

# The Importance of Nutrition during Treatment for Oesophageal Cancer—The Patient’s Perspective

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## Abstract

**Background and Objectives:** Nutritional issues are prevalent in patients with oesophageal cancer (OC) across all aspects of treatment, including chemoradiotherapy (CRT) and surgery. There are limited studies investigating nutritional issues faced by people undergoing neoadjuvant or definitive CRT from the patient’s perspective. This study aimed to explore the importance that people with OC place upon nutrition during their treatment which included neoadjuvant or definitive CRT, explore the nutritional issues faced in this patient group and identify areas for improvement of dietetic services. **Methods and Study Design:** Nine people who had undergone curative treatment for OC in the previous 2 - 25 months participated in semi-structured phone interviews. Interviews were tape-recorded and transcribed verbatim and analysed using an inductive thematic analysis approach. **Results:** Interviews revealed severe difficulties in food consumption during and following CRT and a period of struggling to adjust eating habits post oesophagectomy. There was significant difficulty in following nutrition advice and, despite participants expressing the importance of nutrition; this was not reflected in attitudes towards weight loss. The medical team significantly influenced the perceptions of some participants in regards to their weight loss. **Conclusions:** Implications for clinical practice include the need for dietetic services before, during and after treatment for OC, irrespective of treatment type. Patient education regarding detrimental effects of rapid weight loss and effects on body composition is crucial, and this should be consistent from all members of the healthcare team.

## Keywords

Oesophageal Neoplasm, Qualitative Research, Nutritional Management,

## 1. Introduction

Oesophageal cancer (OC) is an aggressive and largely silent disease with poor prognosis and low 5-year survival rates [1] [2]. Nutritional status is related to quality of life in people with cancer [3] and in those following major upper gastrointestinal (UGI) surgery [4].

Prevalence of malnutrition in people with OC is reported at 60% - 80% [5]. The high nutritional risk of people with OC is due to increased metabolic demands and inadequate oral intake due to nutrition impact symptoms. Poor intake can be further exacerbated by treatment-related toxicities such as pain on swallowing, taste changes and dry mouth [6] [7] as well as issues following oesophagectomy including early satiety and eating problems [8]. Dietitian-delivered intensive nutrition support has been shown to prevent preoperative weight-loss and minimise complications following surgery for OC [9], with similar results shown in people receiving definitive chemoradiotherapy (CRT) [10].

Currently no comprehensive evidence-based guidelines exist that address the nutrition care pathway for people with OC. High-level evidence supports referral to a dietitian for all patients receiving radiotherapy to the gastrointestinal tract (National Health and Medical Research Council (NHMRC) Grade A) [11], whilst further evidence is required for recommendation development for patients receiving chemotherapy [12]. Optimised nutritional status is an important factor in improving outcomes in people with OC receiving multimodality treatment [13] and affects mortality [14]. To date there is limited published research exploring the importance people with OC place upon nutrition. A recent study by Alberda and colleagues [15] explored the experience of patients with feeding jejunostomy tubes; however, there may be very different experiences and attitudes in those without feeding tubes.

The attitude of people with OC towards unintentional weight loss is currently unclear. One study reporting attitude appears to be related to nutritional status following major UGI surgery, with well-nourished people finding their post-surgical weight loss a positive experience, whereas malnourished people perceive this negatively [16]. In contrast another study describes negative attitude towards weight loss in this patient group, being viewed as a sign of illness [15]. As attitudes towards weight loss may affect adherence to high-energy nutritional advice [17], it is imperative to gain further insight into how people with OC perceive their weight loss during and following treatment.

Qualitative research provides unique insight into ways to improve services and direct best practice guidelines by giving people receiving treatment a voice and imparting practitioners and policy makers with an understanding of their experiences. The current study aimed to explore the importance that people with

OC place upon nutrition during curative treatment, including surgical and definitive chemoradiotherapy. It also aimed to explore the nutritional issues faced and identify areas for improved dietetic services.

## 2. Methods

### Study design:

A retrospective descriptive qualitative study design was used.

### Participant selection

Using a convenient sample, participants were initially contacted by their treating dietitian to discuss the research. Participants who expressed interest were phoned by the researcher (GH) to discuss the purpose of the study, and gain consent. All participants had undergone curative treatment for OC, within a large tertiary referral hospital in Sydney, Australia. Treatment included neoadjuvant CRT followed by Ivor-Lewis oesophagectomy, or definitive CRT. Treatment was completed between June 2013 and July 2016. Recruitment continued until saturation of themes. Participant information handouts, consent forms and a reply paid envelope for return of signed consent forms were mailed to participants.

### Data collection

1) Semi-structured interviews were conducted over the phone at a prearranged time. Questions focused on the experiences of the participants with nutrition and their dietetic care during their cancer treatment and attitudes towards weight loss at this time (**Table 1**). Interviews were audiotaped using an

**Table 1.** Interview guide: final list of questions included in interviews.

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#### Key Questions

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1. Can you tell me about how you came to be diagnosed with oesophageal cancer?
  2. Can you tell me which hospital or centre you started your treatment, and expand a little bit about your journey through the health system?
  3. How were you eating throughout your treatment?
    - a) Did anyone enquire about your eating?
  4. What was happening with your weight throughout your treatment?
    - a) Were you weighed during this time?
  5. What nutrition advice, if any, were you given during your treatment?
    - a) How useful was this advice?
  6. What written information on nutrition, if any, did you receive during the time?
    - a) How useful was this advice?
  7. Were you offered a referral to the dietitian?
  8. During your treatment, did you worry about your eating or weight, or were there other things that you were more concerned about?
  9. If you could have changed one thing about the nutrition advice you received, what would it be?
  10. What sort of role do you think nutrition has played in your recovery?
  11. What was the most helpful piece of nutrition advice you received?
  12. That's all the questions I had. Is there anything else you would like to add?
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Olympus Digital Voice Recorder WS-110. Brief, reflective field notes were also made following each interview. Interview duration ranged from 10 - 41 minutes with an average of 22 minutes.

2) Interview questions were piloted with 4 in-patients who had undergone similar gastrointestinal surgeries prior to study commencement to refine the questions. In accordance with an inductive approach, interview questions were altered in response to answers given during the data collection process. Demographic and medical information was obtained from medical records. One participant wrote a letter with further comments she wanted to add after reflection on the interview, which was included in the analysis.

#### **Research team and reflexivity**

Interviews and demographic data were collected by the researcher (GH). As the researcher had not worked within the clinical field, this allowed for minimal assumptions and preformed bias, however the interviewer made a conscious effort to ensure previous experience and knowledge did not affect the interview process. A reflective journal was kept by the researcher (GH) throughout data collection and analysis to help identify any assumptions or bias which may be influencing the study.

#### **Data analysis**

Interviews were transcribed verbatim and organised using NVivo version 10.0.138.0 (64 bit) software (QSR International 2012). A thematic analysis approach was undertaken [18], where initial coding of the data was performed by the researchers to generate an extensive list of potential codes. Coding of the data was undertaken systematically and further analysis lead to a refined list of codes which were organised into themes. Analysis was independently performed by two researchers (GH and SC), and themes and ideas were compared.

#### **Rigour**

Credibility and consistency of results were increased by the use of a secondary coder. Credibility was further increased by using introductory questions that allowed the participant to describe their journey which helped to build rapport with the researcher. Furthermore, anonymity associated with phone interviews may increase respondent candour [19]. Neutrality was ensured with the use of open ended questions, withholding researchers' assumptions/bias and by transcribing all interviews in participants own words.

#### **Ethics**

All procedures performed were in accordance with the ethical standards of the Sydney Local Health District Human Ethics Review Committee (HREC/14/RPAH/482, Protocol No X14-0358).

### **3. Results**

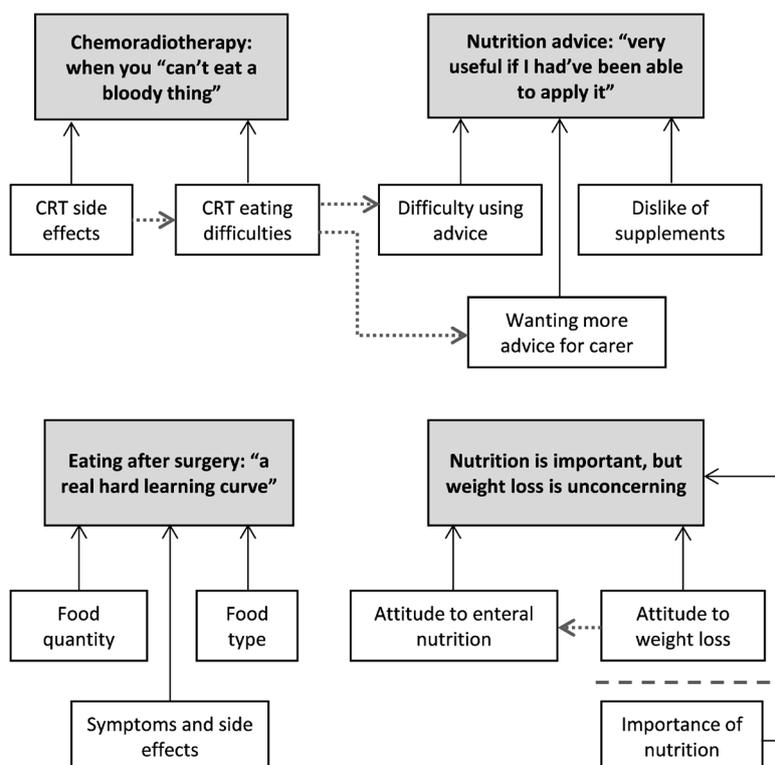
Thirteen participants were invited to participate, ten gave consent and nine participants were interviewed. Reasons for non-participation included being unwell, and lack of time to commit to the interview. One participant who agreed was not

contactable. Given the participants intimate knowledge of the research topic and ability to provide rich and insightful data set, data saturation was able to be reached within the given sample size. Basic demographic, treatment and weight information are shown in **Table 2**. Mean age at time of treatment was 51 years, five males and four females participated and the average premorbid BMI was 33.7 (obese). Four main themes were identified (**Figure 1**), including eating difficulties following CRT and surgery which were largely related to side effects of

**Table 2.** Demographics, treatment information and weight history.

Participant number	Age <sup>a</sup> (years)	Sex	Area of residence	Treatment type(s)	Treatment centre(s)	Treatment completion date	Premorbid BMI	Weight loss <sup>b</sup> (%)
1	57	F	Suburban	CRT & OSx <sup>c</sup>	RPAH & COBL	February 2015	36.4	23
2	59	M	Suburban	CRT & OSx <sup>c</sup>	RPAH & COBL	September 2014	36.9	18
3	68	F	Rural	CRT & OSx <sup>c</sup>	RPAH & NCCI	October 2014	54.9	24
4	43	M	Suburban	CRT <sup>c</sup> & OSx	RPAH & Mater	December 2013	29.6	31
5	39	F	Suburban	CRT <sup>c</sup>	RPAH	June 2013	22.3	18
6	42	M	Suburban	CRT & OSx <sup>c</sup>	RPAH & COBL	February 2014	38.3	23
7	41	M	Suburban	CRT <sup>c</sup>	RPAH	March 2013	29.4	39
8	59	F*	Suburban	CRT & OSx <sup>c</sup>	RPAH & COBL	July 2016	34.3	26
9	55	M	Suburban	OSx <sup>c</sup>	RPAH	March 2016	21.0	23

<sup>a</sup>Age at treatment completion; <sup>b</sup>Calculated based on self-reported total weight loss throughout treatment and/or post-treatment and “usual weight” as recorded in medical notes; <sup>c</sup>Carried out at RPAH; COBL, Chris O’Brien Lifehouse, CRT, Chemoradiotherapy; F, Female; NCCI, North Coast Cancer Institute; M, Male; OSx, Oesophagectomy; RPAH, Royal Prince Alfred Hospital.



**Figure 1.** Qualitative coding summary including themes (bold) and subthemes (non-bold).

the treatment. The importance of nutrition was expressed; however this did not translate to concern over unintentional weight loss, whilst the medical team influenced attitudes towards weight loss in some patients. Finally, difficulty in applying nutrition advice was a strong theme across treatment modalities, with several barriers identified.

**Theme 1: Chemoradiotherapy: when you “can’t eat a bloody thing”**

Five of the 9 participants discussed the extreme difficulties in managing to eat during and following CRT:

“It was post-treatment that was the worst because after all the effects of the radiation” ... “I couldn’t even swallow my own saliva by that stage” [participant 5].

These participants found the CRT side effects greatly impacted their eating. Side effects were described as having a delayed onset and continuing into the post treatment period. Participants acknowledged the significance of good nutrition during this time, and the impact of minimal nutrition on physical status. While people discussed distress during this time, they also described the predicament of needing to continue treatment.

**Theme 2: Eating after surgery: “a real hard learning curve”**

The effects of surgery on eating and diet immediately post-surgery and following discharge were described. The physical effects of surgery on digestion were portrayed as a struggle for the body:

“With this operation, your... body has to learn to not only eat again, but how to digest again.” [participant 1].

Early satiety was commonly described and created difficulty in maintaining adequate oral intake. Some participants found that this could be managed when strategies such as having small, frequent meals were implemented. Other participants however described difficulties with early satiety that they did not know how to manage.

Dumping syndrome was depicted as troublesome, requiring careful attention to portion size and food type:

“So that’s been a real hard learning curve for me, not to just be... gutsing myself whatever I want, I’ve had to monitor what I eat very carefully or I get a dumping episode” [participant 3].

It was indicated that dumping was most problematic in the short-term, until participants learnt how to adjust their diets to avoid this complication.

Several participants discussed changes to food preferences as well as the inability to tolerate particular foods:

“Um, but there’s a lot of things I can’t handle, I can’t handle meat much at all and, I can’t handle bread, but if I toast it, I can eat it” [participant 3].

Changes to food preference were expressed as a liking for “healthier” food,

particularly salads.

**Theme 3: Nutrition advice: “very useful if I had’ve been able to apply it”**

All participants expressed difficulty in implementing nutrition advice received, with several barriers being described. Treatment side effects made it challenging by affecting palatability and the ability to keep food down:

“Um you know you don’t really eat anything that they want you to eat, it’s very hard, cause you lose your taste buds and everything tastes funny to you” [participant 6].

Several participants expressed that it was impossible at times to follow nutrition advice, despite their best efforts.

These difficulties were further exacerbated by the food provided in hospital:

“They’d give me the mashed potato and mashed puree foods and they stunk and I just couldn’t keep anything down, so I don’t know, they’ve got to find a different way for people who can’t eat at all” [participant 1].

Issues with hospital food were regarding quality, texture and palatability.

Furthermore, whilst the use of oral nutritional supplements (ONS) was common in this participant group, a strong dislike of the flavours and textures was expressed. This dislike was expressed by 6 of 9 participants despite trialling different brands and flavours of ONS. Consequently most participants reported low compliance with recommended supplementation.

The need for more dietetic advice and support for carers was highlighted by both participants who received definitive CRT:

“as a primary carer my wife needed more advice” [participant 7].

However this need was not expressed by participants who received neoadjuvant CRT and surgery.

**Theme 4: Nutrition is important, but weight loss is not concerning**

The importance of nutrition

All participants acknowledged that nutrition was important and assisted with their recovery. It was characterised as an indicator of positive progress:

“I’ve got it in the back of my head that unless I eat... I’m gonna take a step backwards” [participant 1].

“Being able to eat and hold food down was a huge mental moment of I am getting better, and once I could start doing that my energy just continued to grow exponentially” [participant 7].

This concept of equating the ability to eat with recovery and progress was expressed by participants irrespective of treatment type.

Unintentional weight loss

All participants lost a significant amount of weight, with an average percentage weight loss of 25%.

Participants were able to recall how much weight they had lost during and

following treatment however there was minimal concern about unintentional weight loss, particularly for patients who were overweight:

“No I wasn’t worried about it cause I was overweight to start with so... in a way I didn’t mind, I mean, it’s a rotten way to lose weight but, no I didn’t mind” [participant 2].

Interestingly four participants mentioned their doctors’ attitudes towards their weight loss, which appeared to sway their own perceptions of their weight loss. Three of the participants reported that one of the doctors expressed either no concern or a positive attitude towards their weight loss as they were previously above the healthy weight range:

“I’m down to me normal weight, what I should be... so the doctor says, so I shouldn’t worry about me weight...” [participant 8]

Alternatively the other participant who brought up the doctors attitude towards his weight loss expressed a determination to improve his intake after the medical team expressed their concerns over his continued weight loss:

“They were alarmed about that ‘n’ then it just got to the point where doctor said yep, you’re losing weight, next week come in ‘n’ we’ll weigh you, if you’re below this, you’re coming back into hospital.”... “so I said you know, I’m not going back to hospital, I’m gonna have to start eating” [participant 4].

Family’s perceptions of unintentional weight loss

The attitude of those undergoing treatment was often in contrast to those of loved ones:

“I don’t think I was necessarily worried about eating, I think I was reasonably heavily medicated... But I know that my wife, my sister, and my parents were all very distressed about it” [participant 7].

#### 4. Discussion

This study aimed to explore the experiences of people with OC in relation to nutrition, weight loss and dietetic support. The findings are evidence of the eating and nutrition difficulties faced due to surgical and CRT treatments. Issues and barriers to complying with nutrition advice were uncovered, and attitudes towards unintentional weight loss and nutrition were investigated. This study indicates the need for a more patient-centred approach to the nutrition care of people undergoing neoadjuvant and definitive CRT for OC.

A high prevalence of malnutrition in patients undergoing CRT for OC has been described [20]. Eating difficulties during and following CRT are common, with previous research showing that neoadjuvant CRT impacts nutrition due to treatment-related toxicities such as nausea, anorexia and taste problems as well as dysphagia and eating problems [21]. This study highlights how severe these

symptoms can be, with people undergoing CRT treatment only tolerating minimal oral intake. This finding has significant clinical implications, as it accentuates the need for ongoing dietetic assessment and support during CRT treatment. It gives evidence for the value of nutrition support for people with OC during and following CRT, as well as early intervention for high risk patients to minimise detrimental impacts on nutritional status. There is some limited evidence of benefits of a prophylactic gastrostomy or jejunostomy in people with OC, including those receiving CRT (NHMRC grade C) [11]. The expressions of extreme difficulty in maintaining adequate oral intake in the current study suggest that further research into the potential benefits of routine placement of enteral feeding options prior to CRT could be useful.

The difficulties of eating following surgery for OC have been described by several qualitative studies. Issues described by participants in this study are in alignment with those previously reported including early satiety and/or loss of appetite [8] [16] [17] [22], dumping syndrome and/or diarrhoea [8] [16] [17] [22] and changes to food preferences [17] [22]. The characterisation of post-operative eating as a learning experience is similar to previous studies which described patients needing to “learn” appropriate amounts to eat following surgery [17] [23]. Despite nutrition education delivered by dietitians, patients appear to feel unprepared for what to expect following treatment. Similar reports of a mismatch between expectations and the reality of eating after surgery are evident in qualitative literature both for the patient and carer [24]. This suggests that further preparation for what to expect following treatment would be beneficial. The value of peer support for people who have undergone oesophagectomy has also been described [15] [16]. Conversely not all people with OC find peer support beneficial, as some may find it distressing to hear other people’s cancer experiences [25], and it can increase feelings of vulnerability. Taking this into account voluntary peer support meetings may be a useful way to help people prepare for the physical and emotional effects of oesophagectomy, including food and nutrition issues.

The inability for participants to follow nutrition advice is of great concern. This was largely related to the side effects of treatment. However, the food provided in hospital and the dislike of ONS also contributed to the difficulty in maintaining adequate oral intake as advised by the dietitian. Issues with hospital food have been previously expressed by people with OC [26]. Limited research into hospital food and improving intake of people being treated for cancer has been published. One study in a paediatric sample undergoing cancer therapy found that a “room service” style of ordering improved caloric and protein intake, as well as increasing patient satisfaction [27]. Patients would call the hospital kitchen when they would like to eat, with delivery of the preselected meal within 30 minutes. New, extensive menus were also written. Whilst this style of service may not be feasible in large general hospitals, it provides evidence that thoughtful restructuring of food services and menus may be a promising strategy

to increase oral intake in people with OC during their hospital stay. Another finding of interest was that patients had a strong aversion to ONS, which is in contrast to good compliance rates reported across a range of healthcare settings [28]. However, the taste changes and changes to food preferences described in this study may help to explain the low compliance and dislike of ONS.

Concern regarding weight loss appeared to relate to pre-morbid BMI, with people who were overweight or obese at diagnosis having a positive attitude towards weight loss. Similar results have been reported by Carey and colleagues [16] whereby participants with well-nourished SGA scores perceived weight loss as a positive experience, in contrast to those who were assessed as malnourished.

Rapid weight loss results in the reduction of fat free mass, not just adipose tissue [29], and this is crucial for patients and health professionals to understand. Unintentional weight loss, even in overweight and obese individuals, can impact recovery [14], with sarcopaenic obesity being associated with decreased functional status and decreased survival [30]. It is clear that the perception of weight loss for this population is complex. Some patients also reflected on the attitudes of the medical team towards their weight loss. This appeared to influence their own attitudes towards their weight loss and for one patient increased his motivation to improve his intake. That several participants reported that the doctors were unconcerned about their weight loss due to their previously overweight/obese weight range is particularly concerning. This highlights the influence that the medical team can have on patient's compliance with dietary advice, and the need for nutrition education within the surgical field.

According to participants, carers and families were significantly distressed by their weight loss and poor oral intake. This is in alignment with recent research reporting eating and weight loss as sources of distress for family caregivers of people with UGI cancer [24]. It is not surprising therefore that the participants who underwent definitive CRT, primarily as outpatients expressed a need for greater dietetic support for carers. Particularly as family members are often the primary support and help with preparing meals and taking in information when the patients are unable to [15]. The experience of carers for people who have undergone oesophagectomy [23] and more generally surgery for UGI cancer [24] have been investigated. However, further research directed at the nutrition education and resource needs of carers of people with OC, including those undergoing definitive CRT is required.

There were several limitations to this study which need to be considered. This includes a potential for recall bias, as with all retrospective self-reported information it is possible that participants were unable to accurately recall events and feelings from the time of treatment. There is limited transferability of results due to failing to capture an adequately varied sample, which in the future could be improved through careful purposive sampling and recruiting participants across several sites. Only persons with sufficient English skills were invited to participate. Only two patients had undergone definitive CRT, both with significant nu-

tritional concerns. These findings need to be replicated due to small sample size and is an area for more in-depth exploration.

This study focused on the nutrition issues faced by people undergoing curative treatment for OC, and their attitudes towards nutrition and weight loss. Significant nutritional difficulties were described by both those who underwent definitive CRT and those who had neoadjuvant CRT and surgery. Nutrition advice was reported as difficult to follow due to significant nutrition impact symptoms. A belief that nutrition was important did not translate to patient concern regarding unintentional weight loss. The medical team had a strong influence on some patients' attitudes towards their weight loss. Further research is indicated to investigate UGI surgeons' perceptions of weight loss in overweight or obese people in this patient group. The findings highlight the need for dietetic services for this patient group before, throughout and following treatment, irrespective of treatment type. Explanation of the detrimental effects of rapid weight loss to patients is crucial, and this should be consistent from all members of the multidisciplinary team.

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### **Statement of Authorship**

All authors contributed to the paper. G. Hardy refined the project methodology, collected and analysed the data, and drafted the paper, gave final approval and agrees to be accountable for all aspects of work ensuring integrity and accuracy. M. Findlay contributed to design of the project, critically revised the manuscript, gave final approval and agrees to be accountable for all aspects of work ensuring integrity and accuracy. S. Carey designed the project, contributed to data analyses, reviewed the paper, gave final approval and agrees to be accountable for all aspects of work ensuring integrity and accuracy.

### **Conflicts of Interest**

The authors declare no conflict of interest. The authors have full control of all primary data and agree to allow the journal to review their data if requested.

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