Uncharted territory: Exploring Psychological Adjustment to Esophagectomy Surgery in Adults with Oesophageal Cancer

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Date of Submission: 5th May 2026
Thesis Portfolio Word Count: 28,730
Candidate Registration Number: 100093365

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Thesis Portfolio Abstract

Background: Oesophageal cancer is a significant global health concern, with oesophagectomy being a key curative treatment for many patients. However, the procedure is physically demanding and can result in substantial changes to eating, bodily functioning and quality of life. Despite this, the psychological impact of the surgery remains comparatively under-researched, particularly in relation to longer-term adjustment and survivorship.

Method: This portfolio aimed to explore psychological distress and adjustment following oesophagectomy for oesophageal cancer. The systematic review synthesised quantitative evidence of the prevalence and trajectory of anxiety and depression post-oesophagectomy. The empirical paper explored the psychological experiences of adults living one to five years following oesophagectomy. Semi-structured interviews were conducted with 11 participants and analysed using reflexive thematic analysis.

Findings: Results from the systematic review suggest that psychological distress is a significant and non-linear concern, with anxiety and depression persisting or re-emerging for some individuals beyond the acute postoperative period. The results highlighted a predominantly biomedical focus within the literature, with less attention given to psychological mechanisms of adjustment.

In addition, five interrelated themes were generated from the empirical paper: (1) existential threat and emotional survival, (2) relational trust and safety underpinning engagement, (3) making sense of illness through knowledge and cognitive strategies, (4) negotiating acceptance, control, and autonomy, and (5) living with change: adaptation, loss and quality of life. Findings suggest that adjustment was an ongoing and non-linear process shaped by uncertainty, bodily changes, altered autonomy, identity disruption and relational support.

Conclusion: Together, the portfolio demonstrates that recovery following oesophagectomy extends beyond physical survival and surgical recovery. Psychological adjustment involves the ongoing reconstruction of life and self in the context of bodily and relational change. The area remains sparse with psychological research not keeping pace with advances in surgical procedures and improved prognosis. The findings highlight the need for a broader biopsychosocial survivorship approach, including routine psychological screening, staged information provision, relational continuity and further research into longer-term adjustment following oesophagectomy.

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Table of Contents

Chapter One 10
Introduction to Thesis Portfolio 10
Chapter 2 16
Systematic review 16
Abstract 18
Background 19
Aims: 21
Method 21
Search Strategy 21
Study Selection 22
Data Extraction and Study Quality Assessment 23
Results 24
Study and Sample Characteristics 24
Quality Appraisal of Studies 27
Prevalence of Anxiety and Depression 29
Early Postoperative Period (Pre-surgery to one month) 30
Short-Term Follow-up (>three months post-surgery) 30
Longer-Term Follow-up (>six months post-surgery) 31
Factors Associated with Anxiety and Depression 32
Discussion 33
Summary of Findings 33
Trajectories of Distress After Surgery 34
Factors Associated with Anxiety and Depression 35
Strengths and limitations 35
Implications for Research and Clinical Practice 37
Conclusion 38
Statements and Declarations 39
References 40
Chapter Three 46
Bridging Chapter 46
Chapter Four 48
Empirical Paper 48
Abstract 50
Introduction 51
Research Questions 53

Method: 53
Design 53
Participants 54
Procedure 54
Data Analysis 54
Results 55
Overview of Themes 56
Discussion 64
Strengths and limitations 66
Clinical and Research Implications 67
Conclusion 69
Statements and Declarations 70
References 71
Chapter Five: Extended Methodology 75
Methodological Rationale 75
Ontology and Epistemology 75
Introduction to Reflexivity 76
Personal Reflexivity Applied Within this Study 77
Study Design and Recruitment 78
Ethical Considerations 78
Consent 78
Confidentiality 79
Participant Wellbeing and Distress 79
Participants 80
Inclusion and Exclusion Criteria 80
Sampling Strategy and Recruitment Procedure 81
Development of Interview Topic Guide 82
Data collection 83
Analysis 83
Familiarisation with the data: 83
Generating initial codes: 83
Searching for themes: 84
Reviewing potential themes: 84
Defining and naming themes: 85
Producing the report: 85
Dissemination 85
Chapter Six 86

Critical Evaluation and Discussion....86
Summary of Findings....87
Strengths and Limitations....90
Clinical implications....93
Research Implications and Suggestions for Further Research....95
Conclusion....96
Portfolio References....97
Appendices....113

List of Tables

Introduction to Thesis Portfolio

None

Systematic Review

Table 1. Study Characteristics

Table 2. Quality appraisal of a cross-sectional study

Table 3**.** Quality appraisal of cohort studies

Bridging Chapter

None

Empirical Paper

Table 1. Participant Demographic Information

Extended Methodology for Empirical Paper

None

Critical Evaluation and Discussion

None

List of Figures

Introduction to Thesis Portfolio

None

Systematic Review

Figure 1. Prisma Flow diagram

Bridging Chapter

None

Empirical Paper

Figure 1. Codes and Themes

Extended Methodology for Empirical Paper

None

Critical Evaluation and Discussion

None

List of Appendices

Appendix A: Authors Guidelines for Journal of Cancer Survivorship

Appendix B: Synthesis Without Meta-analysis (SWiM) guidelines

Appendix C: JBI Checklist for Cross-sectional Studies

Appendix D: JBI Checklist for Cohort Studies

Appendix E: Extract from Reflecting Diary

Appendix F: Confirmation of Ethical Opinion from the Health and Social Care Research Ethics Committee

Appendix G: Confirmation of Ethical Opinion from the Health Research Authority

Appendix H: Capacity and Capability Approval from the Norfolk and Norwich University Hospital

Appendix I: Consent Form

Appendix J: Participant Distress Protocol

Appendix K: Participant Information Sheet

Appendix L: Debrief sheet

Appendix M: Advertisement Poster

Appendix N: Confirmation of Amendment Approval from the Health Research Authority

Appendix O: Confirmation of Amendment Approval from the Health and Social Care Research Ethics Committee

Appendix P: Topic Guide and Demographic Questionnaire

Appendix Q: Example of transcript analysis

Appendix R: Example of coding

Appendix S: Example of code refinement on excel

Acknowledgements

I would like to take the opportunity to say a big thank you to my supervisor, Adrian, who has been such a great support throughout my training journey. Thank you for your continued guidance, support and breadth of knowledge you have shared with me over the years. Thank you for always bringing a more balanced and grounded perspective when things were feeling too much.

I would also like to extend my thanks to John and Sophie for your support and without whom this project would not have been possible. I am equally grateful to Tamara and Angela for all of your support with recruiting and for offering a helping hand where possible.

To my family, Mum, Dad, Lyn, Georgia, Declan and my lovely niece and nephews. Thank you for holding onto the belief that I could do this, especially on the days when I struggled to hold it for myself. Thank you for your endless support, encouragement and love, and for giving me the space to escape from work and just be a daughter, sister, and auntie. I love you all very much.

To my partner, Conor, thank you for everything. Thank you for always believing in me and encouraging me to do difficult things. Thank you for the silliness you bring when things feel too serious and thank you for your endless drawings that have kept me beavering away at my desk. I am so grateful for you, and I love you.

Thank you to my lovely friends and fellow trainees, with a special thanks to Ellie B, I feel so grateful to have had you alongside me on this wild three-year ride!

Finally, I would like to say a big thank you to the individuals that took part in my research and shared their stories with me. None of this would be possible without you. Thank you for your openness and vulnerability, I hope I have represented your experiences with the care and respect they deserve.

Chapter One

Introduction to Thesis Portfolio

Introduction to Thesis Portfolio

Cancer Epidemiology and Survivorship

Cancer represents a major public health challenge in the United Kingdom (UK). It is estimated that around 3.5 million people are currently living with cancer in the UK, with nearly 1,100 new cases being diagnosed each day (Cancer Research UK, 2025; Macmillan Cancer Support, 2024). Lifetime risk is estimated at 1 in 2 individuals, reflecting its substantial population level impact (Cancer Research UK, 2025). While incidence rates have increased over recent decades, advances in treatment have contributed to a gradual decline in mortality. Nevertheless, cancer remains responsible for approximately 167,000 deaths annually in the UK, accounting for around one quarter of all deaths (Cancer Research UK, 2025). Cancer is broadly defined as a group of diseases characterised by the uncontrolled cell growth of abnormal cells which can enter surrounding tissues and spread to distant parts of the body, a process known as metastasis (World Health Organisation [WHO], 2025).

Cancers that remain localised to their site of origin (referred to as primary cancers) are often more amenable to curative treatment, whereas metastatic cancer is typically associated with more limited curative treatment options and poorer prognosis (National Cancer Institute [NCI], 2025). Cancer is also described in terms of stage, which reflects the extent to which the disease has spread within the body, with earlier-stage cancers generally associated with better prognosis and greater potential for curative treatment (NCI, 2025). Taken together, these factors contribute to its global impact, with cancer remaining the second leading cause of death worldwide, accounting for an estimated one in six deaths (WHO, 2025).

Advances in early detection and oncological treatment have contributed to steady improvements in survival in recent decades, resulting in increasing numbers of individuals living with and beyond a cancer diagnosis. The national cancer strategy in England has prioritised earlier diagnosis, faster access to treatment and improved long-term outcomes, alongside ambitions to support individuals to live well following cancer (Department of Health and Social Care [DHSC] & NHS England, 2026). Cancer is therefore increasingly conceptualised as a long-term condition, often accompanied by ongoing physical, emotional and social consequences that extend beyond the acute treatment phase.

Despite these advances, research has historically prioritised the development and optimisation of biomedical treatments, including surgery, chemotherapy and radiotherapy,

with a primary focus on improving survival outcomes. While these advances have been critical in improving survival, they have often placed less emphasis on understanding the psychological impact of cancer and its treatment (Pitman et al., 2018; NICE, 2023). This means that psychological research has not kept pace with advances in surgery, treatment and prognosis. Notably, emerging evidence suggests that aspects of health-related quality of life, including emotional functioning, are also associated with survival outcomes, highlighting the clinical relevance of psychosocial factors (Quinten et al., 2009; Lim et al., 2025). Evidence suggests that psychological distress is common within cancer populations, with one-third of individuals with cancer worldwide experiencing clinically significant symptoms of depression and anxiety (Getie et al., 2025). Consequently, focus must extend beyond longevity to consider the broader psychosocial impact of cancer and its treatment.

Oesophageal Cancer

While these trends apply broadly across cancer populations, outcomes vary considerably by diagnosis. Oesophageal cancer remains associated with comparatively poor survival and is currently the seventh most common cause of cancer-related death in the UK (Cancer Research UK, 2025). The disease is characterised by malignant cell growth within the lining of the oesophagus and is commonly classified as either squamous cell carcinoma or adenocarcinoma depending on the type of cells affected (Bollschweiler & Hölscher, 2007). Oesophageal cancer can develop gradually, and early symptoms are often mild or non-specific. Common early symptoms include persistent reflux, nausea, indigestion and mild swallowing difficulties, which may initially be attributed to more common gastrointestinal conditions such as gastro-oesophageal reflux disease (GERD) (Pennathur et al., 2013). As the disease progresses, symptoms may become more noticeable and can include increasing difficulty swallowing (dysphagia), unintentional weight loss, regurgitation of food and persistent chest discomfort.

Because these early symptoms can resemble more common digestive conditions, they may not immediately raise concern. Public awareness of oesophageal cancer symptoms remains relatively low, with survey data suggesting that only around 11% of individuals can identify symptoms associated with the disease (Less Survivable Cancers Taskforce [LSCT], 2025). Combined with the vague nature of early symptoms, this may contribute to delays in help-seeking and diagnosis. As a result, many individuals are diagnosed at a relatively advanced stage of disease.

Data reported by the LSCT (2025) indicate that 20% of oesophageal cancer diagnoses in England occur following emergency presentations, such as attendance to Accident and Emergency departments. This is substantially higher than the proportion of diagnoses for other cancer types such as breast (2.7%) and prostate (7.8%). For some cancers, pathways involve screening programmes or structured primary care investigations such as blood tests and imaging that may allow time for individuals to process symptoms and prepare for potential diagnosis. However, this is often not the case for oesophageal cancer, where diagnosis may occur more abruptly, often in the context of acute deterioration or emergency admission (LSCT, 2025). This can result in a reduced opportunity for psychological adjustment prior to diagnosis, potentially intensifying experiences of shock, uncertainty and distress at the point of diagnosis.

Treatment for Oesophageal Cancer

Treatment for oesophageal cancer is dependent on tumour type, disease stage and overall health of the individual. For patients with potentially curative disease, treatment typically involves a multimodal approach combining chemotherapy and/ or radiotherapy with surgical resection (National Institute for Health and Care Excellence [NICE], 2023). Chemotherapy refers to systemic anti-cancer drug treatment designed to destroy or inhibit the growth of cancer cells, whereas radiotherapy utilises high-energy radiation (e.g., X-rays and protons) to kill cancer cells or shrink tumours by damaging their DNA (Cancer Research UK, 2023).

Surgical treatment most commonly involves an oesophagectomy, a major procedure in which all or part of the oesophagus is removed. The digestive tract is then reconstructed, most often by reshaping and repositioning the stomach to restore continuity (Obermannová et al., 2022). Although potentially life-prolonging, oesophagectomy is considered a complex procedure and is often associated with substantial physical demands and prolonged recovery. Common postoperative complications include pneumonia, anastomotic leak, dysphagia (difficulty swallowing) and dumping syndrome, which can cause symptoms such as nausea, diarrhoea and dizziness following eating (Ahmadinejad et al., 2020; Edmondson et al., 2023; Van Beek et al., 2017). Many individuals also experience longer-term changes including altered eating routines, weight loss, fatigue and reduced physical functioning. As a result, recovery often involves significant lifestyle adjustments that may continue for months to years following surgery.

Evidence suggests that quality of life is often reduced in the months following surgery and may take considerable time to recover, with some studies reporting ongoing difficulties up to three years post-surgery (Djarv et al., 2009). Greater postoperative symptom burden has also been linked to poorer psychological outcomes (Bouras et al., 2017), suggesting that the physical consequences of treatment may exacerbate psychological vulnerability.

Psychological Adjustment

Psychological adjustment to cancer broadly refers to the cognitive, emotional and behavioural processes that individuals respond to and cope with the challenges associated with diagnosis, treatment and survivorship (Brennan, 2001; Stanton et al., 2015). Adjustment is not considered a single outcome, instead being an ongoing process consisting of how individuals make sense of illness, manage uncertainty and adapt to changes in physical functioning, identity and everyday life.

Research suggests that adjustment to cancer is often complex and multifaceted, with individuals experiencing a range of emotional responses including distress, uncertainty, fear of recurrence and changes to self-identity (Helgeson & Zajdel, 2017). At the same time, some individuals also report positive psychological changes such as an increased appreciation of life or shifts in personal priorities. For individuals diagnosed with oesophageal cancer, this adjustment process may be particularly complex due to the life-threatening nature of the disease and the significant physical consequences associated with treatment. Therefore, we should not assume that experiences of cancer are broadly similar, and that subtype and pathology of different cancers will be experienced in a different way.

Given the high mortality rate and complex treatment pathway associated with oesophageal cancer, research has prioritised surgical optimisation and survival outcomes. More recently, attention has turned towards the psychological impact of oesophagectomy. While valuable in quantifying symptom prevalence and identifying risk factors, much of this literature adopts a predominantly quantitative framework, examining postoperative morbidity, mortality rates, and changes in quality of life and mood scores (e.g., Kamarajah et al., 2020; Liu et al., 2022; Ra et al., 2008; Sundaram et al., 2015). Moreover, qualitative research in this area remains comparatively limited (e.g., Nielsen et al., 2021; Graham-Wisener et al., 2019) and, in some cases, dated or conducted within focus-group contexts (e.g., McCorry et al., 2009). Consequently, in-depth exploration of how individuals make sense of and adjust to oesophagectomy across the illness trajectory remains underdeveloped.

Aim and Structure of Thesis Portfolio

In order to further clarify the extent of psychological morbidity within this population, the first paper in this portfolio presents a systematic review examining the prevalence of anxiety and depression following oesophagectomy. By synthesising quantitative evidence across the surgical trajectory, the review aims to provide a clearer understanding of the prevalence and course of psychological distress in individuals undergoing this procedure. While prevalence data offers important insight into the scale of psychological distress, it provides limited understanding of how individuals experience and interpret the psychological impact of diagnosis, surgery and recovery. Therefore, the empirical paper adopts a qualitative approach to explore the lived experiences of psychological adjustment following oesophagectomy, with a particular focus on meaning-making, embodied change and adaptation across the illness trajectory.

Chapter 2

Systematic review

Prevalence of Anxiety and Depression Following Oesophagectomy for Oesophageal Cancer: A Systematic Review

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Word count: 6345 (excluding references)

Prepared for the Journal of Cancer Survivorship

(Author guidelines in Appendix A)

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Abstract

Background: Oesophagectomy is the primary curative treatment for oesophageal cancer. However, this is associated with significant physical and functional changes that may impact psychological wellbeing. While health-related quality of life has been widely studied, less is known about the prevalence of specific psychological outcomes such as anxiety and depression.

Aims: This systematic review aimed to synthesise the prevalence of anxiety and depression in adults at least three months following oesophagectomy, and to explore patterns over time according to study characteristics.

Method: A systematic review was conducted across four databases (CINAHL, PsycINFO, PubMed and Scopus). To be included, studies reported quantitative data on anxiety and/ or depression using validated measures in adults who had undergone oesophagectomy. Of 1,164 records identified, seven studies were included in the final synthesis. Due to substantial heterogeneity in study design, outcome measures and timing of assessment, a narrative synthesis approach was adopted.

Results: Prevalence as defined by scores above threshold on validated measures estimated anxiety ranges from 18% to 37%, and for depression from 13% to 45% at timepoints beyond three months post-surgery. Synthesised literature suggested a non-linear trajectory of distress, with elevated levels in the perioperative period, reduction and improvement in the short-term, and persistence, increase or re-emergence in some patients at longer-term follow-up. Clinical factors, including postoperative complications, dysphagia and chronic pain were associated with higher levels of distress, while psychosocial factors were less frequently examined.

Conclusion: Findings highlight that anxiety and depression affect a significant proportion of patients following oesophagectomy, with evidence of ongoing and fluctuating psychological distress over time. This suggests consideration of routine psychological assessment across the cancer care pathway and for further longitudinal research to better understand psychological adjustment in this population.

Keywords: Oesophageal cancer, Oesophagectomy, Anxiety, Depression.

Prevalence of Anxiety and Depression Following Oesophagectomy for Oesophageal Cancer: A Systematic Review

Background

Oesophageal cancer is a major global health challenge, with over 511,000 new cases being diagnosed annually. It currently ranks as the seventh leading cause of cancer-related mortality worldwide, with men accounting for 72% of all cases (Ferlay et al., 2024; Sung et al., 2021). The disease is characterised by malignant cell growth within the lining of the oesophagus. Whilst the global burden is substantial, incident rates vary considerably by geography. Regions within the 'oesophageal cancer belt' including East Asia and parts of Africa report the highest rates, while Western countries are seeing a rise in prevalence of adenocarcinoma, which is often linked to lifestyle factors (Arnold et al., 2015; Wang et al., 2024).

Whilst treatment for oesophageal cancer varies depending on disease stage, oesophagectomy is the primary curative treatment. This involves surgical removal of all or part of the oesophagus, often alongside resection of the regional lymph nodes (Obermannová et al., 2022). To improve survival outcomes, surgery is typically performed in conjunction with chemotherapy and /or radiotherapy. These advancements in treatment have improved survival in recent years, leading to a growing population of survivors. However, the invasive nature of the surgery can often lead to significant and lasting changes to physical functioning and everyday life. Oesophagectomy has been associated with various complications, ranging from pneumonia, anastomotic leaks, and recurrent nerve injury in the early stages, to dysphagia, dumping syndrome and malabsorption in the longer term (Ahmadinejad et al., 2020; Edmondson et al., 2023; Van Beek et al., 2017).

Psychological distress is widely recognised across cancer populations, with population-based research suggesting higher rates of psychological morbidity among individuals with cancer compared to the general population, particularly for depression (Vehling et al., 2022). A recent umbrella review further estimated a global prevalence of 33.16% for depression and 30.55% for anxiety among individuals with a cancer diagnosis (Getie et al., 2025). However, prevalence estimates vary considerably according to factors such as cancer type, stage of illness and treatment pathway.

Within the oesophageal cancer population, research suggests psychological distress may emerge as early as diagnosis and potentially persist into long-term survivorship

(Bergquist et al., 2007; Dempster et al., 2012; Housman et al., 2021). This is reflected in population-based data showing increased psychiatric morbidity following surgery, including higher rates of psychotropic medication use and greater reliance on mental health services (Wikman et al., 2015). Recent meta-analytic evidence highlights that nearly 30% of patients develop postoperative mental health disorders, most commonly anxiety and depression, whilst preoperative mental health conditions have also been associated with a 33% higher risk of postoperative mortality (Papaconstantinou et al., 2025). Oesophageal cancer survivors also show an elevated suicide risk compared to both the general population and other cancer groups (Chen et al., 2021; Henson et al., 2019).

A growing body of research has examined health-related quality of life (HRQOL) following oesophagectomy (e.g., Färnqvist et al., 2025; Meng et al., 2025; Toh et al., 2022; Yang et al., 2019). While previous systematic reviews highlight persistent impairments across physical, emotional and social domains, the findings regarding emotional wellbeing are inconsistent. Some research suggests emotional functioning may actually improve following surgery, possibly due to a sense of relief after surviving a life-threatening illness (Parameswaran et al., 2011). However, others caution that any potential improvements in mental health status are small and may be overshadowed by the persistence of distressing physical symptoms (Toh et al., 2022).

These conflicting findings suggest that broad HRQOL measures may not be sufficiently specific to capture the prevalence or severity of particular psychological outcomes, such as anxiety and depression. While HRQOL research provides important insight into overall functioning, it may obscure the extent to which individuals experience clinically relevant psychological distress during recovery and longer-term survivorship. This is particularly important as survival following oesophageal cancer improves. Oesophagectomy can increasingly be understood not only as an acute surgical intervention, but as a significant survivorship transition involving long-term physical, functional and psychological adjustment.

Despite the clinical significance of psychological distress, no systematic review has specifically attempted to meta-analyse and synthesise the prevalence of anxiety and depression following oesophagectomy. Understanding the scale of this burden and identifying whether these symptoms fluctuate over time is essential for improving supportive care and patient outcomes.

Aims:

Primary objective:

To synthesise the reported prevalence of anxiety and depression in adults at least three months following oesophagectomy for oesophageal cancer, as defined by clinical cut-offs in validated psychometric assessments.

Secondary objectives:

- To examine how anxiety and depression outcomes vary according to the timing of postoperative assessments.
- To explore differences in reported outcomes across measurement approaches.
- To explore whether findings varied according to study characteristics, including country, study design and participant characteristics.

Method

This review was conducted and reported in accordance with Popay et al.'s (2006) framework and the Synthesis Without Meta-analysis (SWiM) guidelines (Campbell et al., 2020; Appendix B). The review protocol was registered on PROSPERO prior to any searches being complete (registration: CRD420261353944). Ethical approval was not required for this review of previously published data.

Search Strategy

A systematic literature search was conducted on 28th March 2026 using the databases: CINAHL, PsycINFO, PubMed and Scopus. Decisions regarding key search terms were informed by scoping searches, existing literature in the field and database-specific indexing terms (e.g., MeSH terms) alongside consideration of relevant synonyms and variations in terminology (including UK and US spellings). The search terms for oesophageal cancer were:

"Oesophageal cancer", "esophageal cancer", "oesophageal carcinoma", "esophageal carcinoma", "oesophageal neoplasm*", "esophageal neoplasm*", "oesophageal tumour*", "esophageal tumor*.

The search terms included for surgery were: "Oesophagectomy", "esophagectomy", "oesophageal resection", "esophageal resection", "oesophagogastrectomy", "esophagogastrectomy", "oesophageal surgery", "esophageal surgery".

The search terms for psychological outcomes were: “Anxiety”, “depress”, “psychological distress", “distress”, "mental health", "psychological morbidity", "psychiatric morbidity", “HADS”, “PHQ-9”, “GAD-7”.

Search terms were combined using Boolean operators, with “OR” used within each concept group and “AND” used to combine concepts. Both controlled vocabulary (e.g., MeSH terms) and free-text terms were used, with search strategies adapted for each database. Truncation was applied to capture variations of key terms (e.g., depress*, neoplasm*), and alternative spellings (e.g., oesophageal/ esophageal; tumour/ tumor) were included to maximise retrieval.

Study Selection

Studies were initially screened at the title and abstract level, with studies being included if they appeared to assess anxiety and / or depression following oesophagectomy. Following initial screening, 65 papers were identified for full-text review (see figure 1 for full study selection details). These studies were assessed against the predefined inclusion criteria:

- Adult participants (aged 18+) who had undergone oesophagectomy as part of treatment for oesophageal cancer.
- Studies reporting quantitative data on anxiety and / or depression using validated measures or established clinical criteria.
- Outcomes assessed at least three months post-operatively.
- Primary quantitative study designs (e.g., cross-sectional, cohort, longitudinal or interventional studies).

Exclusion criteria:

- Studies not published in English
- Not primary quantitative research (e.g., qualitative studies, systematic reviews, meta-analyses, editorials, study protocols, editorials)
- Case reports and case series with fewer than five participants
- Studies using populations that were not oesophagectomy patients or where outcomes could not be distinguished from other surgical populations
- Studies examining non-malignant oesophageal conditions or pre-malignant oesophageal conditions (e.g., Barrett’s oesophagus).

Data Extraction and Study Quality Assessment

Articles were imported by the lead author into Rayyan and duplicates were removed. The lead author screened all titles and abstracts to exclude articles that did not meet the inclusion criteria. Where there was uncertainty at this stage, articles were retained for full-text review. Full-text articles were then assessed for eligibility, with reasons for exclusion recorded (see Figure 1). To enhance reliability, a secondary researcher independently screened a random sample of 20% of studies (13n) at the full-text stage. Inter-rater agreement was high (95%) with any discrepancies being resolved through discussion until consensus was reached. Where relevant data were missing or unclear, attempts were made to contact study authors for clarification. Two authors were contacted via email; however, no responses were received and studies were included based on available data. Reference lists of included studies were also hand-searched to identify any additional relevant articles. No additional papers were identified by this method.

Quality appraisal

Study quality was assessed using Joanna Briggs Institute (JBI) critical appraisal tools appropriate to study design. These tools assess domains relevant to risk of bias, including sampling, measurement validity, and confounding. The revised JBI checklist for analytical cross-sectional studies (Barker et al., 2026; see appendix C) was used for one study and the JBI checklist for cohort studies (Moola et al., 2020; see appendix D) was used for the remaining six studies. A random sample of 20% was independently assessed by a second reviewer. No discrepancies were noted between reviewers.

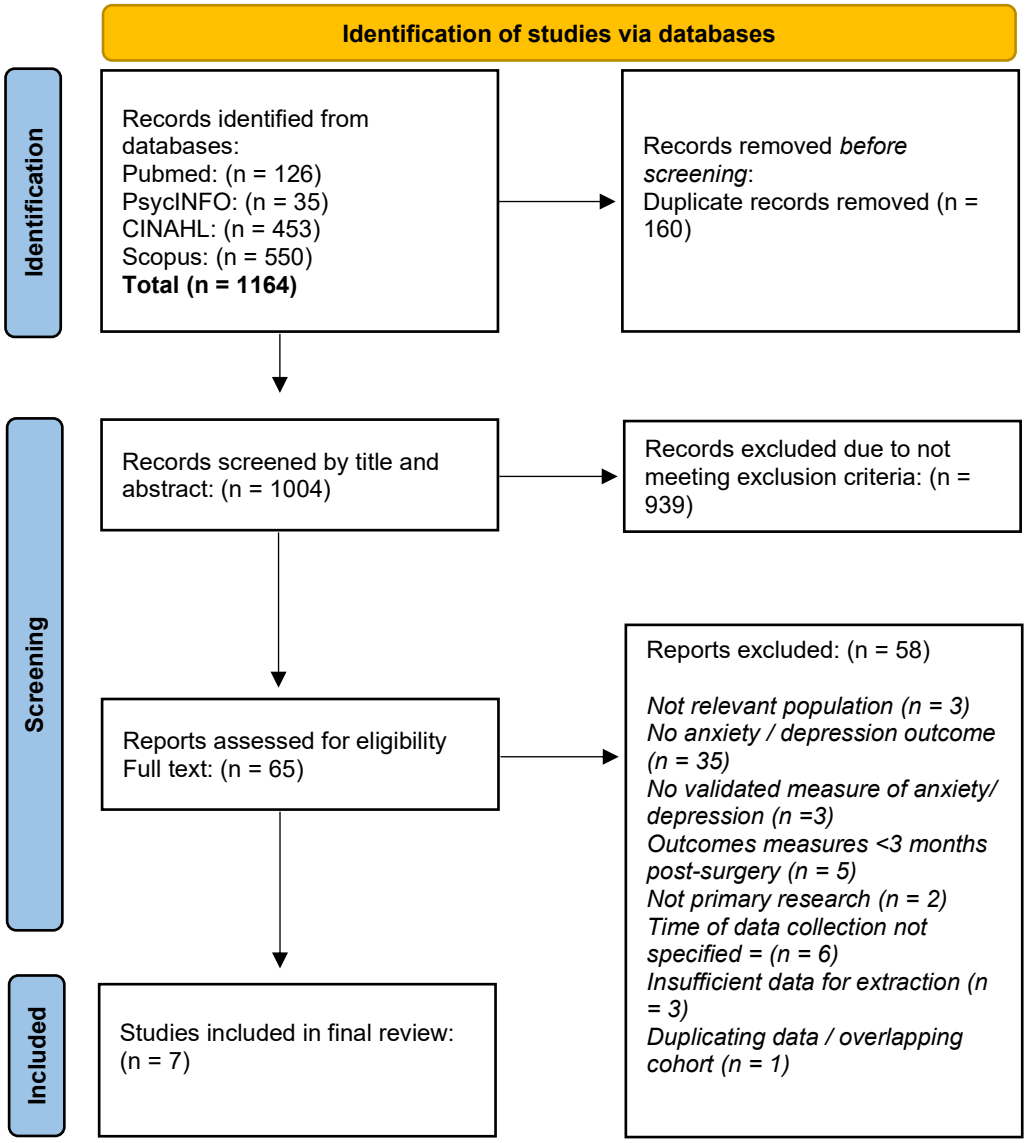
Data analysis

A meta-analysis to estimate the prevalence of anxiety and / or depression following oesophagectomy was planned but could not be performed. This was due to substantial heterogeneity across studies in terms of populations, measurement tools, timing of outcome assessment and reporting of findings. Given this degree of heterogeneity, pooled prevalence estimates were considered inappropriate. For example, studies varied in the use of outcomes measures, most commonly using the Hospital and Anxiety Scale (HADS; Zigmond & Snaith, 1983) or the Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001), cut-off thresholds (e.g., >8 or >11) and timepoints of assessment (ranging from 3 months to 5 years post-surgery) limiting comparability across studies. Consequently, data were extracted and

synthesised descriptively, with prevalence rates and / or mean scores being reported where available. Narrative synthesis was conducted in accordance with guidance from Popay et al. (2006), focusing on identifying patterns, relationships and sources of heterogeneity across studies.

Figure 1

Prisma flow diagram



Results

Study and Sample Characteristics

A total of seven studies were included within this review, comprising 1,007 participants (85% male, 15% female). Sample sizes ranged from 47 to 319 participants. Out of these studies, 85% of participants were males, with 15% being females. The mean age of participants ranged from 63 to 66 years, with a weighted mean age of 64.2 years. Studies

were conducted across six countries including the United Kingdom, the Netherlands, South Korea, China, Japan and Sweden. Most studies employed a prospective longitudinal cohort design (n = 4), with two studies using retrospective cohort designs and one study employing a cross-sectional design. The earliest included study was published in 2015, with the majority (n = 5) published within the past six years.

Reporting of clinical characteristics (e.g., treatment details and post-surgical complications) was inconsistent across studies. The timing of post-operative assessment varied considerably, ranging from three months to five years post-operatively. Several studies also included pre-operative or early postoperative assessments, however, only data from >three months post-surgery were included in this review.

The majority of studies (n = 6) assessed anxiety and depression using the Hospital Anxiety and Depression Scale (HADS). Of those, Jung & Kim (2022) used the Korean version, while Ohkura et al. (2020) used the Japanese version and applied a higher cut-off score (>11). One study assessed for depression only using the Patient Health Questionnaire-9 (PHQ-9).

Table 1:

Study Characteristics

Author (Year)	Country	Design	Sample Size (N)	Age M (SD)	Gender (%)	Cancer stage / Type	Measure	Timing of outcome assessment
Hellstadius et al. (2017)	UK	Prospective longitudinal cohort	218	64 (SD 9.86)	82% M 18% F	68% stage 3 OAC (94%), OSCC (6%)	HADS	Pre, 6m, 12m
Jung & Kim (2022)	South Korea	Prospective longitudinal cohort	49	63 (SD 7.12)	94% M 6 % F	57% stage 0 – 1 Type not specified	HADS	Pre, 1m, 3m
Tan et al. (2025)	China	Retrospective cohort	319	63 (SD 7.6)	87% M 13% F	44.5% stage 1-2, 49.2% stage 3, 6.3% stage 4 OSCC (88.7%), non-SCC (11.3%)	PHQ-9	3m
Hu et al. (2025)	China	Retrospective cohort	92	64 (SD 7.42)	88% M 12% F	4.5% stage 1, 60.2% stage 2, 15.9% stage 3, 19.3% stage 4 OSCC only	HADS	3m, 6m
Ohkura et al. (2020)	Japan	Prospective longitudinal cohort	102	68 (SD N.A)	84% M 16% F	37.3% stage 1, 23.5% stage 2, 31.4% stage 3, 7.8% stage 4. Type not specified	HADS	Pre, 1m, 3m
Liu et al. (2021)	Sweden	Prospective longitudinal cohort	180	66 (SD 8.5)	86% M 14% F	37.2% stage 1, 32.8% stage 2, 30% stage 3. OAC (83.9%), OSCC (16.1%)	HADS	1y, 1.5y, 2y
Haj Mohammad et al. (2015)	Netherlands	Cross-sectional	47	66 (SD 7.2)	72% M 28% F	Stage 2 & 3 (% not specified) Type not specified	HADS	1 -5y (mean 3y)

Note. HADS = Hospital Anxiety and Depression Scale; PHQ-9 = Patient Health Questionnaire. Timepoints refer to time since surgery unless otherwise stated (pre = pre-surgery; m = months; y = years). OSCC = Oesophageal Squamous cell carcinoma; OAC = Oesophageal Adenocarcinoma.

Quality Appraisal of Studies

Methodological quality was assessed using the JBI critical appraisal tools (see table 1 and table 2). In line with JBI guidance, an overall quality score was not calculated, and studies were not categorised using fixed cut-offs. Instead, appraisal was considered at the level of individual domains to identify patterns of strength and limitations across the evidence base.

Across studies, consistent strengths were identified. Most studies clearly defined their samples and settings and used validated and widely recognised measures of anxiety and depression, most commonly the HADS, and in one study, the PHQ-9. Post-operative assessment timepoints were generally specified with reasonable clarity, and several studies employed multivariable statistical approaches to account for potential confounding, including regression modelling, propensity score matching and longitudinal analysis.

However, several methodological limitations were evident. Approaches to missing data were often limited, with most studies relying on complete case analysis and providing little detail regarding sensitivity analyses. Only one study accounted for missing data using imputation methods (Liu et al., 2021), increasing risk of attrition bias across the evidence base. Although some studies included pre-surgical assessments of psychological distress, few accounted for pre-existing psychiatric history, limiting the ability to determine whether postoperative distress represented new-onset difficulties or the continuation of prior mental health conditions.

There was also variability in the extent to which studies accounted for potential confounding variables. While some used robust multivariable approaches, others relied on more limited statistical methods without adjustment for key clinical or demographic variables. Furthermore, several studies used retrospective or single-centre designs, which may reduce generalisability of findings. Although attrition was commonly reported, reasons for dropout were not always fully explored, further contributing to potential bias.

It is important to note that some of the JBI appraisal items for the cohort checklist were not applicable to all studies, particularly those relating to exposure and non-exposure group comparisons, as several studies used single-cohort longitudinal designs rather than comparative designs.

These methodological considerations were considered during synthesis. Findings from studies demonstrating clearer outcome measurement, more robust handling of confounds and better-defined follow-up procedures were given greater interpretive weight, while findings from studies with greater limitations were interpreted cautiously. These limitations are particularly relevant when interpreting prevalence estimates, as issues relating to missing data and baseline assessment may contribute to both under or over-estimation of psychological distress.

Table 2

Quality appraisal of a cross-sectional study

Author (Year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Rating comments
Haj Mohammad et al (2015)	Y	Y	Y	Y	Y	N	Y	Y	Cross-sectional design (no causal inference); small single-centre sample; potential selection bias in survivor/ spousal cohort; information loss via dichotomization; limited power/ model checking.

Note. Y = Yes, N = No, U = Unclear, NA = Not applicable.

Table 3

Quality appraisal of cohort studies

Author (Year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Rating comments
Hellstadius et al (2017)	NA	NA	Y	Y	Y	N	Y	Y	Y	U	Y	Prospective longitudinal design; validated measures, appropriate modelling. P's not outcome free at baseline, attrition increased over time, no previous psychiatric history data.
Jung & Kim (2022)	N.A	NA	Y	N	N	N	Y	Y	Y	N	Y	Prospective design; clear timepoints; validated measures. Small sample; single-centre; no confounder adjustment; short-follow up (3 months).
Tan et al (2025)	NA	NA	Y	Y	Y	U	Y	Y	Y	N	Y	Large sample; appropriate statistical

												modelling. Retrospective design; no baseline psychological assessment; limited handing of missing data.
Hu et al (2025)	Y	Y	Y	Y	Y	U	Y	Y	N	N	Y	Validated measure, multiple timepoints; propensity score matching. No baseline psychological assessment; limited missing data handing; single-centre design.
Ohkura et al (2020)	NA	NA	NA	Y	Y	N	Y	Y	Y	N	Y	Longitudinal design; multiple defined timepoints; multivariable modelling. P's not outcome-free at baseline; short follow-up, complete-case analysis only.
Liu et al (2021)	NA	NA	Y	Y	Y	N	Y	Y	Y	Y	Y	Nationwide longitudinal cohort; large sample; validated measure, robust statistical adjustment; clear follow-up; imputation used. P's not outcome free at first measurement.

Note. Y = Yes, N = No, U = Unclear, NA = Not applicable

Prevalence of Anxiety and Depression

Overall, prevalence estimates for anxiety ranged from 18% to 37% whilst depression ranged from 13% to 45% across studies assessing outcomes at >three months post-surgery. These estimates reflect the proportion of participants scoring above thresholds for psychological distress (e.g., HADS >8, PHQ-9 >5). However, direct comparison of these estimates is limited due to substantial heterogeneity across studies, including the variation in timing of assessment (ranging from three months to five years post-surgery), measurement tools and thresholds, and whether outcomes were reported as separate anxiety and depression scores or combined psychological distress. Furthermore, there was variation in how data were

collected (e.g., self-administration or clinician-administered), although this was not consistently reported. This heterogeneity meant it was not possible to draw meaningful conclusions regarding differences in prevalence across countries or study settings.

Early Postoperative Period (Pre-surgery to one month)

Although not the primary focus of this review, several studies assessed anxiety and depression in the pre-operative and early post-operative period. These consistently found higher levels of distress prior to and immediately following surgery. For example, Jung and Kim (2022) reported that the proportion of participants scoring above the threshold (HADS >8) increased from 36.7% pre surgery to 79.5% at one month, whilst depression increased from 40.8% to 77.6%. Notably, a substantial proportion of these cases were within the moderate to severe range at one month (e.g., 57.1% for anxiety and 63.3% for depression), indicating a high level of psychological burden during the acute postoperative period. However, it should be noted that this was observed in a relatively small sample (n = 49).

Similarly, Hellstadius et al. (2017) reported elevated levels of anxiety (33%) and depression (20%) prior to surgery, although the absence of data on pre-existing mental health diagnoses limits interpretation of whether this reflects new or pre-existing distress.

Studies reporting combined psychological distress demonstrated comparable patterns. For example, Ohkura et al. (2020), using a higher HADS cut-off (>11), reported that combined psychological distress increased across perioperative timepoints, with prevalence increasing from 36.3% at initial consultation to 47.1% at 1-month post-surgery.

Short-Term Follow-up (>three months post-surgery)

At timepoints beyond three months post-surgery, some studies indicated a reduction in distress following the initial postoperative peak. For example, Jung & Kim (2022) reported substantially lower levels of anxiety and depression at three months compared to one-month post-surgery, with the proportion scoring above threshold reducing to 18.4% for anxiety and 44.9% for depression. This reduction was also reflected in a decrease in moderate to severe cases at three months compared to one month, suggesting an overall improvement in both prevalence and severity of symptoms over time.

Similarly, Hu et al. (2025) reported relatively low levels of anxiety and depression at both three and six months post-surgery, with significant improvements over time. However, as outcomes were reported using mean scores rather than the proportion of participants

scoring above a defined threshold, it is not possible to estimate the prevalence of elevated symptoms, limiting direct comparability with other studies.

Despite this reduction, distress remained present in a proportion of patients. For example, Tan et al. (2025) reported a prevalence of depression of 28.2% at three months post-surgery in a large sample (n = 319), although the majority of cases were mild, and only 3.4% were classified as moderate-severe. However, this study assessed for depression only using the PHQ-9 and measured outcomes at a single postoperative timepoint within a study focused on prognostic and biomarker associations. This limits comparability with studies reporting both anxiety and depression outcomes more directly and over time.

Longer-Term Follow-up (>six months post-surgery)

Findings at longer-term follow-up were more variable, with some studies suggesting persistence or increase in the population of participants scoring above the threshold for anxiety and depression over time. For example, Hellstadius et al. (2017) reported anxiety increasing from 28% at six months to 37% at 12 months, with depression increasing from 27% to 32%. However, the sample size did reduce substantially over time (from 218 at baseline, 139 at six months down to 95 at 12 months). Similarly, Liu et al. (2021), using a combined measure of psychological distress, reported an increase from 10.6% at one year to 23.2% at two years post-surgery.

In contrast, Haj Mohammad et al. (2015) reported lower prevalence rates at a mean follow-up time of 38 months, with 18% scoring above the threshold for anxiety and 13% for depression in a small sample (n = 47). Notably, only a small proportion of these cases were in the moderate to severe range (9% for anxiety and 4% for depression). However, this study used a cross-sectional design, excluded those with recurrence or metastasis, and assessed patient psychological outcomes as a secondary measure, with the study primarily focused on caregiver burden. This may therefore limit comparability with other studies.

Taken together, the findings suggest a complex and non-linear trajectory of anxiety and depression following oesophagectomy. Evidence across studies indicates that the proportion of participants scoring above the threshold for anxiety and depression is elevated in the perioperative period, reduces in the short term, and may persist or increase again over longer-term follow up. However, this pattern was not consistent across all studies.

Factors Associated with Anxiety and Depression

Three studies explored factors associated with anxiety and depression, although the range of predictors examined and the analytical approaches varied. Overall, findings suggested both clinical and sociodemographic factors were associated with psychological outcomes; however, the strength of this evidence varied.

Clinical and Physical Factors

Clinical and physical factors were the most consistently examined across studies. For example, postoperative complications, greater activity limitations, and more severe dysphagia were associated with higher levels of both anxiety and depression (Hellstadius et al., 2017). Similarly, Tan et al. (2025) identified chronic post-surgical pain as the only independent predictor of depression in a multivariable model. Depression was also associated with poorer relapse-free survival.

There was also some evidence that changes in depression over time may be explained by underlying clinical and functional factors, rather than time itself. For example, when these variables were included in the analysis, time was no longer a significant predictor of depression (Hellstadius et al., 2017), indicating that changes in depression over time were accounted for by these clinical and functional factors.

Sociodemographic and Psychosocial Factors

Few studies explored sociodemographic and psychosocial factors. Hellstadius et al. (2017) found that younger age, female sex, and living alone were associated with higher levels of anxiety. However, few studies examined psychological or social predictors in depth, with more emphasis placed on physical and clinical variables. This may reflect a predominantly biomedical focus within the literature, potentially overlooking the contribution of broader psychosocial factors to distress.

Association with Patient Outcomes

In addition to identifying predictors, one study examined the association between psychological distress and patient outcomes. Liu et al. (2021) found that higher levels of distress were associated with poorer quality of life across multiple domains, including emotional, social, and eating-related functioning. These effects appeared to persist, and in some cases, increase over time, indicating a consistent association between distress and poorer quality of life over time. However, as these findings are derived from a single study, they should be interpreted with caution.

Discussion

Summary of Findings

This review aimed to synthesise the prevalence of anxiety and depression in adults at least three months following oesophagectomy for oesophageal cancer. In addition, it aimed to explore how these outcomes varied according to timing of assessment, measurement approaches, and study characteristics. To our knowledge, this is the first systematic review to synthesise evidence of the prevalence of anxiety and depression following oesophagectomy.

Overall, the findings suggest that psychological distress is a relevant and ongoing concern within this population, with a proportion of individuals experiencing clinically significant symptoms of anxiety and depression in the months and years following surgery. Although prevalence estimates varied across studies, this variability appeared to reflect differences in measurement approaches, follow-up timepoints and study design rather than indicating an absence of psychological impact.

Notably, the research in this area is still in the early stages, which is reflective of five out of the seven included papers being published in the past six years. This demonstrates the recent shift in interest towards long-term survivorship and could help understand the high degree of heterogeneity found across studies, as standardised psychological protocols have yet to be established.

Prevalence in Context

The prevalence estimates identified in this review, ranging from 18% to 37% for anxiety and 13% to 45% for depression, are broadly comparable with those reported across wider cancer populations (Getie et al., 2025). However, prevalence varies considerably between cancer types. For example, higher rates of depression were reported in breast cancer in comparison to prostate cancer populations. More specifically, a previous meta-analysis found oesophageal cancer to have the highest prevalence of both anxiety (20.6%) and depression (45.2%) among gastrointestinal cancers (Zamani & Alizadeh- Tabari, 2023). Compared with the general population, individuals with cancer have also been found to have twice the odds of meeting diagnostic criteria for major depression, although findings for anxiety are less consistent (Vehling et al., 2022). Given substantial differences in populations, treatment stages and methods of assessment across studies, these comparisons should be interpreted cautiously.

Trajectories of Distress After Surgery

A key finding of this review was the complex and non-linear trajectory of psychological distress over time. Evidence across studies suggested that distress may be elevated in the early postoperative period, reduce in the months following surgery, and persist or increase again over longer-term follow-up. This pattern is consistent with broader literature on psychological adjustment to cancer (e.g., Kim et al., 2020), which highlights the fluctuating nature of distress as individuals move through different phases of illness and recovery, including evidence of renewed anxiety at later follow-up points.

The review illustrates this fluctuating pattern of psychological distress. For example, while distress was highest in the acute phase post-surgery, reaching as high as 77% at one month (Jung & Kim, 2022), it appeared to settle significantly by the three–six-month mark. However, this pattern of early improvement has been described in previous cancer research (e.g., Garofalo et al., 2013), referred to as the 'honeymoon phase', which describes how initial improvements may reflect relief following treatment completion before longer-term adjustment challenges emerge. Both Liu et al. (2021) and Hellstadius et al. (2017) found that distress began to increase again as time went on, with prevalence rates even doubling between the first and second years post-surgery. However, as most studies did not collect data on pre-existing mental health history, it remains unclear whether these spikes reflect new-onset distress or the recurrence of pre-existing difficulties.

Early postoperative distress may reflect the immediate physical and psychological demands associated with surgery and recovery, including pain, fatigue, and uncertainty regarding prognosis. In contrast, longer-term distress may be associated with ongoing symptom burden, changes in physical functioning, and the process of adapting to life following cancer treatment (Malmström et al., 2013). As noted in the results, when physical symptoms like dysphagia or activity limitations were accounted for, time was no longer the main driver of depression (Hellstadius et al., 2017), suggesting that later increases in distress may be driven more by the cumulative burden of functional changes than by time alone.

Whilst the review is unable to answer why this non-linear trajectory exists, a possible hypothesis based on the above literature is that the re-emergence or persistence of distress at longer follow-up periods may reflect specific challenges relating to survivorship. This includes the cumulative burden of long-term symptoms (e.g., dysphagia, fatigue, chronic pain), a possible fear of recurrence, and reduced intensity of clinical support following

treatment completion. As routine follow-up appointments become less frequent, psychological needs may go unnoticed, potentially contributing to unmet psychological distress.

Factors Associated with Anxiety and Depression

The findings also suggest that psychological distress following oesophagectomy is likely influenced by a combination of clinical and psychosocial factors. Physical factors, including postoperative complications, dysphagia and chronic post-surgical pain, were consistently associated with increased levels of anxiety and depression. These findings are consistent with those from a recent systematic review across cancer populations, which identified physical symptoms and functional impairment as among the most consistent predictors of psychological distress (Curren et al., 2024). There is some evidence from other cancer populations that improvements in swallowing function may be associated with reductions in depressive symptoms, suggesting that interventions targeting physical symptom burden may have wider psychological benefits (Zhang et al., 2014).

Although the applicability of these findings to oesophagectomy patients remains unclear, the prominence of dysphagia within this population highlights a potential area for targeted intervention. However, few studies examined psychosocial predictors in depth, with limited consideration of factors such as coping, social support or illness perceptions. This may reflect a more biomedical focus within the literature, with less attention given to psychological and social factors that may also shape individual experiences of distress.

Strengths and limitations

This review employed a comprehensive and systematic search strategy across multiple databases, with the study selection and quality appraisal being conducted with procedures to enhance reliability. Furthermore, the use of established appraisal tools allowed for a structured assessment of methodological quality, and findings were synthesised using a transparent narrative approach in line with the SWiM guidelines (Campbell et al., 2020). The narrative synthesis approach allowed findings to be organised by timepoint and by factors associated with anxiety and depression which supported identification of emerging patterns across studies.

However, several limitations should be acknowledged. The small number of included studies, alongside substantial heterogeneity in study design, outcome measurement and

timing of assessment, limited the ability to draw firm conclusions. The international nature of the included studies should also be considered when interpreting the findings. Studies were conducted across both European and East Asian countries, where differences in the epidemiology of oesophageal cancer, including histological subtype and associated risk factors may shape the populations being studied (Arnold et al., 2015). Cultural factors may also influence how psychological distress is presented and discussed and whether support is sought. Recent international cancer research found that cultural values and mental health stigma shaped both patients' and healthcare professionals' comfort discussing psychosocial concerns, whilst access to psychosocial oncology care remained inconsistent across healthcare contexts (Borda et al., 2026).

Given that the included studies predominantly relied on self-report measures, these cultural and healthcare differences may have contributed to variation in reported prevalence and the identification of distress. These contextual factors should therefore be considered when comparing findings across countries.

The relative recency of the evidence base should also be considered, with five of the seven included studies being published within the past six years. This may reflect a more recent focus on longer-term psychological outcomes and survivorship following oesophagectomy, meaning that standardised approaches to the measurement, timing, and reporting of psychological outcomes may still be developing. While the high degree of heterogeneity justified the decision not to conduct a meta-analysis, reliance on narrative synthesis may increase the risk of subjective interpretation. In addition, attempts to obtain additional data from the study authors were unsuccessful, which may have limited the completeness of the synthesis.

There were also limitations relating to the methodological quality and design of included studies. Although some studies employed longitudinal designs, others were cross-sectional, limiting the ability to draw causal conclusions regarding factors associated with anxiety and depression. In addition, the reliance on self-report measures, particularly the HADS, may have constrained the assessment of psychological distress. While the HADS is a widely used and validated measure found to be an efficient measurement of psychological distress in oncology populations (Luckett et al., 2010; Ziegler et al., 2011), it is not designed as a diagnostic instrument and may not accurately reflect the prevalence of clinically diagnosed anxiety or depressive disorders. As a result, prevalence estimates reported in this

review should be interpreted as indicative of elevated symptoms rather than a confirmed psychiatric diagnosis. Furthermore, variation in cut-off thresholds across studies may have contributed to inconsistencies in reported prevalence and limited comparability across studies.

Finally, the lack of consistent baseline measurements across studies makes it difficult to track individual recovery arcs. Although this review focused on outcomes from three months post-surgery, the lack of consistent pre-diagnosis or pre-operative baseline data across studies limits the ability to determine how psychological distress changes relative to an individual's baseline.

Implications for Research and Clinical Practice

Future research should prioritise longitudinal, multi-centre studies with clearly defined and consistent assessment timepoints to more accurately unpick trajectories of psychological distress following oesophagectomy. There is also a need for greater integration of psychosocial factors, including coping processes, social support, and illness perceptions, to better understand mechanisms of adjustment and identify individuals at heightened risk of ongoing distress. Adopting standardised and comparable outcome measures would further strengthen the evidence base and improve synthesis across studies. Clinically, the non-linear pattern of psychological distress identified in this review suggests that psychological screening should be considered beyond the perioperative period, particularly as distress may persist or re-emerge during longer-term survivorship.

However, repeated psychometric screening of all patients at fixed timepoints may not be feasible within current NHS services. Therefore, psychological needs may be better identified by embedding flexible, opportunistic assessment within existing cancer care and follow-up pathways. This could be through holistic needs assessments and routine conversations about emotional wellbeing, with validated psychometric measures used where concerns are identified or further assessment is indicated. Clear pathways for signposting or referral to appropriate levels of psychological support are also essential for patients requiring more specialised care.

Where psychometric measures are used within routine care, greater consistency in the measures and timepoints used may also help strengthen the evidence base. Routinely collected psychological data, where available and clinically appropriate, could support future

retrospective and longitudinal research and contribute to a clearer understanding of trajectories of psychological adjustment following oesophagectomy.

Future research should also aim to include and report more ethnically and culturally diverse samples to explore potential discrepancies between these groups and the impact of oesophagectomy on psychological distress. In addition, given the complex and multifactorial nature of adjustment to cancer, future research would benefit from taking a more integrated approach to better understand what contributes to psychological distress in this population.

Conclusion

In summary, this review highlights that anxiety and depression are common and persistent concerns following oesophagectomy, with evidence of a complex and non-linear trajectory over time. Importantly, evidence suggests that psychological distress reduces after early recovery but persists or increases again for some individuals during longer-term survivorship. These findings also highlight the importance of ongoing psychological assessment and support beyond the immediate recovery period, as well as the need for more consistent and methodologically robust research in this area.

Statements and Declarations

Ethical Approval:

Ethical approval was not required for this review due to the data obtained from published studies in which ethical approval and informed consent were obtained from all individual participants included in the study.

Consent to participate:

Not applicable. This review used data from previously published studies.

Competing Interests

The authors have no relevant financial or non-financial interests to disclose**.**

Funding Statement

The authors declare that no funds, grants, or other support were received during the preparation of this manuscript. This work was completed as part of a Doctorate in Clinical Psychology at the University of East Anglia, with open access publication funding covered by the UEA publishing agreement.

Author Contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Eleanor Hanton. The first draft of the manuscript was written by Eleanor Hanton and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data Availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Chapter Three

Bridging Chapter

Bridging Chapter

The systematic review presented in the previous chapter provided a narrative synthesis exploring the prevalence and trajectories of anxiety and depression following oesophagectomy. By examining quantitative literature, it demonstrated that psychological distress is often a significant, non-linear and long-term concern for this population. However, the review also highlighted several gaps in our current understanding. Primarily, the reliance on standardised psychometric tools, and the predominant focus on biomedical predictors such as chronic pain or dysphagia which offer limited insight into the broader biopsychosocial impact of the surgery. Whilst the review identified that distress persists over time, it was unable to offer insight into the subjective meaning of these experiences and how survivors navigate life following oesophagectomy.

Although a small body of qualitative research has begun to address this gap, the evidence base remains limited in scope and timeframe. Many existing studies largely focus on the early postoperative period (i.e., Heramb-Aamot et al., 2024; Nielsen et al., 2012; Sun et al., 2024). Furthermore, where longer-term experiences have been explored, researchers have often employed focus group methodologies (Malstrom et al., 2013) and included caregivers within the data collection process (McCorry et al., 2009). While these approaches are valuable for identifying shared challenges or dyadic support needs, they may not fully capture the more subjective and sensitive aspects of adjustment. Taken together, there is currently a need for more in-depth exploration of individual experiences of longer-term psychological adjustment post-esophagectomy.

Therefore, the next chapter attempts to further explore this gap in the literature and moves away from quantitative approaches to present a qualitative empirical study. Using one-to-one interviews with adults between one and five years post-surgery, this study seeks to explore how individuals make sense of their experience and adapt to life after esophagectomy, with a particular focus on the ongoing process of psychological adjustment.

Chapter Four

Empirical Paper

Prepared for the Journal of Cancer Survivorship

(Author guidelines in Appendix A)

Word Count: 6479 (excluding references)

Uncharted territory: Exploring Psychological Adjustment to Oesophagectomy Surgery in Adults with Oesophageal Cancer

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Abstract

Background:

Oesophagectomy is the primary curative treatment for oesophageal cancer but is associated with significant physical morbidity and prolonged recovery. While research has demonstrated increased rates of psychological distress following surgery, less is known about how individuals subjectively experience and adapt to the psychological impact of oesophagectomy across the illness trajectory.

Aims:

This study aimed to explore the psychological experiences of adults who had undergone oesophagectomy for oesophageal cancer, with a particular focus on how they made sense of their recovery and quality of life following surgery.

Methods:

A qualitative approach was employed using one-to-one semi-structured interviews with eleven adults who had undergone oesophagectomy between one and five years previously. Interviews explored experiences of diagnosis, surgery, and postoperative recovery. Data were analysed using reflexive thematic analysis, with themes developed through an iterative process of coding, reviewing and refinement across the dataset.

Results:

Five interrelated themes were generated: (1) existential threat and emotional survival, (2) relational trust and safety underpinning engagement, (3) making sense of illness through knowledge and cognitive strategies, (4) negotiating acceptance, control, and autonomy, and (5) living with change: adaptation, loss and quality of life. Participants described confronting mortality at diagnosis, replying on relational and cognitive strategies to navigate uncertainty during treatment, and adapting to ongoing bodily and identity changes following surgery.

Conclusion:

Oesophagectomy was experienced not only as a life-saving intervention but also as a life-altering psychological event. Findings highlight the importance of integrating psychological understanding and support within surgical pathways to support adjustment and long-term survivorship.

Keywords: Oesophagectomy, Oesophageal cancer, psychological adjustment

Introduction

Oesophageal cancer remains a significant public health concern in the United Kingdom. Approximately 9,000 new cases are diagnosed annually, equating to around 26 cases per day. Incidence rates are notably higher in men, who account for approximately 75% of diagnoses (Cancer Research UK, 2024; National Oesophago-Gastric Cancer Audit [NOGCA], 2025). Oesophageal cancer is characterised by malignant cell growth within the oesophagus, more commonly referred to as the 'feeding tube' which links the throat to the stomach (Obermannová et al., 2022). Despite advances in detection and treatment, oesophageal cancer remains associated with comparatively poor survival outcomes. Current estimates suggest that approximately 45% of individuals survive one year following diagnosis, while around 15% survive five years or more (Cancer Research UK, 2024). Prognosis is strongly influenced by stage at diagnosis, with later-stage disease associated with substantially lower survival rates.

Oesophagectomy is the primary curative treatment for oesophageal cancer (Zheng et al., 2021), commonly in combination with chemotherapy and/ or radiotherapy (National Institute for Health and Care Excellence [NICE], 2023). Oesophagectomy involves partial or complete removal of the oesophagus, sometimes including the top part of the stomach known as an oesophago-gastrectomy (Obermannová et al., 2022). The oesophagus is then reconstructed using the stomach, or less commonly, the small or large intestine. While potentially life-prolonging, the procedure is associated with significant postoperative morbidity and a prolonged recovery period.

Common postoperative complications include internal bleeding, pneumonia, dysphagia (difficulties with swallowing), dumping syndrome (including diarrhoea, vomiting and nausea caused by rapid gastric emptying) and infection (Ahmadinejad et al., 2020; Edmondson et al., 2023; Van Beek et al., 2017). Recovery is often prolonged, and quality of life is significantly reduced for six months post-surgery, with little improvement for up to three years (Djarv et al., 2009). Greater symptom burden has been linked to poorer psychological outcomes and reduced overall wellbeing (Bouras et al., 2017).

Research indicates that oesophagectomy is associated with significant psychological distress. Postoperative distress has been shown to persist over time, with a substantial proportion of patients reporting clinically significant anxiety or depressive symptoms in the

years following surgery (Liu et al., 2022). Greater postoperative symptom burden has been associated with elevated risk of psychiatric morbidity (Bouras et al., 2017), suggesting the physical consequences of surgery may compound psychological vulnerability. Individuals diagnosed with oesophageal cancer also demonstrate elevated suicide risk relative to the general population and other cancer groups (Chen et al., 2021; Henson et al., 2019). Recent systematic review and meta-analytic evidence further estimate perioperative mental disorders in 30% of oesophagectomy patients and links preoperative psychiatric comorbidity to increased postoperative mortality risk. This highlights the clinical significance of psychological vulnerability in this population (Papaconstantinou et al., 2025).

However, much of the existing literature exploring this adopts a quantitative framework, focusing on symptom prevalence, mortality rates and risk factors. While valuable, such approaches offer limited insight into how individuals subjectively experience diagnosis, surgery, and longer-term recovery. Previous qualitative research suggests that an oesophageal cancer diagnosis may be experienced as an existential threat, often associated with stigma and perceptions of a "death sentence" (McCorry et al., 2009). In addition, post-surgical adjustment has been described as a process of "remapping" the body (Wainwright et al., 2007), with individuals navigating altered eating practices, visible physical changes, and shifts in social identity (Bennett et al., 2020; Graham-Wisner et al., 2019).

More recent qualitative studies further emphasise the demanding nature of recovery. Nielsen et al. (2021) reported that surgery and the postoperative period were frequently experienced as more challenging than anticipated, particularly in relation to fatigue and the disruption to eating routines. Similarly, Malmström et al. (2013) examining longer-term survivorship, described enduring embodied change and a sense of loss in relation to pre-surgical functioning. Participants articulated adaptation as an ongoing process rather than a return to previous normality, with eating and social participation often requiring continued negotiation.

Together, these findings suggest that adjustment to oesophagectomy involves complex changes that extend beyond the management of physical symptoms. Nonetheless, in-depth qualitative exploration of how individuals make sense of this experience across the illness trajectory remains limited.

National guidelines recommend psychosocial support before and after oesophagectomy, including preparation for treatment-related uncertainty, changes to family roles, and potential emotional difficulties (NICE, 2023). In practice, access to structured psychological intervention remains inconsistent (Bennett et al., 2020). Emerging evidence from multimodal prehabilitation programmes integrating exercise, nutrition, and psychological support, suggest potential benefits in reducing postoperative complications and maintaining functioning capacity, with some improvements reported in aspects of quality of life (Allen et al., 2022; Barman et al., 2025). Nevertheless, whilst such interventions aim to mitigate distress to support recovery, little is known about how individuals themselves perceive and navigate the psychological impact of surgery.

Therefore, this study aims to address these gaps by exploring the lived experiences of adults who have undergone oesophagectomy as treatment for oesophageal cancer.

Research Questions

- What are individuals' psychological experiences of undergoing oesophagectomy, including the surgical procedure and postoperative recovery?
- How do individuals describe the psychological impact of oesophagectomy following treatment?
- How do individuals perceive and evaluate their quality of life postoperatively?

Method:

Design

Ethical approval for this study was obtained from the NHS Research Ethics Committee (ID 350451), alongside confirmation of capacity and capability from the participating NHS Trust. All data were handled in accordance with General Data Protection Regulation (GDPR, 2019).

A qualitative design using reflexive thematic analysis (Braun & Clarke, 2006; 2021) was adopted, utilising one-to-one semi-structured interviews to explore participants' experiences of undergoing oesophagectomy and subsequent recovery. The topic guide was developed in collaboration with the Upper Gastrointestinal (GI) clinical team to ensure clinical relevance and sensitivity. This study was underpinned by a critical realist epistemological position, acknowledging that participants' accounts reflect both lived

experiences of the surgery and subjective interpretations shaped by social and relational contexts.

Participants

Eleven adults (aged 18 years and above) who had undergone oesophagectomy as part of their treatment for oesophageal cancer participated. Eligible participants were between one and five years post-surgery. A minimum of one-year post-surgery was selected to allow sufficient physical recovery. This timeframe also enabled participants to reflect meaningfully on both the surgical and longer-term adjustment experiences. Individuals currently open to secondary mental health services were excluded. This was to help ensure that participants' accounts reflected the psychological impact of oesophagectomy surgery, rather than being primarily influenced by mental health difficulties.

Procedure

Participants were recruited via a local oesophageal cancer support group. Interested participants were provided with an information sheet and given the opportunity to ask questions prior to providing written consent. Of the 11 interviews conducted, ten took place face-to-face and one was conducted online via Microsoft Teams. Interviews ranged in length from 25 to 100 minutes, with an average duration of 60 minutes.

Data Analysis

Data were analysed using reflexive thematic analysis (Braun and Clarke, 2026, 2021). Analysis followed the six phases: familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Transcripts were read multiple times to support immersion in the data. NVivo (version 14; Lumivero, 2023) was used for initial inductive coding, including analytic memos and to organise and manage coded extracts. Microsoft Excel was used to map codes, cluster related patterns and visually track the development and refinement of codes and candidate themes across the dataset. As part of the analytic process, selected transcript extracts were reviewed collaboratively with the research team. These discussions focused on exploring potential codes and reflecting on how particular extracts could be understood. This supported the refinement of codes and strengthened engagement with the data. Consistent with a reflexive thematic analysis approach, this process was not used to establish coding agreement or reliability, but to enhance reflexivity and strengthen the analysis (Braun & Clarke, 2019).

Themes were developed through an ongoing and iterative process of reviewing, collapsing and refining patterns across the dataset. Rather than emerging in a linear way, themes were shaped through repeated engagement with the data, moving between individual accounts and the wider dataset. Attention was given to both shared patterns of meaning and areas where participants' experiences differed. Pseudonyms are used throughout to protect the anonymity of participants, their family members and members of the medical team. Participant characteristics are presented in Table 1.

Results

Table 1
Participant demographic and clinical characteristics

Participant	Age	Gender	Year of Surgery	Time since surgery	Treatment Pathway
P1	83	Male	2021	4y 2m	NAC (6) + AC (4)
P2	81	Male	2021	3y 8m	Surgery only
P3	65	Male	2020	5y 1m	NAC + AC
P4	81	Female	2022	2y 10m	NACRT
P5	61	Male	2021	3y 7m	NAC (4) + AC (4)
P6	82	Male	2024	1y	NAC (6)
P7	61	Transgender female	2021	4y 1m	NAC (6) + AC (1)
P8	76	Male	2024	1y	NAC (6) + AC (4)
P9	82	Male	2022	3y 6m	NAC (4) + AC (4)
P10	77	Male	2023	2y 6m	NAC + AC
P11	61	Male	2023	1y 11m	NAC (4) + AC (4)
M =	73.6	-	-	3y	-

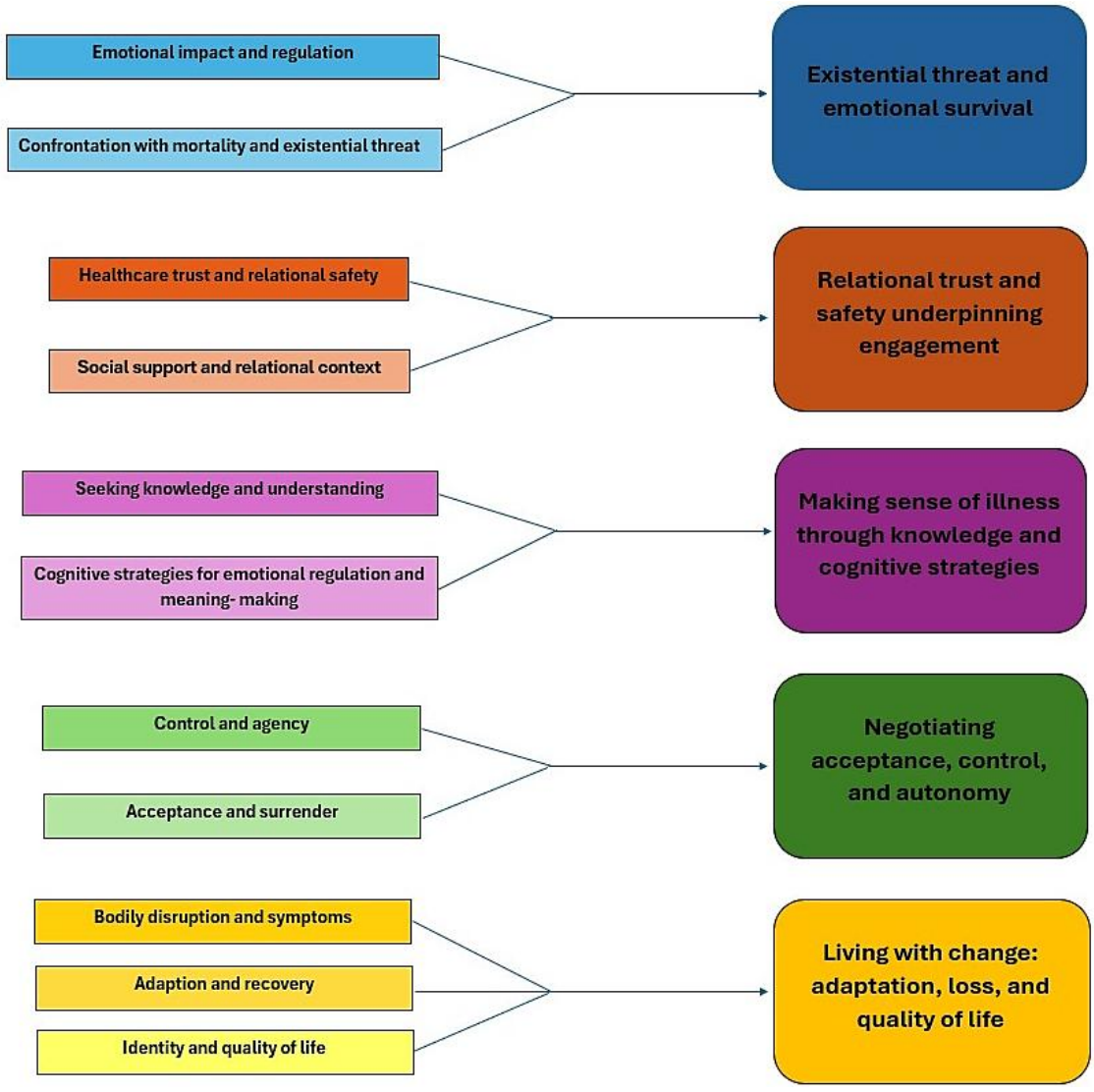
Note. NAC = Neoadjuvant chemotherapy; AC = Adjuvant chemotherapy; NACRT = neoadjuvant chemoradiotherapy. M = mean. Numbers in parentheses indicate number of cycles. The sample comprised of 9 males, 1 female and 1 transgender female.

Overview of Themes

A total of five interrelated themes were generated which capture participants' psychological experiences of undergoing oesophagectomy surgery and subsequent recovery. Together, these themes reflect how participants navigated existential threat, managed their emotional coping, how they engaged with others and health care systems and adapted to ongoing changes both during and following the surgery. Although presented separately for clarity, themes were interrelated and recurring throughout, reflecting the complex and non-linear nature of participants' experiences. Figure 1 illustrates how initial codes were clustered and refined into the final themes.

Figure 1

Codes and Final Themes



Existential Threat and Emotional Survival

This theme captures the initial emotional and existential impact of receiving a cancer diagnosis and undergoing oesophagectomy, framed primarily as an existential threat to life. Participants described becoming very aware of the seriousness of their diagnosis and the possibility of death, often accompanied by a sense that their lives felt unfinished or abruptly disrupted. For some, this threat was experienced as sudden shock and disbelief, characterised by moral questioning, and a perceived incongruence between seeing themselves as healthy and facing serious illness:

> Horrible…I thought of my family, I'm not ready to go yet, I've still got some golf to play… it was traumatic, and the first words that came out of my mouth, why me? what have I done wrong? – P9

For others, the diagnosis was described as more expected or inevitable, prompting a pragmatic focus on survival rather than an overt emotional response:

> If you don't wanna have the operation you're going to feel very bad and die. – P6

Here, mortality was expressed in clear and direct terms, with surgery framed as the only viable option. Across interviews, confrontation with mortality was sometimes reflected in practical actions, such as putting affairs in order or preparing for the possibility of death, which sat alongside a strong emphasis on emotional survival.

Many participants described suppressing or delaying emotional responses during the early stages of diagnosis and treatment, instead prioritising getting through what needed to be done. Although feelings of anxiety, sadness, and helplessness were present for some, these emotions were often held at a distance in the initial phase:

> We were both laughing and joking about it… we were absolutely fine. Then we got home, still fine… then we had a big argument for no reason. I stormed out the house, sat at the top of the road for about three hours, not crying, but really feeling down and I just didn't know what to do... yeah, that was really not good. – P11

This illustrates how the immediate impact of the diagnosis could be managed through humour and apparent composure, before distress surfaced later in less direct ways. Emotional responses were not always evident at the point of receiving the news, instead emerging

gradually, sometimes through withdrawal, irritability or a conversation with loved ones. This prioritisation of emotional survival appeared to shape how participants engaged with both others and their own attempts to manage uncertainty during treatment.

Relational Trust and Safety Underpinning Engagement

This theme captures the importance of relational and systemic safety in enabling participants to engage with treatment and cope with the experience of illness. Many participants described a strong sense of trust in healthcare professionals, often linked to perceptions of competence, clear communication, and feeling cared for as a person. For some, this trust was experienced not only during active treatment but as an ongoing sense of being held in mind by services over time:

> They have, over the past three and a half years, kept that contact to make sure that, you know, you are okay, that you're doing well. And I find that sort of remarkable ….that is really, really helpful it gives you a lift, to know that you still have those people that actually, they don't worry about you, but they want to know, they want to make sure that you're still ok. – P2

This illustrates how continued contact and follow-up provided reassurance and security, reinforcing participants' confidence in the care they were receiving. This relational safety seemed to support engagement with treatment by reducing uncertainty and extending a sense of containment beyond the immediate surgical period.

Alongside the relationships with healthcare professionals, family members also played a central role in providing emotional and practical support across diagnosis, hospitalisation and recovery. Participants described having a strong support network around them:

> Shelley used to come in practically every day… my cousin would come to give her a day off… there was always somebody around… they saw me through, really. – P4

Here, recovery was not experienced in isolation. Having others physically present and involved in everyday tasks appeared to provide stability during an uncertain and physically disorientating period. For some, this support not only involved comfort and reassurance but gentle accountability, which helped sustain motivation and engagement during recovery. In this way, relational support not only provided a sense of comfort, but could also be directive, reinforcing motivation and persistence during recovery.

However, relational closeness also brought a level of complexity. Participants acknowledged the emotional burden associated with these relationships, describing a sense of responsibility to protect friends and family from worry or distress, which sometimes shaped how openly they expressed fears. While relational safety provided an important external scaffold, participants described internal strategies for managing the uncertainty associated with diagnosis and treatment.

Making Sense of Illness Through Knowledge and Cognitive Strategies

This theme reflects how participants attempted to make sense of their diagnosis and manage uncertainty by developing an understanding of the illness and treatment process. For many, the delay or absence of emotional processing described in the previous theme was accompanied by a shift towards gathering information and understanding what was happening to their body, which appeared to provide a greater sense of orientation during an otherwise uncertain and frightening time.

Participants described receiving information about the treatment pathway and prognosis as particularly significant in shaping how they understood the diagnosis. In some cases, specific medical information appeared to transform how participants interpreted their situation, shifting their perspective from fear towards hope:

> He said what they were gonna do, he said we're gonna have four sessions of chemo, and then, you know, you see a surgeon, who will probably do an operation, and then we'll do four more sessions… and I remember him writing on the form, he put down curative for the treatment, so when I saw that I thought wow … the fact that I was so pleased when he put curative down there, and I thought it's going to be okay.– P7

For some, learning more about treatment outcomes and survival also appeared to make the diagnosis feel more understandable and less overwhelming, offering a sense that there may be a future beyond treatment. In addition, information also appeared to help participants interpret unfamiliar physical sensations and treatment effects. Understanding what to expect made symptoms feel more predictable and therefore less frightening, particularly during the early stages of recovery:

> I think something's less terrifying when you know more exactly what it is… when I had all this pain and everything, I could understand why it was rather than thinking,

> oh, dear, the operation has gone wrong because I'm in this terrible pain…you know, this is alright, this is part of it. – P1

Alongside developing knowledge about their illness, some described consciously adopting particular ways of thinking in order to manage fear and uncertainty. This included reframing difficult experiences, focusing attention on positive aspects of recovery, and trying to avoid dwelling on worst-case scenarios:

> I developed a philosophy which is believe the best until the alternative is certain. Why bother thinking of all the worst things?…During and after the operation I would think, well, this is good. I've been told I won't be able to put weight on again, I was quite overweight, isn't it nice that I don't have to go on a diet. And all the positive things that I set myself the task I thought right, I'm going to do some of the things I've always wanted to do and never done…So all the time, I would flood myself with positive thoughts.- P1

These accounts suggest that developing an understanding of the illness and consciously shaping how they responded to it allowed participants to manage the psychological uncertainty surrounding treatment. In this way, knowledge and deliberate ways of thinking appeared to work together to support participants in continuing to engage with treatment despite the existential threat posed by the diagnosis.

Negotiating Acceptance, Control, and Autonomy

This theme reflects the ongoing process through which participants negotiated acceptance, control, and autonomy across the treatment trajectory. Rather than describing a fixed position of either surrender or agency, participants described a continual balancing act between surrendering control in the face of medical necessity and attempting to retain autonomy where possible. For some, this was most prominent at the point of surgical decision-making. Despite fear and uncertainty, participants described actively choosing to proceed, framing surrender as a deliberate act as opposed to being a passive choice:

> I thought when I sat there, right, do I go, or do I stay? But I thought, no, you've got to stay, you have to have it done. How frightened I was, but you sort of overcome it. You think, I'm here now, I'm with a good team, got to have it done. You get like a stronger feeling in yourself. – P3

Here, surrendering control was accompanied by a process of drawing on inner strength. Acceptance did not appear to reflect emotional calm or resolution, but rather an active and deliberate decision to proceed in the presence of fear. Similarly, some participants adopted a pragmatic, stoic stance towards circumstances perceived as unchangeable. A 'get on with it' mentality provided a way of moving forward despite the ongoing limitations imposed:

> You just have to work around all these things and get on with it. And I've said that a lot, get on with it. To me, that's how life is. Quite often you can't change things, and when something's happened it's too late to do anything about it, you've just got to, resolve any problems. – P8

Participants also described efforts to regain autonomy, especially during the early stages of surgical recovery. Being able to resume everyday tasks independently appeared important, and therefore was often accompanied by frustration when they bodies did not respond in the same way as pre-surgery:

> I felt completely useless… I didn't ever ask for any help. I didn't want help. I was a bit pig headed and stubborn, I've got to do it myself. The sooner I do it myself the first time… It was an overall feeling of uselessness, not being able to do things at the speed you normally would. – P5

This quote illustrates the tension between accepting support and preserving independence as a valued aspect of identity. Though support was available, relying on others appeared to challenge participants' sense of competence and self-sufficiency. For some, this negotiation extended beyond early recovery, one participant reflected on the frustration of losing physical control despite feeling mentally capable:

> It was frustrating to lose control. Because you are, after an op like that, you are not in control. Mentally, you're in control, I think, but physically, you're not…. And you have to somehow come to terms with it and accept the restrictions of your life. – P2

Rather than representing a fixed outcome, this demonstrates how control emerged as something participants repeatedly worked at. Although physical capacity was limited, many described maintaining a sense of self-determination through adaptation and persistence. Acceptance and autonomy therefore functioned as intertwined processes that continued

beyond the acute treatment phase, shaping how participants later made sense of the longer-term consequences of surgery.

Living with Change: Adaptation, Loss, and Quality of life

This theme captures how participants experienced and made sense of life following oesophagectomy, balancing the significance of survival against the ongoing physical, psychological and social impact of treatment. Recovery and adjustment were not experienced as simply positive or negative but often involved a complex mix of relief and gratitude alongside frustration, loss, and for some, regret about the lasting changes from surgery. These evaluations continued to shift over time as participants negotiated new bodily realities and considered what quality of life meant to them. These experiences were shaped by the interaction between expectations of surgery and the realities of recovery. Participants entered surgery with varying expectations ranging from hope for recovery to anticipation of persistent pain, physical limitation or even death. In contrast, a small number described holding optimistic expectations of cure and returning to pre-surgery normality.

For some, early recovery confirmed fears about disruption to eating, energy levels and physical functioning. Eating appeared to be central to where expectations were tested. Post-surgery dietary adjustments often required a gradual progression. Many participants described this as challenging, particularly where eating had previously been associated with pleasure and social connection. Some spoke of deliberately going against medical advice to preserve enjoyment, even if this meant experiencing dumping syndrome. For others, adjustment involved learning to recognise which foods no longer agreed with them. Across participants, eating appeared to represent an ongoing negotiation between pleasure and physical discomfort:

> I am restricted now as to, what I eat, when I eat, and that does make a big difference as to where we can go. What we can do… And my life is revolving around food I suppose. – P10

In addition, fatigue was often described as unpredictable, with some participants finding their bodies did not always respond as expected when attempting to resume previous routines:

> Overwhelming fatigue, an absolute wave of barely being able to keep your eyes open, and so very often the best thing is to just let it happen. – P5

However, others described returning to everyday activities sooner than anticipated, challenging pre-surgery assumptions of severe decline. Physical change was experienced as variable rather than consistently negative.

Beyond physical symptoms, some participants described a sense of loss related to pre-surgery identity. Shifts in independence, confidence, spontaneity and social engagement were frequently noted. Eating in public settings, asking for smaller portions or navigating the possibility of dumping syndrome introduced new layers of self-consciousness. For some, physical changes such as weight loss or visible surgical scars contributed to a sense of not fully recognising themselves:

> Before the op I felt good about myself and felt good about my body. Now I'm like the scarecrow…. And I sort of ignore it, but sometimes, I look in the mirror and I couldn't see me…. It is a part of your life, it isn't just your figure, and your weight loss, it's about you as a person. – P2

Living with change therefore involved more than just adapting to physical limitation; it also required renegotiating identity in relation to others and self. Over time, many participants described adapting to these changes and redefining what quality of life meant to them. For some, physical recovery stabilised and life felt largely restored. A new appreciation for everyday experiences, improved energy or expanded opportunities to travel contributed to a sense of gratitude and, for some, a new lease of life. One participant reflected:

> I almost felt that sense of, why have I been so lucky? … why should I be all right and they're not? … I just feel so healthy. I feel good, there's not nothing I can't do that I wouldn't, and in fact, because my loss of weight, I in fact feel I'm more energetic than I was. – P1

This illustrates how survival was experienced not only as a relief, but also as morally complex. Although some participants expressed gratitude, this was often accompanied by comparison to others and a sense of survivor's guilt, together with a renewed sense of energy and purpose. However, this was not always shared and for some, ongoing difficulties led to retrospective reconsideration of their decision to undergo surgery:

> I know that if I hadn't had the surgery, I'd most probably be looking over my shoulder wondering if the cancer would come back. But, if in retrospect, I would not have had

> the surgery. Because I, it has changed me and I'm not for the better. Okay, I don't worry about cancer, but I wouldn't have worried about cancer anyway. I'm going to die of something for heaven's sake and I'm 81. So, I think I would have preferred, I would have preferred quality. – P4

Similar tensions were reflected by others, where ongoing pain, restriction and reduced enjoyment led participants to experience surgery as a loss rather than a gain. This highlights the variability and moral complexity of postoperative adjustment, with quality of life often redefined in diverse and sometimes ambivalent ways.

Discussion

This study sought to explore the psychological experiences of adults undergoing oesophagectomy for oesophageal cancer. The findings illustrate that adjustment to oesophagectomy is not confined to the immediate postoperative period, but is an ongoing psychological process shaped by existential threat, relational support, meaning making, and the negotiation of control and autonomy. Participants described confronting mortality at diagnosis, managing distress through emotional containment or pragmatic focus, while also drawing on cognitive and relational strategies across treatment and recovery. Over time, the impact of surgery extended beyond physical recovery to encompass identity disruption, shifts in independence, gratitude, ambivalence and for some, regret. Taken together, these findings suggest oesophagectomy is experienced not only as a lifesaving intervention but as a life-altering psychological event requiring sustained adaptation.

At diagnosis, participants commonly experienced their cancer as a significant threat, often as a direct confrontation with mortality that prompted existential questioning about life, death and the future. This is consistent with Moorey and Greer's (2011) model of adjustment to cancer, which highlights the role of threat appraisal in shaping emotional and behavioural responses. Similar experiences have been identified in previous qualitative literature exploring oesophageal cancer, with McCorry et al. (2009) reporting that diagnosis was associated with perceptions of poor prognosis and could be experienced as receiving a 'death sentence'. In the present study, surgery was frequently framed as the only viable option for survival, while humour, pragmatism and emotional containment appeared to provide ways of managing this threat whilst continuing to engage with treatment. Diagnosis therefore appeared to disrupt participants' assumed continuity of life, making mortality feel more immediate and personal.

Within this period of uncertainty, relational trust appeared to provide a sense of stability. Experiences of consistent care, clear communication and ongoing follow-up, alongside support from family and friends, appeared to provide more than just practical reassurance, helping participants feel supported and less alone. The significance of this trust is echoed in findings by Nielsen et al. (2021), where 'trusting medical professionals' and 'embracing support' were identified by survivors as important for navigating recovery. In the present study, this relational stability also appeared relevant to how participants negotiated control. Where treatment options felt limited, trusting clinicians appeared to help some participants hand over aspects of control whilst still feeling actively involved in their care.

Alongside relying on trusted professionals, participants actively sought information to make treatment and recovery feel more understandable and predictable. In particular, knowing what to expect allowed them to interpret unfamiliar symptoms as an expected part of recovery rather than as signs that something had gone wrong, reducing fear around difficult bodily experiences. This can be understood in relation to the Common-Sense Model of Self-Regulation (Leventhal et al., 2003, 2016), which proposes that how individuals understand and represent illness influences their emotional and behavioural responses. While previous research suggests that information can be experienced as both threatening and empowering (Graham-Wisener et al., 2019), participants in the present study largely described information-seeking as helpful in reducing uncertainty and restoring a sense of predictability and control.

Although surgery was often framed as medically necessary, participants frequently described proceeding with it as an active decision, preserving a sense of agency at a point of heightened vulnerability. While aspects of treatment were outside their control, including surgery itself, hospitalisation and postoperative side effects, participants appeared to refocus attention towards areas that remained within their influence. Continuing with planned holidays, asserting treatment preferences or choosing what to eat even against medical advice, functioned as small but meaningful expressions of autonomy. In this way, participants appeared to move between accepting what could not be changed and trying to maintain control where this was still possible. This also suggests greater fluidity than might be implied by the discrete adjustment styles described by Moorey and Greer (2011), with participants drawing on different responses according to the circumstances they were facing rather than demonstrating one consistent way of adjusting.

As participants moved beyond acute treatment and recovery, adjustment increasingly involved living with the lasting bodily and social consequences of surgery. Participants described changes to physical functioning, independence and everyday life, consistent with longitudinal qualitative research describing adaptation following oesophagectomy as an ongoing process of adjusting to a 'new normal' (Sun et al., 2025). These changes also shaped participants' sense of self, particularly in relation to work, relationships and independence. This supports findings from Graham-Wisener et al. (2019), who described adjustment as involving recognition and acceptance of a changed body and altered sense of self, particularly in relation to functioning and appearance.

Within these broader changes, altered eating appeared particularly pervasive, at times shaping where participants could go, what they could do and how they engaged socially. This is reflected in previous research highlighting the wider psychosocial impact of altered eating following surgery, including reduced spontaneity, feelings of shame and embarrassment, and difficulties participating in social situations involving food (Gillman et al., 2025; Malmström et al., 2013). Together, these findings suggest that changes to eating can extend beyond a physical consequence of surgery to shape wider aspects of everyday and social life.

Alongside these daily disruptions, participants' longer-term experiences of surgery also shaped how they evaluated their quality of life. For some, adaptation involved finding ways to continue activities that remained important despite ongoing discomfort and restriction. However, adjustment did not always involve reaching a point of acceptance. Instead, it was often marked by ambivalence, with gratitude and relief of survival coexisting with frustration, loss and, for some, regret about the lasting impact of surgery. Similar tensions have been described in wider cancer survivorship research, where life after treatment can involve the coexistence of positive and negative experiences rather than a straightforward return to normality (Cuthbert et al., 2021). For a small number, ongoing pain and restriction led them to retrospectively question the balance between survival and the impact of surgery on their quality of life. These findings suggest that adjustment following oesophagectomy may involve an ongoing negotiation between gratitude for survival and the losses and limitations associated with treatment, rather than a linear movement towards acceptance.

Strengths and limitations

A key strength of this study was its focus on participants' longer-term psychological adjustment following oesophagectomy. By including individuals between one and five years

post-surgery, the study was able to explore experiences extending beyond the immediate postoperative period and consider how adjustment continued to evolve over time. The use of one-to-one semi-structured interviews also enabled participants to describe their experiences in depth and in their own words, including more sensitive or personal aspects of recovery. Reflexive thematic analysis was well suited to the exploratory nature of the study, allowing shared patterns of meaning to be identified whilst recognising the researcher's active role in interpretation. The critical realist position further supported consideration of both participants' lived experiences and the wider relational, social and clinical contexts in which these were situated.

Participants were recruited from a single oesophageal cancer support group within one NHS trust. While this enabled access to individuals willing and able to reflect in depth about their experiences, it may have shaped the perspectives represented. Support group attendees are likely to be more physically able to engage socially and may be more inclined towards help-seeking or reflective meaning-making. Individuals experiencing more severe postoperative complications, mobility restrictions, social withdrawal or ongoing distress may therefore be underrepresented. In addition, participants described largely positive experiences of continuity and follow-up care. Although this provided valuable insight into how relational trust can scaffold psychological adjustment, experiences of postoperative care likely vary across NHS trusts and services. The findings therefore offer limited insight into the contexts where care is less relationally embedded or less consistent.

The sample was also demographically narrow, made up of predominantly older adults, and mostly white male participants. Cultural context, gender norms, socioeconomic position and family structures may meaningfully shape illness representations, coping processes and experiences of recovery. Caution is therefore advised in considering the transferability of these findings to more diverse populations.

Clinical and Research Implications

These findings support a more integrated approach to care within oesophageal cancer surgical pathways across longer-term recovery. Patients would benefit from clear and accessible information about the surgical trajectory, anticipated side-effects, recovery patterns and common emotional responses, alongside consistency in follow-up and opportunities to ask questions. Preoperative preparation should also provide a realistic

account of longer-term recovery, including the possibility that adjustment may continue well beyond the immediate postoperative period. Alongside transparent discussion of risks and potential complications, incorporating realistic accounts of adaptation and survivorship may help patients understand that life following surgery can also retain meaning, enjoyment and possibility. Access to peer support could also be valuable, particularly in reducing isolation, and providing opportunities to discuss shared experiences and practical strategies with others (Sadeghi et al., 2025). Services could therefore consider routinely signposting patients to oesophageal cancer support groups or peer networks where available.

Particular attention should be given to the longer-term practical and psychosocial consequences of altered eating following oesophagectomy. Preoperative and discharge conversations may benefit from preparing patients for changes in meal size and frequency, food tolerance and eating in social settings. Continued access to specialist dietetic support may also be important as dietary needs and symptoms change over time. Given the overlap between eating difficulties, fatigue, physical functioning and psychological adjustment, closer coordination between oncology, dietetic, physiotherapy and psychological services may support a more joined-up response, as also recommended by Sivakumar et al. (2026). Psychological support should also recognise the losses that can accompany these changes, including reduced enjoyment, spontaneity, independence and confidence in social situations.

Practical resources may also help reduce embarrassment and self-consciousness associated with eating-related and gastrointestinal symptoms. For example, restaurant cards which highlight the need for urgent toilet access and smaller portion sizes, may reduce the burden of repeatedly explaining symptoms in public and support continued social participation, particularly where dumping syndrome or urgency might otherwise contribute to avoidance.

Earlier identification of individuals who may require additional support may also be beneficial, with previous research linking greater comorbidity with poorer quality of life and functioning following oesophagectomy (Backemar et al., 2020). Alongside this, routine consideration of social support, pre-existing physical and mental health difficulties and functional limitations before and after surgery could help identify those who may benefit from more proactive input.

Although this study provides in-depth insight into the psychological experiences of undergoing oesophagectomy, further research is warranted. Participants described relatively high levels of relational continuity and follow-up care. Comparative qualitative research could explore how variations in service provision shape psychological adjustment and survivorship experiences. In addition, future studies would benefit from including individuals with more complex or enduring mental health needs to explore how pre-existing psychological vulnerability interacts with surgical recovery. Longitudinal qualitative designs could also examine how the psychosocial consequences of altered eating, including experiences of loss and changes to social participation, interact with identity and quality of life over time.

Conclusion

This study offers insight into the psychological experience of undergoing oesophagectomy for oesophageal cancer. Adjustment was not limited to physical recovery but involved an ongoing process of confronting mortality, managing uncertainty, and adapting to lasting bodily and identity changes. Relational trust in healthcare professionals and family members appeared central in supporting engagement with treatment, while cognitive strategies helped participants tolerate uncertainty and maintain a sense of agency. Over time, participants described redefining quality of life in diverse and sometimes ambivalent ways. Together, these findings highlight the importance of integrating psychological understanding and support within surgical care pathways.

Statements and Declarations

Ethical Approval:

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the NHS Research Ethics Committee (ID 350451), alongside confirmation of capacity and capability from the participating NHS Trust.

The questionnaire and methodology for this study were approved by the NHS Research Ethics Committee (ID 350451).

Consent to participate:

Informed consent was obtained from all individual participants included in the study.

Competing Interests

The authors have no relevant financial or non-financial interests to disclose**.**

Funding Statement

The authors declare that no funds, grants, or other support were received during the preparation of this manuscript. This work was completed as part of a Doctorate in Clinical Psychology at the University of East Anglia, with open access publication funding covered by the UEA publishing agreement.

Author Contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Eleanor Hanton. The first draft of the manuscript was written by Eleanor Hanton and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data Availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Chapter Five: Extended Methodology

This chapter provides additional information regarding the methods and design of the empirical paper, in addition to further elaboration on the qualitative research approach and thematic analysis.

Methodological Rationale

Ontology and Epistemology

Within qualitative research, it is important for researchers to consider their ontological and epistemological positioning and how these shape the research process. Ontology refers to assumptions about the nature of reality, whereas epistemology is concerned with how knowledge about that reality can be generated and understood (Braun & Clarke, 2013). The present study adopts a critical realist stance (Bhaskar, 1978; 1989). Critical realism assumes that a reality exists independently of our knowledge of it. However, our understanding of that reality is shaped by social context and interpretation. In contrast to social constructionist perspectives, critical realism recognises that experiences have real material consequences, while also acknowledging that people interpret and make sense of those experiences in different ways.

Bhaskar (1978) described reality as stratified across three domains: the empirical, the actual and the real. The empirical refers to what is experienced and observed, such as the accounts participants shared during interview. The actual refers to events that occur whether they are directly observed, including the processes participants went through, such as receiving a diagnosis, undergoing surgery and navigating recovery. The real refers to the underlying mechanisms or structures that shape these events and experiences. In the context of the present study, these mechanisms may include factors such as existential threat, loss of control, relational support, identity disruption and broader cultural meanings attached to illness and survivorship.

Critical realism also emphasises the relationship between structure and agency. While individuals act within pre-existing social structures such as healthcare systems, cultural expectations and family roles, they are not entirely determined by them. Individuals actively interpret, respond to and negotiate these conditions. This perspective aligns with the findings of the present study, where participants described navigating medical systems, renegotiating autonomy, and actively making sense of their experiences following oesophagectomy.

Consistent with this epistemological position, participants' accounts were understood as interpretations of real experiences rather than objective facts or purely constructed narratives. Reflective thematic analysis was therefore used to explore patterns of meaning within these accounts, recognising that themes are developed through an interpretive engagement between participants' experiences and the researcher's analytic perspective.

Given that critical realism recognises that knowledge is interpreted through social and contextual lenses, it is important for researchers to reflect on how their own perspectives may shape the research process. Reflexivity therefore formed an important part of this study.

Introduction to Reflexivity

Reflexivity is widely discussed in qualitative research; however, definitions can vary considerably. Drawing on Olmos-Vega et al. (2023), reflexivity can be understood as an ongoing and multifaceted process through which researchers consciously examine how their subjectivity, assumptions and broader context shape the research process. Rather than being a single reflective exercise, reflexivity is continuous and extends across study design, data collection, analysis and write-up. It involves critical attention not only to personal beliefs and experiences, but also to interpersonal dynamics, methodological decisions and the wider social and institutional contexts in which research is conducted.

Within reflexive thematic analysis, researcher subjectivity is viewed as an analytic resource rather than a bias to be eliminated (Braun & Clarke, 2019). Themes are understood as actively constructed through engagement with the data, shaped by the researcher's theoretical positioning and interpretive lens. Consistent with this approach, reflexivity in the present study was embedded throughout the research process and involved ongoing consideration of how my positioning and assumptions influenced the generation and interpretation of themes.

Qualitative researchers engage in reflexivity to account for how subjectivity shapes their inquiry. Reflexivity is closely tied to researchers' ability to make nuanced and ethical decisions while navigating the complexity of generating real-world data that reflects the lived experiences and social contexts of participants (Finlay, 2002; Olmos-Vega et al., 2023). In this sense, the researcher's perspective is inherently intertwined with qualitative research processes. While this subjectivity can enhance interpretation, failure to attend to reflexivity risks limiting transparency in how knowledge is constructed.

Personal Reflexivity Applied Within this Study

To enhance reflexivity throughout the study, a reflective diary was used during study design, data collection and analysis phases. This created space to consider how my experiences, assumptions and professional positioning may have shaped methodological decision-making, interactions with participants and the interpretation of their accounts (Appendix E).

In reflecting on my motivation for conducting research within the health and oncology field, specifically in relation to oesophageal cancer, I recognised that this interest was partly grounded in my previous role as an Assistant Psychologist within a hospital-based mental health liaison team. In that setting, I worked with individuals undergoing a range of medical procedures, including post-oesophagectomy care. I remember being struck by the intensity and invasiveness of the surgery, as well as the psychological impact of prolonged hospitalisation.

Within this role, I frequently supported individuals who were required to surrender significant control to medical systems. Therefore, part of my work involved supporting patients to regain a sense of autonomy, often then re-establishing routines or introducing elements of normality into the hospital environment. I would often reflect on the concept of person-centred care and how this played out in practice. My experience was that, despite its prominence in policy, its implementation was often impacted by systemic pressures, including staffing and resource limitations. This background may have sensitised me to the complex emotional and relational processes that come with serious illness and hospitalisation, shaping my focus to themes of uncertainty, meaning-making, autonomy and adaptation within participants' experiences.

In addition, I frequently worked with older adults facing significant health challenges who were engaged in processes of life reflection and contemplation. Exposure to these conversations may have sensitised me to existential elements of participants experiences in the present study. While this attunement may have enabled me to recognise subtle themes of regret, gratitude and identity renegotiation, it also required ongoing reflection to ensure that such interpretations were grounded in the data rather than shaped predominantly by my prior clinical experiences.

There is also a more personal layer to my understanding of oesophageal cancer. A close family member had metastatic oesophageal cancer and sadly died from the illness.

Although this did not directly determine my choice of research topic, I've reflected on how it shaped my internal representation of the disease as severe and often fatal. Combined with literature highlighting relatively poor survival rates, I think I entered the study with an expectation that many participants would describe predominantly distressing or difficult recovery experiences. When more positive or adaptive accounts emerged, this required me to pause and reflect on whether my prior assumptions were influencing what I was noticing. Ongoing supervision and returning repeatedly to the full transcripts supported me in ensuring that themes reflected patterned meaning across the dataset rather than association with my own expectations.

I have also reflected on my positioning as a white female trainee clinical psychologist in my early thirties and how this may have influenced both the research process and analytic interpretation. Many participants were older than me and predominantly male, which may have shaped relational dynamics within interviews and influenced how certain topics were discussed. For example, participants may have felt more or less comfortable discussing aspects of vulnerability, dependence or emotional impact with someone younger and from a different gender to them. At the same time, my relative distance from participants' life stage and experiences may also have created space for participants to explain their experiences more fully, rather than assuming a shared understanding.

Study Design and Recruitment

Ethical Considerations

Ethical approval for this study was obtained from the NHS Research Ethics Committee and Health Research Authority (ID 350451, Appendix F & Appendix G) alongside confirmation of capacity and capability from the participating NHS Trust (Appendix H). All data were handed in accordance with General Data Protection Regulation (GDPR, 2019). Ethical guidance from the Health Research Authority (2022) was adhered to throughout the study. Consideration was given to issues of participant wellbeing, informed consent and confidentiality, given the sensitive nature of discussing cancer diagnosis and recovery experiences.

Consent

Written informed consent was obtained from all participants prior to any procedures being carried out. Participants were asked to complete a physical consent form (Appendix I).

For the interview taking place online, an electronic consent form was used. Following each interview, participants' General Practitioners were informed of their participation in the study, in accordance with the study's ethical approval. Participants were informed of this requirement during the consent process and provided explicit consent for this contact.

Confidentiality

Participant confidentiality was maintained throughout the research process. During the consent process, participants were informed that any quotations used within the research would be anonymised. Transcripts were reviewed to remove identifying information, including references to healthcare professionals or specific clinical teams. All data were stored securely in accordance with university data protection guidelines.

Participant Wellbeing and Distress

The potential for emotional distress was considered due to the sensitive nature of discussing cancer diagnosis, treatment and recovery. To minimise risk to participants, a participant distress protocol was developed (Appendix J), outlining a two-stage escalation process should significant distress arise during the interview. Participants were encouraged to read the participant information sheet (Appendix K) in advance so they were aware of what participation would involve. At the beginning of each interview, the sensitive nature of the discussion was acknowledged, and participants were reminded that they were free to decline to answer any question, pause or discontinue the interview at any time.

During interviews, the researcher remained attentive to verbal and non-verbal indications of distress and checked in with participants where appropriate. This required balancing attentiveness to participant wellbeing with maintaining the natural flow of the conversation. Particular care was taken to ensure that participants felt they retained control over the interview process, recognising the potential power imbalance that can arise within research settings.

Following completion of interviews, all participants were provided with information about psychological support services. These included the Big C Cancer Charity, Samaritans and Mind. Information about these services was included on the participant debrief sheet (see Appendix L) and reiterated verbally. Participants were also informed about the option of requesting a one-off psychological review with a Clinical Psychologist if needed. This was a Clinical Psychologist working in the Mental Health Liaison Team at the Norfolk and

Norwich University Hospital that was not involved with the study. No participants exercised this option. As a token of appreciation, all participants were offered entry into a £20 voucher prize draw. In addition to considering the safety and wellbeing of participants, researcher wellbeing was also considered. A lone-working protocol was followed, whereby supervisors were informed of interview times and the researcher checked in with them after each interview.

Participants

Previous research has suggested that including carers within interviews can provide richer data, particularly where illness experiences are shared within close relationships. Certainly, relational dynamics were evident within participants' accounts in the present study. However, the decision was made to conduct individual interviews in order to gain a deeper understanding of participants' personal experiences and allow them to speak freely about potentially sensitive topics. Furthermore, the risk of including carers in the actual interviews meant the study might inadvertently answer a different question to the one we were trying to investigate by telling us more about carers' experiences of caring for a loved one with oesophageal cancer.

For example, some participants described tensions with loved ones arising from changes in independence and perceived loss of control following surgery. Therefore, the presence of family members during interviews may have limited participants' willingness to discuss such experiences openly. During interviews, participants also described differing approaches to communicating the psychological impact of cancer and treatment with their families. Some emphasised openness, whereas others described a desire to protect loved ones from distress or avoid burdening them. While including family perspectives may have provided additional insight into these dynamics, the present study prioritised the exploration of individual experiences. Future research may benefit from examining both patient and family perspectives to better understand how adjustment to oesophageal cancer is negotiated within close relationships.

Inclusion and Exclusion Criteria

The study included individuals between one and five years post-surgery. A lower limit of one year was selected to minimise potential participant burden. As the first postoperative year involves ongoing physical recovery, adjustment to bodily changes and the possibility of complications, conducting interviews earlier in the recovery period may have

placed additional physical or emotional demands on individuals still navigating these challenges, meaning the data from potential interviews might tell us more about the physical recovery rather than psychological experiences. In addition, this timeframe allowed participants sufficient opportunity to reflect on their experiences, particularly as previous literature suggests that psychological wellbeing may change as time progresses following treatment (Djarv et al., 2009).

An upper limit of five years post-surgery was applied to balance reflective distance with the accuracy and richness of recall. Allowing some time to pass following treatment enabled participants to reflect more broadly on their experiences, including longer-term adjustment and quality of life. However, extending the timeframe beyond five years may increase the risk of reduced recall.

Sampling Strategy and Recruitment Procedure

Purposive sampling was used to recruit individuals with direct experience of oesophageal cancer and oesophagectomy. Initial recruitment was conducted through a local oesophageal cancer support group. The researcher attended one of the group meetings and presented information about the study to attendees. Attending the support group prior to recruitment allowed the researcher to familiarise themselves with the setting and introduce the research directly to potential participants. This also provided an opportunity to briefly share their professional background, including previous work within the hospital where the support group was hosted, and their own interest in the topic. This approach aimed to facilitate transparency and help establish initial rapport with potential participants.

Following the presentation, individuals were provided with the opportunity to ask questions about the study, and copies of the recruitment advertisement poster (Appendix M) were made available during the meeting. Twelve individuals initially expressed interest in participating, however, only six met the study's inclusion criteria, primarily due to the requirement that participants be at least one-year post-surgery.

Due to recruitment challenges and concerns that six participants may not provide sufficient data to meaningfully explore patterns across experiences, an amendment to the recruitment strategy was submitted and approved by the Health Research Authority (HRA; Appendix N) and Research Ethics Committee (REC; Appendix O). This amendment allowed a recruitment letter to be circulated to members of the support group via the hospital mailing

lit. This process was managed by staff responsible for the group, meaning the researcher did not have access to confidential patient information. This amendment was necessary as the support group only meets twice per year, therefore, waiting for the next meeting would have significantly delayed recruitment beyond the study timeline.

Development of Interview Topic Guide

The interview topic guide (Appendix P) was developed in collaboration with members of the Upper Gastrointestinal (GI) clinical team to ensure that the questions were clinically relevant and sensitive to the experiences of individuals undergoing oesophagectomy. Input from clinicians helped identify key aspects of the treatment trajectory, including diagnosis, surgical decision-making, recovery and longer-term adjustment.

The guide was structured around several areas reflecting this treatment pathway, including participants' experiences of diagnosis, expectations of surgery, postoperative challenges and longer-term adjustment following surgery. Questions were intentionally open-ended to encourage participants to describe their experiences in their own words and to allow space for issues that were personally meaningful to emerge.

Some questions also explored participants' prior understanding of oesophageal cancer and its treatment. This was informed by previous literature suggesting that it is relatively less well known compared to other cancer types, meaning individuals may have limited awareness of the disease or its treatment prior to diagnosis (McCorry et al., 2009). In this way, the topic guide functioned as a flexible framework to support discussion rather than a fixed set of questions.

While clinical expertise informed the development of the guide, formal patient and public involvement (PPI) was not incorporated during this stage of the study design. On reflection, involving individuals with lived experience of oesophageal cancer in the development of the topic guide may have helped ensure that the questions reflected priorities and language that were meaningful from a patient perspective. However, from a pragmatic perspective, this would have been difficult as the first recruitment attempt through the support group only yielded six participants. If any of these participants had been used to inform PPI it would have meant they would have been unable to participate in the study, thus reducing the

overall number of participants. On balance, the research team decided that there is greater benefit in having a larger sample to more clearly draw out themes.

Data collection

Semi-structured interviews were used to explore participants' experiences of undergoing oesophagostomy surgery and subsequent recovery. This approach allowed participants the flexibility to describe their experiences in their own words, while ensuring sufficient structure to address the research questions (Jamshed, 2014). Interviews were audio-recorded using an encrypted recording device and transcribed verbatim. All transcripts were anonymised during transcription, and identifying information was removed. Data was stored on a secure, password protected university drive in accordance with university data protection guidelines.

Analysis

Within the analysis process, the six phases of reflexive thematic analysis outlined by Braun and Clarke (2006; see also Braun & Clarke, 2019; 2021) were utilised:

Familiarisation with the data:

Familiarisation began during the transcription process. Each interview was transcribed verbatim by the researcher, allowing early immersion in the dataset (see Appendix Q). Following transcription, audio recordings were listened to alongside the transcript to ensure accuracy and to support deeper engagement with participants' accounts.

During this stage, early analytic notes were recorded to capture initial observations, reflections and potential patterns within participants' accounts. These notes were documented in analytic memos to support reflexive engagement with the data and to begin identifying potentially meaningful aspects of participants' experiences.

Generating initial codes:

Initial coding involved identifying and labelling segments of the data relevant to the research questions. Consistent with a critical realist stance, coding was primarily inductive, allowing patterns of meaning to develop through engagement with participants' accounts rather than being guided by pre-existing theoretical frameworks.

Coding was conducted using NVivo (version 14) to support the organisation and management of coded data. Both semantic and latent coding were used. Early coding tended

to focus on semantic content (i.e., what participants were explicitly describing), whereas more interpretive latent codes were developed later as the researcher reflected on the underlying meanings across the dataset (see Appendix R). In the early stages of analysis, coding was conducted closely, often focusing on smaller segments of text to ensure that potentially meaningful aspects of the data were not overlooked.

As familiarity with the dataset increased and patterns across interviews became clearer, coding became more flexible, allowing broader segments of text to be coded where they captured shared meanings across participants' experiences. Analytic memos were used to record reflections about emerging ideas, similarities across interviews and areas of conceptual interest.

Searching for themes:

Following initial coding, codes were reviewed across the dataset to explore broader patterns of shared meaning. Within reflexive thematic analysis, codes are understood as analytic tools used to organise and explore the data, whereas themes represent broader patterns of shared meaning across the dataset (Braun & Clarke, 2021). Codes that appeared conceptually related were clustered together, and overlapping codes were refined or combined where appropriate (see Appendix S). This stage involved moving iteratively between the coded data and the full transcripts to ensure that developing interpretations remained closely connected to participants' experiences.

To support this process, Microsoft Excel was used to organise and visualise codes across the dataset. This enabled the researcher to examine how different codes related to one another and to explore potential groupings that reflected broader patterns within participants' experiences. Through this process of clustering and comparison, groups of related codes were progressively organised into a smaller number of candidate themes that captured recurring patterns of meaning across the dataset. These developing themes were considered provisional at this stage and were refined further through continued engagement with the data.

Reviewing potential themes:

Once the thematic structure had been established, each theme was examined in greater depth to clarify its central organising concept. This stage focused on identifying what was distinctive about each theme and how it contributed to the overall analytic narrative.

Attention was given to ensure that each theme captured a clear and coherent aspect of participants' experiences while remaining distinct from the other themes.

Defining and naming themes:

Once the themes had been reviewed, each theme was explored in greater depth to clarify its meaning. This involved returning to the coded extracts and full transcripts to ensure that the themes captured coherent patterns across participants' accounts and remained relevant to the research question. During this stage, theme boundaries were refined and the focus of each theme was clarified to ensure that they represented distinct aspects of participants' experiences. Theme names were then developed to reflect the central concept of each theme in a way that remained closely connected to the meanings within the dataset.

Producing the report:

The final stage involved developing the narrative presented in the results section. Quotes were selected from across the dataset to illustrate how each theme was grounded in participants' accounts and to reflect the range of experiences described. In keeping with reflexive thematic analysis, the process of writing the results section also formed part of the analytic process. During this stage, attention was given to how the themes related to one another and how they collectively told the story of participants' experiences in relation to the research questions.

Dissemination

During the interview process, participants were offered the opportunity to receive a lay summary of the research findings via email. In addition, findings will also be presented to the oesophageal cancer support group from which participants were recruited. As the group is facilitated by the members of the Upper Gastrointestinal team, this will provide the opportunity for both patients and clinical staff to engage with the findings in a reflective context.

Chapter Six

Critical Evaluation and Discussion

Critical Evaluation and Discussion

This chapter provides a discussion and critical evaluation of the thesis portfolio in its entirety. It includes a summary of the findings across the systematic review and the empirical paper, a reflection on the thesis's strengths and limitations, and a discussion of the clinical and research implications with suggestions for areas for further research.

Summary of Findings

The systematic review aimed to synthesise the prevalence of anxiety and depression in adults following oesophagectomy for oesophageal cancer and to explore factors influencing these psychological outcomes. The review identified a complex, non-linear trajectory of distress, with prevalence rates at their highest in the early postoperative period, declining in the short-term and frequently persisting or rising again in the longer-term follow up. These findings suggest that psychological distress is an ongoing concern that extends beyond the acute surgical phase, and there is a danger its longer-term impact is missed as the trajectory of the distress often settles initially before spiking. The review also highlighted a predominately biomedical focus within the existing literature, where clinical factors such as chronic pain and dysphagia were the most consistent predictors of distress. However, it was determined that the substantial heterogeneity in measurement tools, such as the Hospital Anxiety and Depression scale (HADS) and the Patient Health Questionnaire- 9 (PHQ-9), and varied follow-up timepoints limited the ability to draw definitive conclusions across different studies.

The empirical paper aimed to explore individuals' psychological experiences of undergoing esophagectomy surgery, including their perspectives on quality of life and the long-term impact on their sense of identity. To achieve this, one-to-one semi-structured interviews were conducted with participants between one and five years post-surgery. Five interrelated themes emerged from the data: 1. *Existential Threat and Emotional Survival,* 2. *Relational Trust and Safety Underpinning Engagement,* 3. *Making Sense of Illness Through Knowledge and Cognitive Strategies,* 4. *Negotiating Acceptance, Control and Autonomy* and 5. *Living with Change: Adaptation, Loss and Quality of Life.*

In summary, these themes highlighted the profound psychological impact of surgical experiences, beginning with the shock of the initial diagnosis and the subsequent emotional survival required to navigate the procedure. A key finding was the transition from this early

survival phase to a longer-term process of living with change, where participants navigated their new normal, both by trying to reconnect with elements of their pre-surgery self and adapting to their permanently altered post-surgical body.

The findings from the empirical paper suggest that psychological adjustment is not a linear recovery, but instead a continuous negotiation. For many, it involved a perceived loss of autonomy, with daily life and social engagement increasingly focused on the new rules around food, leading to a sense of restriction, as well as embarrassment and shame for some. The findings also propose that relational safety and the sense of being held in mind both by clinicians and loved ones provided a vital scaffold for adjustment. However, the analysis also highlighted the complexity of these relationships, specifically the responsibility to protect family members, which led to some trying to manage quietly due to fear of burdening. Finally, the study highlighted the variability in how quality of life is made sense of, with some survivors expressing gratitude for a new lease of life, whilst others retrospectively questioned the trade-off between the quantity of their lives and the quality of their daily lived experience.

Together, the findings of both papers highlight the complexity and variability of psychological adjustment and recovery following oesophagectomy. They suggest that it is a non-linear process that extends far beyond the acute surgical phase. Whilst the systematic review identifies a fluctuating trajectory of distress, notably a resurgence of anxiety and depression in the years following the surgery, the empirical paper may provide some insight into the why behind this resurgence. This interpretation is consistent with wider cancer survivorship literature, which highlights that life after treatment often involves multiple interconnected challenges, including ongoing physical symptoms, fatigue, altered body image, fear of recurrence, changes to relationships and difficulties establish a ‘new normal’ (Fitch et al., 2020).

The transition away from active cancer treatment has also been described as akin to ‘falling off a cliff’ (Bell, 2019), reflecting the sudden reduction in structure and support that some survivors experience. It is possible that, as survivors move away from this structure, the longer-term psychological work of living with bodily change, altered identity and reduced autonomy becomes more prominent. This may also be the point at which some individuals begin to fully recognise the permanence of some changes, including altered bodily functioning, reduced spontaneity and shifts in identity. Understood through Bury’s (1982)

concept of biographical disruption, these changes may disrupt continuity with the pre-surgery self and life, evoking grief for what has been lost as well as the ongoing task of adaptation.

Collectively, the portfolio suggests that while physical symptoms are among the most consistent predictors of distress in the literature, they are experienced by survivors more than biomedical complications. Instead, symptoms such as dysphagia, pain and changes to eating habits can represent profound and ongoing challenges to identity, autonomy and everyday life. Both papers also highlight the importance of the social environment, with the findings suggesting that adjustment is not just an individual experience but also influenced by the relational context in which recovery takes place. Ultimately, this portfolio demonstrates that the biomedical focus that the literature currently has on survival post-oesophagectomy is insufficient, as the psychological impact of the surgery involves a long-term, individual effort to reconstruct a sense of self, which remains only partially understood within the current literature.

Critical Evaluation of the Evidence Base

An additional core finding of the portfolio was the disparity between the variables prioritised in the existing literature and the lived priorities of survivors. While the systematic review confirmed that biomedical factors such as chronic pain and dysphagia are important in understanding the psychological distress, these variables offer limited insight into the psychosocial factors of recovery. The empirical paper begins to address this gap by showing that the ‘frustration of lost autonomy’ and the ‘threat to identity’ also often play significant roles and are interrelated with the physical symptoms.

This suggests that in the existing literature, there is a lack of exploration regarding predictors outside of a biomedical view. A potential reason for this predominately biomedical focus could be the relatively recent shift towards prioritising understanding longer-term survivorship. Historically, oesophageal cancer was associated with very poor survival rates, meaning research was understandably focused on prioritising survival and overcoming immediate postoperative complications. This is reflected in the publication dates of the papers included in the systematic review, with the majority being published within the last six years, suggesting that there is some attempt in the literature to try and better understand the consequences this has in relation to psychological experiences.

Furthermore, much of this research is conducted within medical and surgical teams. Whilst these expertise are important for physical recovery; a predominantly surgical lens may unintentionally overlook the psychological mechanisms that underpin long-term recovery and adjustment. This contrasts to more well researched oncology areas such as breast cancer care, where research highlights the profound impact changes from treatment can have on psychological wellbeing and body image (see Davis et al., 2020 and Paterson et al., 2016). This could suggest that oesophageal cancer is currently in a state of transition from a curative model to more of a survivorship-focused approach.

Strengths and Limitations

Systematic Review

The systematic review contributed to understanding the prevalence and trajectory of psychological distress, including anxiety and depression following oesophagectomy. It provided a focused synthesis of the available quantitative literature and highlighted that psychological distress may persist or fluctuate beyond the immediate postoperative period. A strength of the review was its use of predefined inclusion criteria, systematic search methods and validated measures of anxiety and depression which supported methodological rigour and transparency.

However, the review also highlighted the substantial variability in how psychological distress is currently measured and quantified within this population. Studies used a range of psychometric tools, including the HADS and the PHQ-9, alongside inconsistent cut-off scores and differing reporting styles such as mean scores versus prevalence estimates. This lack of standardisation contributed to substantial heterogeneity of this review and limited the extent to which findings could be compared across studies. As a result, it was difficult to draw firm conclusions about the true prevalence and trajectory of psychological distress following oesophagectomy.

Psychometric measures have a significant value in offering clinicians a structured way of quantifying distress and monitoring changes over time. However, they can also be reductionist and may miss important aspects of an individual's lived experience. The findings in the systematic review suggest that the standard tools used in oncology, particularly within the oesophageal cancer population, may be too generic to fully capture the specific psychological experiences identified in the empirical paper. For example, distress may be under-recognised when measures do not capture experiences such as uncertainty, fear of

recurrence, altered bodily trust, social embarrassment related to eating or changes to body image. At the same time, symptoms commonly associated with depression, such as reduced appetite, fatigue, sleep disturbance or weight loss, may be interpreted as expected consequences of the surgery, rather than being considered as possible indicators of depression or psychological distress. This creates a risk that the overlap between physical recovery and psychological wellbeing is either over-pathologized or under-recognised. Therefore, an individual may score below threshold on a depression measure or have their symptoms attributed solely to surgical recovery, while still experiencing significant psychological impairment.

The decision to include only validated and standardised measures of anxiety and depression was guided by the need to maintain methodological rigour and ensure a focused synthesis aligned with the review aims. However, this did pose the issue of excluding non-validated or symptom-specific questionnaires such as the Oesophageal Anxiety and Hypervigilance Scale (Taft et al., 2018), or the EORTC QLQ-OGS25 (Lagergren et al., 2007) which capture more condition specific or symptom-specific distress. Whilst such tools may have offered a more nuanced understanding of the unique experiences identified in the empirical paper, their exclusion was necessary to maintain the validity and comparability of the review. This highlights a tension between the need for rigorous, generalisable data and the need for a deeper, more clinically representative understanding of the survivor's experience.

Finally, a further limitation of the literature included in the systematic review was its predominantly biomedical focus. Many of the included studies examined physical or clinical predictors of anxiety and depression, such as pain, dysphagia, activity limitations and postoperative complications. However, psychosocial factors were less consistently explored. This limits the review's ability to synthesise the broader mechanisms that may contribute to psychological distress following oesophagectomy.

Empirical paper

The empirical paper helps provide a deeper understanding of the psychological experiences of undergoing oesophagectomy at both an individual and collective level. The use of one-to-one interviews allowed participants to describe their experiences in depth and in their own words. This may have enabled them to share more intimate or sensitive aspects of their experiences than they may have felt able to disclose in the presence of peers or family

members. In addition, by including participants with experiences ranging from one year to just over five years post-surgery, the study offered insight into longer-term adjustment and the ongoing psychological impact of oesophagectomy beyond the immediate postoperative period.

In addition, the use of reflective thematic analysis was appropriate given the exploratory nature of the research questions and the limited qualitative literature focusing specifically on individual experiences. This approach allowed shared patterns of meaning to be generated across the dataset, whilst also recognising the researcher's active role in interpretation. The critical realist stance further supported an analysis that attended to both participants lives experiences and the clinical, relational and social contexts shaping those experiences.

However, several limitations should be acknowledged. Participants were primarily recruited through a support group organised by one NHS trust. Therefore, this may have influenced the nature of the sample. Support group attendees are likely to be more physically able to engage socially and may be more inclined towards help-seeking or reflective meaning-making. Individuals experiencing more severe postoperative complications, mobility restrictions, social withdrawal or ongoing distress may therefore be underrepresented. As a result, the study may underrepresent individuals with more negative experiences of care. However, the participant accounts were not uniformly positive and included complexity, ambivalence and ongoing difficulties following surgery. In addition, the later amendment to recruit through the support group mailing list, rather than solely through active group attendance may have broadened the sample to include individuals who were less directly involved in the group.

In addition, the sample was also demographically narrow, made up of predominantly older adults, and mostly white male participants. Though this somewhat reflects the wider epidemiology of oesophageal cancer (Ferlay et al., 2024; Sung et al., 2021), it does limit the transferability of the findings. In addition, it also tells us little about how cultural context, gender norms, socioeconomic position and family structures may meaningfully shape illness representations, coping processes and experiences of recovery. In addition, the decision to exclude those open to secondary mental health services aided in getting a better understanding of the psychological impact. However, it provides little understanding into how the surgery may impact those with more complex psychological needs. Given evidence

suggesting that pre-existing mental health difficulties can influence outcomes following oesophagectomy (see Papaconstantinou et al., 2025), this remains an important area for future research.

Finally, the study was conducted within a specific healthcare context, and most participants described largely positive experiences of continuity and follow-up care. Although this provided valuable insight into how relational trust can scaffold psychological adjustment, experiences of postoperative care likely vary across NHS trusts and services. The findings therefore offer limited insight into the contexts where care is less relationally embedded or less consistent.

Clinical implications

The findings from the portfolio suggest that routine psychological screening should be embedded across the oesophagectomy pathway, rather than being limited to the preoperative or immediate postoperative period. Screening at yearly follow-ups could help clinicians identify psychological needs that may otherwise remain hidden once active treatment and intensive follow-up reduces. Routine collection of psychological outcome data may also support future longitudinal research by providing a clearer understanding of how distress and adjustment change over time.

However, clinicians should not solely rely on more generic measures of anxiety and depression. Though tools such as the HADS or PHQ-9 may provide a useful baseline, they may not capture the more specific adjustment difficulties described. Broader assessments could involve measures of illness perceptions (i.e., The Brief Illness Perception Questionnaire; Broadbent et al., 2006), fear of cancer recurrence (i.e., Fear of Cancer Recurrence Inventory; Simard & Savard, 2009), uncertainty (i.e., The Mishel Uncertainty to Illness Scale, Mishel, 1981) in addition to measures exploring overall distress (i.e., the Distress Thermometer; National Comprehensive Cancer Network, 2019).

Where possible, screening tools would benefit from also including open-ended or qualitative questions, allowing individuals to describe concerns that may not be reflected in standardised scores, which might allow clinicians to better unpick what is related to the procedure and what is more likely psychological distress, i.e. “I want to eat but know I can’t eat” and “I have no motivation to eat”, might score the same on a psychometric assessment, but the qualitative information would allow the clinician greater opportunity to understand

this. This would support a more holistic understanding of psychological adjustment following oesophagectomy and may help clinicians identify those who would benefit from further psychological support.

In addition, findings suggest that clear, timely and accessible information may play an important role in reducing uncertainty and supporting psychological adjustment. However, information sharing should be staged and repeated rather than delivered as a one-off event. Given the heightened stress and emotional threat associated with diagnosis and treatment decision-making, individuals may find it difficult to absorb or retain complex information during the early stages of the pathway. Therefore, key information about surgery, recovery, side effects and emotional responses may therefore need to be revisited throughout the pathway. Regular check-ins could help clinicians assess what has been understood, clarify uncertainties and tailor information to the individual's current stage of recovery. This stepped approach may also support psychological adjustment by reducing ambiguity and uncertainty and help individuals regain a sense of control over time.

Relational trust emerged as central to adjustment and should be considered a key component of clinical care. Participants appeared to benefit from consistency, openness and opportunities to ask questions, particularly during periods where control and choice felt constrained. Feeling listened to and held in mind by clinicians may help individuals tolerate fear and engage with treatment easier. This highlights the importance of continuity of care within surgical and follow-up teams, as well as the role of wider multidisciplinary teams in providing relational containment throughout the pathway. Alongside professional relationships, peer support may also be valuable. Support groups can provide opportunities for survivors to share practical knowledge, normalise difficult experiences and feel less alone in the longer-term adjustment process.

Overall, clinical care following oesophagectomy should adopt a more biopsychosocial survivorship approach. This would involve routine psychological monitoring beyond 12-months post-surgery, condition-specific preparation, relational continuity and clear pathways into psychological support where needed. Such support may be particularly important for individuals living alone, those with limited social support, people with pre-existing or complex psychological needs and those struggling with the longer-term impact of physical symptoms on identity, autonomy and quality of life.

Research Implications and Suggestions for Further Research

The overall findings highlight the need for more longitudinal, multicentre research to better understand trajectories of psychological distress and adjustment following oesophagectomy. Future quantitative studies would benefit from using clearly defined assessment points, including preoperative baselines and repeated follow-up beyond the immediate postoperative period. Longitudinal qualitative research would also be valuable as it could explore not only whether symptoms change over time, but how the meaning of those symptoms shift as individuals move from physical recovery into longer-term survivorship.

In addition, future research should aim to include more diverse and inclusive samples to understand how factors such as age, gender, ethnicity, socioeconomic position and culture shape the experiences of undergoing oesophagectomy and psychological adjustment. Moreover, future studies would benefit from including individuals with more complex or enduring mental health needs pre-surgery to explore how pre-existing psychological vulnerability interacts with surgical recovery and survivorship.

Furthermore, future research should also explore the relational nature of recovery. The empirical paper highlighted the importance of relational trust, family support but also the concerns about burdening loved ones. Therefore, dyadic research involving survivors and partners, family members or informal carers could provide valuable insight into how adjustment is negotiated within relationships. This may be particularly important given that some survivors rely heavily on others for practical, emotional and dietary support (Haj Mohammad et al., 2015).

Finally, comparative research could explore how variations in service provision shape psychological adjustment and survivorship experiences. Participants in the empirical paper described relatively high levels of continuity and follow up care, however, this may not reflect experiences across all NHS trusts or healthcare contexts. Comparative qualitative or mixed-methods studies could examine how differences in follow-up models, access to specialist clinicians including nurses, dieticians, psychology and peer support influence recovery. This could help identify which aspects of care are most important in supporting longer-term psychological adjustment and recovery following oesophagectomy .

Conclusion

Overall, this portfolio demonstrates that psychological adjustment following oesophagectomy is complex, variable and extends beyond the acute surgical phase. By bringing together quantitative evidence of psychological distress with qualitative accounts of lived experiences, the portfolio highlights the limitations of predominantly biomedical models of survivorships and highlights the need for a broader biopsychosocial approach to post-oesophagectomy care. In doing so, the thesis contributes to an emerging survivorship literature that seeks to understand not only how people survive oesophageal cancer, but how they reconstruct their life and self after surgery.

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Chapter One: Portfolio introduction

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Appendices

Appendix A

Authors Guidelines for Journal of Cancer Survivorship

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Please follow the hyperlink "Submit manuscript" and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Submitting Declarations

Please note that Author Contribution information and Competing Interest information must be provided at submission via the submission interface. Only the information submitted via the interface will be used in the final published version. Please make sure that if you are an editorial board member and also a listed author that you also declare this information in the Competing Interest section of the interface.

Please see the relevant sections in the submission guidelines for further information on these statements as well as possible other mandatory statements.

Please note: This journal prioritizes papers that focus on cancer survivors *post primary treatment for cancer* although the journal will accept longitudinal or prospective studies that follow individuals prior to, during and following treatment when these papers highlight the impact on the post primary cancer treatment period for *any length of time thereafter*.

Title Page

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address and telephone number of the corresponding author

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusions
- Implications for Cancer Survivors

Keywords:
Please provide 4 to 6 keywords which can be used for indexing purposes.
Manuscripts are typically 15-20 double-spaced typed pages.

Table and figures should be limited to 3-4 total. If you think your article will be significantly shorter or longer than that average, please include an explanation along with your submission.

Text

Text Formatting
Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature's LaTeX template.

Headings
Please use no more than three levels of displayed headings.

Abbreviations
Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes
Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Scientific style

- Please always use internationally accepted signs and symbols for units (SI units).
- Please use the standard mathematical notation for formulae, symbols etc.: Italic for single letters that denote mathematical constants, variables, and unknown quantities; Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative); Bold for vectors, tensors, and matrices.

References

Citation
Reference citations in the text should be identified by numbers in square brackets. Some examples:

1. Negotiation research spans many disciplines [3].
2. This result was later contradicted by Becker and Seligman [5].
3. This effect has been widely studied [1-3, 7].

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. The entries in the list should be numbered consecutively. If available, please always include DOIs as full DOI links in your reference list (e.g. “https://doi.org/abc”).

- Journal article

Smith JJ. The world of science. Am J Sci. 1999;36:234–5.

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- Online document

Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. http://www.rsc.org/dose/title of subordinate document. Accessed 15 Jan 1999.

Always use the standard abbreviation of a journal's name according to the ISSN List of Title Word Abbreviations.

Statements & Declarations

The following statements must be included in your submitted manuscript under the heading 'Statements and Declarations'. This should be placed after the References section. Please note that submissions that do not include required statements will be returned as incomplete.

Funding

Please describe any sources of funding that have supported the work. The statement should include details of any grants received (please give the name of the funding agency and grant number).

Example statements:

"This work was supported by […] (Grant numbers […] and […]). Author A.B. has received research support from Company A."

"The authors declare that no funds, grants, or other support were received during the preparation of this manuscript."

Competing Interests

Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Interests within the last 3 years of beginning the work (conducting the research and preparing the work for submission) should be reported. Interests outside the 3-year time frame must be disclosed if they could reasonably be perceived as influencing the submitted work.

Example statements:

"Financial interests: Author A and B declare they have no financial interests. Author C has received speaker and consultant honoraria from Company M. Dr. C has received speaker honorarium and research funding from Company M and Company N. Author D has received travel support from Company O. Non-financial interests: Author D has served on advisory boards for Company M and Company N."

"The authors have no relevant financial or non-financial interests to disclose."

Please refer to the "Competing Interests" section below for more information on how to complete these sections.

Author Contributions

Authors are encouraged to include a statement that specifies the contribution of every author to the research and preparation of the manuscript.

Example statement:

"All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript."

Please refer to the "Authorship Principles " section below for more information on how to complete this section.

Data Availability

This journal encourages authors to provide an optional statement of data availability in their article. Data Availability Statements should include information on where data supporting the results reported in the article can be found, including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. Data availability statements can also indicate whether data are available on request from the authors and where no data are available, if appropriate.

Example statements:

"The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT LINK TO DATASETS]"

"The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request."

Please refer to the "Research Data Policy and Data Availability" section below for more information on how to complete this section.

In addition to the above, manuscripts that report the results of studies involving humans and/or animals should include the following declarations:

Ethics approval

Authors of research involving human or animal subjects should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee and reference number, if available). For research involving animals, their data or biological material, authors should supply detailed information on the ethical treatment of their animals in their submission. If a study was granted exemption or did not require ethics approval, this should also be detailed in the manuscript.

"This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No....)."

"This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required."

For detailed information on relevant ethical standards and criteria, please refer to the sections on "Research involving human participants, their data or biological material", "Research involving animals, their data or biological material".

Consent to participate

For all research involving human subjects, freely given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript.

Example statement:

"Informed consent was obtained from all individual participants included in the study."

"Written informed consent was obtained from the parents."

Please refer to the section on “Informed Consent” for additional help with completing this information.

Consent to publish

Individuals may consent to participate in a study, but object to having their data published in a journal article. If your manuscript contains any individual person’s data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. This is in particular applicable to case studies. A statement confirming that consent to publish has been received from all participants should appear in the manuscript.

Example statement:

“The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.”

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Appendix B

Synthesis Without Meta-analysis (SWiM) guidelines (Campbell et al., 2020)

Table 1 | Synthesis Without Meta-analysis (SWiM) items: SWiM is intended to complement and be used as an extension to PRISMA

SWiM reporting item	Item description	Page in manuscript where item is reported	Other*
Methods			
1 Grouping studies for synthesis	1a) Provide a description of, and rationale for, the groups used in the synthesis (eg, groupings of populations, interventions, outcomes, study design)		
	1b) Detail and provide rationale for any changes made subsequent to the protocol in the groups used in the synthesis		
2 Describe the standardised metric and transformation methods used	Describe the standardised metric for each outcome. Explain why the metric(s) was chosen and describe any methods used to transform the intervention effects, as reported in the study, to the standardised metric, citing any methodological guidance consulted		
3 Describe the synthesis methods	Describe and justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates		
4 Criteria used to prioritise results for summary and synthesis	Where applicable, provide the criteria used, with supporting justification, to select the particular studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (eg, based on study design, risk of bias assessments, directness in relation to the review question)		
5 Investigation of heterogeneity in reported effects	State the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity		
6 Certainty of evidence	Describe the methods used to assess the certainty of the synthesis findings		
7 Data presentation methods	Describe the graphical and tabular methods used to present the effects (eg, tables, forest plots, harvest plots)		
	Specify key study characteristics (eg, study design, risk of bias) used to order the studies, in the text and any tables or graphs, clearly referencing the studies included		
Results			
8 Reporting results	For each comparison and outcome, provide a description of the synthesised findings and the certainty of the findings. Describe the result in language that is consistent with the question the synthesis addresses, and indicate which studies contribute to the synthesis		
Discussion			
9 Limitations of the synthesis	Report the limitations of the synthesis methods used and/or the groupings used in the synthesis and how these affect the conclusions that can be drawn in relation to the original review question		

PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses.
*If the information is not provided in the systematic review, give details of where this information is available (eg, protocol, other published papers (provide citation details), or website (provide the URL)).

Appendix C

JBI Checklist for Cross-sectional Studies (Barker et al., 2025)

RoB assessor:		Date of appraisal:	Record number:			
Study author:		Study title:	Study year:			
Internal validity		Choice: comments/ justification	Yes	No	Unclear	N/A
Bias related to selection and allocation						
1	Were the criteria for inclusion in the sample clearly defined?		☐	☐	☐	☐
2	Were objective, standard criteria used for measurement of the condition?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐
	Outcome 2		☐	☐	☐	☐
	Outcome 3		☐	☐	☐	☐
	Outcome 4		☐	☐	☐	☐
	Outcome 5		☐	☐	☐	☐
	Outcome 6		☐	☐	☐	☐
	Outcome 7		☐	☐	☐	☐
Bias related to classification of the exposure						
3	Was the exposure measured in a valid and reliable way?		☐	☐	☐	☐
Bias related to assessment, detection, and measurement of the outcome						
4	Were the outcomes measured in a valid and reliable way?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐
	Outcome 2		☐	☐	☐	☐
	Outcome 3		☐	☐	☐	☐
	Outcome 4		☐	☐	☐	☐
	Outcome 5		☐	☐	☐	☐
	Outcome 6		☐	☐	☐	☐
	Outcome 7		☐	☐	☐	☐
Bias related to confounding factors						
5	Were confounding factors identified?		☐	☐	☐	☐
6	Were strategies to deal with confounding factors stated?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐
	Outcome 2		☐	☐	☐	☐
	Outcome 3		☐	☐	☐	☐
	Outcome 4		☐	☐	☐	☐
	Outcome 5		☐	☐	☐	☐
	Outcome 6		☐	☐	☐	☐
	Outcome 7		☐	☐	☐	☐
Statistical conclusion validity						
7	Was appropriate statistical analysis used?					
	Outcome 1		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐
	Result 2		☐	☐	☐	☐
	Result 3		☐	☐	☐	☐
	Outcome 2		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐

Appendix D

JBI Checklist for Cohort Studies (Moola et al., 2020)

Reviewer _____

Date_____

Author_____Year_____ Record Number_____

	Yes	No	Unclear	Not applicable
1. Were the two groups similar and recruited from the same population?	☐	☐	☐	☐
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were confounding factors identified?	☐	☐	☐	☐
5. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	☐	☐	☐	☐
9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	☐	☐	☐	☐
10. Were strategies to address incomplete follow up utilized?	☐	☐	☐	☐
11. Was appropriate statistical analysis used?	☐	☐	☐	☐

Appendix E

Extract from Reflecting Diary

Interview process

May 2025: I have been reflecting on my first set of interviews. In particular, the process of being an 'interviewer/ researcher' versus a psychologist and taking on more of that therapist role. I recognised my natural tendency to be more inquisitive and then the worries that I was moving too far away from the research questions. I think this experience has then made me more conscious to not take on too much of the 'therapist role'. However, I think this has now run the risk of missing out on potentially useful data through edging on the side of caution and not exploring more around a particular response.

June 2025: I had two interviews today; one was an hour and half and the other wasn't even half hour. I've been reflecting on how the short one felt like a 'fail' because it was so short. I've also been reflecting on whether there were things I could have done differently to make the participant feel more comfortable to open up. Or, maybe they were saying exactly what they wanted and needed to say, and it speaks more to my own expectations. It then made me reflect on my own biases and expectations I am bringing to the study. I think what has struck me the most is how positive the participants have been about their experience. Did I come into this (due to the research I've read and the personal experience I've had) thinking most people had a really tricky time and difficult recovery? I wonder how this comes up in the room when I'm asking the questions? It also made me reflect on the differences in social graces between myself and the participants. A big one is obviously age, with all p's being over 65, some over 80, and what that experience is like talking to someone in their 20's, who, though genuinely interested in their experience, does come with the agenda of wanting to create a piece of research and the inherent worries of that not being 'good enough'. I also come with a lack of experience of significant health conditions/ surgery/ recovery, I wonder how they experience that?

Appendix F

Confirmation of Ethical Opinion from the Health and Social Care Research Ethics Committee

IRAS project ID	350451

Health and Social Care Research Ethics Committee B (HSC REC B)
07 March 2025

[redacted]
Department of Psychological Sciences
Norwich Medical School
University of East Anglia
NR4 7TJ
[redacted]

Study title:	**Unchartered territory – a thematic analysis exploring psychological adjustment to oesophagectomy surgery in adults with cancer**
REC reference:	**25/NI/0017**
Protocol number:	**0.1**
IRAS project ID:	**350451**

Thank you for your letter of 18 February 2025, responding to the Research Ethics Committee's (REC) 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 Vice-Chair.

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

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants

4. sharing study data and tissue

Conditions of the favourable opinion

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

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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 management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.
Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)
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).
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, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research	1.0	25 November 2024
Cover Letter [Cover Letter]		14 January 2025
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA EL&PL 2024-25]		01 August 2024

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA PI 2024-25]		01 August 2024
GP/consultant information sheets or letters [GP Information Letter]	1.0	25 November 2024
Interview schedules or topic guides for participants [Interview schedule and Questionnaire]	1.0	25 November 2024
IRAS Application Form [IRAS_Form_14012025]		14 January 2025
Other [Participant Distress Protocol]	0.1	18 February 2025
Other [HRA and REC review amendments]	0.1	18 February 2025
Participant consent form [Participant consent form]	0.3	18 February 2025
Participant information sheet (PIS) [Participant information sheet]	0.3	18 February 2025
Research protocol or project proposal [Thesis Proposal]		
Summary CV for Chief Investigator (CI) [Summary CV for CI]		07 November 2024
Summary CV for student [Summary CV for student]		07 November 2024
Summary CV for supervisor (student research) [CV for supervisor]		02 November 2024
Summary, synopsis or diagram (flowchart) of protocol in non technical language [protocol flowchart]	1.0	25 November 2024

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.

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: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 350451 Please quote this number on all correspondence

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

Yours sincerely

[redacted]

[redacted]

Email:recb@hscni.net

Appendix G

Confirmation of Ethical Opinion from the Health Research Authority





[redacted]
Department of Psychological Sciences
Email: approvals@hra.nhs.uk

Norwich Medical School
University of East Anglia
NR4 7TJN

18 March 2025

Dear [redacted]

HRA and Health and Care

Study title:	**Unchartered territory – a thematic analysis exploring psychological adjustment to oesophagectomy surgery in adults with cancer**
IRAS project ID:	**350451**
Protocol number:	**0.1**
REC reference:	**25/NI/0017**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.
Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.
If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.
Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **350451**. Please quote this on all correspondence.
Yours sincerely,
[redacted]
Approval Specialist

Appendix H

Capacity and Capability Approval from the Norfolk and Norwich University Hospital

[redacted]

Research Manager
Faculty of Medicine and Health Sciences
Research & Innovation Services
University of East Anglia
Norwich Research Park, Norwich
NR4 7TJ
[redacted]

Please reply to: Research Operations Office
Norfolk & Norwich University Hospitals NHS Foundation Trust
Quadram Institute
Rosalind Franklin Road
Norwich
Norfolk NR4
7UQ
Direct Dial: 01603 647240
Internal: 7240

e-mail: rdoffice@nnuh.nhs.uk
Website: www.nnuh.nhs.uk

26 March 2025 | 10:45 GMT

Dear [redacted],

Confirmation of Capacity and Capability

IRAS & R&D reference: 350451 (177-11-24)

Full Study Title: Unchartered territory – a thematic analysis exploring psychological adjustment to oesophagectomy surgery in adults with cancer

This letter confirms that **Norfolk and Norwich University Hospitals NHS Foundation Trust** has the capacity and capability to deliver the above referenced study. Please find attached our Contract/Agreement as confirmation.

We agree to start this study on a date to be agreed when the sponsor gives the green light to begin.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

[redacted] **Research Governance Coordinator**
PP. [redacted] **Research Services Manager**

Cc[redacted]

Appendix I

Consent Form

University of East Anglia

Uncharted territory: Exploring psychological adjustment to oesophagectomy surgery in adults with oesophageal cancer

Name of Researcher: Miss Eleanor Hanton
Name of Supervisor(s): Dr Adrian Leddy

	Please initial box
I confirm that I have read the information sheet dated … for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to stop the interview at any time without giving any reason, and without my medical care or legal rights being affected.	☐
I understand that anonymised quotes from the interview may be used in dissemination of the results of this study.	☐
I agree to be recorded by teams and via a recording device (such as a Dictaphone or NHS phone) I understand the recording will be destroyed once transcribed.	☐
I understand that the information held and maintained by the University of East Anglia will be held and stored in accordance with UK General Data Protection Regulation (GDPR).	☐
I agree to take part in the above study.	☐
I agree to my General Practitioner being informed of my participation in the study.	☐
I wish to receive a lay summary of the study findings and consent to the researcher contacting me after the study has finished for this purpose.	☐

Preferred contact method (please circle one):

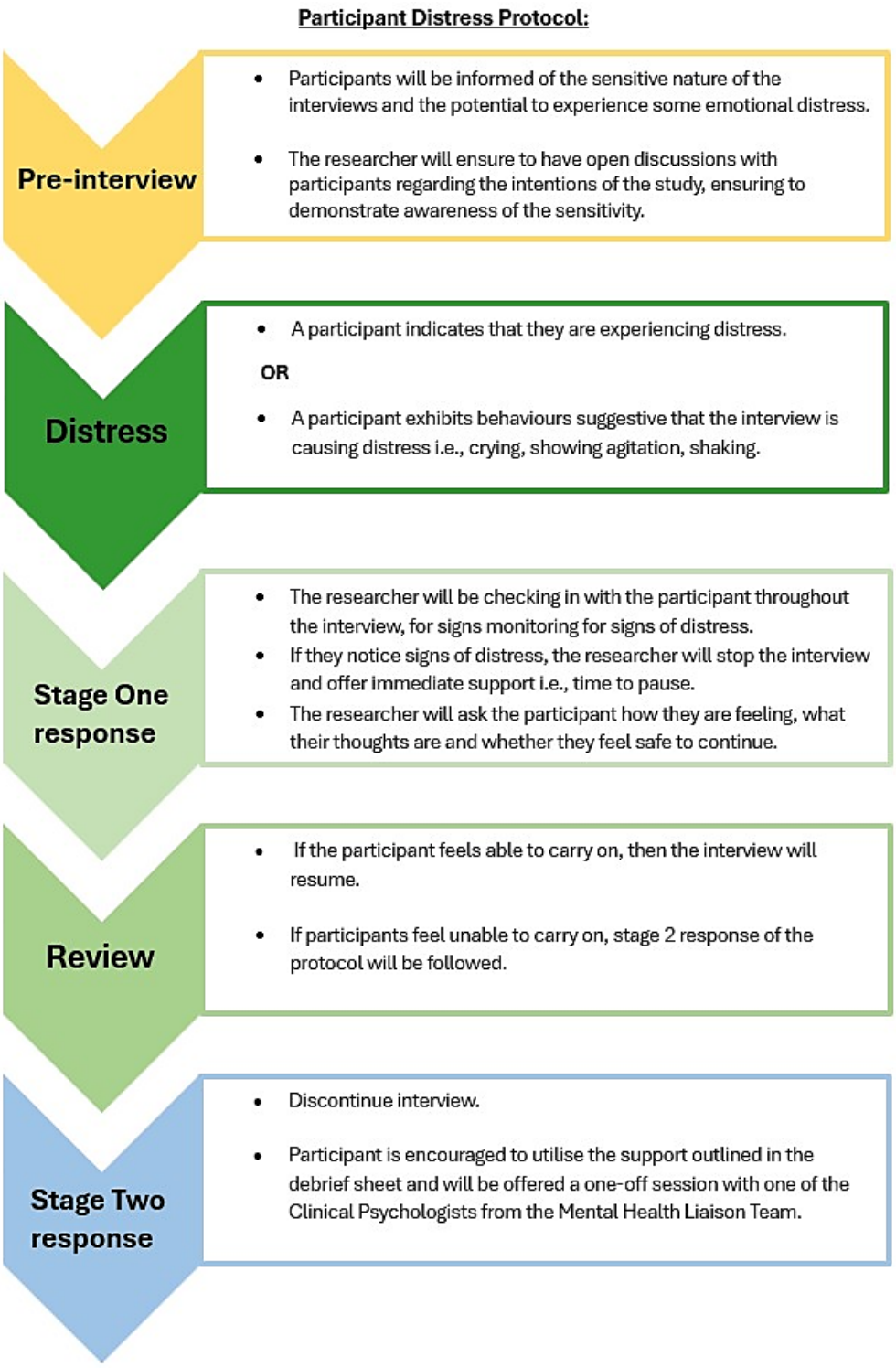
Email Post

Name of Participant Date Signature

Name of Researcher Date Signature

Appendix J

Participant Distress Protocol



Appendix K

Participant Information Sheet

Uncharted Territory: A Thematic Analysis exploring psychological adjustment to oesophagectomy surgery in adults with cancer

Researcher: Eleanor Hanton (Trainee Clinical Psychologist)
Research supervisors: Dr Adrian Leddy, Dr Sophie Oakes-Rogers and Dr John Davies

What is the purpose of this research?
This research is interested in exploring individual's experiences of undergoing an oesophagectomy as part of their oesophageal cancer treatment. Within this research I would like to talk to you about your journey from receiving the initial cancer diagnosis, your experiences of receiving the news you would need oesophagectomy surgery, and the process of undergoing the surgery including your recovery and adjustment to life following the treatment. During these discussions, I really want to capture the physical, psychological, and social aspects of your experiences. This research is being conducted jointly through both the Norfolk and Norwich University Hospital and University of East Anglia as part of a doctoral research project. It has been reviewed and received a favourable opinion from the Research Ethics Committee (REC) and received approval from Health Research Authority (HRA).

What would taking part involve?
If you would like to take part in this research, you will be invited to take part in an interview with the researcher. The interview will last approximately 60 minutes, with an extra 10 minutes allocated prior to and following the interview to answer any questions or concerns you may have. The interviews will typically take place during working hours (9am- 5pm), however, reasonable adjustments can be made if needed. You will have the option of taking part in the interview either in person in a booked room in the Bob Champion Building next to the Norfolk and Norwich University Hospital, or, online via Microsoft Teams. Please note that the interviews will be recorded for research purposes.

Do I have to take part?
Your participation in this research is completely voluntary. Please contact me with any questions you have regarding the research which may help inform your decision. If you decide to take part, you will be asked to sign a consent form. If you no longer wish to take part in the study, you will be free to withdraw up until the point of your data being transcribed.

What are the potential benefits of taking part?
Your participation in the current study will help to increase our understanding of what is like to undergo oesophagectomy surgery and the experiences of recovery following it.
Participants will also have the choice of being entered in a £20 prize draw as a thank you for your contribution in the research.

What are the potential disadvantages of taking part?
The topics discussed during the interview are of a sensitive nature and may therefore be distressing at times. Please be aware that regular check in's will be provided throughout the interview process, and you are free to take breaks or stop the interview at any time. Additionally, if you no longer wish to continue with the interview, you will be able to withdraw, and the information you provided will be confidentially discarded.

How will we use information about you?
We will need to use information from you for this research project. This information will include your name, age, gender, postcode, details regarding your cancer diagnosis / treatment and your contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. The University of East Anglia is the Sponsor of this research and is responsible for looking after your information. We will keep all information about you safe by following measures outlined in the next section.

What will happen to my information?
All information will be used in accordance with the UK General Data Protection Regulation Legislation (GDPR). Basic demographic information such as your name, age, gender and details regarding your cancer diagnosis (i.e., the date received) and treatment (i.e., date of treatment and type of treatment) will only be available to the researchers involved in the study and will be de-identified in reports and publications. Please note that, as part of the participation process, with your consent, your General Practitioner will be notified of your involvement in the study. This is a precautionary measure and should not affect the care you receive.

All interviews will be recorded by an NHS phone, an encrypted and password protected laptop, or using Microsoft teams. These will be securely stored and only accessible to the researcher. Your information will only be stored for the duration needed to complete the research and will be deleted following this. You can ask for you data to be deleted up until the point of transcription by contacting the researcher using the details provided at the bottom of this form.

The information you provide during the interviews will only be shared with the researcher and co-researchers involved in the study. The findings from this research will be included as part of a doctorate thesis project. Additionally, they may also be published in academic journal articles. The information including any quotes used from the interviews will be anonymised and pseudonym names will be used to ensure no identifiable information is included. Please note your data will not be shared outside the UK.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used?
You can find out more about how we use your information by:

- By sending an email to the UEA data protection team (dataprotection@uea.ac.uk) who will be able to appoint you to a data protection officer if required.
- By asking one of the research team
- By visiting the HRA website **www.hra.nhs.uk/patientdataandresearch**

How do I take part?
If you wish to take part in the study, please contact the researcher via email using the details below.

Contact details:
Eleanor Hanton
Trainee Clinical Psychologist
University of East Anglia
Email: E.hanton@uea.ac.uk

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact Professor Sian Coker (s.coker@uea.ac.uk) who acts as the independent spokesperson for the University of East Anglia.

Appendix L

Debrief sheet

Thank you for taking part in this study looking to understand the psychological experiences of individuals who have undergone an oesophagectomy for oesophagus cancer. If you wish for your data to be removed, please contact me by email (e.hanton@uea.ac.uk) to discuss issues of concern. Please note that your data can be removed up until the time of transcription.

If you wish to review your transcript (written script of the interview) and did not previously say yes at the interview, please contact me by email within 2 weeks of the date of your interview (e.hanton@uea.ac.uk).

You can also contact to request a lay summary of our findings via email (e.hanton@uea.ac.uk).
If you feel you need further support about your experiences, please access support via the following places:

BIG Cancer Charity — EST. NORFOLK 1980 —	The big C- A charity that offer free support either face to face (group or individual) or via the telephone.	Call free on 0800 092 7640 (Lines open Mon-Fri 9am-5pm exc bank holidays) https://www.big-c.co.uk/support-and-information/our-support/
SAMARITANS	Samaritans – a charity dedicated to reducing feelings of isolation and disconnection that can lead to suicide.	Call free on 116 123 (Available 24/7) https://www.samaritans.org/
mind	Mind – a charity that provides advice and support to those experiencing mental health difficulties.	https://www.mind.org.uk/need-urgent-help/using-this-tool/
	Your local GP who can help with discussions about further support.	
	Mental Health Liaison Team (MHLS)– Norfolk and Norwich university Hospital. If you require more immediate support, a psychologist in the MHLS can provide you with a one-off support session focused on reflecting on your interview experience and explore and potential distress	Please contact the researcher for more details of how to access this support.

	caused. They can also signpost you to additional psychological support services if needed.	

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact Professor Sian Coker (s.coker@uea.ac.uk) who acts as the independent spokesperson for the University of East Anglia.

Kind regards,

Eleanor Hanton
Trainee Clinical Psychologist
Doctorate in Clinical Psychology (ClinPsyD)
Email: e.hanton@uea.ac.uk

Appendix M

Advertisement Poster

PERSONAL EXPERIENCES OF OESOPHAGECTOMY AND LIFE AFTER SURGERY

Expressions of Interest

If you have undergone an oesophagectomy for cancer then we would love to hear from you.

We are currently developing a study which aims to capture the voices of individuals that have undergone the surgery. The aim is to conduct 1 hour interviews exploring the physical, psychological and social impact in addition to the challenges you have faced during your recovery.

If this is something you would be interested in, please contact us on the details attached below to find out more.

If you do take part in the study, you will be entered into a £20 prize draw as a token of gratitude for your participation.

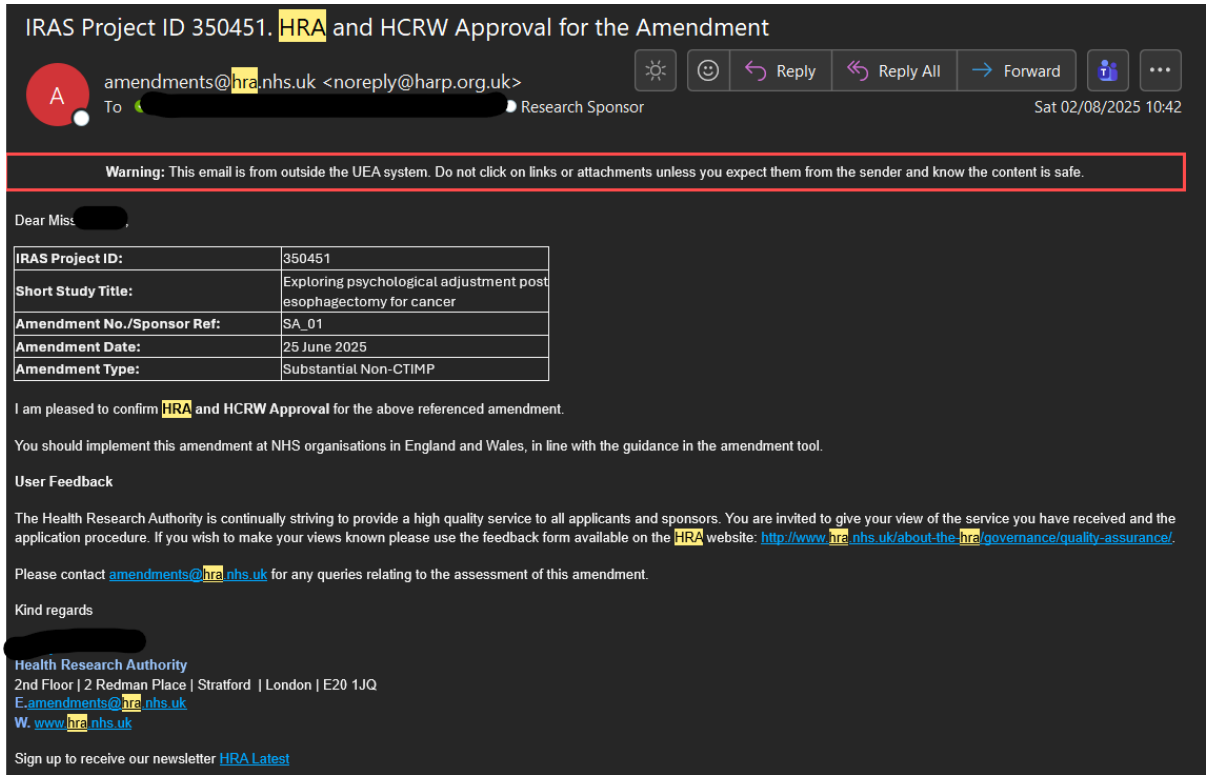


E.hanton@uea.ac.uk (Eleanor Hanton- Trainee Clinical Psychologist)

University of East Anglia

Appendix N

Confirmation of Amendment Approval from the Health Research Authority



IRAS Project ID 350451. HRA and HCRW Approval for the Amendment

A

amendments@hra.nhs.uk <noreply@harp.org.uk>

To [redacted] Research Sponsor

Reply | Reply All | Forward

Sat 02/08/2025 10:42

Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

Dear Miss [redacted],

IRAS Project ID:	350451
Short Study Title:	Exploring psychological adjustment post esophagectomy for cancer
Amendment No./Sponsor Ref:	SA_01
Amendment Date:	25 June 2025
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm HRA **and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

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/.

Please contact amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

[redacted]

Health Research Authority

2nd Floor | 2 Redman Place | Stratford | London | E20 1JQ

E.amendments@hra.nhs.uk

W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest

Appendix O

Confirmation of Amendment Approval from the Health and Social Care Research Ethics Committee

HSC Business Services Organisation

INVESTORS IN PEOPLE® We invest in people Silver

Health and Social Care Research Ethics Committee B (HSC REC B)
21 July 2025
Miss Eleanor Hanton
Department of Psychological Sciences
Norwich Medical School
University of East Anglia
NR4 7TJ
Dear Miss Hanton

Study title:	**Unchartered territory – a thematic analysis exploring psychological adjustment to oesophagectomy surgery in adults with cancer**
REC reference:	**25/NI/0017**
Protocol number:	**0.1**
Amendment number:	**SA_01**
Amendment date:	**25 June 2025**
IRAS project ID:	**350451**

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 July 2025 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment tool IRAS ID 350451]	1.8	20 June 2025
Letters of invitation to participant [Recruitment Letter IRAS ID 350451]	0.1	25 June 2025

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Office for Research Ethics Committees Northern Ireland (ORECNI)
Lissue Industrial Estate West, 5 Rathdown Walk, LISBURN, BT28 2RF
Tel (028) 95 36400 General Email: info.orecni@hscni.net

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website.
During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.
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.
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improvingresearch/learning/

IRAS Project ID - 350451:	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

E-mail: recb@hscni.

Appendix P

Topic Guide and Demographic Questionnaire

1) **Can you tell me about your experience of receiving a diagnosis of oesophageal cancer?**
    a. What was your perception or understanding of oesophageal cancer?
    b. What was your understanding of the treatment for oesophageal cancer?

2) **What was your experience of undergoing oesophagectomy surgery?**
    a. What were your expectations of having the surgery?
    b. Were there any differences or similarities between these expectations and the reality of having the surgery? If so, could you tell me about these?
    c. How would you describe the role of family and friends through your initial surgery and recovery?

3) **Did you experience any challenges after your surgery? If so, would you be able to tell me more about them.**
    a. How did you navigate these challenges?

4) **Do you think having oesophagectomy surgery has impacted you in any way? Would you be able to tell me more about this?**
    a. Can you tell me about any changes to your mental health?
    b. Can you tell me about any changes to your social life?
    c. Can you tell me about any other changes you noticed?

5) **Is there anything I have missed or anything you think would be important to share about your reflections on this experience?**

General Prompts:
- Can you provide any more information regarding that?
- Can you tell me a bit more about that?
- What do you mean by that?
- Can you think of an example of that?

Demographic and surgery information questionnaire

Q1: What is your age?

Q2: What is your gender?

Q3: What date did you receive your initial cancer diagnosis?

Q4: What was the date of oesophagectomy surgery?

Q5: Did you require any other treatment alongside your surgery (i.e., chemotherapy, radiotherapy etc)

Appendix Q

Examples of transcript analysis

were going through the surgery and recovery?

Um, well part of it was reading. When you're stuck in bed, you know, there's not much you can do and um, I'm not a great TV person, so, we don't have a TV in the bedroom and stuff so. Yeah, it's, you know, sort of mainly reading because that, you know, that's all you've got, or, you know, you've got the radio and listened to music or, you know, politics or discussions or whatever. Yeah. It's, you know, it's so restricted, isn't it? You know, when you're, after an op, um, you have this recovery period, depending on what operation you've had, um, what your recovery time is, in terms of being able to do things for yourself and not rely on somebody else. And that's another big thing actually. It's a minor achievement when you've found that, things that you've had to ask your wife to do, or your partner to do, you don't have to, because you say, well I can do it myself.

Yeah, and, I guess when we speak about this, we speak about your surgery and the recovery as well, do you think having the surgery has impacted you in any way?

Yeah, it has to really. I mean, because, there's the rules of the game, really, you know. Again, this bloody food thing, five meals a day you know. And also, there's some vanity there too. When I was, before the op, because I've, you know, I was physically able to do a lot of stuff and swimming, you know, I felt good about myself and felt good about my body. Now I'm like, you know, the scarecrow you put up in the field, it's like, 8.5 stone. And I sort

ons

Content

There appears to be a process of learning to accept support from others during a period of reduced independence. Although he frames this in physical terms, this dependence may have had emotional implications that he finds harder to articulate. As his physical abilities improved, this seems to coincide with a renewed sense of autonomy and agency.

Interviewee: Urm, enormously supportive. Again, it's possibly a different story to others because of COVID at the time. So many people urm were saying let us know as soon as we can come around, two or three of the customers urm were my most regular visitors when I had the sort of 18 months to two years whatever it was of really not doing anything other than recovering. Urm so that urm put them in a different light, I think. Although one of them was a friend anyway, she was, you know my tennis and badminton partner for when we play mixed. So already a friend. Then I started working for her and because of how much she wanted to visit and bring me up box of lollies to put in freezer or whatever it was. Urm, yeah, it's, I'm going to say changed some of the relationships for the better, definitely because I'll see them in a different light. Urm, and two of the… because we played doubles in badminton, I mean I played singles as well but the the all the others only played doubles because they're all a bit older than mem urm, two of them are higher up on my list of friends, now, before they were good mates, played badminton with them, that was it. But now because they've come round and I've been round theirs because my time too. So that's changed. And that's helped enormously urm Karen, obviously, has been an enormous help not not like I say physically, but just being around and urm, no getting away from it, worked ever so hard urm to keep money coming into the house as well. As, you know, how would it have been if she hadn't? If she had lost her job or hadn't got the job that she'd got? That would have had an enormous effect. So, tremendous support, even if it's only regular texts at that time. Urm…..yes, you see people in a different light because of how good they've been.

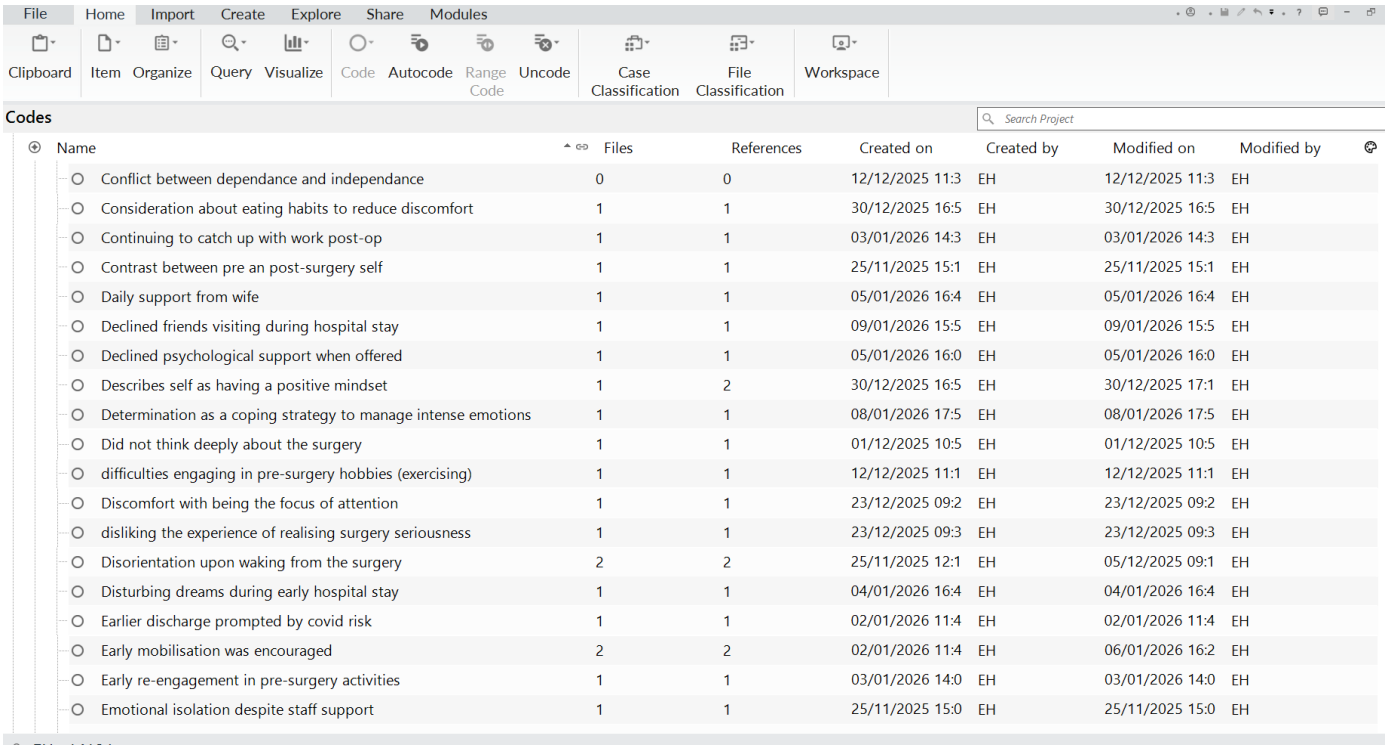
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Content

He describes recovery as strongly supported by others, with illness prompting a reassessment of relationships and greater appreciation of those who showed up consistently during a period of vulnerability.

Appendix R

Example of coding



Name	Files	References	Created on	Created by	Modified on	Modified by
Conflict between dependance and independance	0	0	12/12/2025 11:3	EH	12/12/2025 11:3	EH
Consideration about eating habits to reduce discomfort	1	1	30/12/2025 16:5	EH	30/12/2025 16:5	EH
Continuing to catch up with work post-op	1	1	03/01/2026 14:3	EH	03/01/2026 14:3	EH
Contrast between pre an post-surgery self	1	1	25/11/2025 15:1	EH	25/11/2025 15:1	EH
Daily support from wife	1	1	05/01/2026 16:4	EH	05/01/2026 16:4	EH
Declined friends visiting during hospital stay	1	1	09/01/2026 15:5	EH	09/01/2026 15:5	EH
Declined psychological support when offered	1	1	05/01/2026 16:0	EH	05/01/2026 16:0	EH
Describes self as having a positive mindset	1	2	30/12/2025 16:5	EH	30/12/2025 17:1	EH
Determination as a coping strategy to manage intense emotions	1	1	08/01/2026 17:5	EH	08/01/2026 17:5	EH
Did not think deeply about the surgery	1	1	01/12/2025 10:5	EH	01/12/2025 10:5	EH
difficulties engaging in pre-surgery hobbies (exercising)	1	1	12/12/2025 11:1	EH	12/12/2025 11:1	EH
Discomfort with being the focus of attention	1	1	23/12/2025 09:2	EH	23/12/2025 09:2	EH
disliking the experience of realising surgery seriousness	1	1	23/12/2025 09:3	EH	23/12/2025 09:3	EH
Disorientation upon waking from the surgery	2	2	25/11/2025 12:1	EH	05/12/2025 09:1	EH
Disturbing dreams during early hospital stay	1	1	04/01/2026 16:4	EH	04/01/2026 16:4	EH
Earlier discharge prompted by covid risk	1	1	02/01/2026 11:4	EH	02/01/2026 11:4	EH
Early mobilisation was encouraged	2	2	02/01/2026 11:4	EH	06/01/2026 16:2	EH
Early re-engagement in pre-surgery activities	1	1	03/01/2026 14:0	EH	03/01/2026 14:0	EH
Emotional isolation despite staff support	1	1	25/11/2025 15:0	EH	25/11/2025 15:0	EH

Appendix S:

Example of code refinement on excel

