone calls from all over the world and that feeling's good.

Audrey, like Carole, emphasises connections with others. Although her description shares some similarities with Matthews' (pp. 67-68), for example "ignore it" is similar to "carrying on", however she more directly acknowledges that "...having cancer is difficult".

In line with Audrey's description of keeping busy, many participants spoke of ways of trying to reduce the time they thought about the operation in the lead up to it.

Abdul: ...so if I stay here, I'm thinking all the time about the operation 'what's happening, what's going on', but if I go [on holiday] for two weeks, building, makes my mind strong, thinking about something else, not thinking all of the time about the operation you know".

Joe: "Then I just went into practical mode you know 'how am I going to deal with this, how can I put the appointments in to fit with work?' because I was determined to work, and I'm bloody glad I did because otherwise you're just giving yourself time to be miserable otherwise.

These extracts show that as well as trying to maintain a positive attitude, participants worked to structure their lives in ways that distracted from thoughts about cancer and surgery. This sub-theme led me to consider identity and the wish by cancer patients to not be defined by cancer, as well as the protective function of avoiding difficult thoughts and feelings. This could be seen as an adaptive way of coping in a situation that requires them to retain functioning in order to adhere to the programme of preparation for surgery.

### 3.4 Staff Thematic Analysis

Two overarching themes were developed, each with two sub-themes as depicted in the below table.

*Table 3: Staff analysis themes*

<b>THEME</b>	<b>SUB THEMES</b>
<b>“Between the devil and the deep blue sea”</b>	“Long journey to the goal of surgery”
	Dilemmas of surgery
<b>Predicting the unpredictable</b>	“More complicated than one factor”
	“Supporting patients to take ownership”

#### 3.4.1 Setting the context

The interview schedule invited staff participants to describe their experiences with patients and encouraged them to draw on their knowledge gained from all patients they have worked with. Many staff talked about the extremely wide variation in patients’ experiences of this particular form of cancer, in contrast to other oncology specialties they have worked in.

#### **THEME 1: “BETWEEN THE DEVIL AND THE DEEP BLUE SEA”**

This theme captures staff participants’ description of pre-operative treatment and the tensions this brings through the long journey to prepare for surgery, with it offering a potential cure while bringing great risks and uncertain consequences.

### ***Subtheme 1: “Long journey to the goal of surgery”***

Participants described the team and patients working towards the goal of surgery. They spoke about the hope and potential cure that surgery offers to patients:

Interviewer: From your experience what do you think the process from diagnosis leading up to surgery tends to be like for these patients?

Cathy: I think if you look at the transitions or the journey that people go through, when you're first diagnosed I think you go through the shock of 'oh my god am I gonna die, if I die..' and just the reverberations of what that means and you go to the worst case scenario and back. But then your healthcare team give you hope and they say 'but don't worry you know we've got a treatment for you or several treatments, this is what we're going to do' and I think a lot of people while anxiety and worry might be there ( ) the actual processing of what's happened to them is often pushed back and put in a little box because they are actually in survival mode and actually getting through day-by-day those treatments, particularly chemo.

The above extract from Cathy shows the dynamic processes patients experience and the ways that surgery can provide reassurance that there is a treatment, despite the risks. She also suggests that in getting through the treatments day-by-day, patients' emotions may be overridden by a focus on “survival mode”.

Staff also described the motivating effect of surgery acting as a goal to work towards and that having worked with patients with different cancers, the focus on surgery brings unique characteristic as articulated by Emma:



Emma: I find the sense of seriousness is much more pronounced... so the understanding of how close they are to not making it is much more pronounced and the willingness to do anything that's advised is much bigger too... It is a huge goal () I find them incredibly wilful and strong that they work towards this. It's very interesting to experience this. I have not experienced this in this strong sense in other patient groups... It is partly the chemotherapy () and being so focused on surgery and getting the chemotherapy to work. They often have such hopefulness that the tumour will shrink but they understand if it can't shrink it won't be taken out... It is a different journey really [to other cancer treatments], very driven by the focus on the surgery.

It is interesting to consider what makes the experience of this treatment seem different from the other cancer contexts staff had worked in. Emma articulates thinking that the long journey to reach the "huge goal" of surgery and the risk of death differentiates the experience of this treatment from others. The continuing uncertainty during pre-operative treatment was described as a difficult balance for staff between wanting patients to be hopeful but also aware of the risks. Emma stated that patients have awareness of the uncertainty and yet strong "hopefulness". While reporting that patients often view surgery as symbolising hope, staff talked about the importance of fostering realistic expectations during this time and supporting patients to prepare psychologically for surgery:

Jay: ...obviously what we don't appreciate is the psychological preparation for surgery. They've got to know what to expect. If they don't know what to expect in terms of what they need to do but also in terms of the drastic complications of such a serious operation then they just fall in a heap. So if they know what they need to do...then they are much more likely to do those things because they feel that they are contributing to their own erm () improvement, their recovery...

As demonstrated by Jay, many staff made a link between patients being aware of what to do and feeling in control of their own recovery. During the period of preparing for surgery, staff described exercise as relating to control:

Lucy: She [a patient] realised she could do more than she thought she could do, which gave her a huge psychological boost...She said, 'I feel back in control again' (). That's the one area where they have full control over. The rest of it is down to everyone else, but this is the thing that () we can guide them, but they need to do the stuff. So it's control I think, that's the key thing.

They described that during this time it is hard for patients to know what is ahead and the focus often moves from getting through chemotherapy to surgery:

Cathy: Then comes the point that the surgery's looming nearer and nearer, they've been told about the surgery from the beginning and it's not that they're ignoring it, but I think they're so focused on getting through the treatment and not worrying about it just now because actually they need to get through the chemo, also they're going to have to be scanned to know whether the chemotherapy is having an effect. The certainty in this is the treatment but I think there must be uncertainty there. Everybody has a plan, I'm going to have this treatment, this many cycles and then I'm going to have surgery, but it's not until they get to the scanning bit that the uncertainty becomes a reality in that it's how you responded to chemo means whether you have the operation or not.

It seems significant that during this period of active treatment, there was a sense from staff that patients are in "survival mode", trying to successfully overcome each obstacle to access the cure. Staff described it as frightening for patients to know that surgery and its potential consequences are ahead. Cathy in the above extract and Emma (p. 73) implied that the uncertainty of whether or not patients could go forward for surgery may be concealed by their focus on

getting through treatment. It seemed that perhaps the hopefulness and focus on treatment leads the uncertainty to become hidden for many patients.

Many staff conveyed the idea that patients who understood the treatment process coped better but equally patients who were struggling may decline information:

Interviewer: So it is a really tricky balance of how much information to give?

Olivia: I think it's experience you get to know and you get a feel for how much information people may want, it's got to be a phased approach and you've got to be guided by them as well so I tend to... go through the surgery and what to expect and when to expect it... It's trying to give it them in a phased approach, trying to be responsive to their body language, some people say, 'look I don't want to know anything' ( ) you have to, you just have to negotiate a little bit because you know from experience if people don't want to know anything then sometimes they are doing themselves a disservice and then maybe at that stage you say, well come back, you just have to tailor. We're lucky we haven't got huge numbers so we can tailor the preoperative information to their needs. You might give them just a little bit of information you won't go into the nitty gritty of what happens in the surgery etc. So it's as much about offering them psychological support as it is about giving technical information.

As described by Olivia, tailoring information to patients' different wishes and needs was a consistent dilemma staff discussed. I wondered how emotion and information preferences related to one another, and the ethical issues raised in relation to decision-making when patients request no information despite the magnitude of the surgery. It was clear from staff's descriptions that the role of this surgery, the long lead-up to it, intensive preparation and the high risks means that O.C. treatment has a distinctive quality to other cancer treatments.

### ***Sub-theme 2: Dilemmas of Surgery***

Staff participants described the risks of oesophagectomy as amongst the greatest of any surgery and that while potentially lifesaving, the seriousness of this surgery and the potential consequences are immense and may not be possible to understand prior to experiencing it.

Josh: I think what a lot of people don't understand...is that oesophagectomy involves at least 2 organ cavities...and sometimes 3 stages to the operation. So that means not only a major operation opening the abdomen but also a major operation opening the thorax and also sometimes the neck erm () and the physiological insult is absolutely astronomical, it takes sometimes 12 hours to do this operation... So it's a hugely intense physiological hit and even the fit young patients who have it () you know take weeks and months to recover and I think people, patients in particular, probably don't understand the implications of that, of all the patients who have this surgery mightn't expect to be back to normal for months after surgery, if at all and for many people it will be a life-changing process who will never retain their previous independent living and quality of life. So I think those are the key things and they are not necessarily talked about.

The above extract captures the physiological impact of surgery as well as its effect on HR-QOL. Josh's descriptions of patients not understanding the consequences of such major surgery points to ethical questions of how much understanding is necessary for informed consent. His discussion of the potentially brutal implications of surgery highlights systemic influences of the implications not being spoken about. In line with Josh's suggestion that the gravity of this treatment may not be talked about, staff consistently described grappling with how much information to share with patients. These dilemmas were articulated by staff as challenging. There was a feeling that no matter how

much information patients are given, it may be impossible for them to grasp the seriousness prior to surgery, as described by Olivia.

Olivia: I tend to use this with patients you get the impression that they feel they're stuck between the devil and the deep blue sea, on the one hand they desperately don't want to have the surgery and they're terrified of it and the impact it will have and the way it will interfere with their life as they know it, but on the other hand they know that it's the only key to life and living and so it's that huge unknown. Nobody would ever want to be in that position and trying to see as well that with a lot of people as well, when you're giving them information they're processing it to a certain extent but invariably you'll see them after the operation and then they'll say, no matter how much information you try and give them no matter how much peer-to-peer support or how much you try to prepare them invariably there'll always be a part of them that will say 'I had no idea it was going to be so big... and we really need to improve on that. So we can just alleviate their fears and anxieties to the extent that they do start to have some realistic concept of what life will be like after the operation and they can start to plan accordingly.

Olivia raises the question of whether it is possible to understand the implications of surgery prior to going through it and whether more could be done to prepare patients so that their expectations are closer to the reality of surgery. This was discussed by many participants as raising ethical dilemmas, particularly in relation to informed consent and shared decision-making. Central to the dilemma for staff is wanting patients to understand and prepare for potential consequences whilst not wishing to frighten or dissuade patients from life-saving treatment.

## **THEME TWO: PREDICTING THE UNPREDICTABLE**

This theme was chosen to capture staff participants' views on factors that may influence patients' experiences. While many shared ideas about demographic factors, they described that patient engagement and adherence was the most crucial variable in patients' experience and surgical outcome. However, the resounding message was that predicting which patients are likely to engage is complicated and intangible. Staff articulated that the care pathway aims to tailor support to individual needs in order to increase engagement.

### ***Sub-theme 1: "More complicated than one factor"***

There was a strong sense with numerous examples that physical effects alone could not predict experience or adjustment and some participants suggested that this might relate to an attitude:

Sarah: If patients know why they are getting the toxicities, I think they cope a little bit better with that...patients who tend to be positive whatever that means because I don't know if I can quantify being positive, I don't mean a patient who's always happy but I mean a patient who doesn't spend too long wondering 'why did this happen to me'. In here the majority of patients I see say 'why me', I don't know how many times I hear that and it depends how long, I call it the 'why me' stage... and I think the longer the patient spends there determines how well they cope with their chemo essentially. If they spend too long with 'why me' (...). Even if they don't have toxicities they still struggle. I don't think toxicities from chemo are the determining factor in how people cope... I used to think because people have someone supporting them but now I've seen a mixture of patients suffering just equally as much () I think it's a little bit easier when you have support but I don't think that completely is the reason because I've seen people having an amazing support around them but they're completely not coping because they are spending so much time in that period 'why me'.

Like Sarah, many other participants described believing that social support was the strongest influence with family members acting as advocates, motivators and reasons to live for, however, it was clear that this was not the only factor. Others talked about class and education, with some saying that more educated people were more anxious and struggled more than those who were less educated. Others described more educated people as more likely to fully engage with the programme. Masculinity was repeatedly spoken about as influential, with the demographic of this cancer as mostly older men, some staff felt that perhaps this influenced their relationship to help:

Sean: It seems a lot of the male patients coming in have come in with a sense of bravado. They look at the self-efficacy and the social support questionnaires and they meet the question how confident do you feel about this this and this and it's maximum scores just circling 10/10 10/10 10/10. Now when I see that I question in my mind what's that about because when you see and speak to them...they're actually demonstrating they're quite anxious and worried about things but when it comes to filling out forms, they don't want to put that down on paper.

Overall staff reported that patients' experiences are much more complicated than one factor:

Interviewer: Do you have a sense of what makes a difference to how patients experience this treatment? Are there factors you think predict how patients experience it?

Olivia: No it's really interesting... So it never ceases to amaze me, you know you'd love to, because our patient demographic tends to be predominantly older men and you'd love to say they're going to be disengaged, they're not going to be interested. We do love to stereotype people, but I am permanently surprised, you know you can have young

females who are in their 30s and they're totally disengaged. So I would say the one factor that we need to look at is patient activation [engagement] and how activated they are at the outset and how we can move them up that trajectory. So I wouldn't say that social factors come into play or the tumour burden or anything like that, I think it's far more complicated than that personally.

As well as describing that patients' experiences are more complicated than a quantifiable social or physical factor, Olivia identified that using stereotypes to predict patient responses, whilst being an appealing idea, could impede clinicians' idiosyncratic understanding. These quotes suggest that there is vast variation in all aspects of patients' experiences. For example, at diagnosis O.C. can range from asymptomatic to extremely symptomatic (as demonstrated by the patient analysis). Patients' emotional responses are also diverse with some who seemed to particularly struggle to adapt at first to the diagnosis, coping surprisingly well later in the pre-operative process and others struggling more than anticipated.

### ***Sub-theme 2: "Supporting patients to take ownership"***

This sub-theme was chosen to capture staff's belief that patients who were most engaged with the care pathway had less difficult experiences of treatment and adhered to medical advice, which led to better physical health. They described that the aim of the care pathway is for staff and patients to work together in order to bolster a sense of "ownership", "activation" or "engagement" which they said in their experience more strongly relates to patients' experience, adherence and medical outcomes.

There are wide variations in patients' engagement with preparation for surgery. The team described working to support all patients to engage in the programme



because they know this leads to the best outcomes, but for some patients this is more challenging:

Jay: ...obviously not everybody is going to be as engaged with a patient engagement programme and it all depends on how engaged, there's this term called 'activation' how activated a patient is. And obviously speaking there are some of us, all our lives we've been told what to do and even though we've been told what to do we don't listen to them, other people telling us what to do. That's our personality, and on the other hand you've got people who are totally active in their own care, they're organised people, they want to be well-informed. They want to know exactly what's going to happen... So there are different levels of engagement and activation amongst human beings and it's similar with patients as well.

Jay's description highlights the great variation in patients, which interacts with the diverse treatment context. Staff continually described trying to adapt their approach to wherever patients were on the continuum of 'patient ownership'. They reported that the care pathway was designed with all of these differences in mind, aiming to offer a very different context to traditional paternalistic healthcare which positions patients as passive recipients of expert medical care. In contrast, patients are expected to influence care and staff aim to build strong alliances based on person-to-person communication, seeing beyond the cancer diagnosis and aiming to provide personalised and holistic care as outlined by Sean:

Sean: I always had a habit of giving out my mobile number... A direct number to get through to someone in hospital is basically non-existent these days... but even just having a direct line makes a massive difference and because we are seeing patients numerous times... having that personal relationship with patients I think makes a difference for them and for the team. Bringing everything closer together, I think it has made a difference to a lot of people.

Participants reported that the pathway's cohesive support structure offers patients confidence through knowing that they are cared for by a whole team

rather than just one member of staff. The structure and clarity of the pathway aims to foster increased ownership and realistic expectations, consequently improving motivation and adherence. These are all things that the team have found helps patients to be in the best possible position when the time for surgery arrives.

Jay: There are quite a few patients who say things like 'if the team are investing so much in us, we've got to do something for ourselves as well' and I think that's the feeling that they get 'people are looking after us and if people are giving so much energy and time to looking after us, then let's help them by us engaging with them and helping ourselves.

The idea of reciprocal efforts with both the team and patient investing in preparation for surgery was described by many.

Interviewer: Would you be able to say a bit more about what difference you think it makes to patients having that experience where you're looking at them as a person rather than just the diagnosis?

Olivia: Again it just goes back to, it makes a huge difference, you'll read it everywhere all the clichés, patients are people just like we are, just because they're in a hospital setting doesn't mean we need to label them... It's just person-to-person, as opposed to clinician-to-patient because then that sounds very hierarchical, paternalistic. I often say to patients that they are like the nucleus of the whole programme, if they are not engaged then all of us around them flounder, they are the one constant in the whole pathway, if they can make it work then we'll fall into line around them so I think it makes a huge difference.

The above extract depicts the primary responsibility held by patients in adhering to medical advice perceived to enable the optimal chance of cure.

## **4. DISCUSSION**

### **4.1 Overview**

In this chapter I return to the findings, considering them in the context of the study's aims, methodology and the literature. I will then suggest a critical appraisal of the methodology, making suggestions for future research and practice. I have aimed to write reflexively and critically throughout, making links to my own position and thought processes and I will conclude with a reflective section. I have made connections between the findings and a range of theoretical paradigms, recognising that in line with this study's critical realist stance, connections I make to theory are one possible way of thinking, rather than claiming any 'truth' about facts.

### **4.2 Contextualising the Analysis**

The overarching objective of the study was to explore patients' experiences of pre-operative treatment for O.C. through hearing their perspectives as well as staff descriptions based on a plethora of experiences with patients. In particular, I hoped that the qualitative analysis would increase depth of understanding of patients' experiences and the psychosocial impact of this gruelling treatment process. I was interested in finding out about the connections patients and staff made between different aspects of their experiences and how they made sense of relationships between their context and emotional responses, and what was helpful and unhelpful to them during this process. I hoped that this understanding would provide opportunities to consider the shared and unique aspects of this treatment in relation to findings with people with other cancers and that this could inform clinical practice and future research.

## 4.3 Summary of Findings

### 4.3.1 Patient analysis

Participants conveyed seemingly unwavering confidence and certainty in their decision to have surgery. They communicated wishing to avoid the suffering and constraints that surgery would cause. Yet with the knowledge that it was the only chance for cure, they expressed strong commitment to the process. Juxtaposed with this certainty about their choice, patients' descriptions showed an awareness of the intensely unpleasant and frightening consequences they would likely face following surgery. For example, weight loss was alluded to by many participants, on occasion in the emotive terms of becoming 'a skeleton'. However, all participants described measures they took to control cognitions about this, with a rational approach of "getting on with it" seeming to dominate expressions of emotional responses. There was a tension between feelings of fear about surgery and their commitment to adhering to medical advice and trying to prevent O.C. from taking over too much of their life and thoughts, with an idea that they must remain positive and focused on the goal of curative surgery.

Patients articulated a strong sense of the surgery hanging over them throughout the pre-operative treatment process, like an ever-present threatening 'sword of Damocles'. They faced immense uncertainties, both in a day-to-day sense with potential hospitalisations and highly unfamiliar systems and processes, and with survival, efficacy and consequences of treatment all remaining unknown. However, in spite of this patients articulated a sense of hope, which appeared to motivate them to work towards the goal of surgery.

### 4.3.2 Staff analysis

Staff described the predicaments and challenges of this treatment for patients who were required to make a drastic decision between the option of the

extremely high risk surgical treatment, with no guarantee of cure or alternatively choosing non-curative treatment leading to almost certain rapid O.C. progression and a short prognosis. Once patients have decided to pursue potentially curative treatment, staff reported that patients tend to experience the period between diagnosis and surgery as a long and arduous process. However, they also portrayed that the imminence of the surgery tends to provide patients with a sense of direction and focus on the 'goal' of surgery. Staff highlighted that as well as active treatment and exercise therapy, uncertainty about whether surgery can go ahead persists during pre-operative treatment, awaiting scans to check the efficacy of chemotherapy. They alluded to patients' rare acknowledgement of this, stating that while patients know about the uncertainty, they typically focus more on remaining hopeful and focused on pre-operative treatment and the goal of surgery. Staff however expressed an awareness from clinical experience that some patients do not reach surgery.

Staff spoke candidly about the risks of oesophagectomy, reflecting on the experience of this treatment feeling experientially different to other cancer specialties they had worked in. They described thinking that this related to the seriousness of O.C and the high risks associated with it. They highlighted that while the shocking risks were known by patients, the uncertainty was often hidden by their concentration on getting through pre-operative treatment and reaching the goal of surgery. This raised many dilemmas for staff when considering decision-making about surgery and the limits of informed consent.

There was a strong sense that patients' experiences of this treatment were idiosyncratic and varied. Although some suggested that social support, educational level or gender might make a difference, the overarching message was that it was impossible to predict. However patient engagement or 'activation' was described as a predictor of patients' experiences, adjustment and health outcomes. They described that it seemed impossible to predict which patients would possess this. Staff spoke about the multidisciplinary pre-habilitation care pathway being designed around these great differences and

that it attempted to foster greater 'ownership' and adherence in all patients in order to maximise the likelihood of successful cure.

#### 4.4 Connections between patient and staff themes

The patient and staff themes, although originating from different perspectives, have many related features. The following figure depicts the relationships I see between patient and staff themes.

Figure 4: diagram of themes

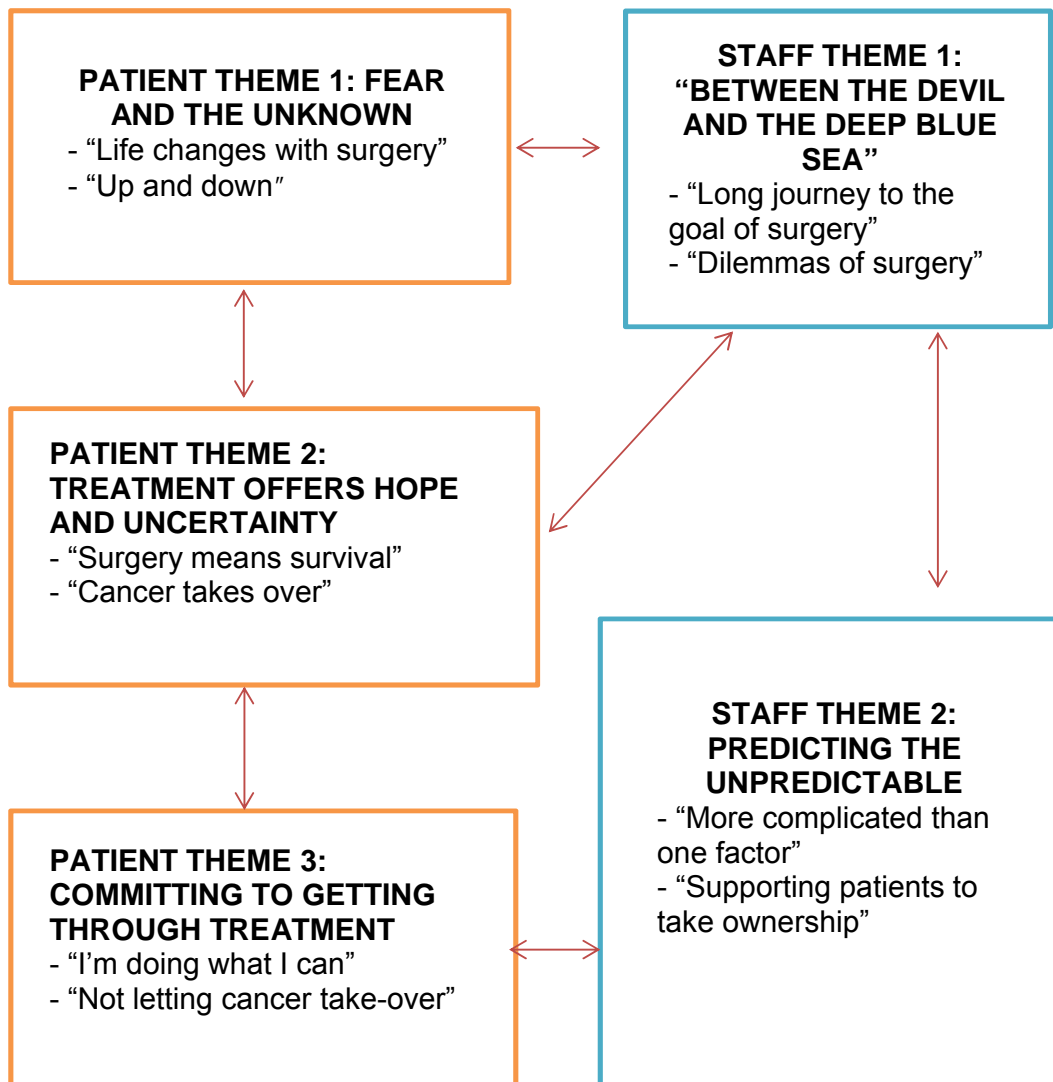


Figure 4 shows connections between the patient themes of *fear and the unknown* and *treatment offers hope and uncertainty* and the staff theme of “*between the devil and the deep blue sea*” as they all depict the characteristics of traversing pre-operative treatment. All of these point towards both the harrowing effects of treatment and its status as offering the sole possibility for survival. Staff alluded to the clash between the apparent hopefulness of pursuing treatment juxtaposed with the seriousness of the somewhat bleak circumstances they face. The staff theme of *predicting the unpredictable* is also connected to “*between the devil and the deep blue sea*” as patients’ responses to this extreme situation are unique and difficult to predict. The second staff theme of *predicting the unpredictable* is connected to the third patient theme of *committing to getting through treatment*, because all participants spoke of ways to do their ‘part’ and take ‘ownership’ of the process which fits with staff’s emphasis on patient engagement as a predictor of experience and outcome. Patients demonstrated awareness of the medical advice and commitment to following this, for example through describing exercise therapy as their “end of the bargain”. Staff described patients’ focus on the end goal of surgery driving them to get through the pre-operative preparation processes and that exercise gives them a sense of control.

Although patients and staff were speaking from completely different positions, there were many similarities between their descriptions. For example, both groups described patients’ dread of approaching surgery, as well as keenness to go ahead with it, perceiving it to offer a cure providing them with an unmissable opportunity. The main difference between staff and patient accounts was staff’s direct discussion of the risks and potential consequences of O.C. and the problems this can present for decision-making and consent. Patients, conversely, spoke with certainty about surgery as providing cure and hope. Although patients are likely to have been made aware of the continuing uncertainty of needing to be re-scanned to determine whether the surgery can go ahead, no patients spoke about this directly. Staff described that this

uncertainty often remained concealed despite repeated conversations with patients about this process and risks.

#### **4.5 Contribution Towards Understanding of Patients' Experiences**

This section will pick up some key elements of the findings, suggesting what this might contribute to understanding of patients' experiences of pre-operative treatment for O.C. I will draw connections with the wider literature and highlight some outstanding questions.

Overall, patients conceptualised their experiences of this treatment as both offering salvation and bringing unknown but potentially overwhelming changes to their lives. On one level, patients were determined to progress to surgery and expressed relief and gratitude for the possibility of it. In describing their awareness of "life-changing with surgery", patients seemed to acknowledge a trade-off between survival and the aftermath of treatment, anticipating that achieving a cure would likely have a considerable impact on their HR-QOL. Fallowfield (1990) highlighted that some patients in all parts of healthcare would choose to sacrifice HR-QOL for the smallest chance of cure. This can be applied to all participants in this study, despite their individual differences and contexts.

There was a consistent sense from both staff and patients, that patients experienced the surgery as hanging over them throughout the pre-operative treatment process. Unlike other areas of cancer where treatment is surgical, these patients are required to endure months of physical and psychological preparation for surgery, which is unusual in oncology. However, the stress of long periods of preparation has been well-documented within the transplant literature (e.g. Kennedy, 2012). Patients in the present study described varying relationships to this time period, with some stating they would prefer to have surgery 'tomorrow' and others commenting that they would delay it forever if



possible. This illustrates that the wish to have surgery is coupled with some doubts. I would suggest that when faced with an operation as threatening as oesophagectomy, where the timescale is decided by factors beyond the patients' control (such as response to chemotherapy, optimal time period post-chemotherapy, hospital procedures and medical opinion) this would be likely to evoke varied threat responses. As such it is understandable that some people would wish to run away and others to "fight" it as soon as possible (Rosenbaum & Rosenbaum, 2005).

In listening to both patients and staff I thought about the stark choice between having no treatment leading to a likely quick progression and death within months, or a treatment which offers a chance of cure, but which is considered more harrowing than most other cancer treatments (which as a whole are some of the most unpleasant treatments in medicine and have been described as 'cutting, burning and poisoning'; Brennan, 2004, p.2). However, patient participants repeatedly described the decision to have surgery as a 'no brainer' and were emphatic that surgery was the correct decision for them.

#### 4.5.1 Engagement with treatment

Staff unanimously took the view that patient ownership and engagement was bi-directionally related to their experience of treatment and the outcome of surgery. This was because by adhering to changes in exercise and diet they could maximise the chances of effective treatment. The literature on pre-habilitation pathways with people with O.C. further supports this, as engagement with the process and adherence to exercise and dietetic programmes is central to the efficacy of the pre-operative treatment (Viklund & Lagergren, 2007). This could suggest that an adjustment to the areas where they have no control, balanced with engagement with the areas they can control (such as participation in the exercise programme) is adaptive and potentially helpful. From a psychological perspective, this fits with the literature for adherence which suggests that an active style of engagement with healthcare is

associated with less distress and better outcomes, whereas a passive style is related to higher distress (Brennan, 2001).

For staff participants to so clearly express a position of unpredictability in their assertion that they could not predict patients' experiences based on measurable characteristics seemed counter to the dominant ideas and focus in research on demographic factors and patients' experiences of cancer. One participant argued that by considering demographic factors as predictive of patients' experience, our understanding of them might be limited. The view that patients' experiences of this treatment cannot be predicted by one factor fits with the ideas of intersectionality and ecological systems theories which suggest that meaning is created by multiple intersecting levels of context (e.g. Bronfenbrenner, 1979; Cronen & Pearce, 1985). This seems compatible with Brennan's (2004) critique of research which seeks to quantify psychiatric morbidity in cancer patients, in the process overshadowing the need to understand people's distress in context and find ways of preventing as much of it as possible.

The social-cognitive transition model of adjustment (Brennan, 2001) described in chapter one can be applied to these findings. The shocking event of being diagnosed with O.C. leads to feelings of being overwhelmed by threat to patients' assumptions about the world and their health. The offer of potentially curative treatment provides hope of survival, and yet the average five year survival rates of 30% post-oesophagectomy creates great uncertainty and a much bleaker picture than for most other cancers (for example testicular cancer's 98% rate of cure; CRUK, 2016). The O.C. context is highly stressful and patients struggle to adapt as their mental maps of self, others and the world attempt to accommodate the unexpected and frightening uncertainties. These adjustment processes will continue to take place as patients manage the recurrent threats of uncertainty throughout treatment. As these processes are influenced by context and individual meanings, it is reasonable that staff would struggle to predict the outcome of these processes (Brennan, 2004). The care pathway aims to increase certainty in a highly uncertain situation (for example

helping patients to have realistic expectations while maintaining hope). On the other hand, my impression is that patients' lack of description of emotion or struggle might link with the particular characteristics of the situation they are in. For example, staff proposed that they go into "survival mode".

Patients seemed focused on and dedicated to adhering to medical advice. Parsons (1951) idea of sick role was highly influential across medical sociology until at least the 1980s (Burnham, 2014). This posits that when people become ill, they adopt a new role which supersedes their usual roles and that when this is communicated to members of the sick person's immediate social network, they legitimise the sick role. This means that the person will be excused from their usual responsibilities, with a new responsibility of trying to become well enough to resume normal functioning as promptly as possible, seeking and adhering to the advice of professionals to aid this. When applied to this patient group, we see that they adhered to perceived expectations, followed medical advice and did not express negative emotion or ambivalence. The concept of sick roles has become unfashionable within the literature, critiqued for its determinism and focus on the patient rather than on the power of healthcare professionals or the systemic factors that position patients and healthcare professionals in particular ways (Burnham, 2014). However, it can usefully inform thinking about how patients might be positioned to follow medical advice, as part of their commitment to resuming their healthy roles as soon as possible. Alongside this they may also perceive an expectation that they do not express negative emotions.

Patient participants often seemed to speak in pragmatic terms alluding to difficult emotions that might overwhelm them if they were to speak or think about them too much. As well as an attempt to take control and avoid distressing thoughts and feelings, this could also be seen as fitting with wider discourses that suggest cancer patients should think positively. One disadvantage of this, which is highlighted by Tod, Warnock and Allmark (2011), is that patients can feel it is unacceptable to express negative emotions and may even feel a sense of failure and responsibility for being insufficiently

positive. They may even have ideas that their lack of positivity is in some way responsible for progression or unsuccessful treatment.

Patients depicted coping as consisting of practical strategies to prevent negative thinking from becoming overpowering. Lazarus and Folkman's classic coping theory (1984), which has been a highly influential framework in psycho-oncology, suggests that coping entails: "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984: 141). Towsley et al. (2007) highlight that with cancer these processes are compounded by uncertainty about the impact and outcomes of the condition and treatment.

#### 4.5.2 Gender

While being cautious not to reduce patients' experiences to any one characteristic, I perceive the text to show multiple examples of the effects of hegemonic masculinity. This refers to the social processes which convey an idealised form of masculinity, which includes strength and robustness, suppression of needs and resistance of help-seeking (Mahalik et al. 2007). Courtenay (2000) suggests that men interact with and understand health and their bodies through this lens. Gannon, Guerro-Blanco and Abel (2010) report that male participants responded to the side effects of surgical treatment for prostate cancer using discourses associated with hegemonic masculinity.

Devisser and McDonnell (2013) argued that participants with more traditional gender role beliefs also had stricter ideas about the masculinity of various health behaviours through which they accrue 'masculine capital' (such as not attending the GP). Whilst this can act as a resource for men (Cameron & Bernandes, 1998), it can present challenges when faced with a health problem which evokes strong emotions and might require help-seeking. In circumstances of O.C., hegemonic masculinity suggests that men would seek to conceal perceived weakness such as fear. For example Peter's description of losing weight post-surgery, which he seemed to cushion with "...it might be

good for me you never know“ (p.54) could be a way of continuing to appear ‘strong’ in the face of frightening surgery. There were countless other examples from male participants conveying seemingly measured and coherent descriptions of their experiences. While female participants also spoke in pragmatic and certain terms, they described worries which fit with traditional ideas about femininity, for example about others around them. It also seemed notable that the two female participants became tearful during the interviews and none of the male participants visibly displayed distress in this way. Male participants described their female partners as consistent carers or as being upset by the man not seeking emotional support from them in the context of cancer. This is in line with literature from other cancers. For example Gray et al. (2000) found that men with prostate cancer expressed little emotion and did not seek emotional support which negatively impacted on their relationships.

#### 4.5.3 Decision-making and consent

Patient participants in this study made it clear that their certainty about their choice to have oesophagectomy stemmed from the hope of cure and that they prioritised life above all other factors. There was often an accompanying sentiment that it would be irrational not to choose the potentially life-saving option. Some described declining HCPs suggestions to take time to think the decision over, instead wishing to proceed with treatment immediately. I was surprised by the lack of turmoil patient participants expressed in explaining their decision to have such serious surgery. My response of surprise is likely to have been influenced by my personal thoughts that in such a position I would likely need time to weigh it up (while acknowledging my belief that until we have been in a situation it is impossible to know how we will respond). This is also linked with my experiences of working in oncology and palliative care, contributing to ethically complicated and difficult multidisciplinary discussions about treatment decisions, weighing up risks and benefits often labelled in terms of HR-QOL (with the complexity and subjectivity this brings). I wondered whether participants had crossed through a process of doubt and struggle before arriving at their decision. However, their retrospective accounts suggested they were quickly certain that it would be ‘foolish’ to choose not to have surgery.

This led me to consider issues of decision-making, which raises complicated and multifactorial dilemmas across most areas of healthcare (Street, Ashcroft, Henderson & Campbell, 2000; Degner & Sloan, 1992). The shifts in the culture of oncology from expert-led, to shared decision-making and the Department of Health's Expert Patient Programme has changed the landscape of decision making within healthcare (Martin & Lawrence et al., 2015). Charles, Gafni and Whelan (1997) suggest that the traditional paternalistic model of healthcare, where patients are passive recipients of doctors' expert decisions is in direct contrast to shared decision-making models of patient care.

In the present study, along with patients' seeming certainty and rapid decision-making, some staff participants described a concern that the consequences of oesophagectomy surgery had historically not been spoken about often enough. Other staff participants described how, in their experience, however much the risks and potential consequences were discussed with patients it seemed impossible for them to grasp the gravity of surgery's implications until afterwards. They also suggested that for most patients uncertainty was concealed and infrequently acknowledged. This reflects my interpretation of the data and reaction of feeling puzzled that patients did not express more emotional dilemmas or concerns. For example, participants mostly spoke in a measured tone and yet used graphic terms to describe their imagined post-oesophagectomy selves. For example, Matthew's description of wanting "to get it over and done with and see what kind of a skeleton is going to be left" seems to allude to an acknowledgement of frightening consequences of surgery, although he did not state this explicitly.

Although staff spoke about the continuing uncertainty through treatment, with the final decision about surgery depending on response to chemotherapy, no patient participants spoke about this. I speculated that the complex uncertainty and fear evoked by the situation may have necessitated patients' seeming certainty and trust in the medical intervention on offer. There was a consistent sense from patients of privilege and relief in the surgeon agreeing to offer

potentially life-saving surgery, with the acknowledgement that the alternative would be death. In reflecting on this, I wondered whether other patients might show less confidence than participants who agreed to take part in interviews. By the nature of agreeing to participate in this study, I hypothesised that they may be likely to have a particularly confident narrative which may differ from other patients.

McKneally and Martin's (2000) Canadian paper suggests that the findings of the present study are reflected elsewhere. They carried out a grounded theory study with oesophagectomy survivors and asked them about the beliefs and values that informed their decision-making. They developed a model of 'entrustment' and expressed surprise that patients reported not considering themselves to be making an 'informed decision'. Rather, they saw the expert's recommendation as consent to treatment and felt in control of the decision-making process through their trust in the surgeon rather than because of any analytic process. I would suggest that in the present data there was also a sense of patients delegating their decisions to their medical team. McKneally and Martin (2000) found that where doctors offered a choice between alternative treatments, patients reported losing confidence in their doctor's competence. This suggests that they associated certainty and medically-led decisions with competence, which is problematic in the context of a drive towards shared decision-making. Patients also perceived themselves to not be qualified to absorb and process medical information as they did not possess the necessary expertise and felt stunned by anxiety and fear. The authors reported that patients were resigned to the risks of treatment and believed that analysing the risks was irrelevant as while the chances of survival were low, without surgery they were zero. This could be connected to the present research finding that patients expressed considering any option other than surgery would be irrational.

Sommers and Helft (2009) examine the idea of informed consent from surgeons' perspectives, highlighting the particular complexity of this with people with O.C. They suggest that this relates to the poor overall outcomes for O.C., the contested benefits of adjuvant chemotherapy, the great impact of the

treatment and disease on HR-QOL and varied decision-making preferences. They also articulated that HCPs' ability to communicate and patients' ability to process information are both central to the efficacy of explanations for improving patients' understanding. Sommers and Helft (2009) highlighted that there is wide variation in individual preferences for information from their doctor. However Jenkins, Fallowfield and Saul (2001) found that 87% of patients wished for full information regardless of whether it was positive or negative. Swenson, Buell, Zettler et al. (2004) also found that most patients (69%) valued shared decision-making.

Levine and Gafni et al. (1992) described a method for supporting this communication process using a 'decision board' which is a visual tool to assist decision making. The assumption inherent in decision making tools is that with correct information patients are able to make decisions that are right for them. This assumption is compatible with the expert patient agenda, but the challenge is how clinicians assess that information has been transmitted to patients. For example, at times of high emotion, memory processing has been shown to be altered (e.g. Brewin, 2001). The present data suggests that a wish to survive overrides all other elements of oesophagectomy for patients.

The literature described in chapter one demonstrated that post-surgery patients often report a wish to have had more information (e.g. Malmstrom et al., 2013b; Andreassen et al., 2007; Wittmann et al., 2011). Authors such as Viklund et al. (2006a) emphasise the importance of detailed and honest information prior to surgery. However, the present study's findings suggest that preparation for surgery may not be as straightforward as a thorough process of information exchange. Rather, multidimensional factors that might obstruct patients' capacity to weigh up and make informed decisions must be considered.



#### 4.5.4 Shared and unique features

The findings of this study suggest that the experience of potentially curative treatment for O.C. can be seen as having characteristics both unique to this context and shared with other cancers and treatments.

The frightening feelings of unpredictability and unfamiliarity with the system, as well as the “up and down” of uncertainty described by these participants, are common to many people’s cancer experiences (Rosenbaum & Rosenbaum, 2005). Treatments are notoriously tough and unpleasant side effects are frequent, yet as articulated by Brennan (2004; p.27), ‘...for most people survival becomes the overriding concern’ and many people focus on this as the priority, at the expense of other areas of life. This suggests that the focus on survival for these participants in itself is not unique to O.C. However, the risks and impact of this surgery are greater than for most cancers and this, along with the long period of preparation for surgery, makes it a somewhat unique experience. Staff particularly highlighted experiences of working with people with other cancers, and feeling that there were qualitative differences in patients’ experiences which they attributed to the seriousness of O.C. Although surgery is always a major intervention, staff described that oesophagectomy is both emotionally and physically in a different league because of the complexity and risks.

Many patient participants spoke about never having heard of O.C. prior to diagnosis. I hypothesised that the experience of being diagnosed with a form of cancer that one has not heard about previously would be different to being diagnosed with a high profile cancer that you have some familiarity with. Parallels can be drawn with Garau’s (2016) depiction of the qualitatively different experience of diagnosis of rare cancer compared with a more common diagnosis. The demands to then take on information about the illness and treatment are likely to be more difficult to process with no pre-existing framework, especially at this time of shock and threat.

## 4.6 Implications

### 4.6.1 Clinical practice

These findings have shed some light on the complexity of potentially curative treatment for O.C. and the great variation in patients' experiences of this. This provides no easy answers other than emphasising the importance of attending to the great differences in meaning for people and their diverse contexts.

Some pointers for clinical practice are that, where possible, patients feeling that they have some degree of control is important. As part of their dedication to survival patients often align themselves with professionals, implementing HCP advice such as exercise, and working towards the goal of surgery which is seen as symbolising hope and survival. However, while acknowledging the challenges of not wishing to scare patients and also the uncertainty of the future, HCPs must consider their responsibility in working with patients to temper hope with realistic expectations. The findings of this study suggest that providing detailed information in a traditional form may not be sufficient. Rather, HCPs need to tailor the approach to individual patients, perhaps drawing on decision-making tools. As Levine et al. (1992) demonstrated, consideration of how to improve this transfer of information between clinicians and patients in clinical practice is imperative, in order to enhance patients' preparation for surgery.

Psychological theory suggests that information processing is likely to be altered at times of trauma (Brewin, 2001) and high emotion (Kahneman, 2012) This can be helpfully applied to understanding that complicated psychological processes and multiple factors are likely to influence patients' capacity to process information when diagnosed with O.C.. In order to support information processing at these times, a multimodal approach to providing information should be used. This could include involving carers as much as possible to

provide patients with support to process information following consultations. Research on information needs reviewed in chapter one suggested that carers report feeling less well informed than patients. Carers can have multifaceted roles in supporting patients and it is crucial to acknowledge the strain that O.C. can create in those around the individual patient as well as their capacity to influence patients' experiences. Joining with carers is likely to increase the possibility of patients grasping necessary information. There is also evidence to suggest that audio recording consultations is another effective way to support this, while also reducing decision-regret (Good et al., 2015).

Staff data emphasised that it is not possible to predict patients' experiences based on one factor. This suggests that working with this group requires openness and flexibility. This emphasises the importance of multidisciplinary care pathways with the scope to offer care tailored to the individual in the way that both patients and staff described as crucial here, working to not underestimate patients' fears even where they appear confident. Clinical psychologists have a role in supporting multidisciplinary staff to achieve this.

The findings suggest that there are unique features to patients' experience of this treatment, particularly related to the unusually high risks of surgery and this provides further evidence to suggest that HR-QOL scores cannot capture the whole picture and should be used with caution as a tool for conversations, rather than as a 'scientific' measure of wellbeing.

In terms of survival, O.C. is where breast and prostate cancer were at least 30 years ago (CRUK, 2016a). It also seems that research knowledge on decision-making is behind other specialties and this is an area that requires urgent attention. From my own experience of searching for information, I found little clear information for patients on the risks of oesophagectomy and alternative treatments. On finding the National Comprehensive Cancer Network (2015) guidelines, which purported an intention to aid decision-making, I was disappointed to find little information on the disadvantages of pursuing

oesophagectomy. I would anticipate that unbiased accounts with information on prognosis and potential consequences would be available, in the spirit of truly informed consent. Perhaps the unavailability of such information reflects a wish to protect patients and their carers from the often shocking and painful details of this procedure and the implications of decision-making where this is the only potentially life-saving option. There is no easy solution in these circumstances and I wonder whether a collective avoidance is evoked by the extreme suffering, uncertainty and distress in this area. However, counter to the idea that shielding patients from harrowing details is protective, there is evidence to suggest that exposure to potentially shocking and difficult experiences can improve psychological outcomes in other settings. For example, family members witnessing resuscitation in emergency rooms has been shown to improve later psychological adjustment and grieving processes (Leske & Brasel, 2010; Hanson & Strawser, 1992). Applying these findings to decision-making in oesophagectomy, I think it is important to develop ways of sharing the likely and possible implications of surgery with patients and their carers through clear and concrete information on the disadvantages and implications of this treatment, as well as the benefits.

The overarching implication of the findings is that clinical psychologists' have a multifaceted role in this context. This includes helping teams to reflect on their own emotional responses to the prospect of sharing more information with patients, perhaps considering defences against anxiety as a framework for understanding team processes in response to highly distressing work (Menzies-Lyth, 1959). Psychologists can also support teams to think about decision-making as relational, for example, it takes place in a context where patients' representations of how doctors and patients relate will influence the interaction. In a time of the Expert Patient Agenda and emphasis on collaborative decision making, it is crucial to acknowledge that many patients continue to look to medical professionals to make decisions, as highlighted by McKneally and Martin's (2000) research. This is likely to be influenced by both historical hierarchies between doctors and patients and a common preference at times of illness, fear and vulnerability to gain confidence and containment from expert and paternalistic figures taking decisions in our best interests. Psychologists

should support teams to confront the complexity of these issues and to consider how they would know if a patient was sufficiently prepared and if consent was thoroughly informed. Former patients who have undergone oesophagectomy could also helpfully contribute to considering these issues through drawing on and sharing their own experiences with pre-operative patients in order to foster balanced expectations.

#### 4.6.2 Research

In an ideal world, it would be optimal to do a prospective longitudinal study next, interviewing the same patients following surgery and then perhaps at yearly intervals post-oesophagectomy. The feasibility of such a study is likely to be challenging, but it would provide meaningful information to inform understanding beyond the current evidence base, which is mainly derived from quantitative measures. The numbers of patients from the original group surviving for five years is likely to be low and patients' wish to take part may change. That said, several patient participants spontaneously offered to speak again following the surgery "if you want to see how I got on". I wondered whether this may have been influenced by their own wish to think beyond the surgery and maintain hope. Interviewing carers as well as staff and patients would also be of great value. Participants did not express expectations of psychologically changing post-surgery which is counter to Clarke et al.'s (2011) finding that patients post-oesophagectomy described a sense of change in identity between pre-surgery and afterwards. Research exploring this prospectively would be of great value providing an opportunity to learn from patients whether they think anything further could be provided to support them. Including both carers and staff in this study would offer further multiperspective information.

In particular research examining in detail how decisions are made is crucial to inform ethical practice and professional guidelines for HCPs working with patients undergoing this treatment. This could begin by using a prospective design to extend McKneally and Martin's (2000) study with a UK sample, through asking participants to describe their decision-making at key points pre-

and post-surgery. The study could explore whether decision-regret is an issue for patients post-oesophagectomy.

The inclusion of HR-QOL as a central part of the parlance and practice about holistic care across cancer services reflects a positive acknowledgement that thinking of experience as subjective and individual is central to meeting patients' needs. However, it is important to pursue research which deepens understanding of patients' experience in order to inform care. The use of pre-determined measures with this population should be considered carefully, with the acknowledgment that relatively little research has been carried out with this patient group and further research is required to consider the kinds of measures we should be working to develop.

#### **4.7 Critical Evaluation**

As with all research, this study's findings must be considered in the context of both strengths and limitations. A strength of this study was that all participants were part of the same treatment pathway at the same hospital and so some homogeneity of experience can be assumed, however, this also limits the generalisability of the findings. Another strength is that patients were speaking about their current experiences of pre-operative treatment, which provides greater proximity to their experiences than retrospective accounts. This also means that participants' accounts would be likely to differ if interviewed about the same experiences in the future, although it is impossible to know what the differences would be. It is also possible that the setting of the interview will have influenced patients' experiences of being interviewed. For example, patient participants who chose to be interviewed at hospital might have been more likely to associate the conversation with clinical conversations they shared with medical professionals in the same setting. Conversations at home could be seen as a more intimate frame for interviews and may have encouraged increased openness.

The sample size of seven interviews for the patient group and eight interviews for the staff group (with the relatively high homogeneity) is acceptable according to Guest, Bruce and Johnson (2005). However, the sample could be viewed as relatively small. I would have liked to have continued interviewing, but unfortunately within the constraints of the thesis, it was not possible. The process of recruiting patient interviewees was especially challenging due to small numbers of potential participants going through pre-operative treatment at any one point and patients' busy appointment and treatment schedules, and frequent experiences of side effects during the pre-operative preparation period. Patient participants were united by all undergoing pre-operative treatment for oesophageal cancer where oesophagectomy was anticipated. However, there were differences in patients' medical pathways and stage as outlined in chapter one (pp. 47-48). It would have been optimal to interview patients at the same point in their medical treatment in order to more directly compare their experiences. However, as this population of patients has widely varied treatment needs and medical experiences, it was not possible to directly compare their experiences at the same time point. Future research attempting to do this would need to adopt a large-scale trial design.

I would have liked to have co-produced this research with people with experience of O.C. and hope that this will be central to future research. I am aware that the patient participants interviewed for this study are likely to represent a biased proportion of patients. Staff accounts aimed to address this in part through hearing their descriptions of a full range of patients, however, I recognise that this is no substitute for hearing directly from patients.

The choice of research method and epistemology inevitably opens some possibilities and closes down others. The critical realist stance of this study made it possible to draw on a range of conceptual tools to explore how participants made sense of their experiences of this treatment. However, a social constructionist position would have allowed greater focus on discourse, perhaps revealing less of an individualised account and more about how participants constructed their experiences in relation to wider societal ideas.

Individual interviews created a private, one-to-one conversation, which has many strengths, particularly where the topic is as sensitive as cancer. Yet for future studies, I would be interested in the possibility of focus groups providing the opportunities to elicit data created through conversation. This would fit with Susan Sontag's (1978) suggestions that experience of cancer is shaped by societal metaphors and discourses.

As I conducted the interviews, I became intensely familiar and connected with the data which was helpful during all phases of analysis. My own emotional impressions at the time of the interview inevitably will have impacted on the analysis, although in the spirit of qualitative research I do not see this as negative. I have reflected on how participants might have perceived me as a relatively young white female and wondered how this might have influenced their responses. In order to encourage them to be as open as possible I explained that I had become interested in this topic while working in cancer care, emphasising confidentiality and hoping to position myself as a robust and non-judgmental professional, able to hear difficult or distressing experiences. Although my questions during interview intended to be as open and neutral as possible, both staff and patients are likely to have been heavily socialised by the culture of the care pathway which is likely to have shaped what they prioritised and shared in their answers as well as the position they took.

#### 4.7.1 Quality assessment

The idea of quality in qualitative research is controversial, as the aims differ greatly from those of traditional scientific experimental methods and therefore do not strive for the same result. There are several frameworks for assessing the quality of qualitative research in psychology. I have chosen to use Elliott, Fischer and Rennie's (1999) seven suggested criteria:

1. *Owning one's perspective*: This refers to the researcher attempting to acknowledge and be explicit about their values and assumptions and



how these influence the research. I have aimed to do this as much as possible by being clear about my epistemological stance and through trying to convey reflexivity throughout this thesis. I have written in the first person and have aimed to explain the decisions I made in both the analysis and discussion chapters, making links between my observations, interpretations and my personal beliefs and experiences. I have used a reflective diary and field notes throughout this research process as a way of making my own thoughts and interpretations explicit.

2. *Situating the sample*: This relates to providing sufficient details to put the participants in context. Through describing the details of the care pathway in chapter one and the age, gender and ethnicity of patient participants, and the job roles of staff participants in chapter three, I aimed to meet this criterion by depicting the participants in appropriate detail.
3. *Grounding in examples*: Qualitative methods require the selection of appropriate examples to demonstrate the analysis. I aimed to carefully select examples for chapter 3 that optimally demonstrated the data analysis while also complying with the word limit constraints. I did this through a methodical process of recording all extracts relevant to each code during the coding process and then narrowing this with each revision of the report until the extracts fitted within the word limit. I tried to include quotes that were substantial enough to give the reader a sense of the data and its context. Following Braun and Clarke's (2013) suggestions, I included quotes from the full breadth of participants, giving multiple examples to demonstrate key points. I have also provided varied examples of the maps involved in the analytical process in the appendices (Appendix R) which show the development and refinement of themes during the course of the analysis.
4. *Providing credibility checks*: This criterion refers to the importance of checking the credibility of the analysis. During the process of analysis I shared the codes, quotes and developing themes with a peer researcher working in psycho-oncology who reviewed the themes and I amended them as a result of this discussion. I later received feedback on my developing analysis from my field supervisor, a senior psychologist in

psycho-oncology, with expertise in oesophageal cancer and with my director of studies who has extensive psycho-oncology research experience. This provided assurance of the plausible standards of my own analysis in line with my inductive aims.

5. *Coherence*: This criterion relates to the importance of a coherent account of the analysis in qualitative research. I aimed to balance a clear account of the analysis whilst depicting the nuances of the text and tensions. I also described both the overarching themes and where participants overall differed in their experiences. The process was iterative and involved multiple re-drafts.
6. *Accomplishing general versus specific research tasks*: This relates to the challenge of attending to both shared, general themes and more specific details within the data. I attempted to achieve this balance by focusing on the overall themes, whilst highlighting specific details where I perceived them as highlighting nuances which might be of significance.
7. *Resonating with readers*: The final criterion describes the standard to which the analysis is assessed by readers to have “clarified or expanded their appreciation and understanding” (Elliott et al., 1999, p. 224) of the phenomena. This has been my aim and the reader will assess whether I have achieved this.

#### **4.8 Reflection**

The complex, systematic and creative process of this research has personally changed my perspective. I felt profoundly moved by meeting patients and staff, hearing their experiences of O.C. and immersing myself in their descriptions. I will continue to grapple with the complex ethical dilemmas this area presents and feel inspired by the staff members' efforts to navigate these.

Hearing the stories of patients' suffering, their hopes and the experiences of staff in enduring this too, led me to question my own assumptions. For example, on hearing from staff the harrowing risks and consequences of the surgery and

knowing the low 5-year survival rates, my emotional reaction was strong. I initially felt shocked that this treatment is offered despite such high risks. On reflection, however, my view now is that the essence of quality of life is being able to make choices that would be inconceivable to others. The patients I met were emphatic that this was the optimal choice for them. However, in striving for shared-decision making, I believe that more must be done to understand how decisions are made with people with O.C., in order to guide ethical practice and ensure informed consent.

I continue to feel affected by the conversations I had during the interviews and hold the patients I met in mind, hoping that their surgery goes well and has a positive outcome. I also feel curious about whether their descriptions or perspective would change, if we were to speak again following surgery. Although I would consistently have argued for the importance of HR-QOL as a subjective and self-defined construct, I feel that my perspective has been irrevocably changed by this project. It has left me with a heightened awareness of the challenge of facilitating decision-making that is truly responsive to patients' subjective sense of quality of life, in extraordinarily difficult circumstances. As HCPs I believe that we have a duty to struggle with this complexity and yet during this project I have keenly felt the intense challenges this brings.

Keeping field notes throughout this research helped me to notice how I had been influenced by powerful assumptions about the meaning of quality of life. This emphasises for me the importance of time to critically reflect and hold our own ideas to account. When speaking with staff about these issues in the future, I will hold in mind my own process of becoming more conscious of how professional definitions of the meaning of HR-QOL can creep in, influencing practice which if unnoticed, could close down possibilities for truly person-centred care.

## 7. REFERENCES

- Abitbol, J., Laub, S., Agnihotram, V., Ramanakumar, J.Z., Drummond, N., Rosberger, Z.,... & Gotliebb, W. H. (2014). Prospective Quality of Life Outcomes Following Robotic Surgery in Gynecologic Oncology. *Gynecologic Oncology*, *134*, 144–149. doi: 10.1016/j.ygyno.2014.04.052.
- Akkerman, R., Haverkamp, L., Van Rossum, P., Van Hillegersberg, R. & Ruurda, J.(2015). Long-term quality of life after oesophagectomy with gastric conduit interposition for cancer. *European Journal of Cancer*, *51*, 1538-1545. doi: [10.1016/j.ejca.2015.05.006](https://doi.org/10.1016/j.ejca.2015.05.006)
- Andreassen, S., Randers, I., Naslund, E., Stockeld, D. & Mattiasson, A. C. (2006). Patients' experiences of living with oesophageal cancer. *J. Clin. Nurs.*, *15* (6), 685–695. doi: 10.1111/j.1365-2702.2006.01412.x
- Andreassen, S., Randers, I., Naslund, E., Stockeld, D. & Mattiasson, A.C. (2007). Information needs following a diagnosis of oesophageal cancer; self-perceived information needs of patients and family members compared with the perceptions of HCPs: a pilot study. *European Journal of Cancer Care*, *16*, 277–285. doi: 10.1111/j.1365-2354.2006.00742.x
- Avis, N. E., Levine, B., Naughton, M. J., Case, D.L., Naftalis, E. & Van Zee, K.J. (2012). Explaining age-related differences in depression following breast cancer diagnosis and treatment. *Breast Cancer Research and Treatment*, *136* (2), 581–591. doi: 10.1007/s10549-012-2277-0
- Baker, D. & Middleton, E. (2003). Cervical screening and health inequality in England in the 1990s. *Journal of Epidemiology and Community Health*; *57*, 417-423. doi:10.1136/jech.57.6.417

- Barker, C., Pistrang, N. & Elliott, R. (2003). *Research methods in clinical psychology: An introduction for students and practitioners*. London: John Wiley & Sons.
- Ben-Shlomo, Y., Evans, S., Ibrahim, F., Patel, B., Anson, K., Chingwundoh F., ... & Persad R. (2008). The risk of prostate cancer amongst black men in the United Kingdom: The PROCESS cohort study. *European Urology*, 53, 99-105. doi: [10.1016/j.eururo.2007.02.047](https://doi.org/10.1016/j.eururo.2007.02.047)
- Berry, P.H., Chapman C.R., Covington, E.C. , Katz, J., Miaskowski, C., McLean, M. & Dahl, J. (2001). *Pain: Current understanding of assessment, management and treatments*. The Joint Commission for the Accreditation of Healthcare Organizations: The National Pharmaceutical Council. Retrieved July 18, 2016 from <http://www.npcnow.org/system/files/research/download/Pain-Current-Understanding-of-Assessment-Management-and-Treatments.pdf>
- Bhaskar, R. (1989). *Reclaiming Reality*. London: Routledge.
- Blazeby, J.M., Farndon, J.R., Donovan, J. & Alderson, D. (2000). A prospective longitudinal study examining the quality of life of patients with esophageal carcinoma. *Cancer*, 88 (8), 1781-1787. doi: [10.1016/j.ejca.2015.05.006](https://doi.org/10.1016/j.ejca.2015.05.006)
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101. doi: 10.1191/1478088706qp063oa
- Braun, V. & Clarke, V. (2013) *Successful qualitative research*. London: Sage.
- Brennan, J. (2001). Adjustment to cancer – coping or psychosocial transition? *Psycho-oncology*, 10: 1-18. doi: 10.1002/1099-1611(200101/02)10:13.3.CO;2-K

- Brennan, J. (2004). *Cancer in Context: a practical guide to supportive care*. Oxford: Oxford University Press.
- Brewin, C. R. (2001). A cognitive neuroscience account of posttraumatic stress disorder and its treatment. *Behavior Research and Therapy*, 39, 373-393. doi: /10.1016/ S0005-7967(00)00087-5
- Brinkmann, S. & Kvale, S. (2008). Ethics in Qualitative Research. In C. Willig & W. Stainton Rogers (Ed.), *The Sage Handbook of Qualitative Research in Psychology* (pp. 263-279). London: Sage.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press.
- Bultz B. D. & Carlson L.E. (2005) Emotional distress: the sixth vital sign in cancer care. *J Clin Oncol*, 23 (26), 6440–6441. doi: 10.1200/JCO.2005.02.3259
- Burnham, J. C. (2014). Why sociologists abandoned the sick role concept. *History of the human sciences*, 27 (1), 70-87. doi: 10.1177/09526951113507572
- Calman, K. C. (1984). Quality of life in cancer patients--an hypothesis. *Journal of Medical Ethics*, 10, 124-127. doi: 10.1136/jme.10.3.124
- Cameron, E. & Bernardes, J. (1998). Gender and disadvantage in health: men's health for a change. *Sociology of Health and Illness*, 20 (5), 673-693. doi: 10.1111/1467-9566.00124
- Cancer Research UK (2004). *Reduce the Risk Survey*. UK: Cancer Research UK. Retrieved November 25, 2016 from: <http://www.cancerresearchuk.org/cancer-info/healthyliving/reducetherisk>

Cancer Research UK (2012). Oesophageal Cancer (C15): Number of Deaths, Crude and European Age-Standardised (AS), Mortality Rates per 100,000 Population. UK: CRUK. Retrieved April 14, 2016 from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oesophageal-cancer/mortality#heading-Three>

Cancer Research UK (2014). Annual Review 2014/2015. UK: CRUK. Retrieved November 21, 2016 from: <http://www.cancerresearchuk.org/about-us/our-organisation/annual-report-and-accounts/annual-review>

Cancer Research UK (2016a). *Statistics by Cancer Type*. Retrieved March 17, 2016 from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oesophageal-cancer#heading-Zero>

Cancer Research UK (2016b). *Oesophageal cancer survival*. Retrieved March 17, 2016 from: <http://beta-about-cancer.cancerresearchuk.org/about-cancer/oesophageal-cancer/survival/>

Cancer Research UK (2016c). *Oesophageal cancer incidence*. Retrieved April 10, 2016 from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oesophageal-cancer/incidence#ref-0>

Carlson, L.E. & Bultz, B. D. (2003). Cancer distress screening: Needs, methods and models. *Journal of Psychosomatic Research*, 55, 403-409. doi: [10.1016/j.jpsychores.2004.04.366](https://doi.org/10.1016/j.jpsychores.2004.04.366).

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, ... & Clark, K.C. (1993). How coping mediates the effects of optimism on distress: a study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65, 375-90.

- Cavallin, F., Pinto, E., Saadeh, L. M., Alfieri, R.M, Cagol, M.,Castoro, C. & Scarpa, M. (2015). Health related quality of life after oesophagectomy: elderly patients refer similar eating and swallowing difficulties than younger patients. *BMC Cancer*, 15, 640. doi: 10.1186/s12885-015-1647-5
- Chang, Y-L., Tsai, Y-F, Wu, Y-C & Hsieh, M-J. (2014). Factors relating to quality of life after esophagectomy for cancer patients in Taiwan. *Cancer Nursing*, 37, 1, 4-13. doi: 10.1097/NCC.0b013e318277dc53
- Charles, C., Gafni, A. & Whelan, T. (1997). Shared Decision-Making in the Medical Encounter : What does it mean ? (Or it takes at least two to tango) *Soc. Sci. Med.*, 44 (5), 681-692.
- Christensen, A. J., Howren, M. B., Hillis, S. L., Kaboli, P., Carter, B. L., Cvengros, J. A., Wallston, K. A. & Rosenthal, G. E. (2010). Patient and physician beliefs about control over health: association of symmetrical beliefs with medication regimen adherence. *Journal General Internal Medicine*, 25 (5), 397:402. doi: 10.1007/s11606-010-1249-5
- Clarke, A., MacIntyre, P. & Cruickshank, J. (2007). A critical realist approach to understanding evaluating a heart health programme. *Health*, 11 (4), 513-39. doi: 10.1177/1363459307080876
- Clarke, C., McCorry, N. & Dempster, M. (2011). The role of identity in adjustment among survivors of oesophageal cancer. *Journal of health psychology*, 16 (1), 99-108. Doi: 10.1177/1359105310368448
- Cooper, C. & Denner, J. (1998). Theories Linking Culture and Psychology : Universal and Community-Specific Processes. *Annu Rev. Psychol.* 49, 559-84.
- Cronen, V. E., & Pearce, W. B. (1985). Toward an explanation of how the Milan method works: A invitation to a systemic epistemology and evolution of



family systems. In D. Campbell & R. Draper (Eds.), *Applications of systemic family therapy: The Milan approach* (pp. 69-86). London: Grune & Stratton.

Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Soc Sci Med*, *50*, 1385-1401.

Crouch, M., & McKenzie, H. (2000). Social realities of loss and suffering following mastectomy. *Health*, *4*, 196–215.

De Angelis, R., Sant, M., Coleman, M. P., Francisci, S., Baili, P., Pierannunzio, D.... & Capocaccia, R. (2014). Cancer survival in Europe 1999–2007 by country and age: results of EURO CARE-5-a population-based study. *Lancet Oncology*, *15* (1), 23-34. doi: 10.1016/S1470-2045(13)70546-1

de Boer, A. G., van Lanschot, J. J., van Sandick, J. W., Hulscher, J. B., Stalmeier, P. F., de Haes, J. C., ... & Sprangers, M. A. (2004). Quality of life after transhiatal compared with extended transthoracic resection for adenocarcinoma of the esophagus. *Journal of Clinical Oncology*, *22* (20), 4202–4208. doi: 10.1200/JCO.2004.11.102

Degner, L. F. & Sloan, J. A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of clinical epidemiology*, *45* (9), 941-950.

Dempster, M., Mccorry, N., Brennan, E., Donnelly, M., Murray, L. & Johnston, B. (2010). Do Changes in Illness Perceptions Predict Changes in Psychological Distress among Oesophageal Cancer Survivors? *Journal of Health Psychology*, *16*, 3, 500-509. doi: 10.1177/1359105310386633

Dempster, M., Mccorry, N., Brennan, E., Donnelly, M., Murray, L. & Johnston, B. (2011). Illness perceptions among carer–survivor dyads are related to psychological distress among Oesophageal cancer survivors. *Journal of*

*Psychosomatic Research*, 70, 432-439. doi:

10.1016/j.jpsychores.2010.07.007

Department of Health (2000). *The NHS cancer plan*. London: HMSO. Retrieved December 3, 2016 from:

[https://www.thh.nhs.uk/documents/\\_departments/cancer/nhscancerplan.pdf](https://www.thh.nhs.uk/documents/_departments/cancer/nhscancerplan.pdf)

Department of Health (2003). *Tackling Health Inequalities: A programme for Action*. London: HMSO. Retrieved December 3, 2015 from:

<http://webarchive.nationalarchives.gov.uk/20031220221853/http://doh.gov.uk/healthinequalities/programmeforaction/programmeforaction.pdf>

Department of Health (2007). *Cancer reform strategy*. London: HMSO.

Retrieved December 3, 2015 from:

<http://www.nhs.uk/NHSEngland/NSF/Documents/Cancer%20Reform%20Strategy.pdf>

Department of Health (2010). *National Cancer Patients Experience Survey Programme: 2010 National Survey Report*. London: HMSO. Retrieved December 3, 2015 from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216682/dh\\_122520.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216682/dh_122520.pdf)

Department of Health (2011). *Improving Outcomes: A Strategy for Cancer* .

London: HMSO. Retrieved December 3, 2015 from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213785/dh\\_123394.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf)

Department of Health (2014). *Improving Outcomes: A Strategy for Cancer – Fourth Annual Report*. UK: DOH. Retrieved December 3, 2016 from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/388160/fourth\\_annual\\_report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/388160/fourth_annual_report.pdf)

Derogar M & Lagergren P (2012). Health-related quality of life among 5-year survivors of esophageal cancer surgery: a prospective population-based

study. *Journal of Clinical Oncology*, 30, 4, 413-418. doi:  
10.1200/JCO.2011.38.9791

Derogar, M., Orsini, N., Sadr-Azodi, O. & Lagergren, P. (2012). Influence of major postoperative complications on health-related quality of life among long-term survivors of esophageal cancer surgery. *Journal of Clinical Oncology*, 30 (14), 1615-1619. doi: 10.1200/JCO.2011.40.3568

Djärv, T. & Lagergren, P. (2012). Quality of life after oesophagectomy for cancer. *Expert Rev Gastroenterol Hepatol*; 6 (1), 115-22. doi:  
10.1586/egh.11.91.

de Visser, R. O. & McDonnell, E (2013). 'Man points': masculine capital and young men's health. *Health Psychology*, 32 (1), 5-14. doi:  
10.1037/a0029045

Elliott, J., Fischer, C., & Rennie, D. (1999). Evolving guidelines for publications of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-29.

Fallowfield, L. (1990). *The Quality of Life: the missing measurement in healthcare*. London: Souvenir press.

Gannon, K., Guerro-Blanco, M. and Abel, P.D. (2010). Reconstructing masculinity following radical prostatectomy for prostate cancer. *The Aging Male*, 13, 4, 258–264. doi: 10.3109/13685538.2010.487554

Garau, R. (2016). The medical experience of a patient with a rare disease and her family. *Orphanet Journal of Rare Diseases*, 11, 19. doi:  
10.1186/s13023-016-0401-7.

Gibbs, G.R. (2007). *Analyzing qualitative data*. London: Sage Publications Limited.

- Good, D. W., Delaney, H., Laird, A., Hacking, B., Stewart, G. D. & McNeill, S.A. (2015). Consultation audio-recording reduces long-term decision regret after prostate cancer treatment: a non randomised comparative cohort study. *Surgeon Jan 27* doi: 10.1016/j.surge.2014.10.006
- Gotze, H., Ernst, J., Brahler, E., Romer, G. & von Klitzing, K. (2014). Predictors of quality of life of cancer patients, their children and partners. *Psycho-Oncology, 24*, 7, 787-795. doi: 10.1002/pon.3725
- Gray, R. E., Fitch, M.I., Philips, C., Labrecque, M. & Fergus, K. (2000). Managing the impact of illness: the experiences of men with prostate cancer and their spouses. *Journal of Health Psychology, 5*, 531-548.
- Guest, G., Bruce, A. & Johnson, L. (2005). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*, 59-82. doi: 10.1177/1525822X05279903
- Hallas C., Patel N., Oo A., Jackson M., Murphy P., Drakeley M., Soorae A. & Page, R. (2001). Five-year survival following oesophageal cancer resection: psychosocial functioning and quality of life. *Psychology, Health & Medicine, 6* (1), 85-94. doi: [10.1080/13548500124671](https://doi.org/10.1080/13548500124671)
- Han, Y., Hu, D., Liu, Y., Lu, C., Luo, Z., Zhao, J.,...& Mao, J. (2014). Coping styles and social support among depressed Chinese family caregivers of patients with esophageal cancer. *Eur J Oncol Nurs, 18* (6), 571-7. doi: 10.1016/j.ejon.2014.07.002
- Hanson, C. & Strawser, P. (1992). Family presence during cardiopulmonary resuscitation. Foote Hospital Emergency Department's nine-year perspective. *Journal of Emergency Nursing, 18* (2): 107-9.

- Harper, D. (2012). Choosing a qualitative research method. In D. Harper, & A.R. Thompson (Eds.) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 83-97). Oxford: Wiley-Blackwell.
- Hellstadius, Y., Lagergren, P., Lagergren, J., Johar, A., Hultman, C. M. & Wikman, A. (2015). Aspects of emotional functioning following oesophageal cancer surgery in a population-based cohort study. *Psycho-Oncology*, 24 (1), 47-53. doi: 10.1002/pon.3583
- Henselmans, I., Jacobs, M., Van Berge Henegouwen, M., De Haes, H., Sprangers, M. & Smets, E. (2011). Postoperative information needs and communication barriers of esophageal cancer patients. *Patient Education and Counselling*, 88, 138-146. doi: 10.1016/j.pec.2011.12.004
- Hirai, K., Suzuki, Y., Tsuneto, S., Ikenaga, M., Hosaka, T. & Kashiwagi T. (2002). A structural model of the relationships among self-efficacy, psychological adjustment, and physical condition in Japanese advanced cancer patients. *Psycho-Oncology*, 11 (3), 221-229. doi: 10.1002/pon.561
- Hodgson, T. (2006) Oesophageal cancer: experiences of patients and their partners. *British Journal of Nursing*, 15 (21), 1157-1160. doi: 10.1111/j.1365-2702.2006.01412.x
- Homs, M.Y., Essink-Bot, M.L., Borsboom, G.J., Steyerberg, E.W. & Siersema, P.D. (2004). Quality of life after palliative treatment for oesophageal carcinoma – a prospective comparison between stent placement and single dose brachytherapy. *Eur J Cancer*, 40 (12), 1862–1871. doi: 10.1016/j.ejca.2004.04.021
- Jacobs, M., Rhiannon, A., Macefield, C., Blazeby J., Korfage I., Van M., & Sprangers, A. (2013). Systematic review reveals limitations of studies evaluating health-related quality of life after potentially curative treatment

for esophageal cancer. *Qual Life Res*, 22, 1787–1803. doi:  
10.1007/s11136-012-0290-8

Jacobs M., Sitnikova Á., Smets Á., Henselmans I., De Haes J., Sprangers Á.,... & Blazeby, J. (2014). Meta-analysis shows clinically relevant and long-lasting deterioration in health-related quality of life after esophageal cancer surgery. *Qual Life Res*, 23, 1155-1176. doi: 10.1007/s11136-013-0576-5

Jaromahum, J. & Fowler, S. (2010). Lived Experiences of Eating After Esophagectomy: A Phenomenological Study. *Medsurg Nursing*, 19 (2), 96-100.

Jeffrey, D. (2003). What do we mean by psychosocial care in palliative care. In Lloyd-Williams M (Ed.), *Psychosocial Issues in Palliative Care* (pp. 1-12). Oxford: Oxford University Press.

Jenkins, V., Fallowfield, L. & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *Brit J Cancer*, 84, 48-51. doi: [10.1054/bjoc.2000.1573](https://doi.org/10.1054/bjoc.2000.1573)

Jim, H. S. & Jacobsen, P.B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: a review. *Cancer J*, 14 (6), 414-9. doi: 10.1097/PPO.0b013e31818d8963.

Kahneman, D. (2012). *Thinking, Fast and Slow*. London: Penguin.

Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science and Medicine*, 67, 79–87. doi: [10.1016/j.socscimed.2008.03.036](https://doi.org/10.1016/j.socscimed.2008.03.036)

Kennedy, P. (2012). *The Oxford Handbook of Rehabilitation Psychology*. Oxford: Oxford University Press.

- Kimble, G.A. (1984). Psychology's two cultures. *American Psychologist*, 39, 833–839.
- Lagergren, P., Avery, K. N., Hughes, R., Barham, C. P., Alderson, D., Falk,...& Blazeby, J. (2007). Health-related quality of life among patients cured by surgery for esophageal cancer. *Cancer*, 110 (3), 686–693. doi: 10.1002/cncr.22833
- Lagergren, P. (2010). Oesophageal Cancer, Clinical Review. *BMJ*, 341. doi : 10.1136/bmj.c6280.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Leske, J. S. & Brasel, K. (2010). Effects of family-witnessed resuscitation after trauma prior to hospitalization . *Journal of Trauma Nursing*, 17 (1): 11-8. doi: 10.1097/JTN.0b013e3181d915b0.
- Leventhal, H., Meyer, D. & Nerenz, D. R. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to Medical Psychology* (Vol. 2; pp. 17-30). New York: Pergamon Press.
- Levine, M. N., Gafni, A., Markham, B., & MacFarlane, D. (1992). A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. *Annals of Internal Medicine*, 117, 53-58.
- Macmillan (2012). *People living with cancer*. UK: Macmillan. Retrieved December 10, 2015 from: [http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/peoplelivingwithcancer\(generalsurvivorship\).pdf](http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/peoplelivingwithcancer(generalsurvivorship).pdf)
- Macmillan Cancer Support (2013). *Throwing light on the consequences of cancer and its treatment*. UK: Macmillan. Retrieved December 10, 2015 from:

<http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

Macmillan (2014a). *Cancer in the UK in 2014 State of the Nation report*. UK: Macmillan. Retrieved December 10, 2015 from: <http://www.macmillan.org.uk/documents/aboutus/whatwedo/cancerintheuk2014.pdf>

Macmillan (2014b). *A competence framework for nurses. Caring for patients living with and beyond cancer*. UK: Macmillan. Retrieved December 10, 2015 from: [http://www.macmillan.org.uk/documents/aboutus/health\\_professionals/competence-framework-for-nurses.pdf](http://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf)

Macmillan (2015). *Statistics Fact Sheet*. UK: Macmillan. Retrieved December 10, 2015 from: <http://www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf>

Macmillan (2009). *Self-management programmes for cancer survivors: a structures review of outcome measures. Amended version*. UK: Macmillan. Retrieved December 10, 2015 from: <http://www.ncsi.org.uk/wp-content/uploads/Outcome-Measures-for-Evaluating-Cancer-Aftercare.pdf>

Mackay, N. & Petocz, A. (2011). Realism and the state of theory in psychology. In Mackay, N. & Petocz, A. (Eds.), *Realism and Psychology: Collected Essays* (pp. 17-51). Leiden: Brill.

Maddams J, Utley M. & Møller H. (2012). Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of Cancer*, 107, 1195-1202. doi: :10.1038/bjc.2012.366



- Mahalik, J., Burns, S. & Syzdek, M. (2007). Masculinity and perceived normative health behaviours as predictors of men's health behaviours. *Social Science Medicine*, 64 (11), 2201-2209. doi: [10.1016/j.socscimed.2007.02.035](https://doi.org/10.1016/j.socscimed.2007.02.035)
- Malmström, M., Ivarsson, B., Johansson, J. & Klefsgård, R. (2013a). Long-term experiences after oesophagectomy/gastrectomy for cancer - A focus group study. *International Journal of Nursing Studies*, 50, 44-52. doi: [10.1016/j.ijnurstu.2012.08.011](https://doi.org/10.1016/j.ijnurstu.2012.08.011)
- Malmström M., Klefsgård R., Johansson J. & Ivarsson B. (2013b). Patients' experiences of supportive care from a long-term perspective after oesophageal cancer surgery e A focus group study. *European Journal of Oncology Nursing*, 17, 856-862. doi: [10.1016/j.ejon.2013.05.003](https://doi.org/10.1016/j.ejon.2013.05.003)
- Malmström M., Klefsgård R., Ivarsson, B., Roman, M. & Johansson J. (2015). Quality of life measurements as an indicator for timing of support after oesophagectomy for cancer: a prospective study. *BMC Health Services Research*, 15, 96. doi: [10.1186/s12913-015-0747-x](https://doi.org/10.1186/s12913-015-0747-x).
- Marks, D. F. (2009). How should psychology interventions be reported? *Journal of Health Psychology*, 44, 475-489. doi: [10.1177/1359105309103567](https://doi.org/10.1177/1359105309103567)
- Martin, N., Lawrence, V., Murray, J., Janssen, A., Higginson, I. & Lyall, R (2015). Decision Making About Gastrostomy and Noninvasive Ventilation in Amyotrophic Lateral Sclerosis. *Qualitative Health Research*. doi: [10.1177/1049732315583661](https://doi.org/10.1177/1049732315583661)
- Mccorry, N., Dempster, M., Clarke, C. & Doyle, R. (2009). Adjusting to Life After Esophagectomy: The Experience of Survivors and Carers. *Qualitative Health Research*, 19 (10), 1485-1494. doi: [10.1177/1049732309348366](https://doi.org/10.1177/1049732309348366)
- McKneally, M. F. & Martin, D. K. (2000). An entrustment model of consent for surgical treatment of life-threatening illness: perspective of patients

requiring esophagectomy. *J Thorac Cardiovasc Surg*, 120, 264–269. doi: [10.1067/mtc.2000.106525](https://doi.org/10.1067/mtc.2000.106525)

Menzies Lyth, Isabel (1959) 'The Functions of Social Systems as a Defence Against Anxiety: A Report on a Study of the Nursing Service of a General Hospital', *Human Relations* 13: 95-121

Mills, M. E. & Sullivan, K. (2000) Patients with operable oesophageal cancer: their experience of information-giving in a regional thoracic unit. *Journal of Clinical Nursing*, 9, 236-246. doi: 10.1046/j.1365-2702.2000.00359.x

Moynihan, C. (2002). Men, women, gender and cancer. *Eur J Cancer Care*, 11 (3), 166-172. doi: 10.1046/j.1365-2354.2002.00348.x

Mystakidou, K., Tsilika, E., Parper, E. & Galanos, A. (2015). The influence of sense of control and cognitive functioning in older cancer patients' depression. *Psycho-Oncology*, 24 (3), 311–317. doi: 10.1002/pon.3642

National Comprehensive Cancer Network (2015). *NCCN Guidelines for Patients Esophageal Cancer*. USA: NCCN. Retrieved December 10, 2015 from: <https://www.nccn.org/patients/guidelines/esophageal/index.html>

National Cancer Intelligence Network (2014). *Major resections by cancer, site in England; 2006-2010*. UK: NCIN. Retrieved December 10, 2015 from: [www.ncin.org.uk/view?rid=2947](http://www.ncin.org.uk/view?rid=2947)

National Cancer Survivorship Initiative (2013). *Living with and Beyond Cancer: Taking Action to Improve Outcomes*. London: NCSI. Retrieved December 10, 2015 from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/181054/9333-TSO-2900664-NCSI\\_Report\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf)

National Oesophago-Gastric Cancer Audit Progress Report (2014). The Royal College of Surgeons of England: National Oesophago-gastric cancer

audit. Retrieved December 10, 2015 from: [http://www.augis.org/wp-content/uploads/2014/05/NOGCA-PROGRESS-Report-2014\\_Final.V2.pdf](http://www.augis.org/wp-content/uploads/2014/05/NOGCA-PROGRESS-Report-2014_Final.V2.pdf)

Parker, P.A., Baile, W.F., de Moor, C. & Cohen, L. (2003). Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology*, 12, 183– 193. doi: [10.1002/pon.635](https://doi.org/10.1002/pon.635)

Parker, I. (2005). *Qualitative Psychology: Introducing Radical Research*. Berkshire: Open University Press.

Parkes, C. M. (1971). Psychosocial transitions: a field for study. *Social Science and Medicine*, 5, 101-115.

Parsons, T. (1951). Illness and the role of the physicians: A sociological perspective. *The American Journal of Orthopsychiatry*, 21 (3), 452–460.

Payne, S., Seymour, J., & Ingleton, C. (2008). *Palliative care nursing: principles and evidence for practice*. Maidenhead: McGraw-Hill / Open University Press.

Price, P., Sikora, K. & Illidge, T. (2008). *Treatment of Cancer*. London: Arnold Hodder.

Rankow, E. J. & Tessaro, I. (1998). Cervical cancer risk and Papanicolaou screening in a sample of lesbian and bisexual women. *J Fam Pract*, 47, 139–143.

Rapley, M. (2003). *Quality of Life Research. A Critical Introduction*. London: Sage.

Rapley, M., Moncrieff, J. & Dillon, J. (2011). *De-Medicalizing Misery: Psychiatry, psychology and the human condition*. Hampshire: Palgrave Macmillan.

- Rodrigue, J. R., Behen, J. M., Tumlin, T. (1994). Multidimensional determinants of psychological adjustment to cancer. *Psycho-Oncology*, 3, 205-14.
- Rosenbaum, E. & Rosenbaum, I. (2005). *Everyone's guide to cancer supportive care*. Kansas: Andrews McMeel Publishing.
- Rotter, J. B. (1954). *Social learning and clinical psychology*. New York: Prentice-Hall.
- Rouvelas, I., Zeng, W., Lindblad, M., Viklund, P., Ye, W. & Lagergren, J. (2005). Survival after surgery for oesophageal cancer: a populationbased study. *Lancet Oncol*, 6, 864-870. doi: 10.1016/S1470-2045(05)70347-8
- Rowlingson, K. (2011). *Does income inequality cause health and social problems? Joseph Rowntree foundation*. Retrieved on May 1, 2016 from: <https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/inequality-income-social-problems-full.pdf>
- Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research*, 14, 1366–1386. doi: 10.1177/1049732
- Schumacher, M., Olscchewski, M & Schulgen, G. (1991). Assessment of quality of life in clinical trials. *Statistic in Medicine*. 10, 1915-30.
- Silver, J.K. & Baima, J. (2013). Cancer prehabilitation: an opportunity to decrease treatment related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. *Am J Phys Med Rehabil*, 92, 715-727. doi: 10.1097/PHM.0b013e31829b4afe
- Sommers, S. & Helft, P. (2009). Informed Consent in the Esophageal Cancer Patient. In B., Thomas, C. & Hunter, J. (Ed.), *Oesophageal cancer: principles and practice* (pp. 369-379). New York: Demos Medical Publishing.

- Sontag, S. (1978). *Illness as Metaphor*. New York: Farrar, Straus and Giroux.
- Street, K., Ashcroft, R., Henderson, J. & Campbell, A. V. (2000). The decision making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital. *J Med Ethics*. 26, 346-352. doi: 10.1136/jme.26.5.346
- Sweed, M. R., Schiech, L, Barsevick, A., Babb, J. S. & Goldberg, M. (2002). Quality of life after esophagectomy for cancer. *Oncol Nurs Forum*; 29 (7), 1127–31.
- Swenson, S.L., Buell, S., Zettler, P., White, M. & Ruston, D. C. (2004). Patient-centered communication: do patients really prefer it? *J Gen Intern Med*, 19, 1069–1079. doi: 10.1111/j.1525-1497.2004.30384.x
- Tatematsu, N., Hasegawa, S., Tanaka, E., Sakai, Y. & Tsuboyama, T. (2013) Impact of oesophagectomy on physical fitness and health-related quality of life in patients with oesophageal Cancer. *European Journal of Cancer Care*, 22, 308–313. doi: 10.1111/ecc.12030
- Thomas, C., Morris, S., McIlmurray, M.B., Soothill, K., Francis, B. & Harman, J.C. (2001). *What are the psychosocial needs of cancer patients and their main carers?* Lancaster: The Institute for Health Research, Lancaster University.
- Tod, A.M., Warnock, C. & Allmark, P. (2011). A critique of positive thinking for patients with cancer. *Nursing Standard*, 25 (39), 43-47. doi: [10.7748/ns2011.06.25.39.43.c8544](https://doi.org/10.7748/ns2011.06.25.39.43.c8544)
- Towsley, G., Beck, S. & Watkins, J. (2007). “Learning to live with it”: Coping with the transition to cancer survivorship in older adults. *Journal of Aging Studies*, 21 (2): 93-106. doi: 10.1016/j.jaging.2006.08.003

- Van't Spijker, A., Trijsburg, R. W. & Duivenvoorden, H. J. (1997). Psychological sequel of cancer diagnosis: a meta-analytical review of 58 studies after 1980. *Psychosomatic Medicine*, 59 (3), 280–293
- Verschuur, E.M.L., Steyerberg, E. W., Kuipers, E.J., Essink-Bot, M. L., Tran, K.T.C., Van Der Gassta,...& Siersema, P. D. (2006). Experiences and expectations of patients after oesophageal cancer surgery: an explorative study. *European Journal of Cancer Care*, 15, 324–332. Doi: 10.1111/j.1365-2354.2006.00659.x
- Vickery, L. E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck*, 25, 289–296. doi: 10.1002/hed.10206
- Viklund, P., Wengstrom, Y., Rouvelas, I., Lindblad, M. & Lagergren, J.(2006a). Quality of life and persisting symptoms after oesophageal cancer surgery. *Eur. J. Cancer*, 42 (10), 1407–1414. doi: 10.1016/j.ejca.2006.02.005
- Viklund, P., Wengstrom, Y. & Lagergren, J. (2006b). Supportive care for patients with oesophageal and other upper gastrointestinal cancers: The role of a specialist nurse in the team. *European Journal of Oncology Nursing*, 10, 353-363. doi: <http://dx.doi.org/10.1016/j.ejon.2006.01.009>
- Viklund, P. & Lagergren, J. (2007). A care pathway for patients with oesophageal cancer. *European Journal of Cancer Care* 16, 533–538. doi: 10.1111/j.1365-2354.2007.00790.x
- Wainwright, D., Donovan, J., Kavadas, V., Cramer, H. & Blazeby, J. (2007). Remapping the body: learning to eat again after surgery for esophageal

cancer. *Qualitative Health Research*, 17 (6), 759-771. doi:  
10.1177/1049732307302021

Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, D. S., Bliss, J. & Tunmore, R. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine*, 21, 51-57.

Wilkinson, R. & Pickett, K. (2009). *The Spirit Level*. London: Penguin.

Wikman, A., Smedfors, G. & Lagergren, P. (2013). Emotional distress -- a neglected topic among surgically treated oesophageal cancer patients. *Acta oncologica* , 52 (8), 1783-5. doi: 10.3109/0284186X.2013.771820

Wikman, A., Ljung, R., Johar, A., Hellstadius, Y., Lagergren J., & Lagergren P. (2014). Psychiatric morbidity and survival after surgery for esophageal cancer: a population-based cohort study. *Journal of Clinical Oncology*, 33 (5), 448-454. doi:10.1200/JCO.2014.57.1893

Willig, C. & Stainton Rogers, W. (2008). *The sage handbook of qualitative research in psychology*. London: sage.

World Health Organisation (2009). *Mental health, resilience and inequalities*. Copenhagen: WHO Regional Office for Europe. doi:  
[http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0012/100821/E92227.pdf](http://www.euro.who.int/__data/assets/pdf_file/0012/100821/E92227.pdf)

Wittmann, E., Beaton, C., Lewis, W. G., Hopper, A. N., Zamawi, F., Jackson, C.,...& Crosby TD. (2011). Comparison of patients' needs and doctors' perceptions of information requirements related to a diagnosis of oesophageal or gastric cancer. *Eur J Cancer Care (Engl)*, 20 (2), 187-95. doi: 10.1111/j.1365-2354.2009.01169.x.

Wu, X.-D., Hui-Ying, Q., Zhang, J.E., Zheng, M. C., Xin, M-Z, Liu, L.,...& Zhang, M-F. (2015). The prevalence and correlates of symptom distress and

quality of life in Chinese oesophageal cancer patients undergoing chemotherapy after radical oesophagectomy. *European Journal of Oncology Nursing*, 19 (5), 502-508. doi:  
<http://dx.doi.org/10.1016/j.ejon.2015.02.010>

Zhang, C., Wu, Q. C., Hou, P. Y., Zhang, M., Li, Q., Jiang, Y. J. & Chen, D. (2011). Impact of the method of reconstruction after oncologic oesophagectomy on quality of life a prospective, randomised study. *European Journal of Cardio-Thoracic Surgery*, 39 (1),109–114. doi:  
[10.1016/j.ejcts.2010.04.032](http://dx.doi.org/10.1016/j.ejcts.2010.04.032)



## 8. APPENDICES

### APPENDIX A: LITERATURE REVIEW TABLE 1

#### *Summary table of studies measuring HR-QOL post-surgery (p. 26-29)*

<b>Authors</b>	<b>Sample</b>	<b>Country</b>	<b>Measure and time points</b>	<b>Key conclusions</b>
<b>Viklund et al. (2006a)</b>	282 patients	Sweden	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC) C-30 & OES-18 <sup>6</sup> : 6 months post-operatively	HR-QOL was generally considerably lower for those 6 months post-oesophagectomy than for a general population reference group and a group of mixed cancer patients. Role and social subscales were particularly reduced. They suggest that this reflects the magnitude of this treatment and its implications.
<b>Akkerman, Haverkamp, Rossum, van Hillegersberg &amp; Ruurda (2015)</b>	92 patients	The Netherlands	EORTC C-30 & OES-18: time point varied from at least 1 year (with a median point of 36 months; range 12-76 months) post-	Global HR-QOL scores were similar to the general population reference group. However, patients scored significantly lower on physical, cognitive, role and social domains, demonstrating a continuing impact of

<sup>6</sup> The most widely used measures across the literature review were the *The European Organization for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30 and QLQ-OES-18)*. The EORTC-QLQ is a cancer specific questionnaire that intends to measure HR-QoL. The main EORTC scale, the C-30, is a 30 item questionnaire with components for global health status, function and symptoms. The disease specific component for oesophageal cancer, the OES-18, has been designed to be used alongside the main scale (Lagergren et al., 2007). All scales are scored on a 5 point or 7 point Likert-scale. The scales have been found to have good convergent and divergent validity and multi-item correlations with Cronbachs alpha >0.7 (Lagergren, et al. 2007).

			oesophagectomy.	oesophagectomy on a range of functions.
<b>Hallas, Patel, Jackson, Murphy, Drakeley, Soorae &amp; Page (2001)</b>	37 patients	UK	EORTC C-30 & OES-24 and the Medical Outcomes Study SF-36: 5 years post-oesophagectomy.	The majority of participants reported physical HR-QOL was lower than the general population group. Most patients experienced persisting symptoms including fatigue, pain, dysphagia and anxiety and tended to have lower physical functioning than the control group. A small proportion of patients reported severe physical symptoms. However, the majority of patients' overall HR-QOL was reported as comparable to the general population group.
<b>Derogar, Orsini, Sadr-Azodi &amp; Lagergren (2012)</b>	141 patients	Sweden	EORTC C-30 & OES-18: 6 months, 3 years and 5 years post-operatively	They focused on the relationship between major post-operative complications and HR-QOL in 5-year survivors. They found major post-operative complications were a predictor of poor HR-QOL 5 years post-oesophagectomy.
<b>Wu et al. (2015)</b>	102 during post-oesophag ectomy	China	M.D. Anderson Inventory (symptom distress), Hospital Anxiety and Depression Scale (HADS), the Medical	There was found to be a negative relationship between symptom distress and quality of life. They found patients who were working, had more social support and better economic

	chemotherapy.		Coping Modes Questionnaire (MCMQ) and the Functional Assessment Cancer Treatment-General (Quality of Life)	conditions reported less symptoms. Higher symptom distress was inversely associated with lower quality of life.
<b>Derogar &amp; Lagergren (2012)</b>	117 patients	Sweden	EORTC C-30 & OES-18: 6 months, 3 years and 5 years post-operatively.	The majority of patients reported similar HRQOL compared to general population but a limited subgroup's HRQOL deteriorated over time.
<b>Hellstadius et al. (2015)</b>	401 at 6 months and 140 of these at 5 years.	Sweden	EORTC C-30 emotional functioning scale: 6 months and 5 years post-operatively.	A majority of participants reported problems with worry and low mood at 6 months and this persisted in the majority at 5 years. They found lower educational experience to be associated with more tension and patients living alone were less likely to report worry at 6 months. Participants with low scores at 5 years tended to have low scores at 6 months, but a substantial minority deteriorated.
<b>Malmstrom et al. (2015)</b>	79 patients	Sweden	EORTC C-30 & OES-18: before surgery, 2, 4, 6, 9 and 12 months after surgery.	During the first year post-oesophagectomy HR-QOL scores were low, with the lowest point at 2 months. The authors therefore recommend that additional supportive care input should be focused at the 2

---

months point.

---

## APPENDIX B: LITERATURE REVIEW TABLE 2

*Summary table of prospective studies on HR-QOL (p. 29-31)*

<b>Authors</b>	<b>Sample</b>	<b>Country</b>	<b>Measures and time points</b>	<b>Key conclusions</b>
<b>Sweed et al. (2002)</b>	23 patients	U.S.A.	EORTC (C30, OES-18): before chemotherapy, before surgery and 3 and 6 months post-surgery.	Global HR-QOL declined over time but the change was not statistically significant. Physical symptoms increased significantly over time before surgery and the highest levels were immediately before surgery. These increased symptoms were associated with decreased HR-QOL. Overall there were only small changes in HR-QOL during this time period.
<b>Tatematsu et al. (2013)</b>	30	Japan	EORTC (C30) & objective measures of physical fitness (knee-extensor muscle strength and 6-min walking distance): diagnosis and on the last day in hospital post-surgery (median time 21 days).	They found a significant decrease in physical fitness and global HR-QOL between the two points. All domains of HR-QOL reduced pre- and post-surgery except the emotion subscale where there was no significant difference.
<b>Chang et al.</b>	99	Taiwan	EORTC (C30, OES-18):	Global HR-QOL decreased significantly

<b>(2014)</b>	patients		before surgery and 1 month and 6 months after surgery.	between baseline and 1 month post-surgery. It gradually improved between 1 and 6 months but by 6 months had not returned to the original level.
<b>Cavallin et al. (2015)</b>	109	Italy	EORTC (C-30 & OES-18): admission for surgery, discharge and 3 months after surgery.	There was no significant difference in HR-QOL scores over time, for older and younger patients.
<b>Lagergren et al. (2007)</b>	90 patients (47 who survived 3 years post-surgery)	UK	EORTC (C30 and OES-18): 6 weeks before surgery, 6 weeks, 3 months, 6 months, 9 months, 12 months, 18 months, 24 months and 36 months postoperatively.	Most aspects of HR-QOL improved between 6 and 12 months post-surgery. Even after 3 years patients reported persistent problems with physical symptoms, although emotional function was significantly improved between pre-operatively and 3 years post-surgery. Global HR-QOL was lower at 3 years than pre-surgery. However, due to the improved emotional function, the authors conclude that overall patients who survive for more than 3 years can expect a good HR-QOL.
<b>Verschuur et al. (2006)</b>	30 patients	The Netherlands	Modified Patient's Needs in Palliative Care-checklist (PNPC-checklist), EuroQol Visual Analogue Scale (VAS)	Patients frequently reported physical and psychosocial problems after oesophagectomy. They expressed an expectation that professionals would

---

and semi-structured interview 1 week following questionnaires: less than 1 year post surgery.	help with physical problems but not psychosocial problems as they viewed this as the role of their social network.
--	--

---

## APPENDIX C: LITERATURE REVIEW TABLE 3

*Summary table 3: HR-QOL Qualitative papers (p. 31-33)*

<b>Authors</b>	<b>Sample</b>	<b>Country</b>	<b>Method</b>	<b>Key conclusions</b>
<b>Malmstrom et al. (2013a)</b>	17 patients (2-5 years after surgery), in 4 focus groups.	Sweden	Semi-structured focus groups: qualitative content analysis.	Patients were particularly affected by long-term symptoms which impacted them emotionally and socially as well as physically. They described struggling with feelings of losing control of their lives and consequent anxiety and fear. Learning to live with symptoms rather than allowing them to constrain their lives was highlighted as positively influencing coping.
<b>Malmstrom et al. (2013b)</b>	17 patients (2-5 years after surgery), in 4 focus groups.	Sweden	Semi-structured focus groups, data analysed with qualitative content analysis.	The theme 'the need for a guiding light in the new life situation' was created to capture patients' descriptions of their experiences of supportive care. They expressed that support from friends and family and the healthcare system was crucial to managing the transitions and challenges of treatment and recovery. Honest information and clear and structured plans were highlighted as central to patients developing realistic expectations.

---

<b>Hodgson (2006)</b>	9 patients (2-6 years since surgery) and three partners.	UK	Qualitative and quantitative questionnaire: qualitative content analysis and quantitative descriptive statistics.	The majority of patients described feeling well-informed before surgery but stated they would have liked more information about post-operative recovery. All participants said that their main goal was to survive surgery, then gain confirmation that the cancer had successfully been removed and they could then focus on recovery. Post-operative adjustment to reducing activity and accounting for persisting symptoms was challenging. A positive attitude in believing recovery is possible, from both participants and healthcare professionals was viewed as essential.
-----------------------	--	----	---	--

---



#### APPENDIX D: LITERATURE REVIEW TABLE 4

*Summary table of quantitative studies on experience of oesophagectomy (pp. 33-35)*

<b>Authors</b>	<b>Sample</b>	<b>Country</b>	<b>Measures and time points</b>	<b>Key conclusions</b>
<b>Andreassen, Randers, Naslund, Stockeld &amp; Matthiasson (2007)</b>	15 patients 16 family members 34 HCPs	Sweden	Study specific questionnaire: 2-3 weeks since diagnosis.	HCPs believe patient and family members' needs for information to be lower than patients and family members themselves.
<b>Wittmann, Beaton, Lewis, Hopper, Zamawi, Jackson, Dave, Bowen, Willacombe, Blackshaw, Crosby (2011)</b>	100 patients and 100 doctors	UK	Socio-economic deprivation scores (Welsh Index of Multiple Deprivation)	Junior doctors' perceptions of information needs were reported as lower than patients' wishes for information which participants rated as very high. Low socioeconomic rating was associated with poor access to internet information.
<b>Dempster et al. (2011)</b>	317 patient-partner dyads	UK	Illness Perception Questionnaire-Revised, the Cancer Coping Questionnaire, the Hospital Anxiety and Depression Scale.	Patients' illness perceptions were found to explain the majority of variance in anxiety and depression. They found positive-focus coping strategies were associated with better psychological wellbeing. Carer illness perceptions were found to mediate the relationship between patients' perceptions and

---

				psychological distress.
<b>Dempster et al. (2010)</b>	189 patients	UK	The Hospital Anxiety and Depression Scale, The Cancer Coping Questionnaire, Illness Perception Questionnaire-Revised: a median of 48 months post diagnosis, repeated one year later.	They found that changes in psychological wellbeing are related to changes in illness perceptions. They report that participants' levels of anxiety and depression were similar to those reported for people with head and neck cancers but higher than for breast, prostate, bronchial and gastrointestinal cancers. They hypothesise this relates to the social implications of head and neck and oesophageal cancers. They found rates of anxiety and depression increased during the 12 months of the study.
<b>Wikman et al. (2015)</b>	1615	Sweden	National health registries' information on psychiatric diagnoses from 2 years pre-surgery until 2 years post-surgery.	Patients without a history of accessing psychiatric care were found to have accessed psychiatric inpatient care within 2 years post-operatively at a rate of 2.5%, psychiatric out-patient care at 4.2%, and treatment with psychotropic drugs at 32.3%. The authors conclude that this shows the importance of identifying psychiatric difficulties in oesophageal cancer patients.

---

## Appendix E: LITERATURE REVIEW TABLE 5

Summary table of qualitative studies on experience of oesophagectomy (pp. 35-40)

Authors	Sample	Count ry	Design	Conclusions
<b>Clarke, McCorry &amp; Dempster (2011)</b>	Five patients who had undergone oesophagectomy (3-17 years since diagnosis)	Northern Ireland, UK	Semi-structured interviews: Interpretative Phenomenological Analysis.	The theme of identity became central as participants tried to make sense of their experiences of O.C. and find meaning. Changed relationships with food, family and societal roles and the biomedical aspects of O.C. threatened their self-concept. The authors suggest that identity is a helpful framework for considering the impact of O.C. and its treatment. Social networks that nurture a positive sense of self should be encouraged and healthcare professionals must recognise the range of challenges to identity. Surviving patients may be able to help with adjusting patient expectations.
<b>Wainwright, Donovan, Vas Kavadas et al. (2007)</b>	11 patients (at least 3 months post-surgery)	UK	Qualitative interviews: thematic analysis	The study found that physical difficulties encountered by oesophagectomy survivors influenced their psychosocial wellbeing and a long period of adjustment

---

is likely to be required. The authors concluded that the magnitude of learning to eat again should not be underestimated and intensive professional support would enhance patients' experiences and adaptation.

**Jaromahum and Fowler (2010)**

Seven patients (between first and third meals post-oesophagectomy)

U.S.A.

Interviews:  
phenomenological analysis

This study aimed to explore patients' lived experiences of initial eating following oesophagectomy. Both physical and psychological problems were found to influence patients' experiences of eating. The authors reported that eating for the first time post-surgery was an emotional experience for all patients and healthcare professionals should recognise this. Participants expressed determination and that they would do whatever was required to improve.

**McCorry et al. (2009)**

12 oesophagectomy survivors (7 months to 17 years since surgery) and 10 carers.

Northern Ireland, UK

Focus groups:  
thematic analysis

They found three key themes for patients of '*coping with a death sentence*', '*adjusting to and accepting an altered self*' and '*unique benefits of peer support*' and for carers '*carer as buffer*', '*representations of recovery and recurrence*' and '*normalising experiences through peer support*'. The authors emphasise a holistic approach to support

---

---

in this context of threat to social, emotional and physical wellbeing, as well as the value of peer support.

**Andreassen et al. (2006)**

13 patients post-oesophagectomy

Sweden

Qualitative interviews: qualitative content analysis

Four themes were reported: *experiences of becoming a patient diagnosed with oesophageal cancer, experiences of undergoing investigations and treatment, experiences of intrusions in daily life, managing a life-threatening illness*. The authors found that participants were unprepared for receiving the diagnosis of oesophageal cancer and that their everyday lives were particularly affected by dysphagia, fatigue and uncertainty. Seeking information was a strategy used by participants for managing the illness, with healthcare professionals viewed as the main source of knowledge. Patients believed their partners to be struggling emotionally more than they themselves.

**Henselmans et al. (2011)**

20 patients, at least 3 months post-oesophagectomy.

The Netherlands

Semi-structured interviews: qualitative content analysis.

Patients' reported needing information in order to anticipate the future and reduce uncertainty. The authors described that factors influencing communication included: patient characteristics (e.g. a belief in their right to have information, experience with similar conversations), healthcare professional characteristics

---

---

(patients believing they will not be able to give an answer, or topics are not part of the staff members' jobs, or that they appear unfriendly hinder communication) and interaction characteristics (such as time and duration of knowing the physician). For patients, support of companions or pre-meeting preparation also reportedly made a difference. Many patients thought that facilitating interventions would be helpful (such as a written question prompt sheet, website or preparatory conversation a nurse prior to consultations with a doctor). Some patients also talked about appreciating example questions. They felt that these would show the type of questions appropriate to ask, reflecting the worry that their concerns may not fit the doctors' remit.

**Mills and Sullivan (2000)**

Seven patients: within 18-months since oesophagectomy.

Northern Ireland, UK

Semi-structured interviews: qualitative content analysis.

Patients described a wish for more information pre- and post-operatively. They emphasised expecting honest information from staff and valued staff who took time to speak with them, conveying interest and concern. Where staff were perceived as inaccessible this created barriers to communication. The

---

---

authors also identified that written information could be improved though being updated and that a staff education programme could improve delivery of information.

---

## APPENDIX F: NRES COMMITTEE ETHICAL APPROVAL



### Health Research Authority

NRES Committee London - London Bridge

Skipton House

80 London Road

London

SE1 6LH

Telephone: 020 7972 2491

21 September 2015  
Ms. Kirsten Stewart-Knight  
Camden and Islington NHS  
Department of Clinical Psychology  
University of East London  
Water Lane, Stratford E15 4LZ

Dear Ms. Stewart-Knight

**Study title:** The psychological impact of pre-operative chemotherapy treatment for oesophageal cancer: a mixed methods study.  
**REC reference:** 15/LO/1356  
**IRAS project ID:** 180740

Thank you for your letter of 15 September 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Kirstie Shearman on [nrescommittee.london-londonbridge@nhs.net](mailto:nrescommittee.london-londonbridge@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](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

#### Ethical review of research sites

##### NHS sites

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

##### Non-NHS sites

#### Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>	
Covering letter on headed paper [Cover letter, response to committee]	2	10 September 2015	
Covering letter on headed paper [Cover letter, response to committee]	3	15 September 2015	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of indemnity]	3	03 August 2015	
GP/consultant information sheets or letters [Key worker letter]	3	03 August 2015	
GP/consultant information sheets or letters [Clinical Nurse Specialist letter ]	4	04 September 2015	
GP/consultant information sheets or letters [GP letter]	4	04 September 2015	
Interview schedules or topic guides for participants [Interview schedule]	3	03 August 2015	
IRAS Checklist XML [Checklist_10092015]		10 September 2015	
IRAS Checklist XML [Checklist_15092015]		15 September 2015	
Other [email confirmation of lead sponsor ]		31 July 2015	
Participant consent form [Participant consent form]	3	03 August 2015	
Participant consent form [Participant consent form clean]	4	04 September 2015	
Participant consent form [Participant consent form]	5	15 September 2015	
Participant information sheet (PIS) [Participant Information Sheet]	3	03 August 2015	
Participant information sheet (PIS) [Participant Information Sheet clean]	4	04 September 2015	
Participant information sheet (PIS) [Participant Information Sheet]	5	15 September 2015	
REC Application Form [REC_Form_20072015]		20 July 2015	

Referee's report or other scientific critique report [Referee report]	3	03 August 2015	
Research protocol or project proposal [Research protocol]	3	03 August 2015	
Summary CV for Chief Investigator (CI) [Summary CV for CI]	3	03 August 2015	
Summary CV for supervisor (student research) [Summary CV for supervisor]	3	03 August 2015	
Validated questionnaire [Validated questionnaire (Hospital Anxiety and Depression Scale) ]	3	03 August 2015	
Validated questionnaire [Validated questionnaire (ESSI Social support measure)]	3	03 August 2015	
Validated questionnaire [The European Organization for Research and Treatment of Cancer quality of life questionnaire (specific)]	3	03 August 2015	
Validated questionnaire [The European Organization for Research and Treatment of Cancer quality of life questionnaire (general)]	3	03 August 2015	
Validated questionnaire [Self-Efficacy for Managing Chronic Disease Scale]	3	03 August 2015	

### Statement of compliance

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

### After ethical review

#### Reporting requirements

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

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>15/LO/1356</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

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

Yours sincerely

P.P. 

**Professor David Bartlett**  
Chair

Email: [nrescommittee.london-londonbridge@nhs.net](mailto:nrescommittee.london-londonbridge@nhs.net)

**APPENDIX G: UNIVERSITY OF EAST LONDON ETHICAL APPROVAL**

**NOTICE OF ETHICS REVIEW DECISION**

For research involving human participants

**BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology**

**SUPERVISOR:** Kenneth Gannon

**REVIEWER:** Jane Lawrence

**STUDENT:** Kirsten Stewart-Knight

**Title of proposed study:** The psychological impact of pre-operative chemotherapy treatment for oesophageal cancer: a mixed methods study.

**Course:** Professional Doctorate in Clinical Psychology

**DECISION** (*Delete as necessary*):

**APPROVED**

**APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to

her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

**NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**Minor amendments required** (*for reviewer*):

**Major amendments required** (*for reviewer*):

**Confirmation of making the above minor amendments** (*for students*):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*):

Student number:

Date:

**ASSESSMENT OF RISK TO RESEACHER** (*for reviewer*)

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

MEDIUM

X

LOW

*Reviewer comments in relation to researcher risk (if any):*

**Reviewer** (*Typed name to act as signature*): Jane Lawrence

**Date:** 6/6/2015

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)*

**PLEASE NOTE:**

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here:

<http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

UNIVERSITY OF EAST LONDON

School of Psychology

**REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mark Finn (Chair of the School Research Ethics Committee).

#### HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Mark Finn at [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk)
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are not to commence until your proposed amendment has been approved.

#### REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant:	Kirsten Stewart-Knight
Programme of study:	Professional Doctorate in Clinical Psychology
Title of research:	'The Psychological impact of pre-operative chemotherapy treatment for oesophageal cancer: a mixed methods study'
Name of supervisor:	Dr. Ken Gannon

Briefly outline the nature of your proposed amendment(s) and associated rationale(s)

in the boxes below

Proposed amendment	Rationale
Additional interviews with staff members of the NHS multidisciplinary team, who are working with patients we have ethical approval to interview (NHS and University of East London approvals).	In order to gain knowledge of staff members' valuable perspective on what patients say influences their experiences. This will also aid recruitment.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	YES	

Student's signature (please type your name): K Stewart-Knight

Date: 4<sup>th</sup> January 2015

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: M Finn

Date: 4/01/15



**APPENDIX H: CHANGE IN TITLE**  
**SCHOOL OF PSYCHOLOGY**  
[uel.ac.uk/psychology](http://uel.ac.uk/psychology)

Date: 30/03/2016

Student number: u1331817

Dear Kirsten,

**Notification of a Change of Thesis Title:**

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Both the old and new thesis titles are set out below:

**Old thesis title:** The Psychological impact of pre-operative chemotherapy treatment for oesophageal cancer: a mixed methods study.

**New thesis title:** Pre-Operative treatment for oesophageal cancer: perspectives and experiences.

Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K. Gannon'.

Dr Kenneth Gannon  
School Research Degrees Leader  
Direct line: 020 8223 4576  
Email: [k.n.gannon@uel.ac.uk](mailto:k.n.gannon@uel.ac.uk)





## Research Study Information Sheet

### UNIVERSITY OF EAST LONDON

School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

### Project Title

The psychological impact of pre-operative chemotherapy treatment for people with Oesophageal Cancer.

### Principal researcher

My name is Kirsten Stewart-Knight and I am a Trainee Clinical Psychologist at the University of East London. This study is being conducted as part of my Doctorate in Clinical Psychology.

### Introduction

I am doing a research study about people's experiences of chemotherapy treatment before surgery for Oesophageal Cancer. This information sheet is the first part of the informed consent forms for patients. We are inviting you to take part and the purpose of this information sheet is to explain what the study involves so that you can decide whether to participate.

Once you have read the information sheet, if you are interested in taking part let the member of staff who gave this to you know and I will contact you to arrange a time to meet. After reading this information sheet and taking time to think about whether you are interested in taking part in the study (and discussing this with another person you feel comfortable with if you wish to), we can arrange to meet and you will have an opportunity to ask any questions you have. If you are still interested in taking part in the study, you will be asked to read and sign a consent form. If you choose to participate, you will be given a copy of the full information sheet and consent form. You can ask questions at any time.

If you change your mind about taking part in the study you can withdraw at any time without giving a reason. It is your choice about whether you wish to participate or not. If you choose not to participate, all of the healthcare services you received will continue and nothing will change.

### Purpose of research

The project aims to understand the experiences and psychological wellbeing of patients currently having chemotherapy treatment for oesophageal cancer, where it is expected that they will later have surgery. There is currently little research that asks patients having this treatment about their experiences and psychological wellbeing. We are inviting patients who are having this treatment for Oesophageal Cancer at xxx NHS to take part in an interview. We believe that this might help us to better understand what patients who are having this treatment say about their experiences and what they think influences their psychological wellbeing during these experiences. We hope that this can help us to think about whether the way patients are currently supported could be improved.

### Why have I been asked to participate?

You have been selected to participate in this study because you are currently receiving chemotherapy treatment for Oesophageal Cancer and are expecting to have surgery at xxx NHS Trust. We are selecting patients at xxx NHS Trust who are having this particular treatment for Oesophageal Cancer.

### What is involved?

If you decide you are interested in taking part we will arrange to meet for an interview at a time and place convenient to you (this could be at your home or at a hospital). During this meeting, if after reading all of the information sheet and asking any questions you think you would like to take part, you will be asked to sign a consent form. If you give your consent to go ahead with the study we will begin the interview. You can change your mind and withdraw from the study at any time without giving a reason. This will not affect your medical care in any way.

### Risks of the study

We are asking you to share with us some personal and confidential information, and you may feel uncomfortable or distressed talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

If during the interview you would like to take a break or to end the interview early, you can do so at any time without having to give a reason. This would not affect your care in any way. We will write to your Clinical Nurse Specialist to let them know that you are taking part in the study and if you would like us to also notify your GP we can do so (you will be asked about this on the consent form). If during or after the interview you would like to talk further about your experiences of the interview, I will be happy to do so.

### Benefits of taking part

There will be no direct benefit to you, but your participation is likely to help us find out more about how to give better care and whether we should support people who are having this treatment differently in the future. Taking part in the study will provide an opportunity to talk about your experiences of this type of cancer and treatment and how you have coped with this, with the possibility of improving our understanding of the impact of this type of cancer treatment.

### Will my input remain confidential?

Yes. This study will follow strict ethical guidelines and legal practice to ensure that all of the information that you provide will remain anonymous. To ensure anonymity, identification numbers will be used for participant identification instead of names. Only the researcher (Kirsten Stewart-Knight) will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Electronic data will be stored on a password protected database and hard copies of recorded data will be kept in a locked filing cabinet. Once the study is finished identification numbers will be deleted and only anonymized transcripts will be kept. If you change your mind you can withdraw from the study at any time. If you do, up until the point of transcription, any information that you have given will not be used and this will not affect your care in any way.

Please note, it may be the case that some direct quotes will be included within the final report. However, all personal details that could be used to identify any one participant will be removed. Moreover, although it is not expected that the interview will reveal any information concerning harm to yourself or others, you should be aware that if such information should be disclosed, the researcher is duty bound to report this to the relevant professionals. We will routinely write to your Clinical Nurse Specialist to let them know that you are taking part in the study and your GP on your request.

### Arranging an interview

The interview will last less than one hour. You can choose for the interview to take place at a location of your choice which could be at a hospital or at your home.

The interview will be with Kirsten Stewart-Knight. I have an enhanced Criminal Record Check and am currently employed by the NHS with experience of working with people with cancer. During the interview, I will sit down with you in a comfortable and private place at the hospital or at your home. No one else but the interviewer will be present unless you would like someone else to be there. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question.

The format of the interview will be semi-structured, meaning that I will ask you some questions about your experiences of cancer and treatment and how you have coped

with this, but you are free to talk about the topics you wish to in relation to these general areas.

The whole interview will be tape recorded but only I (Kirsten Stewart-Knight) will access the information documented during your interview. No-one will be identified by name on the tape and the tape will be kept in a locked cabinet and on a password protected computer. The tapes will be destroyed after the words have been transcribed (this will be within a maximum 4 weeks of the interview).

If you are interested in taking part, when I contact you I will ask you about your preferences and will be happy to answer any questions you have.

### Reimbursement

If you travel to the hospital solely to meet for the interview, if you get a receipt for the specific journey we will be able to reimburse your travel expenses.

### Sharing the Results

At the end of the study (May 2016), I will be happy to send you a summary of the results. If you would like a copy of this please send a request to Kirsten Stewart-Knight using the contact details below. You will also be welcome to ask any questions you have at any point in the study. Following this, we aim that the research findings will be shared more broadly through a research journal and conferences.

### Do I have to take part?

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your medical care or the services you receive any way. You may stop participating in the interview] at any time that you wish without any disadvantage to you. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those.

### Who to Contact

My contact details are: Kirsten Stewart-Knight, 0780 44 99 125, [u1331817@uel.ac.uk](mailto:u1331817@uel.ac.uk) - please feel free to ask me any questions.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor: Dr. Kenneth Gannon at School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone: 020 8223 4174 or Email address: K.N.Gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

This proposal has been reviewed and approved by the University of East London Ethics committee and by the London National Research Ethics Service (London Bridge) which is a committee whose task it is to make sure that NHS research participants are protected from harm.

Please retain this information sheet for reference.

YOUR DECISION ABOUT WHETHER TO TAKE PART IN THIS STUDY WILL NOT EFFECT YOUR CARE IN ANY WAY

Thank you in anticipation.

Yours sincerely,

Kirsten Stewart-Knight

(Trainee Clinical Psychologist, Study's Chief Investigator)



## UNIVERSITY OF EAST LONDON

### Consent to participate in a research study:

*The psychological impact of pre-operative chemotherapy treatment  
for people with Oesophageal Cancer*

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research and the processes in which I will be involved have been explained to me. I have had the opportunity to discuss the details and ask questions about this information and any questions that have been asked have been answered to my satisfaction.

I have been told that my involvement in this study, and data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. I have been told that the researcher will write to my Clinical Nurse Specialist to inform them that I am participating in this study.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand **that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.** I also understand that should I withdraw following the transcription of the interview, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

I consent voluntarily to be a participant in this study:

Participant's Name (BLOCK CAPITALS) .....

Signature of Participant .....

Date .....

In addition to my Clinical Nurse Specialist, I **would** like you to write to my GP to let them know that I am participating in the study:

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

..... Date .....

GP name and  
address.....

.....

....

## **APPENDIX J: STAFF INFORMATION SHEET AND CONSENT FORM**

### Research Study Information Sheet

#### UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

### Project Title

The psychological impact of pre-operative chemotherapy treatment for people with Oesophageal Cancer.

### Principal researcher

My name is Kirsten Stewart-Knight and I am a Trainee Clinical Psychologist at the University of East London. This study is being conducted as part of my Doctorate in Clinical Psychology.

### Introduction

I am doing a research study about people's experiences of chemotherapy treatment before surgery for Oesophageal Cancer. This information sheet is the first part of the informed consent forms for patients at xxx NHS Trust. We are inviting you to take part and the purpose of this information sheet is to explain what the study involves so that you can decide whether to participate.

Once you have read the information sheet, if you are interested in taking part please respond to this email and I will contact you to arrange a time to meet. After reading this information sheet and taking time to think about whether you are interested in taking part in the study (and discussing this with another person you feel comfortable with if you wish to), we can arrange to meet and you will have an opportunity to ask any questions you have. If you are still interested in taking part in the study, you will be asked to read and sign a consent form. If you choose to participate, you will be given a copy of the full information sheet and consent form. You can ask questions at any time.

If you change your mind about taking part in the study you can withdraw at any time without giving a reason. It is your choice about whether you wish to participate or not. If you choose not to participate, all of the healthcare services you received will continue and nothing will change.

### Purpose of research

The project aims to understand the experiences and psychological wellbeing of patients currently having chemotherapy treatment for oesophageal cancer, where it is expected that they will later have surgery. There is currently little research that asks

patients having this treatment about their experiences and psychological wellbeing. We are inviting patients and staff to take part in an interview. We believe that this might help us to better understand what patients who are having this treatment say about their experiences and what they think influences their psychological wellbeing during these experiences. We hope that this can help us to think about whether the way patients are currently supported could be improved.

### Why have I been asked to participate?

You have been selected to participate in this study because you are a member of the Upper GI team working on the treatment pathway we are studying. We are inviting all members of the team to participate.

### What is involved?

If you decide you are interested in taking part we will arrange to meet for an interview at a time and place convenient to you (this could be at any of the hospital sites). During this meeting, if after reading all of the information sheet and asking any questions you think you would like to take part, you will be asked to sign a consent form. If you give your consent to go ahead with the study we will begin the interview. You can change your mind and withdraw from the study at any time without giving a reason. This will not affect your employment in any way.

### Risks of the study

We are asking you to share with us some personal and confidential information, and you may feel uncomfortable or distressed talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

If during the interview you would like to take a break or to end the interview early, you can do so at any time without having to give a reason. If during or after the interview you would like to talk further about your experiences of the interview, I will be happy to do so.

### Benefits of taking part

There will be no direct benefit to you, but your participation is likely to help us find out more about how to give better care and whether we should support people who are having this treatment differently in the future. Taking part in the study will provide an opportunity to talk about your experiences of this type of cancer and treatment and how you have coped with this, with the possibility of improving our understanding of the impact of this type of cancer treatment.

### Will my input remain confidential?

Yes. This study will follow strict ethical guidelines and legal practice to ensure that all of the information that you provide will remain anonymous. To ensure anonymity,



identification numbers will be used for participant identification instead of names. Only the researcher (Kirsten Stewart-Knight) will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Electronic data will be stored on a password protected database and hard copies of recorded data will be kept in a locked filing cabinet. Once the study is finished identification numbers will be deleted and only anonymized transcripts will be kept. If you change your mind you can withdraw from the study at any time. If you do, up until the point of transcription, any information that you have given will not be used and this will not affect your care in any way.

Please note, it may be the case that some direct quotes will be included within the final report. However, all personal details that could be used to identify any one participant will be removed. Moreover, although it is not expected that the interview will reveal any information concerning harm to yourself or others, you should be aware that if such information should be disclosed, the researcher is duty bound to report this to relevant professionals.

### Arranging an interview

The interview will last less than one hour. You can choose for the interview to take place at a location of your choice.

The interview will be with Kirsten Stewart-Knight. I have an enhanced Criminal Record Check and am currently employed by the NHS with experience of working with people with cancer. During the interview, I will sit down with you in a comfortable and private place at the hospital or at your home. No one else but the interviewer will be present unless you would like someone else to be there. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question.

The format of the interview will be semi-structured, meaning that I will ask you some questions about your experiences of cancer and treatment and how you have coped with this, but you are free to talk about the topics you wish to in relation to these general areas.

The whole interview will be tape recorded but only I (Kirsten Stewart-Knight) will access the information documented during your interview. No-one will be identified by name on the tape and the tape will be kept in a locked cabinet and on a password protected computer. The tapes will be destroyed after the words have been transcribed (this will be within a maximum 4 weeks of the interview).

If you are interested in taking part, when I contact you I will ask you about your preferences and will be happy to answer any questions you have.

### Sharing the Results

At the end of the study (May 2016), I will be happy to send you a summary of the results. If you would like a copy of this please send a request to Kirsten Stewart-Knight using the contact details below. You will also be welcome to ask any questions you

have at any point in the study. Following this, we aim that the research findings will be shared more broadly through a research journal and conferences.

### Do I have to take part?

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your medical care or the services you receive any way. You may stop participating in the interview] at any time that you wish without any disadvantage to you. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those.

### Who to Contact

My contact details are: Kirsten Stewart-Knight, 0780 44 99 125, [u1331817@uel.ac.uk](mailto:u1331817@uel.ac.uk) - please feel free to ask me any questions.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor: Dr. Kenneth Gannon at School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone: 020 8223 4174 or Email address: [K.N.Gannon@uel.ac.uk](mailto:K.N.Gannon@uel.ac.uk)

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk))

This proposal has been reviewed and approved by the University of East London Ethics committee and by the London National Research Ethics Service (London Bridge) which is a committee whose task it is to make sure that NHS research participants are protected from harm.

Please retain this information sheet for reference.

YOUR DECISION ABOUT WHETHER TO TAKE PART IN THIS STUDY WILL NOT EFFECT YOUR EMPLOYMENT IN ANY WAY

Thank you in anticipation.

Yours sincerely,

Kirsten Stewart-Knight

(Trainee Clinical Psychologist, Study's Chief Investigator)



**UNIVERSITY OF EAST LONDON**

**Consent to participate in a research study:**

*The psychological impact of pre-operative chemotherapy treatment  
for people with Oesophageal Cancer*

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research and the processes in which I will be involved have been explained to me. I have had the opportunity to discuss the details and ask questions about this information and any questions that have been asked have been answered to my satisfaction.

I have been told that my involvement in this study, and data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand **that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason**. I also understand that should I withdraw following the transcription of the interview, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

I consent voluntarily to be a participant in this study:

Participant's Name (BLOCK CAPITALS) .....

Signature of Participant .....

Date .....

## **APPENDIX K: PATIENT INTERVIEW SCHEDULE**

### *Patient interview schedule*

As the interviews will be semi-structured the following will guide the areas to be discussed.

#### **Introduction**

Explain consent, confidentiality and that the participant may withdraw at any time. Agree approximate length of interview and answer any questions or concerns participant wishes to discuss. Once consent process is complete, begin audiorecording.

#### **Areas for questions**

1. Can you tell me how you found out you had oesophageal cancer?
2. What has the experience of receiving treatment in preparation for the operation been like for you?
3. During these experiences, what have been the things you have found most difficult?
4. What have been the things that have been helpful in getting through this?

**Prompts:** What do you mean? What was that like for you? How does that make you feel? How do you think about that? Can you give me an example?

#### **Debriefing:**

- How do you feel about the conversation we have had today?
- Is there anything that bothered you about the interview?
- Is there anything that you'd like me to leave out of the transcript?
- Is there anything you would have wanted to say but didn't get to?
- Do you have any questions?
- You can contact me if you have any questions and here are some contact details for support organisations if you feel you'd like to talk to someone later on.

## **APPENDIX L: STAFF INTERVIEW SCHEDULE**

### *Staff interview schedule*

As the interviews will be semi-structured the following will guide the areas to be discussed.

#### **Introduction**

Explain purpose, consent, confidentiality and that the participant may withdraw at any time. Agree approximate length of interview and answer any questions or concerns participant wishes to discuss. Once consent process is complete, begin audiorecording.

#### **Areas for questions**

1. Can you explain to me your role in the team? How long have you been working with patients with potentially curable oesophageal cancer?
2. From your experience, what is the process leading up to surgery like for patients having chemotherapy? Can you give examples?
3. What do you think the biggest challenges are for patients? Can you give examples?
4. What do patients say is most helpful? Can you give examples?
5. Do you have a sense of what makes a difference to patients' experiences? (Demographic and individual differences?)
6. Within your role what makes a difference to whether you feel you are effective are not? What are the skills, environmental factors, experiences or attitudes patients might have that make a difference to how effective your role is?
7. Anything I have not asked you about that you think is important to understand about the experiences of patients having this treatment?

**Prompts:** What do you mean? How do you understand that? Why do you think that is? How do you think about that? Can you give me an example?

**Debriefing:**

- How do you feel about the conversation we have had today?
- Is there anything that bothered you about the interview?
- Is there anything that you'd like me to leave out of the transcript?
- Is there anything you would have wanted to say but didn't get to?
- Do you have any questions?
- You can contact me if you have any questions and here are some contact details for support organisations if you feel you'd like to talk to someone later on.

**APPENDIX M: TRANSCRIPTION KEY, PARKER (2005)**

( ) Indicates pause in speech

[unclear] Indicates speech was unclear

[ ] Indicates when a comment has been added by the author

< > Indicates interruption

/ Indicates overlapping speech

- Indicates unfinished word

APPENDIX N: EXAMPLE OF TRANSCRIPT WITH INITIAL OBSERVATIONS

Interviewer: Would you mind saying a bit more about what it's been like to have chemotherapy?

Peter: The answer is (), I expected it to be worse than it is. I expected to feel much more sick, the sickness tablets worked very well and when I ran out my GP just prescribed 100 more tablets and said 'you can take these for the rest of your life if you like, they won't do anything'. I expected to lose weight, the first round my weight was stable, the second I actually put on weight which convinced me that the thing was shrinking because I was swallowing better. The pain had gone too because the lymph nodes were swollen around it. There is always any uncertainty with chemotherapy about a) whether it's working and b) what are the side effects going to be, erm and is it damaging anything else and the experience in the suite when they do the liquid injection of noxis fluids, was actually really nice, it's like an airport waiting room with relaxing chairs and stuff. They did actually talk about what they're doing all the time which was nice.

Media portrayals of cancer patients?

Side effects better than expected

Noticing effects of chemo.

Aware of uncertainties and risks

Nicer than expected.

Explanations are important.

As though it was somewhere else?

They would also answer a question if you didn't know what they were doing and the funny thing was they keep asking who you were but that's ok I can understand why that is. You could actually see the process working very well. You know I'm into process. I like to see a process running well and their systems for checking clearly ran very well () and that gives you great confidence you know. The process of sitting there and injecting you and telling you what it's for or whatever else and letting you get up because when they've injecting 2 litres of saline you need to go to the loo, there's no question, so you trot off with your stand. They were very helpful and people brought sandwiches and coffee and it was not unpleasant at all () it was much longer than I expected but that's ok. The second time you know. The first time, not knowing what to expect that's the thing. The other thing was that my sleep pattern was wrecked. You know I kept waking. I think the tablets I was taking were slightly diuretic, which as you get older isn't good anyway, so I was still waking up every 2 hours and because you're drinking a lot of fluids because you've been told to. No body warns you that you

unfamiliar hospital processes. Seeing them running well increases confidence.

HCPs have control?

Learning through experience.

Not knowing what to expect.

No warning! Side effects unexpected

might get sleep pattern interruption. It would have helped to know that. You know 'it may hit your sleep pattern and don't worry about it just'. The other thing that happens is they said 'don't stay in bed all day'. But then when you think you know 'I must go to sleep this afternoon' you feeling guilty about going off to sleep in the afternoon for a couple of hours, but when you're so tired because you've only had six hours or five hours sleep ()

Reassuring

Knowing what might happen helps.

Trying to follow medical advice.

Impact of chemo

Feeling guilty/ needing to justify.

Interviewer: For you personally what's been the most difficult part of this?

Side effects impact on everyday

Peter: The muzziness () and how bad it could be, it hasn't stopped me from doing work but I've had to remember to do it <laughter> And information about how bad it could be and my daughter and son-in-law have both said 'you've managed brilliantly when we see what some people get up to, you haven't been sick' and I haven't. My wife () and that's the other thing,

Sharing experience with wife.

Idea of 'it could be worse'

people who are single it must be terrible. At least you can say, 'I feel like shit I'm sorry', and the funny other thing is you've got your personal trainer, the exercise therapist, sending you things to do, and the exercise therapist the instructions say 'even if you don't feel like it get on and do it'. There was one day when I just couldn't I just said I'm sorry I am not going for a three mile walk today and she said 'listen to your body' and I said why don't you say that on there and she said because if I did everybody would not do it. I said you know there are days when I just don't feel up to doing all of this power walking but I've done it, almost every day I have done some walking and I've got a cross trainer in there, it was in the garage but we've brought it back in here to keep me warm. Mind you I only do 2 or 3 minutes on it because it's actually on quite a high setting, the whole thing has been manageable but I've felt stupid at times because I've thought 'did I not listen' because that's one very distinct possibility that when somebody's

Trying to follow medical advice.

Pushing self to follow programme

Lots of information - hard to absorb

giving you a lot of information that you didn't listen to what they said erm () but my wife has always been with me for every meeting but she says 'no they didn't say that' she's very useful. Care and help from wife

Worry of being stupid or not listening.



## APPENDIX O: INITIAL PATIENT CODEBOOK

1. My responsibility/my part
2. Continuing uncertainty through chemotherapy
3. Preparation now will have an impact on surgery
4. Doctor's expertise and power
5. Prioritising work over health
6. Regrets not presenting earlier
7. Current circumstances pushed to do things would usually avoid
8. Response typical of me
9. Impact on everyday life
10. Difficult life experiences at the same time as beginning to notice symptoms
11. Symptoms worsening and worry increasing
12. Family experiences of cancer
13. Symptoms seeming insignificant until later
14. Trying not think about it
15. Not looking like someone with cancer (linked with not being defined as someone with cancer)
16. Never heard of oesophageal cancer
17. Risks and responsibility for smoking/drinking/weight
18. It's about luck
19. Loss of eating (food everywhere, feeling excluded)
20. Worries about the gravity of this operation and aftermath
21. Advocating for self/navigating the healthcare system
22. Stopping cancer taking over
23. Others not always getting it right but their efforts help
24. Waiting for next step in treatment
25. Not knowing what to expect from chemo
26. Process of getting familiar
27. Staff help
28. Determination
29. Prayer helps
30. Not being alone for operation
31. Varied experience of chemo
32. Taking your mind off it
33. Change in speed once at cancer centre
34. Being in professionals hands - giving over control.
35. Whole team thinking about and explaining
36. Surgery - best chance
37. Seeing results from chemo encouraging
38. Other patients are worse off than me
39. Constantly thinking about next step
40. Practical concerns
41. Explaining properly and knowing what to expect
42. Family support helpful
43. You need a point of contact in the team

44. Surprised myself by not being frightened
45. Get on with it attitude
46. Risk of death
47. Still the same me
48. NHS admin system
49. Worry about loved ones
50. How do others less confident/intelligent/more anxious cope
51. People assuming you know
52. Life changes after surgery
53. Not feeling ill pre-op
54. Surgery offers hope/cure
55. Turning worries into positives
56. Pushing myself to follow advice
57. Work as important
58. Feeling stupid
59. Support of friends
60. Being open about cancer
61. Life happens
62. Others' responses
63. Hope and disappointment
64. Staying positive
65. Focusing on what needs to be done
66. Physically feeling well
67. Decision to have treatment no brainer
68. Seeing results from chemotherapy
69. Making sense of it
70. Choosing happiness
71. Treated like an individual
72. Building up fitness
73. Wanting to get the operation over
74. Wanting to delay the operation
75. Cancer diagnosis
76. Relying on yourself
77. Recovery taking time

## APPENDIX P: INITIAL CODEBOOK, STAFF

1. Uncertainty: curative plan, changing to palliative.
2. Surgery offering cure
3. Massive journey to get to surgery
4. Diverse responses to the long journey
5. Ideas about chemotherapy
6. Completely different experiences of chemo
7. Anxiety at the beginning, likely to struggle with treatment
8. Unpredictable how patients will experience treatment
9. Some who struggle at the start surprise the team
10. Family pressure leads patients to comply and be more engaged.
11. Patients without a family network more likely to struggle
12. A lot of information to take in
13. Patients who have been active more likely to engage in preparing for surgery.
14. Support from other patients
15. Engagement predicts experience
16. Different context to healthcare in previous times, expectation patients influence care
17. Team offering a personalised approach - likely to be different from previous experiences of healthcare
18. Masculinity influencing experience
19. Initially patients not reporting difficulties
20. Seeing a whole team not just 1 member of staff
21. Staff delivering on promises makes patients more confident
22. Small proportion of older patients fit for surgery
23. Physiological insult of surgery
24. Implications not talked about
25. Not wanting to dissuade people from treatment
26. Influence of home environment on experience
27. Nutritional impact of surgery
28. Patients don't understand implications
29. Everyone trying to be positive in contrast to awful ideas about cancer in the past
30. Oesophageal cancer worst procedure
31. Differences in expectation and outcome
32. Central role of family
33. Some patients frustrated by so many appointments and tests
34. Need to move quickly with this cancer
35. Some patients frustrated that system can't be flexible around them.
36. Younger patients tend to be more anxious
37. Higher social class more anxious
38. Older patients often more resigned
39. Demographics make a difference to experience
40. Supportive family as advocates
41. Anxiety can lead to demanding things that can't be done
42. Consumerist approach of some patients trying to get the process to move quicker than it can

43. Decisions about how much information to share
44. Passive role of patient - often want to be told what to do
45. Patients wishes often different from patient centric fashion
46. Oesophageal cancer less possible to be positive
47. Human support makes a difference
48. Structured pathway fits for some and not others
49. willingness to engage with structured pathway relates to class (active and passive related to class)
50. Key nutritional challenges
51. Pre surgical health predicts outcome of surgery
52. Uncertainty about whether surgery can go ahead
53. Wide variety of pre-op symptoms
54. Process of coming to terms with diagnosis
55. Best case scenario - early cancer
56. Worst case scenario - very rapid
57. More difference between patients in OC than other cancers
58. Social support makes more of a difference in OC than other cancers
59. Family support has a role in food preparation
60. Central role of food in this cancer
61. Carers need perserverance
62. Seriousness of O.C.
63. Patients knowing they are close to not making it
64. Motivated by goal
65. Different from other cancers
66. Hope and risks
67. Chemo seen as something that will move them closer to the goal
68. Ethnicity seems less influential than other areas
69. Education higher anxiety
70. Patient ownership influences experience
71. Structure and clarity of care pathway leads to more ownership
72. Social support and survival
73. Optimising pre-op through exercise aiming to prevent weight loss
74. Push patients hard in exercise pre-op
75. Pre-op exercise the one thing patients can control
76. Patients' support needs vary
77. Working to maintain activity through chemotherapy
78. Optimising pre-op is counterintuitive and educating patients about this
79. Supporting patients to no be fearful of the fatigue
80. Control is the key thing
81. Post chemotherapy tough
82. Exercise and maintaining fitness leading to feeling in control
83. Having understanding of what's happening in body helps
84. Small breakthroughs
85. Patients' psychology makes a difference
86. Not having social support, more difficult
87. Normalising helps

88. Other patients, unique shared experience
89. Social support and adherence
90. Carers - someone else to take the pressure off
91. Social support = reasons to get better (MOTIVATION)
92. Loss of control
93. Knowing history helps to make sense of behaviour
94. Past experiences influence experience of OC
95. Pre-op phase a fragile stage
96. Respecting patients' time
97. Class or intelligence makes a difference
98. Adherence and mental health
99. Patients more likely to tell non-medical staff things
100. O.C. toll physically and psychologically
101. Particular characteristics of this cancer relating to demographics
102. Risks with this surgery
103. Psychological preparation for surgery
104. Information helps patients to prepare for surgery
105. Motivation linked with feeling ill
106. Information , motivation and psychological preparation
107. Engagement
108. Exercise improving mood
109. Knowing whole team is looking after me helps
110. Reciprocal efforts
111. Variations in engagement with treatment
112. Tailoring staff approach to individual patient
113. Family support mediates language barriers
114. Patient factors influence how successful care can be
115. Some patients wish it could be removed straight away
116. Seeing results of chemo psychologically helps
117. Why can't you just do the surgery now?
118. If the patient understands why they cope better
119. Not spending too long at 'why me' helps patient cope better
120. Physical effects don't predict psychological
121. Social support isn't the full story of who copes better
122. People who know the most more anxious
123. Making a decision 'this is not going to consume me
124. Having someone makes a difference
125. Believing in something you can rely on helps
126. Huge loss of eating
127. Aim to be holistic
128. Chemo can give time to adjust
129. Trying to get into the best possible position
130. Different patients want different levels of information
131. Between the devil and the deep blue sea
132. A cohesive support structure makes a difference
133. Thinking about the whole person makes a difference

134. Demographics don't predict, it's more complicated than one factor
135. Reasons to live for
136. Seeing beyond diagnosis
137. Person to person
138. adjusting to being 're-plumbed'
139. Survival mode
140. Surgery offering hope
141. Some feeling unwell when they present, chemotherapy makes it worse.
142. Focus moves from getting through chemotherapy to surgery
143. Uncertainty (hidden)
144. The treatment plan gives hope
145. Worry about chemotherapy (media representations)
146. Side effects of chemo
147. Wanting the cancer to be cut out
148. Uncertainty post-surgery
149. Realistic expectations and reducing uncertainty
150. Other patients, reducing fear
151. Controlling what they can
152. Individual differences
153. Trying to get into the best possible position
154. Pre-surgery scary to know what's ahead
155. Difficult to process feelings pre-op
156. Hard to get your head round the information pre-op

## APPENDIX Q: EXTRACT FROM CODING TABLES

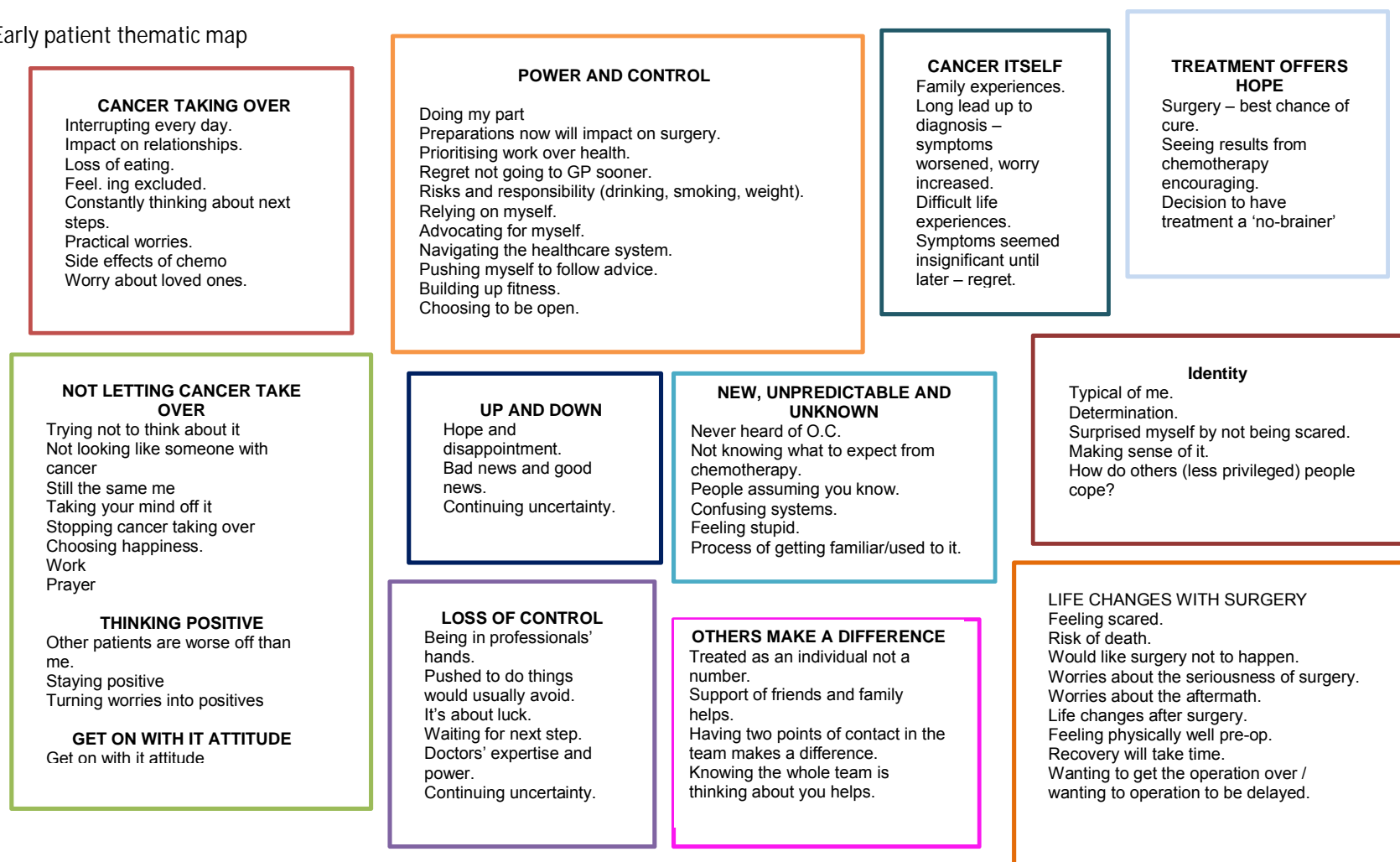
Code	Example Extracts
PATIENTS:  Taking your mind off it	<p data-bbox="667 348 1409 730">Audrey: "I was a bit shocked to be truthful, and walking it home, walking to the bus stop I'm thinking about it, on the bus I'm thinking about it and my mind said 'look, stop thinking about it you're just going to wear yourself down thinking about it all the time'. So sometimes I think about it, sometimes I don't think about it, I try to take it off my brains because otherwise it's just going to put me down and make me feel sad and miserable and (laughter) I don't want to feel like that."</p> <p data-bbox="667 800 1409 1031">Audrey: "It has been working for me [not thinking about it]....It's like if you have a problem and you think about it like a problem with your boyfriend and you have an argument and you think about it constantly you won't concentrate on you're doing at work and so forth, so you have to cast it off your mind."</p> <p data-bbox="667 1052 1409 1188">Abdul: "My children say to me you have to be positive and brave, they always tell me don't think about too much, just stay positive. It helps me."</p> <p data-bbox="667 1209 1409 1388">Carole: "I'm trying not to think too much about the next bit because it's quite a big bit, just the way I'm trying to compartmentalise things at the moment and keep them in little blocks."</p> <p data-bbox="667 1409 1409 1692">Joe: "...if you're still above that line there's a good chance you're not going to die from it and so you should bloody well treat it as though you're not going to die and be as positive as you can and do as much as you can. Just assume and act as though you are about to not die...so when he said treatable and curable, I think my head kicked into that."</p>
STAFF: Hope and risks	<p data-bbox="667 1709 1409 1900">Emma: "It is partly the chemotherapy () and being so focused on surgery and getting the chemotherapy to work . They often have such hopefulness that the tumour will shrink but they understand if it can't shrink it won't be taken out."</p>

	<p>Olivia "...I think sometimes and I tend to use this with patients you get the impression that they feel they're stuck between the devil and the deep blue sea, on the one hand they desperately don't want to have the surgery and they're terrified of it and the impact it will have and the way it will interfere with their life as they know it, but on the other hand they know that it's the only key to life and living and so it's that huge unknown . Nobody would ever want to be in that position."</p>
	<p>Josh: "We don't want to dissuade people from having a potentially curative operation or scare them but it is rather brushed over historically and so not often covered. And so inevitably erm () this often results in people losing aspects of their independence and requiring additional support from family and so forth () and whether that is something that's attainable depends on the family set up, the network, the home....and you know that I think is a huge impact for the people."</p>
	<p>Sarah: "If we're just talking about the neoadjuvant it doesn't always turn out that way, meaning they don't always end up having the surgery and with that group of patients it's more challenging. Because they start off with this goal and if the goal shifts a little bit I think that's where things get more challenging for patients and for medical staff too for some degree because if you're scanning them to prepare them for surgery, then all of a sudden they have liver bone mets and they can't go onto have that treatment because intent of their surgery switches from neoadjuvant to palliative now, it can be a little bit challenging."</p>



## APPENDIX R: EXAMPLES OF PROGRESSING THEMATIC MAPS

Early patient thematic map



## Intermediate provisional patient themes

### **TAKING POWER AND CONTROL**

Doing my part  
Preparations now will impact on surgery.  
Prioritising work over health.  
Regret not going to GP sooner.  
Risks and responsibility (drinking, smoking, weight).  
Relying on myself.  
Advocating for myself. Navigating the healthcare system.  
Pushing myself to follow advice.  
Building up fitness.  
Choosing to be open.

### **LOSS OF CONTROL**

Being in professionals' hands.  
Pushed to do things would usually avoid.  
It's about luck.  
Waiting for next step.  
Doctors' expertise and power.  
Continuing uncertainty.

### **CANCER TAKING OVER**

Interrupting every day.  
Impact on relationships.  
Loss of eating.  
Feeling excluded.  
Constantly thinking about next steps  
Practical worries.  
Side effects of chemo.  
Worry about loved ones.

## Theme 1: POWER

### **NOT LETTING CANCER TAKE OVER**

Trying not to think about it  
Not looking like someone with cancer  
Still the same me  
Taking your mind off it  
Stopping cancer taking over  
Choosing happiness.  
Work  
Prayer

### **THINKING POSITIVE**

Other patients are worse off than me.  
Staying positive.  
Turning worries into positives.

### **GET ON WITH IT ATTITUDE**

Getting on with it  
Focusing on what needs to be done

## Theme 2: CHALLENGES OF TREATMENT

### NEW, UNPREDICTABLE AND UNKNOWN\*

- Never heard of O.C.
- Not knowing what to expect from chemotherapy.
- People assuming you know.
- Confusing systems.
- Feeling stupid.
- Process of getting familiar/used to it.

### TREATMENT OFFERS HOPE

- Surgery – best chance of cure.
- Seeing results from chemotherapy encouraging.
- Decision to have treatment a ‘no-brainer’

### CANCER ITSELF\*

- Family experiences.
- Long lead up to diagnosis – symptoms worsened, worry increased.
- Difficult life experiences.
- Symptoms seemed insignificant until later –

### UP AND DOWN

- Hope and disappointment.
- Bad news and good news.
- Continuing uncertainty.

### Identity

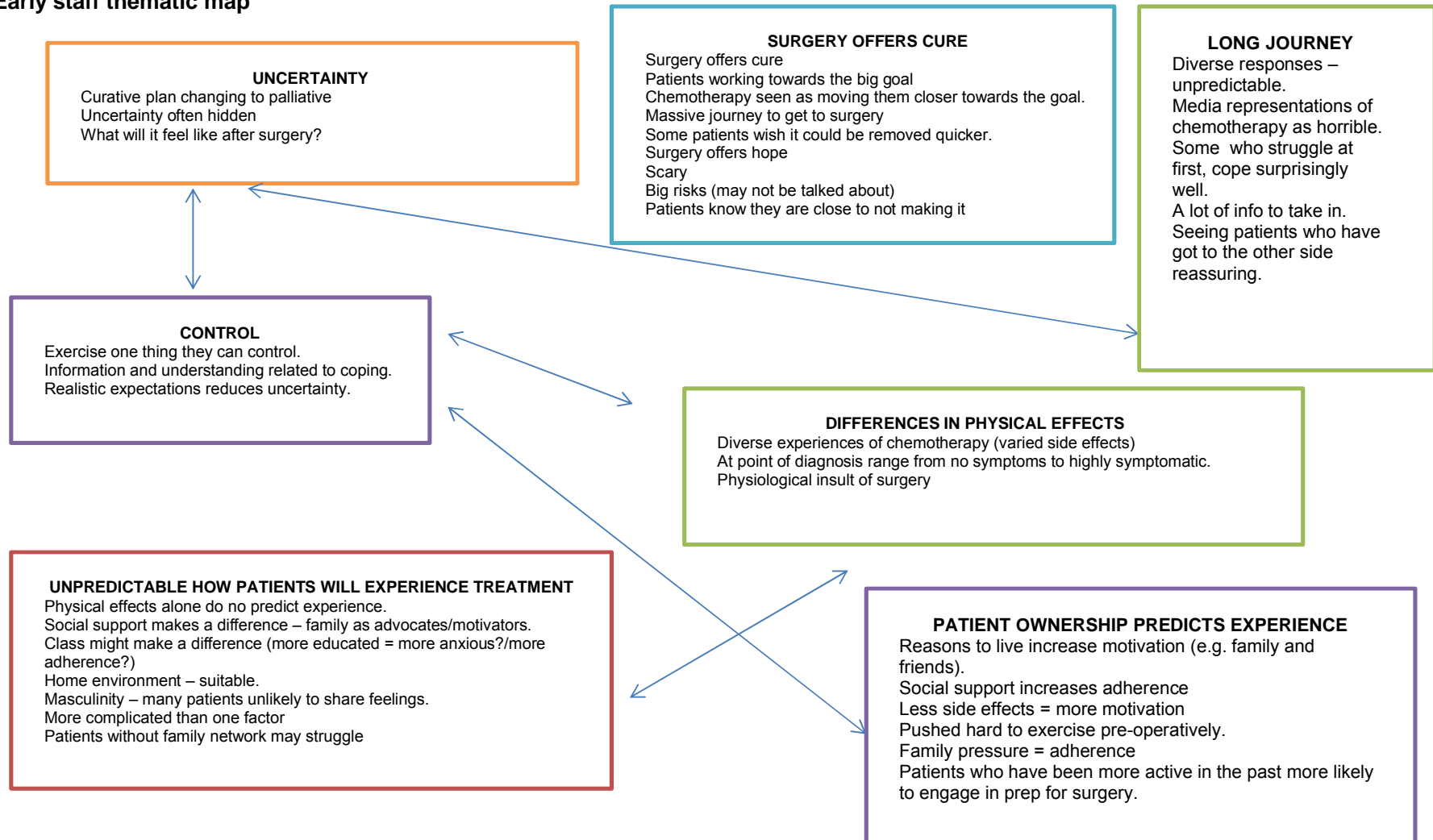
- Typical of me.
- Determination.
- Surprised myself by not being scared.
- Making sense of it.
- How do others (less privileged) people cope?

## Theme 3 EFFECTS ON SELF AND OTHERS

### OTHERS MAKE A DIFFERENCE

- Treated as an individual not a number.
- Support of friends and family helps.
- Having two points of contact in the team makes a difference.
- Knowing the whole team is thinking about you helps.
- Staff explaining everything –helps to know what to expect.

## Early staff thematic map



## Intermediate staff themes

### LONG JOURNEY

Massive journey to get to surgery, diverse responses –unpredictable.  
Uncertainty (hidden) – whether surgery can go ahead  
Worry about chemotherapy (media representations)  
May be keen to have cancer cut out ASAP – why can't you just do the surgery now?  
A lot of info to take in.  
Seeing patients who have got to the other side reassuring.  
CONTROLLING what they you can – control key  
Exercise, information and understanding related to coping.  
Realistic expectations reduces uncertainty.  
Hard to get your head around the information pre-op.  
In survival mode/difficult to process feelings.  
Scary to know what's ahead  
Focus moves from getting through chemotherapy to surgery  
Some feeling unwell when they present, chemotherapy makes it worse.  
Some patients frustrated by appointments and tests.  
Chemotherapy seen as something that will move them closer to the goal.  
Chemotherapy can allow time to come to terms with situation.  
treatment plan gives hope. seeing results of chemo encouraging.  
Between the devil and the deep blue sea  
Central role of food and loss for patients who cannot eat.  
If patients understand what is happening, they cope better.  
Patients want different levels of information.

### THE GOAL OF SURGERY

Surgery offers cure  
Motivating to work towards this goal.  
Chemotherapy seen as moving them closer towards the goal.  
Some patients wish it could be removed quicker.  
Surgery offers hope  
Scary

“Between the devil and the deep blue sea”

### RISKS OF SURGERY

Biggest procedure possible – huge physiological insult.  
Implications difficult to talk about because of tension of not wanting to dissuade people from life-saving treatment – dilemmas about how much information to share.  
Big risks (may not be talked about)  
Patients know they are close to not making it: seriousness of O.C. changes experience and motivation.  
Impossible for patients to understand the implications – differences in expectation.

### CARE PATHWAY AS A BUFFER

Different context to paternalistic healthcare in previous times – expectation that patients influence care.  
Team offering a personalised approach - likely to be different from previous experiences of healthcare  
Seeing a whole team looking after them, not just 1 member of staff  
Staff delivering on promises makes patients more confident  
Need to move quickly with this cancer  
Pre surgical health predicts outcome of surgery  
Seeing beyond the diagnosis to the person.  
Person to person relationships.  
A cohesive support structure makes a difference  
Thinking about the whole person makes a difference  
Trying to get into the best possible position  
Aim to be holistic  
Structure and clarity of care pathway leads to more ownership  
Realistic expectations and parameters reduce uncertainty  
Reciprocal efforts (team and patient)  
Working to maintain activity through chemotherapy  
Optimising pre-op is counterintuitive and educating patients about this  
Supporting patients to not be fearful of the fatigue  
Exercise therapy – small breakthroughs – push patients hard during pre-op phase.  
Exercise improves mood  
Tailoring approach to individual patient  
Normalising  
Information about what they need to do part of psychological preparation for surgery  
Information, motivation and psychological preparation  
Patient factors influence how successful care can be (like nucleus)

### UNPREDICTABLE HOW PATIENTS WILL EXPERIENCE TREATMENT

Physical effects alone do not predict experience.  
Social support makes a difference – family as advocates/motivators/ reasons to live for but not the full story of who copes better.  
Class might make a difference (more educated = more anxious? / more adherence?)  
Home environment – suitable.  
Masculinity – many patients unlikely to share feelings.  
More complicated than one factor  
Patients without family network may struggle

### DIFFERENCES IN PHYSICAL EFFECTS

Diverse experiences of chemotherapy (varied side effects)  
At point of diagnosis range from no symptoms to highly symptomatic.  
More differences between patients experiences in this cancer than others – role of food?  
Decision – this will not consume me, not spending too long thinking 'why me'

### PATIENT OWNERSHIP PREDICTS EXPERIENCE

Reasons to live increase motivation (e.g. family and friends).  
Social support increases adherence  
Less side effects = more motivation  
Pushed hard to exercise pre-operatively.  
Family pressure = adherence  
Patients who have been more active in the past more likely to engage in prep for surgery.  
Variations in engagement with treatment

