Experiences of managing nutritional status, of people with oesophagogastric cancer: a qualitative literature review.

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Abstract

This literature review sought to explore the experiences of patients with oesophagogastric cancer, of managing their nutritional status, in order to identify how nurses can improve care and support for them. Analysis of data from six primary qualitative research papers led to the development of three themes: ‘feelings associated with eating and maintaining nutritional status’, ‘social disengagement and isolation’, and ‘managing body impairments.’ The challenges of managing nutritional status cause clear psychosocial impacts that influence the wellbeing of patients and their families and that negatively affect their quality of life. These experiences provide a call to action to nurses, to initiate early discussions to assess patients’ individual needs and wishes, to ensure prompt referrals to a Dietitian and Clinical Nurse Specialist in nutrition, where available, and to provide information and signpost support services that facilitate proactive implementation of coping strategies before psychosocial impacts become difficult to overcome.

Key words: Oesophagogastric cancer. Nutrition experiences. Feelings associated with eating and maintaining nutritional status. Social disengagement and isolation. Managing Body impairments. Clinical Nurse Specialist.

Introduction

Oesophageal cancer is the ninth most common cancer in UK males, with around 6,400 cases per year between 2016-2018 and fifteenth in UK females, with around 2,800 new cases per year between 2016-2018. The latest survival data, from 2013-2017, indicates that 12% of people in England and Wales with oesophageal cancer survived for 10 years or more (Cancer Research UK, Undated). People are living with oesophageal cancer for longer and since dysphagia, weight loss and malnutrition can become a cause for concern, post oesophagectomy, there is an imperative to provide effective nutritional support to improve patients' quality of life.

An oesophagectomy is the surgical removal of part of the oesophagus where the cancer is, to treat it at an early stage (Macmillan Cancer Support, 2019). Whilst enhanced recovery after surgery programmes focus on the early introduction of enteral nutrition after oesophagectomy, in some cases artificial feeding is required to ensure adequate nutritional support (Berkelmans et al., 2017). Following oesophagectomy, patients commonly go home with a feeding tube in situ, to support nutritional intake and the maintenance of a healthy body weight (Macmillan Cancer Support 2019). Sometimes enteral nutrition is introduced alongside a feeding tube. Interprofessional working is key to supporting nutritional care for people with oesophageal cancer. Dieticians are instrumental in supporting patients with oesophageal cancer, developing individual meal plans with them to address issues such as swallowing problems, changes in taste, dry mouth, oesophageal sores, nausea, vomiting and constipation, all of which impact on nutritional intake. Dietician interventions seek to help patients manage these side effects to improve their energy levels, to potentiate the healing process after treatment and to help patients feel 'better as a whole' (The Tracey Birnhak Nutritional Counseling Program at the Hospital of the University of Pennsylvania, 2020).

Research about nutrition status for patients with oesophageal cancer has historically had a quantitative focus, serving to develop understanding about the impact of weight loss and the impact of nutritional interventions on disease and treatment outcomes. Deftereos et al's recent systematic review (2020) notes that despite some evidence to support the positive impact of preoperative nutrition on wound infection rates, length of hospital stay and hospital costs, there is not clear evidence on the optimal methods of nutrition. Maintaining nutritional status is complex, impacted by biopsychosocial factors. This literature review analyses the qualitative nutritional experiences of patients with oesophageal cancer, developing understanding of the nursing role in nutritional support. Recommendations for nursing practice are proposed. The aim is to influence practice to enhance the experience of patients with oesophageal cancer, in all areas of their life impacted by nutrition.

Method and search strategy

The PEO framework (figure 1) was used to develop the research question. The search used key words precisely focused on the research question. These were "oesophageal cancer" or "esophageal cancer"; impact or affect or influence N3; artificial feed* or nasogastric* or enteral feed*; experience or perspective; and qualitative research. Boolean logic and truncation were used to broaden the search results. A proximity operator was applied within the search to limit results to terms that appear within a specified number of words in a phrase. Search results were returned in Directory of Open Access Journals, Complementary Index, CINAHL Complete, ScienceDirect, Academic Search Ultimate and PsycINFO databases.

Population	People with oesophageal cancer
Exposure	Nutritional interventions or problems
Outcome	Experiences or perceptions

Figure 1: Developing the question using the PEO framework.

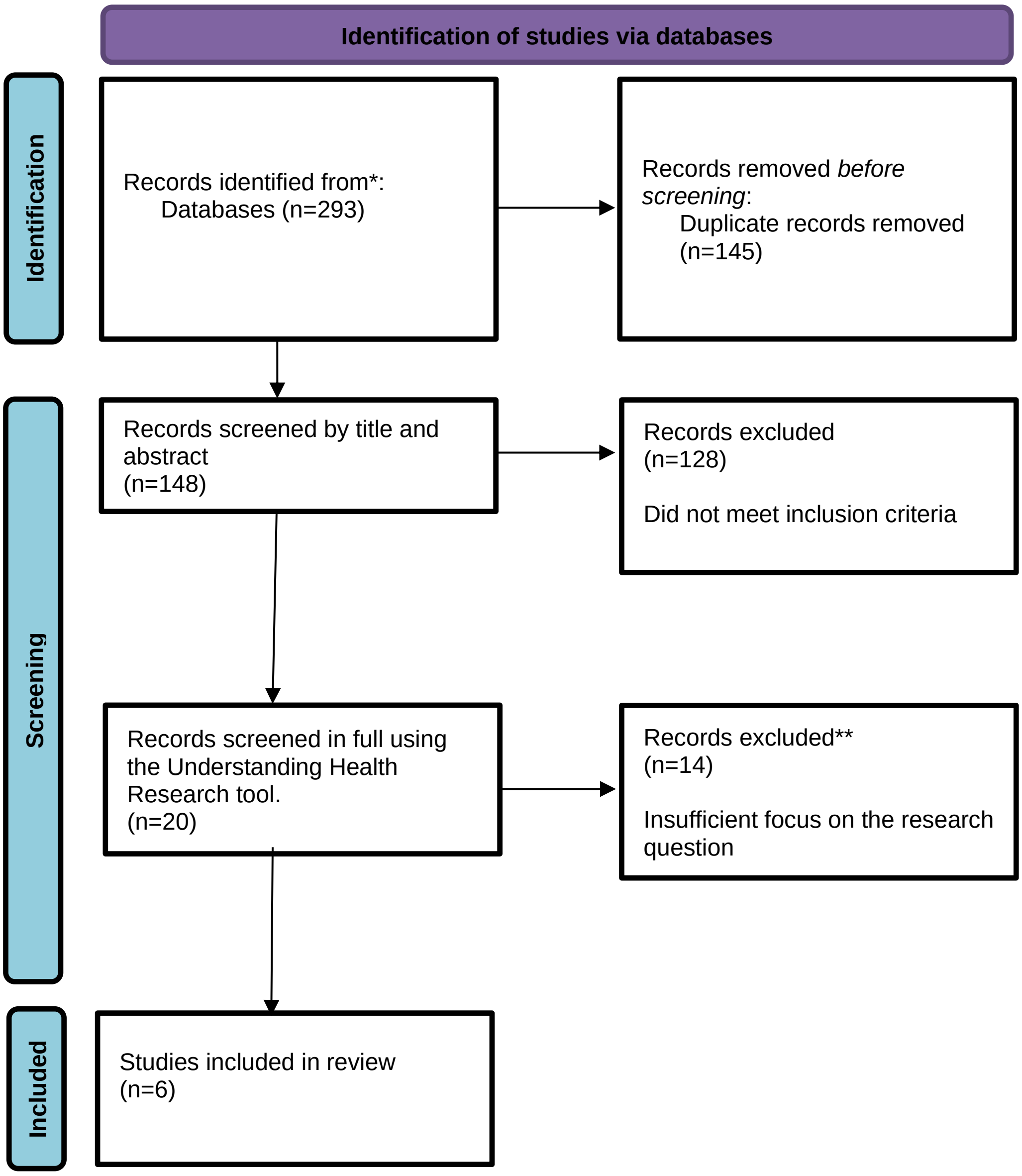
A PRISMA flowchart (Page et al., 2021) (figure 2) illustrates how papers were filtered, to ensure the most relevant and meaningful studies remained for the review. The initial return was 293 research papers, 148 after duplicates were removed. 128 papers were removed because the studies did not meet the inclusion criteria outlined in table 1. The remaining 20 papers were read in full to assess their eligibility for the literature review; 14 were discarded because of their insufficient focus on the research question.

Inclusion Criteria	**Exclusion Criteria**
Adult patients with oesophageal cancer Focus on nutrition Primary, qualitative research English language Peer reviewed Published within 10 years	Not focused on experiences of patients with oesophageal cancer Not peer reviewed Not English language

Table 1: Inclusion and exclusion criteria.

Ultimately, six primary research papers were systematically analysed using the Understanding Health Research critical appraisal tool (MRC/CSO Social and Public Health Sciences Unit: University of Glasgow, 2016). Each demonstrated suitable quality and focus for inclusion in the literature review. Data from the six papers were entered into a table of findings (table 2), which formed the basis of thematic analysis. Themes were tested in peer and academic supervision. Three clear themes were identified within the data; ‘feelings associated with eating and maintaining nutritional status’, ‘social disengagement and isolation’ and ‘managing body impairments’.

Figure 2: PRISMA Flow Diagram (2020)



From: Page MJ et al (2021). For more information, visit: http://www.prisma-statement.org/

Findings

Feelings associated with eating and maintaining nutritional status

The prominent theme in the data is ‘feelings associated with eating and maintaining nutritional status’. Although slightly dated, the study by Jaromahum and Fowler (2010) was included to expand the amount of data available for the review. The researchers used a phenomenological approach to describe seven patients’ lived experiences of eating after oesophagectomy. Participants described a range of feelings about eating, from happiness about being able to eat (again), to fears about relying on family/carers who would be supporting them, managing a feeding tube at home or managing nutrition. Although some were worried about vomiting at home, they expressed determination to eat, to get stronger. These findings were reflected in the work of Malmström et al. (2013), who conducted focus group interviews with 17 patients who had undergone surgery for oesophagogastric cancer two-to-five years previous. ‘Most’ participants described having lost weight, attributed to lack of appetite and taste changes. This caused them worry and anxiety. Weight loss was not universal in this group, with ‘some’ participants maintaining weight, however they described ‘a fine balance’ between eating sufficient to maintain weight and avoiding over-eating that caused nausea.

A qualitative study, exploring chemosensory and food-related changes for eight patients with advanced oesophagogastric cancer who were receiving palliative chemotherapy highlighted their fears about not being able to swallow their food, in addition to feeling panic about gastric reflux at night if they did not watch what and when they ate (De Vries et al., 2016). These fears were reinforced in Alberda et al’s (201) descriptive qualitative study. Eight males and two females aged between 50-75 took part. They highlighted increased levels of stress, fear, and concern about difficulty in swallowing, that along with associated pain resulted in reduced nutrition, leading to weight loss. Data was collected near to completion of cancer treatment for this group and the treatment may have exacerbated eating difficulties at that time. A hermeneutic phenomenological study by Laursen et al. (2019) with seven women and ten men aged between 54-74 who were receiving palliative chemotherapy reinforced the correlation between difficulties swallowing, fears about weight loss and altered appearance. Participants described anxiety around mealtimes being a ‘struggle for survival’. Missel et al. (2018) present a phenomenological study, from the same centre, but with eight male and two female participants, that describes how the fear and anxiety around eating meant an unnatural loss of freedom to enjoy food without self-awareness. Pre-discharge educational support from nurses was valuable for participants, whilst family members were acknowledged as being supportive for managing low mood associated with fears about eating and maintaining nutritional status. It is unclear whether there was an overlap of participant data in the papers from Laursen et al (2017) and Missel et al (2018), however different perspectives are offered.

The data in this theme highlight that feelings experienced in relation to eating and maintaining nutritional status are not universally negative, but on balance, few patients reported positive feelings. Positive experiences arose when individuals could now eat again, after a period of not being able to eat. Generally, participants across the studies felt anxious and fearful in relation to functional difficulties with swallowing. They described a fine balance between eating sufficiently to maintain nutrition, but not so much they would become physically uncomfortable or nauseous. Education from nurses was valued and family members/carers were key in providing support in response to fears and anxiety around eating.

Social disengagement and isolation

Feelings of social disengagement and isolation were evident across four studies. Overall, participants described a loss of pleasure around eating, due in part to the need to plan what and when to eat to avoid pain and nausea, or to avoid the embarrassment of nausea and vomiting as a result of eating (Laursen et al., 2019, Alberda et al., 2017). A lack of energy due to the need to forward plan for eating out, to explore suitability of the menu, as well as to manage the prolonged act of eating arising from treatment related functional changes, caused participants to withdraw from social opportunities (Alberda et al., 2017, De Vries et al., 2016).

Most participants referred to the social aspect of mealtimes being particularly difficult, with many feeling embarrassed and undignified when eating around other people (Laursen et al., 2019). Mealtimes were especially difficult when patients were fed through a feeding tube. Participants in the studies described feeling hurt and upset when they could not participate in family occasions like they used to. Participants in Malmström et al's. (2013) study described a reducing social network due to their difficulties around eating, that led to isolation. The lack of social contact was a 'source of grief' to them.

Not all participants avoided eating around other people. Some continued to socialise because they received valuable support from family members in the home, or from those who had invited them to eat out. They did however, express feelings of anxiety about wasting food, or offending family members or their hosts if they could not finish a meal (Malmström et al., 2013). The challenges of eating resulted in altered social roles in some cases. De Vries et al. (2016) described how participants receiving chemotherapy disengaged with cooking to avoid appetite loss associated with cooking aromas. One solution was to engage with the shopping, enabling some choice and control over their nutritional intake.

The data in this theme reinforce a predominant feeling of social isolation resulting from treatment for oesophagogastric cancer. Whilst some participants maintained social activities around eating, most avoided eating in with others at home and in public. A loss of spontaneity around eating, as well as physical problems causing participants to eat slowly or not finishing their meal to avoid the risk of aspiration or vomiting, caused feelings of anxiety. These aspects combined caused participants to withdraw from social situations and led to feelings of isolation.

Managing body impairments

The final theme in this literature review is 'managing body impairments'. Requiring a feeding tube and/or physical problems swallowing food, as well as taste changes and loss of appetite, pain, bloating, nausea or diarrhoea and weight loss presented challenges to participants that they had to manage. Where feeding tubes were used, some participants expressed anxiety about managing them their selves, or with the support of partners (Jaromahum and Fowler, 2010). The requirement to plan nutrition in advance caused eating to feel like an obligation (Malmström et al., 2013) and reduced the pleasure associated with eating (Alberda et al., 2017). Advice given by nurses helped patients and their families to prepare for managing their nutrition at home (Missel et al., 2018). Diet plans were described as helpful for managing nutrition and enabled family members to give patients support with meal planning.

Oesophagogastric cancer treatment resulted in some cases, in participants having an altered sense of self, attributed to the changes in their body (Missel et al., 2018). Where a feeding tube was in place, it became a visible indicator of illness, which resulted in withdrawal from social situations to avoid people asking questions (Laursen et al., 2019). In some cases participants described changing their patterns of eating to avoid reflux at night (De Vries et al., 2016), whilst participants in Malmström et al's. (2013) study described avoiding leaving home altogether, due to uncertainty about managing nausea and diarrhoea. Only one study made reference to nursing support specifically, but did highlight the benefit of education from nurses in respect of managing the impairments that arose from the oesophagogastric cancer and its treatment.

The data in this theme reinforce the challenge of managing body impairments in order to maintain nutrition. This was predominantly portrayed as a burden that impacted on the spontaneity and pleasure of eating, including the social aspects of eating. Information from nurses is viewed as helpful in managing body impairments.

Discussion

The findings in this literature review highlight the biopsychosocial impact of nutritional experiences for patients with oesophagogastric cancer, arising from the disease, or its treatment. Malnutrition, both pre and post-operatively, poses a significant challenge and is correlated with prognosis for patients with oesophagogastric cancer (Anandavadivelan et al., 2021). Dietitians have a fundamental role in providing nutritional support for patients with oesophagogastric cancer, focusing on assessment and diet planning through regular contact with patients, to improve the patient's nutritional status throughout their cancer journey. Whilst post-operative nutritional support from the dietitian is well established, preoperative support is typically only offered to those patients who are malnourished at diagnosis (Anandavadivelan et al., 2021).

The themes within this literature review portray, for the most part, challenges with nutrition that present and become established over time, often following discharge from hospital. This observation highlights the rich opportunity for nurses involved with patients, both pre-op and post-operatively to begin specific discussions in relation to nutritional support following surgery and during cancer treatment, based on their understanding of the themes. Nurses are instrumental in providing person-centred education and care, that supports patients to manage the changes they are experiencing due to their cancer (Eriksson et al., 2018). Understanding patients' individual concerns and wishes with respect to their care, through the development of a therapeutic relationship, enables nurses to provide and/or signpost educational support and to discuss strategies for managing their situation, in partnership with the multidisciplinary team and particularly the dietitian, as part of a patient-centred plan of care. Of particular importance is the need for professional support when patients are discharged home after their surgery.

A study by Anandavadivelan et al. (2021), which explored the impact of preoperative dietitian support for patients with oesophagogastric cancer revealed that early interventions did not result in a statistically significant mean postoperative weight loss, compared to postoperative intervention alone. This finding is based on data from a review of records, where 57% (n=142) of participants had contact with a dietitian pre-operatively. Some were contacted but no interventions delivered (n=11; 7.9%), whilst others had enteral/parenteral nutrition support. Whilst the data provided does not indicate the context of preoperative contact, whether pre-surgery or as support during neoadjuvant treatment, nor provide a significant correlation between interventions and outcome, this striking finding reinforces the very real challenges patients and their families/carers face in managing nutritional intake in the face of impaired body function caused by the disease itself, the surgery and cancer treatment. Davies et al. (2021) found a correlation between patients who had weight loss of ≥10% prior to surgery and mortality rates. Their retrospective chart review supported that early nutritional support resulted in reduced weight loss, measured one year post-operatively.

Whilst patients are naturally, primarily concerned about maintaining weight, the themes in this literature review portray the nuanced impacts of their efforts to manage nutrition. Quality of life is not directly stated as an impact, however, the substantial efforts required in planning what to eat, with whom, when, where and how, in order to avoid pain, nausea, or offence to hosts, often result in patients and their families, avoiding eating out with others and in some cases eating with others in the home (Chujo and Ueda, 2020). This has a direct and significant impact on socialisation, connection with and support from others, which is a key factor in promoting wellbeing (Michaelson, 2013) and which negatively impacts quality of life.

Nurses are responsible for establishing a therapeutic relationship with patients and their families, to hear their story and learn what their individual needs and wishes are, helping them to access relevant information and support (Nursing and Midwifery Council, 2018). Making Every Contact Count (Health Education England, 2018) is a powerful health promotion approach that optimises brief interactions between health professionals and patients to identify how they can act to improve their health (National Institute for Health and Care Excellence 2021). Cooperative working with allied health professionals is vital to providing the best possible support for patients and their families/carers. Hazzard et al's. (2021) study explored the impact of an interprofessional clinic for people with head and neck cancer. Patients' experiences of integrated support from a dietitian, cancer nurse specialist and speech therapist, reinforced the importance of early discussions about nutrition that prepare the patient and their family for the nutrition burden to follow and that encourage their access to the support available.

Informed by the themes in this literature review, it is recommended that nurses utilise early opportunities for brief interactions with patients, to begin sensitive conversations around the future nutritional challenges they face. This is challenging since there is a fine balance between providing realistic information to patients about potential nutrition challenges and maintaining optimism and hope for the future in the face of a cancer diagnosis. A lack of experience or confidence can lead to avoidance of initiating these sensitive discussions, however, the discussions are important because raising awareness of potential issues identified in this literature review means that patients and their families are not surprised by them. They will have the opportunity to proactively plan strategies to manage them, before they become issues that significantly impact socialisation and quality of life, that become harder to resolve. The Clinical Nurse Specialist (CNS) in nutrition is fundamental in supporting the patient (Hazzard et al., 2021), but is also a source of expert knowledge for nursing staff and can offer educational support to them. Junior or inexperienced nurses can increase their confidence at initiating sensitive discussions about nutrition by observing and reflecting on how the CNS manages these discussions with patients and through practical strategies such as role play discussions with the CNS. With the focus on maintaining the best possible quality of life, prompt referral to the CNS in nutrition, for every patient with oesophagogastric cancer, ensures the best possible ongoing support for the patient and their family, after they have been discharged, when the impact of challenges in maintaining nutrition and weight tend to present.

Review Limitations

The limited qualitative data available for the review led to one slightly dated study being included. The papers by Missel et al. (2018) and Laursen et al. (2019) appear to come from one centre and there is not a clear indication whether the data overlaps. Although sponsor involvement is outlined, the study by De Vries et al. (2016) should be viewed with caution, as it was supported by a public-private partnership for precompetitive research in food and nutrition.

Conclusion

Nutritional status has a direct impact on mortality for patients with oesophagogastric cancer. The challenge of managing nutritional status during or after treatment requires significant energy and attention. The three themes, ‘feelings associated with eating and maintaining nutritional status’, ‘social disengagement and isolation’ and managing body impairments’ reflect patients and their families’ psychosocial responses to the challenges of maintaining weight and nutrition after treatment for oesophagogastric cancer. They signify a call to nursing action with the aim of supporting the best possible quality of life, through the early provision of education, information and psychosocial support, as well as referral to a CNS in nutrition, where available. In addition, signposting of external support groups and networks (see Box 1), expands the range of support resources available to patients and their families.

Box 1: Oesophageal cancer support support links

Heartburn Cancer UK (HCUK) https://www.heartburncanceruk.org/barretts-and-oesophageal-cancer-online-support-group?gclid=CjwKCAjwrNmWBhA4EiwAHbjEQDK5cVdvsxpiBK8af9wVFoINqkMy47fLn3cUwOofBuY59P6VTj9l7BoC95cQAvD_BwE

The Oesophageal Patient's Association (OPA) https://opa.org.uk/
Macmillan Cancer Support https://community.macmillan.org.uk/cancer_types/gullet-oesophagus-cancer-forum
Local oesophageal cancer support networks

Key points:

- Nutritional status impacts on mortality for patients with oesophagogastric cancer.
- The challenge of managing nutritional status during or after treatment requires significant energy and attention.
- The three themes of 'feelings associated with eating and maintaining nutritional status', 'social disengagement and isolation' and managing body impairments', reflect psychosocial impacts of managing nutritional status, that negatively impact on wellbeing and quality of life
- Nurses are well placed to use early brief interactions with patients and their families to understand their needs and wishes and to assess their understanding of the potential nutrition challenges
- Early discussion about potential nutritional challenges and prompt referral to the CNS in nutrition supports the proactive planning of strategies to manage these, reducing the burden on individuals' wellbeing and quality of life

References

Alberda C, Alvadj-Korenic T, Maya M et al (2017) Nutrition Care in Patients with Head and Neck or Esophageal Cancer: The Patient Perspective. Nutrition in Clinical Practice. 32**,** 664-674. doi: 10.1177/0884533617725050
Anandavadivelan P, Wikman A, Mälberg K et al (2021). Role of dietitian support in improving weight loss and nutrition impact symptoms after oesophageal cancer surgery. European journal of clinical nutrition. 75**,** 1134-1141. doi: 10.1038/s41430-020-00830-0
Berkelmans GH, Van Workum F, Weijs TJ et al (2017). The feeding route after esophagectomy: a review of literature. Journal of thoracic disease. 9**,** S785-S791. doi: 10.21037/jtd.2017.03.152
Cancer Research UK. Undated. Oesophageal cancer statistics. Cancer Research UK. Available: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oesophageal-cancer#heading-Zero [Accessed 14th June 2022].
Chujo M, Ueda Y (2020). Eating Behaviors of Postoperative Esophageal Cancer Patients During the First Year After Surgery. Yonago Acta Medica. 63**,** 173. doi: 10.33160/yam.2020.08.005
Davies SJ, West MA, Rahman SA et al (2021). Oesophageal cancer: The effect of early nutrition support on clinical outcomes. Clinical Nutrition ESPEN. 42**,** 117-123. doi: 10.1016/j.clnesp.2021.02.006
Deftereos I, Kiss N, Isenring E et al (2020). A systematic review of the effect of preoperative nutrition support on nutritional status and treatment outcomes in upper gastrointestinal cancer resection. European Journal of Surgical Oncology. 46, 8. 423-1434. doi: 10.1016/j.ejso.2020.04.008

De Vries YC, Helmich E, Karsten A et al (2016). The impact of chemosensory and food-related changes in patients with advanced oesophagogastric cancer treated with capecitabine and oxaliplatin: a qualitative study. Supportive Care in Cancer. 24, 3119–3126 doi: 10.1007/s00520-016-3128-z

Eriksson I, Lindblad M, Möller U et al (2018). Holistic health care: Patients' experiences of health care provided by an Advanced Practice Nurse. International Journal of Nursing Practice. 24**,** e12603 doi: 10.1111/ijn.12603

Hazzard E, Haughton J, Fish J et al (2021). The experience of nutritional care according to patients with head and neck cancer involved with a combined dietitian, specialist nurse and speech pathologist clinic in a regional Australia: a qualitative longitudinal study. Supportive Care in Cancer. 29**,** 4329-4337. doi: 10.1007/s00520-020-05917-9

Health Education England (2018). Making every contact count: person centred care. Leeds: Health Education England. Available: http://makingeverycontactcount.co.uk/linked-resources/person-centred-care/ [Accessed 19th July 2022].

Jaromahum J, Fowler S (2010). Lived experiences of eating after esophagectomy: a phenomenological study. Medsurg Nursing: official journal of the Academy of Medical-Surgical Nurses. 19**,** 96-100.

Laursen L, Schønau MN, Bergenholtz HM et al (2019). Table in the corner: a qualitative study of life situation and perspectives of the everyday lives of oesophageal cancer patients in palliative care. BMC Palliative Care. 18, 60. doi: 10.1186/s12904-019-0445-2

Macmillan Cancer Support. 2019. Oesophagectomy. Macmillan Cancer Support. Available: https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/oesophagectomy [Accessed 14th June 2022].

Malmström M, Ivarsson B, Johansson J et al (2013). Long-term experiences after oesophagectomy/gastrectomy for cancer—A focus group study. International Journal of Nursing Studies. 50**,** 44-52. doi: 10.1016/j.ijnurstu.2012.08.011

Michaelson J (2013). Forward from Foresight: The uses of the new economics foundation's well-being work. Journal of Public Mental Health. 12**,** 98-102. doi: 10.1108/JPMH-03-2013-0009

Missel M, Hansen M, Jackson R et al (2018). Re-embodying eating after surgery for oesophageal cancer: Patients' lived experiences of participating in an education and counselling nutritional intervention. Journal of clinical nursing. 27**,** 1420-1430. doi: 10.1186/s12904-019-0445-2

MRC/CSO Social and Public Health Sciences Unit: University Of Glasgow. 2016. Understanding Health Research Tool. MRC/CSO Social and Public Health Sciences Unit: University of Glasgow,. Available: https://www.understandinghealthresearch.org/ [Accessed 7th July 2022].

Nursing and Midwifery Council (2018). The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. London: Nursing and Midwifery Council.

Page MJ, Mckenzie JE, Bossuyt PM et al (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ: British Medical Journal. 373**,** 1-9. doi: 10.1136/bmj.n71

The Tracey Birnhak Nutritional Counseling Program at the Hospital of the University Of Pennsylvania (2020). Nutrition for Patients with Esophageal Cancer. Available: https://www.oncolink.org/print/pdf/25198?print_25198.pdf [Accessed 14th June 2022].

Table 2: Summary of data reviewed

Authors and location of study	**Sample size**	**Research method**	**Data Collection**	**Results** T1: Feelings associated with eating and maintaining nutritional status T2: Social disengagement and isolation T3: Managing body impairments
Jaromahum and Fowler (2010) USA.	n=7	Phenomenology	Semi-structured interviews, between the first and third meals post-oesophagectomy.	T1: Happiness about being able to eat again. Felt good to be able to swallow. Optimistic about the future. T3: Discomfort from feeling bloated and/or full. Anxiety about spouse’s skills to help with the jejunostomy tube at home. T1: T3: Determined to eat to get stronger.
Malmström et al. (2013). Sweden.	n=17	Descriptive exploratory method	Semi- structured focus group interviews (2-5 years after elective surgery)	T1: Eating issues caused anxiety and worry. Lack of appetite. T2: Smaller social networks; isolation. T3: Altered taste/weight loss. Eating as (a planned) obligation. T1; T3: Fine line between eating too little/too much, resulting in weight loss or nausea.
De Vries et al. (2016). Holland.	N=8	Cross sectional design and template analysis	Semi-structured interviews.	T1: Fears about difficulty swallowing food. T2: Avoidance of eating out; fear of not having appropriate food choices. Mealtimes less sociable; feeling guilty for not eating the food family had made. Reduced/no enjoyment/pleasure in food. Altered roles regarding food shopping and cooking. T3: Changed patterns of eating to stop nocturnal reflux. Eating/swallowing takes longer.

				T1: T3: Loss of appetite as food smells different.
Alberda, C et al. (2017). Canada	n=10	Descriptive qualitative method	Semi structured interview, near to completion of cancer treatment	T1: Difficulty eating and swallowing, often painful. Increased stress, fear and concern around eating. Physical discomfort; weight loss. T2: Avoidance of social situations; fear of aspiration and reduced eating speed. T3: The need to 'plan' eating reduced the pleasure of eating.
Missel et al. (2018). Denmark.	n=10	Phenomenology	Semi-structured interview, four weeks after discharge following surgery.	T1: Family help and support with diet plan and low mood. T3: Altered perception of body/self after surgery. Education and counselling was helpful. Advice given by nurse on discharge prepared for what to expect at home. T1: T3: Loss of freedom to enjoy food without self-awareness.
Laursen et al. (2019) Denmark.	n=17	Hermeneutic phenomenology.	Semi Structured Interviews between 1 and 23 months after diagnosis.	T1: Weight loss and altered appearance due to difficulties in swallowing. T2: Social interactions reduced due to embarrassment, indignity and lack of energy. Feelings of hurt and upset when joining in with family interactions. T3: Loss of appetite and energy due to coughing and pain caused by the stent. T2: T3: The feeding tube is a symbol of illness.