

Psychosocial Support in Cancer Cachexia Syndrome: The Evidence for Supported Self-Management of Eating Problems during Radiotherapy or Chemotherapy Treatment

Jane Hopkinson

School of Healthcare Sciences, Cardiff University, Cardiff, UK



Corresponding author: Jane Hopkinson, PhD, RN

School of Healthcare Sciences, Cardiff University, Cardiff, UK

Tel: +44 29 2068 8562

E-mail: hopkinsonjb@cardiff.ac.uk

Received: February 27, 2018, Accepted: March 07, 2018

ABSTRACT

People receiving cancer treatment are at nutritional risk. Their eating problems can lead to malnutrition and weight loss. Involuntary weight loss is also a defining characteristic of tumor-induced cachexia. Weight loss is associated with poor tolerance of treatment, poor treatment outcomes, morbidity, and mortality. Support for self-management of nutritional risk may protect against malnutrition and be important in multimodal therapies to arrest the progression of cachexia. Nurses can help patients by supporting self-management of eating problems. This scoping review is about eating problems during cancer treatment. It considers patient experience and self-management of eating problems during cancer treatment for the proactive management of malnutrition and cachexia. It draws on a systematic search of Medline, CINAHL, PsycINFO, and the Cochrane Library for publications about people with cancer who have eating problems during treatment. Limits were

English language; January 2000 to December 2017; adults. The search found studies about eating problems in patients treated with chemotherapy or radiotherapy for head-and-neck cancer, lung cancer, gastrointestinal cancer, breast cancer, testicular cancer, and ovarian cancer. Nutritional counseling can improve nutritional intake, quality of life, and weight. However, the patient perspective on self-management and how to motivate engagement in nutritional care is unexplored. There is a potential for reducing nutritional risk during cancer treatment using psychoeducation to support behavioral change, thus empower self-management of eating problems. Benefits are likely in subgroups of people receiving cancer treatment, such as those with head and neck, gastrointestinal, and lung cancers.

Key words: Anorexia, cancer, eating, narrative synthesis, systematic review, treatment, weight

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon_12_18

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

Cite this article as: Hopkinson J. Psychosocial Support in Cancer Cachexia Syndrome: The Evidence for Supported Self-Management of Eating Problems during Radiotherapy or Chemotherapy Treatment. *Asia Pac J Oncol Nurs* 2018;5:358-68.

Introduction

Involuntary weight loss is a defining characteristic of cancer cachexia syndrome (CCS),^[1] although it can also be caused by malnutrition.^[2] In cancer, it is associated with less treatment, poor treatment outcomes including quality of life, treatment toxicity, and mortality.^[3,4] Eating problems are caused by cancer or its symptoms and treatment. They contribute to weight loss, which is common. For example, during chemotherapy, weight loss occurs in 40%–92% of patients 65 years and older, depending on tumor site.^[5]

In clinical practice, it is difficult to know if involuntary weight loss is due to cachexia or malnutrition. CCS, which can arise at any cancer stage, cannot yet be treated or arrested with nutritional support; however, it will resolve if the cancer itself is treated successfully. In contrast, malnutrition can respond to nutritional intervention at any cancer stage. Thus, support for nutritional intake can help correct involuntary weight loss in some cases and may assist clinical judgment of causation.

Trials of nutritional support and other single component interventions have proven unsuccessful in arresting or reversing CCS weight loss. Expert consensus now recommends multimodal treatment at all stages of the syndrome. It is theorized that interventions with components that act synergistically, complex interventions, could be effective. For example, research is in progress testing nutritional support plus exercise plus an anti-inflammatory agent in the MENAC trial.^[6]

Nutritional care is any activity to help with the management of eating problems. CCS experts agree that it is an important component of multimodal intervention for cachexia throughout the course of cancer. The aim is to prevent malnutrition thus protecting against adverse treatment outcomes, improving treatment tolerance and enabling greater intensity of therapy, in turn, improving survival and quality of life.^[7]

Self-management is the actions taken by people to recognize, treat, and manage their own health.^[8] Eating problems during cancer treatment are usually self-managed. However, many cancer patients in the UK are dissatisfied with their nutritional care during treatment. They want more advice on how to deal with side effects of cancer treatment, weight changes, and what to eat.^[9] There is thus the potential to improve professional support of their self-management.

Aim

This study is a scoping review of eating problems and cancer treatment. It aims to identify ways to help cancer patients reduce their risk of malnutrition and maintain their body reserves to potentiate cancer treatment.

Background

Baldwin *et al.*^[10] conducted a meta-analysis of oral nutritional interventions (food and/or supplements) in malnourished cancer patients. The analysis of 13 studies with 1,414 patients, at all stages of disease, found improvement in nutritional intake and quality of life but no effect on mortality. The meta-synthesis was of mixed cancer sites and all stages of disease, thus making it difficult to know if there is greater benefit for some patient groups.

In parallel with Baldwin's study, a systematic search and mixed-methods synthesis of research about the nutritional care of weight-losing cancer patients off treatment found two dominant views regarding its management. The majority view advocated a nutrition-dense diet facilitated by nutritional counseling to improve nutritional status. The alternative perspective was to advise patients to "eat what they want" to improve the quality of life. Little robust evidence justified either approach.^[11] The study concludes that integration of the perspectives is needed; facilitation of optimal nutritional intake taking into account the person's disease symptoms, treatment side effects, emotional adaptation to illness, and social circumstances. In other words, across the entire course of disease, there should be an offer of personalized nutritional care.

Since 2011, ESPEN^[12] has published guidelines on nutrition in cancer, drawing on available evidence 2006–2013 and expert opinion. It makes recommendations for the management of nutritional and metabolic problems in subgroups of cancer patients, for example, recommending psychosocial support for people with refractory disease to maximize the quality of life. Nutritional counseling is the recommended first-line intervention for patients with a functioning gastrointestinal tract. Nutritional counseling is "a repeated professional communication process that aims to provide patients with a thorough understanding of nutritional topics that can lead to lasting changes in dietary habits. It takes into account resting energy expenditure, lifestyle, disease state, current intake, food preferences, and disease symptoms. Critically, it conveys reasons for nutritional recommendations and motivates adaptation to altered nutritional requirements."^[12] The role of psychosocial support during active cancer treatment, as a component or adjunct to nutritional counseling, is not considered. This review seeks to address this gap.

Context for the research

This review follows on from a program of work to develop and evaluate nurse-led psychosocial support for weight loss and eating problems in people with advanced cancer who are approaching the end of life.^[13-15] The program was a series of mixed-methods studies that led to

toolkits, MAWE,^[16] and FAWE^[17] for clinicians working with people who have advanced cancer, eating problems, and weight loss. Evaluation of these interventions found benefits and no adverse consequences.

Question

What is known about the experience and self-management of eating problems in people receiving cancer treatment?

Methods

The search was of Embase, Medline, CINAHL, PsycINFO, and the Cochrane Library for publications about people with solid tumors who have eating problems during treatment. Limits were English language; January 2000 to December 2017; adults. The search strategy was developed for Medline and then translated into other databases. It combined selected MeSH terms and free text terms. It comprised multiple searches, as the study was a scoping review to map the breadth and depth of literature in the field of interest.

The first search combined search terms for cancer, anorexia (and other terms to capture literature about eating problems), and nutrition assessment/management. It was rerun substituting anorexia with weight loss. The second search combined terms for cancer, anorexia (and other terms to capture literature about the experience of eating problems), and experience (such as distress, adaptation, and conflict). It was rerun substituting anorexia with weight loss. The third search combined terms for cancer, anorexia, and self-management. It was rerun substituting anorexia with weight loss.

The preliminary inclusion/exclusion criteria were refined, as the search progressed. For example, exclusion of surgical and hematological cancer treatments was at the data extraction stage because of the difficulty defining a point in time for evaluation of nutritional care in these treatments. The criteria were broad, allowing inclusion irrespective of research design, methodology, or method. The full text of any eligible citation was read.

The analysis examined data from effectiveness studies (trial data) independently of data from studies that explored experience (case studies, surveys, and qualitative studies) and expert opinion pieces. Contrasts between study designs, methodology, and methods were expected and considered a strength, as the review's purpose was to capture an overview of what is known about the experience and self-management of eating problems during cancer treatment. The three streams of analysis generating information of relevance to the research question were integrated in the narrative synthesis reported here using an approach akin to ethnography.^[18,19] The NHS Centre for Reviews and Dissemination guidance for undertaking

reviews in health care informed the search methodology and methods.^[20]

Results

This review found a limited literature about patient experience of eating problems and factors that can affect self-management of these problems during treatment [Table 1]. It found some work about the experience of eating problems during radiotherapy and chemotherapy, no work about eating problems during the new and evolving antineoplastic cancer treatments, such as immunotherapy, and no work seeking to understand the patient perspective on self-management of eating problems during cancer treatment, such as obstacles and enabling factors. This review assumes that dietary advice and nutritional counseling support self-management.

Studies based on mixed cancer sites

Patients find eating problems, distressing, and lack appropriate dietary instructions.^[9] Yet, patients may be reluctant to engage in nutritional care. One study reported more than a third declined participation because of fatigue or disinterest in nutritional support and that 64% of these people were women.^[30]

Patients' self-management of eating problems can be affected by disease symptoms such as taste change or the side effects of treatment. However, their self-management can also be influenced by beliefs.^[31] For example, obese patients may welcome weight loss without understanding its negative impact on treatment outcomes and survival.^[32] Another counterproductive belief is that fruit and vegetables should be eaten, rather than the ESPEN recommended protein- and energy-rich diet. In Turkey, of 66 patients receiving chemotherapy who completed a questionnaire, 62% reported consuming more vegetables and 23% more fruit and vegetables.^[33]

Obstacles to eating during cancer treatment include taste change, nausea, and gastrointestinal side effects. In 2008, a survey of 518 Swedish cancer patients, postchemotherapy found 75% to report taste or smell change, with onset ranging from 1 to 10 weeks following first treatment. Female gender, younger age, and prior experience of change were predictors^[34] and changes were associated with oral problems, appetite loss, nausea, and depressed mood.^[34] Another obstacle, nausea, has been found in 55%–73% of 104 patients receiving anthracycline-based chemotherapy with appetite loss, feeling bloated, vomiting, taste change, and lack of energy found predictive.^[35,36]

Patients receiving pelvic irradiation have been studied because of the gastrointestinal side effects, flatulence, diarrhea, nausea, and abdominal pain, which can affect eating. In a service evaluation, health-care professionals

Table 1: Action to support self-management of eating problems in people receiving radiotherapy and/or chemotherapy treatment: Interventions with beneficial effect in experimental or quasi-experimental studies

Item	Mixed cancer sites	Head-and-neck cancer	Other cancer sites
Nutritional counseling	Radiotherapy Give information about possible nutritional problems that can arise in treatment, how to minimize treatment side effects and strategies to cope with eating problems. Offer individualized advice to take calorie-dense foods and quick and easy cooking ideas taking into account environment to support adequate energy and protein intake for attainment of nutrition goals ^[21]	Radiotherapy Offer nutritional intake and quality of life counseling. Prescribe a diet that uses regular foods modified to provide for individual calculated energy and protein requirements. Take into consideration, symptoms, as well as psychological factors, any diet restrictions and digestive and absorptive capacity ^[22] Chemotherapy Daily diet plan individualized according to patient status. Follow-up by telephone to enquire about nutritional intake, encourage patient to eat according to diet plan and provide advice on management of adverse treatment effects ^[23] Chemoradiotherapy Advise on food selection and skills for food modification ^[24] Give feedback to reassure advice is being followed correctly ^[24] Radiotherapy with or without chemotherapy Recommend modification of regular foods to improve protein and energy intake to aid maintenance of weight ^[25]	Gastrointestinal cancer - radiotherapy Counseling to improve nutritional intake, quality of life and survival. Specify the type, amount, eating frequency in number of meals, and calorie/protein amounts to achieve daily and modification to regular foods taking into account symptoms and psychological factors, disease stage and progression ^[26] Counseling to achieve the highest adherence, advise changes that are as close as possible the usual dietary pattern, types of food, amounts of foods, and frequency of eating throughout the day ^[26] Lung cancer - radiotherapy with or without chemotherapy Counseling to improve nutritional intake and quality of life, tailor advice to symptoms, food preferences and social circumstance ^[27]
Dietary advice	Radiotherapy - pelvic High fiber diet to help minimize treatment toxicity and maximize protein and fat intake ^[28]	Radiotherapy Adjust usual diet, to prescribe the type, amount and frequency of feeding needed to attain calculated energy and protein requirements ^[22] In patients with protein deficiency, advise oral nutritional supplements in between meals ^[22] Chemotherapy No individualized calorie target but advice to support maximize caloric intake with an appropriate balance of carbohydrates, protein, and lipids. ^[29] Advise highly nutritious and digestible foods, for example, to eat frequent small meals and take high-protein liquid diet (such as milk, Ensure) to increase nutritional intake. ^[23] Radiotherapy with or without chemotherapy Recommend 25-30 kcal/kg/day with 1.2-1.5 g protein/kg/day to aid maintenance of weight. ^[25]	No reported research
Physical activity advice	No reported research	Chemoradiotherapy Encourage walking in addition to giving advice on how to manage eating problems for preservation of nutritional status and functional walking capacity ^[24]	No reported research
Oral care	No reported research	Chemoradiotherapy Advise on oral care to aid preservation of nutritional status ^[24]	No reported research
Other education	No reported research	Chemotherapy Offer a comprehensive guidance plan during chemotherapy and telephone follow-up to include: 1. Education in purpose of chemotherapy and possible related side effects 2. Instruction in the importance of nutritional intake during chemotherapy ^[23]	No reported research
Family support	No reported research	Chemotherapy Provide guidance for caregivers on meal preparation ^[23]	No reported research

gave advice to reduce fiber intake, reduce caffeine intake, and increase water intake.^[37] However, this may not be good advice. In a randomized controlled trial where patients receiving pelvic radiotherapy were advised to take a low-fiber ($n = 55$), habitual-fiber ($n = 55$), or high-fiber ($n = 56$) diet, the high fiber group had significantly less treatment toxicity. Low and habitual fiber intake groups also had reduction in energy, protein, and fat intake.^[28]

Nutritional counseling can improve nutritional intake during chemotherapy^[10,38,39] and radiotherapy.^[40] For example, in a randomized controlled trial of patients of

mixed cancer sites, 44 received a proactive nutritional education with the goal of reducing radiotherapy side effects and the negative impact on eating. Nutritional status was stable in the intervention group and deteriorated in control during treatment.^[21]

However, a cluster randomized controlled study found no effect of a nurse-led self-care program (nutritional counseling, relaxation training, and education on treatment and side effects) to reduce the intensity of nausea, vomiting, and anorexia in 105 patients during chemotherapy compared to 103 controls. The researchers

explain this unexpected result to be the outcome of low levels of eating problems in participants because of effective pharmacological management of nausea and vomiting, as there was only marginal shift in nausea from baseline and no change in eating habits.^[41]

Mixed cancer sites summary

Research in mixed cancer sites has shown eating to be problematic during cancer treatment. Patients find eating problems distressing and can take action that contributes to eating and other cancer-related problems, yet be reluctant to accept nutritional care. Nutritional counseling can improve nutritional intake reducing risk of malnutrition, but health-care professionals can give advice that is inconsistent with best practice guidelines.

Head-and-neck cancer

Patients with head-and-neck cancer receiving chemoradiotherapy experience “major deterioration in eating and drinking abilities” during treatment. These changes arise after the 1st week of treatment and include “excruciating” pain when swallowing, nausea, vomiting, and relentless thick phlegm that can disrupt sleep every 30 min.^[42] Saliva can be nonexistent. Food can stick in the throat and affect breathing. Mouth opening becomes difficult and if able to continue oral intake then this is sloppy or liquid foods. In addition, fatigue reduces energy for food preparation and eating. Patients’ social lives may become limited with their focus on food shifting to its medicinal and nutritional value. Meanwhile, family members try to get patients to increase their oral intake, which can cause conflict.^[42] In Australia, 58% of patients receiving radiotherapy or chemoradiotherapy were found to have swallowing problems and 27% experienced related distress.^[43]

Caregivers of 23 patients receiving treatment for head-and-neck cancer invited to report patient symptoms most frequently reported trouble with appetite and eating, which they considered one of the most distressing symptoms, equivalent to the distress caused by aggression. Only irritability was more distressing.^[44]

Observational studies have investigated the effect of nutritional counseling and oral nutritional supplementation on nutritional status, typically weight. Thirty-eight patients receiving surgery and radiotherapy with or without chemotherapy for head-and-neck cancer were found to lose mean > 10% of body weight during their treatment course. Oral nutritional supplements were offered to patients with an intake below the recommended by ESPEN guidelines. Those who took supplements (most of whom received chemotherapy), lost more weight than those with equivalent intakes who did not take supplements (most of whom did not

receive chemotherapy). The patients who maintained their weight had a minimum energy intake of 33.3 kcal/kg/day and protein intake of 1.6 g/kg/day, which was greater than recommended in ESPEN guidelines. Based on the study findings, the authors recommend nutritional counseling to increase energy and protein intake using regular foods for weight maintenance through treatment.^[25]

Most investigation has been of proactive intervention in the knowledge that treatment for head-and-neck cancer causes eating problems. For example, nutritional counseling offered to 25 patients by a dietitian from the commencement of radiotherapy treatment was shown to improve energy and protein intake along with the quality of life when compared to *ad lib* dietary intake in a randomized control trial.^[22] Similarly, in an observational study of 159 Chinese patients with esophageal cancer receiving radiotherapy, 69% experienced loss of appetite with associated reduction in energy intake. The 60% who received nutritional counseling were at lower risk of weight loss compared to those who received no counseling.^[45] Goal-directed nutritional counseling offered in 78 patients with severe dysphagia receiving chemotherapy, resulted in all but one patient avoiding the need for stenting and none needing tube feeding.^[29] However, while there are no reports of harm from supported self-management of eating problems, not all studies yield positive results. Early rehabilitation to reduce swallowing problems and problems with mouth opening through treatment observed in 190 patients compared to 184 control patients found no benefit.^[46]

The most recent studies investigate multimodal interventions. In a pilot randomized controlled trial with locally advanced esophageal cancer patients, the intervention group had weekly assessment of weight and intake followed by advice on eating difficulties, food selection, oral care, and skills for food modification provided by a nurse. They were found most concerned about how to make foods more appealing and less painful to swallow. They also wanted to know what change to expect in nutritional status and whether they were following advice correctly. The intervention included a nurse-supervised walking program and approximately one-third of the participants received tube feeding. Results were positive, with improvements including preserved nutritional status (mean body weight change pre- to post-treatment, intervention group ($n = 28$) $-0.8 \text{ kg} \pm 1.8$, control group ($n = 28$) -3.5 ± 2.3 , adjusted $P < 0.001$) and preserved functional walking capacity compared to controls, post chemotherapy.^[24]

Head-and-neck cancer summary

The treatment for head-and-neck cancers can cause severe eating problems. Proactive nutritional counseling

before problems arise can improve nutritional intake, quality of life, and reduce risk of weight loss. It can even prevent a need for tube feeding. Modification of regular foods is more successful in improving protein and energy intake than oral nutritional supplementation. However, there is a limited reporting of the nature of nutritional counseling and any underpinning theoretical framework for support of behavioral change and self-management.

Gastrointestinal cancer

Taste changes reduce food enjoyment with social and emotional impact for people receiving chemotherapy for colorectal cancer and their carers.^[47]

In 2011, Elia^[48] critically reviewed studies of oral nutritional support during treatment in patients with gastrointestinal cancer and noted that it had proven difficult to increase dietary intake in real-life situations. Studies conducted after Elia's review have evidenced benefit from nutritional counseling for people receiving treatment for gastrointestinal cancer. In patients with colorectal cancer followed up after radiotherapy for a median 6.5 years, those who had received individualized nutritional counseling to maintain protein and energy intake experienced less treatment toxicity, better quality of life, and lower mortality rate compare to patients randomized to either oral supplements and usual diet or usual diet¹⁶. Ravasco^[26] describes the individualized nutritional counseling and education offered. Prescription of modification to regular foods took into account symptoms and psychological factors. "The prescription had to specify the type, amount, eating frequency in number of meals, and calorie/protein amounts to achieve daily, and simultaneously consider disease stage and progression. To achieve the highest adherence, one had to maintain as close as possible the usual dietary pattern, types of food, amounts of foods, and frequency of eating throughout the day ...". A study of colorectal cancer patients that compared a group of 315 patients receiving nutritional counseling, megestrol acetate and nutritional supplements with 313 patients treated at an earlier time point when this intervention was not available. There was an increase in body weight in 73% (1.5 kg average) and 19% in the comparator group.^[49] However, the weight gain may have been fluid retention, a side effect of megestrol acetate, or due to differences in chemotherapy treatment between groups. In gastric cancer, 144 patients randomized to receive a nutritional and educational intervention throughout chemotherapy had higher calorie intake, higher levels of iron and other markers of adequate nutrition than controls, and a higher proportion received planned treatment (74% compared to 56% in control group).^[24]

Gastrointestinal cancer summary

The only study exploring the experience of eating problems for people with gastrointestinal cancer was about taste change and found social and emotional impact because of decline in the enjoyment of food. Proactive nutritional counseling during either radiotherapy or chemotherapy can improve nutritional intake with long-term follow-up in one study finding a beneficial effect on survival. Compliance with oral nutritional supplements can be poor and support for modifying regular foods successful in improving protein and energy intake.

Lung cancer

Patients with lung cancer also experience taste change during treatment. In 52 patients receiving radiotherapy or chemoradiotherapy, 35 experienced taste change during treatment and only 11 experience no taste change before or during treatment. The impact on food intake and social life varied depending on effect on other symptoms such as nausea.^[50] Taste change can cause eating problems, as evidenced by 44 patients who found that foods became more unpleasant, and nutritional intake declined along with health-related quality of life during two cycles of paclitaxel and cisplatin for lung cancer.^[51]

An observational study of chemoradiotherapy-induced esophagitis in patients with nonsmall cell lung cancer found it can impact nutritional intake within 2 weeks of the start of treatment. By week 5, 75% of patients had a reduced nutritional intake. Although dietary intake remained stable until the 3rd week of treatment, weight loss started early after the initiation of treatment when decline in muscle strength was also observed.^[52]

Dietitians have successfully delivered nutritional counseling to patients with lung cancer in treatment. In a randomized controlled pilot trial, 12 patients with lung cancer receiving radiotherapy with or without chemotherapy, received a structured program of nutritional counseling tailored to their symptoms, food preferences, and social circumstance. More patients were weight stable during treatment in the intervention group (78% vs. 36%) and fewer were malnourished (11% vs. 45%). The quality of life remained stable for the intervention group and declined in the usual care control.^[27] Honey is an intervention used for radiation-induced esophagitis. A randomized controlled trial compared the effect of honey lozenges ($n = 56$) or liquid honey ($n = 54$) for pain on swallowing due to radiation-induced mucositis in lung cancer patients receiving chemoradiotherapy. No difference in pain score was found compared to supportive care ($n = 53$) at 4 weeks.^[53]

Lung cancer summary

The majority of patients with lung cancer experience taste change during treatment. Chemoradiotherapy impacts dietary intake for 75% by week 5 of treatment, but loss of muscle strength and weight loss can commence sooner. A small study of nutritional counseling by dietitians found beneficial effect on nutritional status and quality of life. Honey may not relieve the pain of treatment-induced esophagitis.

Breast cancer

The study of eating problems during chemotherapy for breast cancer has found decline in taste, appetite and hunger along with dry mouth, difficulty chewing and nausea.^[54]

In 52 women receiving adjuvant chemotherapy in Australia, tests on the ability to identify five tastes found sucrose (sweet) and caffeine (bitter) the least accurately identified. Taste change was associated with reduced nutritional intake, but appetite demonstrated a stronger association and was also associated with decline in body mass index. It did not correlate with chemotherapy toxicities (dry mouth, oral mucositis) and resolved within 2 months of chemotherapy.^[55]

An observational study of 55 women with breast cancer receiving chemotherapy found more than half to report “diet needs modification” at the beginning and during treatment according to the Brazilian Healthy Eating Index Revised. The modifications were reduction in consumption of fruit, vegetables and legumes, and reduction in macro and micronutrients. Food enjoyment decreased and nausea increased in intensity yet appetite increased, especially appetite for salty and spicy foods.^[56,57] In 117 women receiving chemotherapy, eating problems were associated with lower energy, fat, protein, and alcohol intake.^[54]

Breast cancer summary

Chemotherapy for breast cancer causes eating problems that include taste change that resolves within 2 months of treatment. Eating problems result in dietary changes compromise nutritional intake and have a negative impact on food enjoyment.

Other cancers

The search also found a study of men receiving treatment for testicular cancer and a study of women receiving chemotherapy for ovarian cancer. The 21 men with testicular cancer preferred milk-based strawberry oral nutritional supplements before and during treatment and found juice-based supplements tasted more metallic during compared to pretreatment.^[58] The 55 women with ovarian cancer had received at least two cycles of chemotherapy. Their 3-day food records revealed dietary intake greatest

in the 3 days before treatment and lowest on the day of treatment.^[59]

Other cancers summary

The studies of men with testicular cancer and women with ovarian cancer show that food intake and taste can change during a cycle and across a course of chemotherapy.

Key findings

Eating can be problematic for patients receiving radiotherapy or chemotherapy for head and neck, gastrointestinal, lung, breast, testicular, and ovarian cancers. The problems include taste change, poor appetite, dry mouth, nausea, dysphagia, and esophagitis and can be distressing for both patient and carer. The subsequent decline in oral intake and loss of enjoyment of food has negative emotional and social impact. Changes can occur during a cycle of chemotherapy and across a whole course of either radiotherapy or chemotherapy treatment. Patients can be reluctant to seek or accept nutritional care.

Nutritional counseling can improve nutritional intake in head and neck, gastrointestinal, and lung cancer. In these cancers, proactive nutritional counseling, before treatment-related eating problems arise, has been trialed with beneficial effects on nutritional intake, quality of life, and weight. Adherence to dietary advice for improvement in protein and energy intake is more likely if advice is to modify regular foods rather than the offer of oral nutritional supplements. There is no reported adverse outcome or harm from nutritional counseling.

Discussion

Our knowledge of the experience of eating problems during radiotherapy and systemic anticancer treatment is limited and has many gaps [Table 1]. This scoping review found studies of eating problems conducted in some, but not all, cancer sites. The studies reveal eating problems in patients treated with chemotherapy or radiotherapy for head and neck, gastrointestinal, lung, breast, ovarian, or testicular cancer, that include taste change, poor appetite, pain, fatigue, dry mouth, nausea, dysphagia, esophagitis, and loss of food enjoyment.

The review sought to understand how patients self-manage eating problems during treatment, thus revealing important factors for successful management of nutritional risk. Nutritional counseling or dietary advice was assumed to support self-management, although this intention is not reported explicitly. Small or single center, observational, quasi-experimental, and experimental studies have shown nutritional counseling can improve nutritional intake, quality of life, and weight. These studies provide limited information on what it is or how it brings about

dietary behavioral change [Table 1]. One study mentions providing information on strategies for coping with eating problems, a second used an individualized diet plan and telephone follow-up to encourage eating, and a third provided feedback on adherence to recommendations. Practical detail of the delivery of these interventions is not given. This precludes replication in other contexts and obscures what may be important components for achieving desired outcomes, such as reduced risk of malnutrition. It is surprising there has not been more extensive and robust study of nutritional counseling during cancer treatment, given the known association between nutritional parameters, weight, and clinical outcomes of treatment, including survival.

Furthermore, there has been no attention to motivating engagement in nutritional care and adherence to dietary advice for best clinical and survival outcomes. In other words, there is a gap in our understanding of how to empower people receiving cancer treatment to self-manage eating difficulties, thereby optimizing their nutritional intake. Clinical guidelines do not set out an approach to support behavioral change. An omission, as adherence to dietary advice is poor and psychological techniques can help people learn new behaviors and take control of their health.^[60,61] However, an interesting and potentially important multisite stepped-wedge randomized controlled trial is in progress in Australia. It is testing the first behavior change counseling intervention to improve nutrition, EAT (eating as treatment), in patients with head-and-neck cancer receiving radiotherapy. Dietitians trained in using behavioral change techniques that include motivational interviewing and cognitive behavioral therapy are delivering the intervention with educational and behavioral objectives for reduction of nutritional risk during radiotherapy.^[62]

This review has also found that the patient perspective on self-management of eating problems during cancer treatment has been overlooked. An understanding of what they do and why is absent from the literature. Cooper *et al.*^[63] reviewed qualitative studies about understanding and management of cancer-related weight loss and anorexia. They similarly conclude that studies are lacking that investigate early stage cachexia, having identified just one study conducted in 2002 that explored eating problems in 22 patients receiving treatment for hematological malignancy. There has also been no study of outcomes from nutritional care beyond the scope of nutritional intake, nutritional status, quality of life, and survival. The influence of emotional and social context on factors likely to impact eating problems, such as distress, anxiety, fatigue, pain, and support from family carers, has not been investigated. Only one of the trialed interventions included support for family caregivers, which was advice on

meal preparation. In advanced incurable cancer, patients experience psychosocial obstacles to eating.^[32] These obstacles include disagreements with family members about what they should eat and misunderstanding of what to eat to stay as well as possible. Not only disease symptoms and treatment side effects but also knowledge, attitudes, and beliefs, relationships and social support, make a difference to what patients eat. These psychosocial factors are not fixed but can change and are therefore amenable to interventions, such as education. A psychosocial component embedded within a multimodal approach to cachexia, either as part of or adjunct to nutritional counseling, may be important for optimal management of eating problems during treatment. Optimal management could:

- Improve treatment tolerance and reduce treatment interruptions
- Improve morbidity and survival outcomes
- Improve the quality of life for patients and their family carers.

Limitations

The review is a rapid scoping review conducted by a single researcher using a limited search strategy, for example, no forward or backward chaining. Thus, a more robust search strategy may identify additional studies about the self-management of cachexia and its symptoms during cancer treatment. A further limitation is that the scope of the review was confined to radiotherapy and systemic anticancer treatments. There is also a literature about both prehabilitation (optimizing patient physical health before treatment) and the management of anorexia and weight loss during and following surgical intervention, which is not included.

Utility and relevance of the review

All cancer patients meet nurses during their treatment. Nurses can help them to manage eating problems by offering support for self-management. This review underpins the following recommendations for supported self-management of eating problems during cancer treatment:

1. Patients receiving treatment for head and neck, gastrointestinal, and lung cancer can benefit from nutritional counseling for eating problems. It is particularly important to provide nutritional care that includes a psychoeducation component to support dietary behavioral change in these groups
2. There is a need to develop and test an approach that can support self-management of eating problems during cancer treatment for maintenance of nutritional status and mitigation of distress. Solutions offered for eating problems should be embedded within behavioral change techniques evidenced effective in other contexts.

Conclusion

This review identifies our current understanding of eating problems and the self-management of these problems in patients receiving cancer treatment for solid tumours. It makes propositions for the improvement of nutritional care with the potential for positive impact on clinical and patient experience outcomes.

Nutritional care has the potential to enhance the effectiveness of oncology treatments.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Fearon K, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, *et al.* Definition and classification of cancer cachexia: An international consensus. *Lancet Oncol* 2011;12:489-95.
2. Stratton RJ, Green CJ, Elia M. Disease-related Malnutrition: An Evidence-Based Approach to Treatment. Wallingford, UK: CAB International; 2003.
3. Andreyev HJ, Norman AR, Oates J, Cunningham D. Why do patients with weight loss have a worse outcome when undergoing chemotherapy for gastrointestinal malignancies? *Eur J Cancer* 1998;34:503-9.
4. Rier H, Jager A, Sleijfer S, Maier A, Levin MD. The prevalence and prognostic value of low muscle mass in cancer patients: A review of the literature. *Oncologist* 2016;21:1-14.
5. Sánchez-Lara K, Ugalde-Morales E, Motola-Kuba D, Green D. Gastrointestinal symptoms and weight loss in cancer patients receiving chemotherapy. *Br J Nutr* 2013;109:894-7.
6. CRUK. A Trial Looking at a Combination of Treatments for Weight and Muscle Loss in People with Advanced Cancer (MENAC); 2017. Available from: <http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-looking-at-a-combination-of-treatments-for-weight-and-muscle-loss-in-people-with-advanced-cancer-menac#undefined>. [Last accessed on 2017 Jan 26].
7. Aapro M, Arends J, Bozzetti F, Fearon K, Grunberg SM, Herrstedt J, *et al.* Early recognition of malnutrition and cachexia in the cancer patient: A position paper of a European school of oncology task force. *Ann Oncol* 2014;25:1492-9.
8. NHS England 2018. Supporting self-management/self-care. Available from: <https://www.england.nhs.uk/ourwork/patient-participation/self-care/>. [Last accessed on 2018 Jan 23].
9. NIHR Southampton Biomedical Research Centre. Cancer and Nutrition NIHR Infrastructure Collaboration: Improving Cancer Prevention and Care. For Patients. For Clinicians. For Researchers. Phase I Report. National Institute for Health Research; 2015. Available from: http://www.cancerandnutrition.nihr.ac.uk/wp-content/uploads/2016/06/Cancer-Nutrition-Full-Report-FINAL_03-06-16.pdf. [Last accessed on 2017 Aug 11].
10. Baldwin C, Spiro A, Ahern R, Emery PW. Oral nutritional interventions in malnourished patients with cancer: A systematic review and meta-analysis. *J Natl Cancer Inst* 2012;104:371-85.
11. Hopkinson JB, Okamoto I, Addington-Hall JM. What to eat when off treatment and living with involuntary weight loss and cancer: A systematic search and narrative review. *Support Care Cancer* 2011;19:1-7.
12. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, *et al.* ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2017;36:11-48.
13. Hopkinson JB. How people with advanced cancer manage changing eating habits. *J Adv Nurs* 2007;59:454-62.
14. Hopkinson JB, Fenlon DR, Okamoto I, Wright DN, Scott I, Addington-Hall JM, *et al.* The deliverability, acceptability, and perceived effect of the Macmillan approach to weight loss and eating difficulties: A phase II, cluster-randomized, exploratory trial of a psychosocial intervention for weight-and eating-related distress in people with advanced cancer. *J Pain Symptom Manage* 2010;40:684-95.
15. Hopkinson JB. Food connections: A qualitative exploratory study of weight- and eating-related distress in families affected by advanced cancer. *Eur J Oncol Nurs* 2016;20:87-96.
16. Macmillan Cancer Support. Macmillan Learnzone. Weight Loss and Eating. Available from: <http://www.learnzone.org.uk/courses/course.php?id=40>. [Last accessed on 2017 Dec 20].
17. Hopkinson JB, Richardson A. A mixed-methods qualitative research study to develop a complex intervention for weight loss and anorexia in advanced cancer: The family approach to weight and eating. *Palliat Med* 2015;29:164-76.
18. Britten N, Campbell R, Pope C, Donovan J, Morgan M, Pill R, *et al.* Using meta ethnography to synthesise qualitative research: A worked example. *J Health Serv Res Policy* 2002;7:209-15.
19. Pope C, Mays N. Synthesising qualitative research. *Qualitative Research in Healthcare*. 3rd ed. Oxford: Blackwell Publishing; 2006. p. 142-54.
20. Centre for Reviews and Dissemination. Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care. New York: University of York; 2009.
21. Um MH, Choi MY, Lee SM, Lee IJ, Lee CG, Park YK, *et al.* Intensive nutritional counseling improves PG-SGA scores and nutritional symptoms during and after radiotherapy in Korean cancer patients. *Support Care Cancer* 2014;22:2997-3005.
22. Ravasco P, Monteiro-Grillo I, Vidal PM, Camilo ME. Dietary counseling improves patient outcomes: A prospective, randomized, controlled trial in colorectal cancer patients undergoing radiotherapy. *J Clin Oncol* 2005;23:1431-8.
23. Xie FL, Wang YQ, Peng LF, Lin FY, He YL, Jiang ZQ, *et al.* Beneficial effect of educational and nutritional intervention on the nutritional status and compliance of gastric cancer patients undergoing chemotherapy: A Randomized trial. *Nutr Cancer* 2017;69:762-71.
24. Xu YJ, Cheng JC, Lee JM, Huang PM, Huang GH, Chen CC, *et al.* A walk-and-eat intervention improves outcomes for patients with esophageal cancer undergoing neoadjuvant chemoradiotherapy. *Oncologist* 2015;20:1216-22.
25. Giles KH, Kubrak C, Baracos VE, Olson K, Mazurak VC. Recommended European society of parenteral and enteral nutrition protein and energy intakes and weight loss in patients with head and neck cancer. *Head Neck* 2016;38:1248-57.
26. Ravasco P, Monteiro-Grillo I, Camilo M. Individualized nutrition intervention is of major benefit to colorectal cancer

- patients: Long-term follow-up of a randomized controlled trial of nutritional therapy. *Am J Clin Nutr* 2012;96:1346-53.
27. Kiss N, Isenring E, Gough K, Wheeler G, Wirth A, Campbell BA, *et al*. Early and intensive dietary counseling in lung cancer patients receiving (Chemo) radiotherapy—a pilot randomized controlled trial. *Nutr Cancer* 2016;68:958-67.
 28. Wedlake L, Shaw C, McNair H, Lalji A, Mohammed K, Klopper T, *et al*. Randomized controlled trial of dietary fiber for the prevention of radiation-induced gastrointestinal toxicity during pelvic radiotherapy. *Am J Clin Nutr* 2017;106:849-57.
 29. Cools-Lartigue J, Jones D, Spicer J, Zourikian T, Rousseau M, Eckert E, *et al*. Management of dysphagia in esophageal adenocarcinoma patients undergoing neoadjuvant chemotherapy: Can invasive tube feeding be avoided? *Ann Surg Oncol* 2015;22:1858-65.
 30. Uster A, Ruefenacht U, Ruehlin M, Pless M, Siano M, Haefner M, *et al*. Influence of a nutritional intervention on dietary intake and quality of life in cancer patients: A randomized controlled trial. *Nutrition* 2013;29:1342-9.
 31. Bernhardson BM, Olson K, Baracos VE, Wismer WV. Reframing eating during chemotherapy in cancer patients with chemosensory alterations. *Eur J Oncol Nurs* 2012;16:483-90.
 32. Hopkinson JB. Psychosocial impact of cancer cachexia. *J Cachexia Sarcopenia Muscle* 2014;5:89-94.
 33. Gunes-Bayir A, Kiziltan HS, Sentürk N, Mayadagli A, Gumus M. A pilot study of self-reported physical activity and eating habits in Turkish cancer patients under chemotherapy. *Nutr Cancer* 2015;67:906-11.
 34. Bernhardson BM, Tishelman C, Rutqvist LE. Self-reported taste and smell changes during cancer chemotherapy. *Support Care Cancer* 2008;16:275-83.
 35. Molassiotis A, Farrell C, Bourne K, Brearley SG, Pilling M. An exploratory study to clarify the cluster of symptoms predictive of chemotherapy-related nausea using random forest modeling. *J Pain Symptom Manage* 2012;44:692-703.
 36. Farrell C, Brearley SG, Pilling M, Molassiotis A. The impact of chemotherapy-related nausea on patients' nutritional status, psychological distress and quality of life. *Support Care Cancer* 2013;21:59-66.
 37. Pallin N, Richardson J. Dietary advice provided to those undergoing pelvic radiotherapy. *J Radiother Pract* 2017;16:119-32.
 38. Bourdel-Marchasson I, Blanc-Bisson C, Doussau A, Germain C, Blanc JF, Dauba J, *et al*. Nutritional advice in older patients at risk of malnutrition during treatment for chemotherapy: A two-year randomized controlled trial. *PLoS One* 2014;9:e108687.
 39. Bauer JD, Capra S. Nutrition intervention improves outcomes in patients with cancer cachexia receiving chemotherapy—A pilot study. *Support Care Cancer* 2005;13:270-4.
 40. Ravasco P, Monteiro-Grillo I, Camilo ME. Does nutrition influence quality of life in cancer patients undergoing radiotherapy? *Radiother Oncol* 2003;67:213-20.
 41. Jahn P, Renz P, Stukenkemper J, Book K, Kuss O, Jordan K, *et al*. Reduction of chemotherapy-induced anorexia, nausea, and emesis through a structured nursing intervention: A cluster-randomized multicenter trial. *Support Care Cancer* 2009;17:1543-52.
 42. Patterson JM, McColl E, Wilson J, Carding P, Rapley T. Head and neck cancer patients' perceptions of swallowing following chemoradiotherapy. *Support Care Cancer* 2015;23:3531-8.
 43. Wall LR, Cartmill B, Ward EC, Hill AJ, Isenring E, Porceddu SV, *et al*. Evaluation of a weekly speech pathology/dietetic service model for providing supportive care intervention to head and neck cancer patients and their carers during (chemo) radiotherapy. *Support Care Cancer* 2016;24:1227-34.
 44. Bond SM, Hawkins DK, Murphy BA. Caregiver-reported neuropsychiatric symptoms in patients undergoing treatment for head and neck cancer: A pilot study. *Cancer Nurs* 2014;37:227-35.
 45. Jiang N, Zhao JZ, Chen XC, Li LY, Zhang LJ, Zhao Y, *et al*. Clinical determinants of weight loss in patients with esophageal carcinoma during radiotherapy: A prospective longitudinal view. *Asian Pac J Cancer Prev* 2014;15:1943-8.
 46. Ahlberg A, Engström T, Nikolaidis P, Gunnarsson K, Johansson H, Sharp L, *et al*. Early self-care rehabilitation of head and neck cancer patients. *Acta Otolaryngol* 2011;131:552-61.
 47. Boltong A, Keast R, Aranda S. Experiences and consequences of altered taste, flavour and food hedonics during chemotherapy treatment. *Support Care Cancer* 2012;20:2765-74.
 48. Elia M. Oral nutritional support in patients with cancer of the gastrointestinal tract. *J Hum Nutr Diet* 2011;24:417-20.
 49. Dobrila-Dintinjana R, Trivanovic D, Zelić M, Radić M, Dintinjana M, Petranović D, *et al*. Nutritional support in patients with colorectal cancer during chemotherapy: Does it work? *Hepatogastroenterology* 2013;60:475-80.
 50. Belqaid K, Tishelman C, McGreevy J, Månsson-Brahme E, Orrevall Y, Wismer W, *et al*. A longitudinal study of changing characteristics of self-reported taste and smell alterations in patients treated for lung cancer. *Eur J Oncol Nurs* 2016;21:232-41.
 51. Turcott JG, Juárez-Hernández E, De la Torre-Vallejo M, Sánchez-Lara K, Luvian-Morales J, Arrieta O, *et al*. Value: Changes in the detection and recognition thresholds of three basic tastes in lung cancer patients receiving cisplatin and paclitaxel and its association with nutritional and quality of life parameters. *Nutr Cancer* 2016;68:241-9.
 52. Op den Kamp CM, De Ruyscher DK, van den Heuvel M, Elferink M, Houben RM, Oberije CJ, *et al*. Early body weight loss during concurrent chemo-radiotherapy for non-small cell lung cancer. *J Cachexia Sarcopenia Muscle* 2014;5:127-37.
 53. Fogh SE, Deshmukh S, Berk LB, Dueck AC, Roof K, Yacoub S, *et al*. A randomized phase 2 trial of prophylactic manuka honey for the reduction of chemoradiation therapy-induced esophagitis during the treatment of lung cancer: Results of NRG oncology RTOG 1012. *Int J Radiat Oncol Biol Phys* 2017;97:786-96.
 54. de Vries YC, van den Berg MMGA, de Vries JHM, Boesveldt S, de Kruif JTCM, Buist N, *et al*. Differences in dietary intake during chemotherapy in breast cancer patients compared to women without cancer. *Support Care Cancer* 2017;25:2581-91.
 55. Boltong A, Aranda S, Keast R, Wynne R, Francis PA, Chirgwin J, *et al*. A prospective cohort study of the effects of adjuvant breast cancer chemotherapy on taste function, food liking, appetite and associated nutritional outcomes. *PLoS One* 2014;9:e103512.
 56. Custódio ID, Marinho Eda C, Gontijo CA, Pereira TS, Paiva CE, Maia YC, *et al*. Impact of chemotherapy on diet and nutritional status of women with breast cancer: A Prospective study. *PLoS One* 2016;11:e0157113.

57. Marinho ED, Custódio ID, Ferreira IB, Crispim CA, Paiva CE, Maia YC, *et al.* Impact of chemotherapy on perceptions related to food intake in women with breast cancer: A prospective study. *PLoS One* 2017;12:e0187573.
58. Ijpma I, Renken RJ, Ter Horst GJ, Reyners AK. The palatability of oral nutritional supplements: Before, during, and after chemotherapy. *Support Care Cancer* 2016;24:4301-8.
59. Mardas M, Mądry R, Stelmach-Mardas M. Dietary intake variability in the cycle of cytotoxic chemotherapy. *Support Care Cancer* 2016;24:2619-25.
60. Hibbert J, Gilbert H. *Supporting People to Manage their Health: An Introduction to Patient Activation*. London: Kings Fund; 2014.
61. Health Foundation. *Supporting Self-management A Guide to Enabling Behaviour Change for Health and Wellbeing using Person-and Community Centred Approaches*; 2016. Available from: <http://www.health.org.uk/sites/health/files/RtVSupportingSelfManagement.pdf>. [Last accessed on 2017 Aug 11].
62. Britton B, McCarter K, Baker A, Wolfenden L, Wratten C, Bauer J, *et al.* Eating as treatment (EAT) study protocol: A stepped-wedge, randomised controlled trial of a health behaviour change intervention provided by dietitians to improve nutrition in patients with head and neck cancer undergoing radiotherapy. *Br Med J Open* 2015; 5:e008921.
63. Cooper C, Burden ST, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: Insights from a systematic review of qualitative research. *J Cachexia Sarcopenia Muscle* 2015;6:99-111.