

# Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research

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## Abstract

The aim of this study was to summarize the existing qualitative literature in order to develop the evidence base for understanding and managing weight loss and anorexia, in order to make recommendations for clinical practice. A systematic search was performed to retrieve English language studies using electronic search and manual checks of selected reference lists. Keywords included qualitative, cancer cachexia, weight loss, anorexia, appetite, malnutrition, food, eating, and drinking. The selection and appraisal of papers were undertaken by two reviewers. Twenty-one qualitative articles were included in the review. There were three major findings emerging from the previous qualitative studies including ‘the multidimensionality of weight loss and anorexia experience’, ‘patients and caregivers’ responses to coping with weight loss and anorexia’, and ‘clinical assessment and management of weight loss and anorexia’. The literature review revealed the multidimensional nature of cachexia and weight loss experience by patients and caregivers, which was not recognized and adequately managed by healthcare professionals. Future research in this area would be helpful in enabling a deeper understanding of the complexity of cachexia and weight loss experience in order to move forward to develop an optimal model of supportive care for patients and caregivers.

**Keywords** Cancer cachexia; Weight loss; Malnutrition; Food; Caregiver; Cancer care; Qualitative

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## Introduction

Cachexia is a severe medical complication of cancer and considered to be a significant cause of morbidity and mortality affecting up to two-thirds of cancer patients.<sup>1</sup> People affected typically experience loss of weight, which is often accompanied by anorexia and other associated symptoms and usually occur in conjunction with the development of cachexia.<sup>2,3</sup> However, cancer cachexia remains under-recognized and untreated in clinical settings because definitions, diagnostic criteria, and classification schemes have not yet been established.<sup>4–6</sup> Studies have shown that cancer cachexia has a complex pathophysiological mechanism and is not solely due to nutritional deficiencies. Cachexia appears to be associated with disease-mediated metabolic disorders, inflammatory responses, and insulin resistance.<sup>7,8</sup> In spite of the emerging knowledge of the aetiology of cachexia, the

emphasis of clinical treatment and management is traditionally focused on patients with weight loss greater than 5% over the past 6 months. It is these patients that are often judged by clinicians as being in a cachectic status.<sup>9</sup>

Currently, treatment for cancer cachexia predominantly focuses on nutritional and pharmacological interventions for improving patients’ calorie intake, albeit the evidence supporting their effectiveness in relation to body weight and quality of life is inconclusive.<sup>10–12</sup> These approaches have had limited success confirming that inadequate oral intake is not the only cause of cachexia and therefore cannot be fully reversed by conventional nutritional support alone.<sup>4</sup> Given the limited capacity of physical management approaches, recent efforts have been directed to incorporate psychosocial elements to minimize the distress of cachexia on patients and their caregivers.<sup>13–15</sup> Overall, these findings highlight the dilemma of treating cachectic patients, which is

hampered by a lack of understanding of cachexia, thus indicating an urgent need for a clearer comprehension of such phenomenon and how to relieve the associated symptoms in order to improve the experience and quality of life of individuals affected.

Research in the area of cancer cachexia remains in its infancy, and in particular, evidence of the experience of weight loss and anorexia is limited. A comprehensive support care model of cancer cachexia should take into account patients' experience and adjustment to the impact of this syndrome. Focusing on the subjective experience of individuals affected by cachexia would provide insights into an additional layer of the complexity of this syndrome, which is vital for developing interventions for cachexia management. A systematic review of qualitative literature enables to enhance our understanding of this clinical phenomenon through drawing on and analyzing individual qualitative studies.<sup>16</sup> Therefore, the present systematic review aimed to summarize the existing qualitative literature in order to further develop the evidence base for understanding and managing weight loss and anorexia. This was undertaken to form the basis of recommendations for use in clinical practice.

## Methods

### *Research question*

The research question for guiding this review was 'what are the experiences of weight loss and anorexia and the clinical management of these phenomena from the perspective of patients with cancer, caregivers, and healthcare professionals?'

### **Definitions of cachexia, weight loss, and anorexia**

There has been recent progress on the conceptualization of cancer cachexia indicating that it is defined as a multifactorial syndrome characterized by loss of muscle mass (with or without loss of fat mass) that is not responsive to nutritional support and consists of three stages, pre-cachexia, cachexia, and refractory cachexia, but are not yet empirically validated.<sup>9,7</sup>

For the purpose of this review, we focus on the experience of weight loss and anorexia since they are historically viewed as two prominent patient-reported symptoms that can be present along the trajectory of cachexia, although focusing on these two symptoms alone is insufficient to reveal the complexity of cachexia.<sup>9</sup> While anorexia is defined as loss of appetite for food or desire to eat, weight loss is refined to losing at least 5% of body weight.<sup>9</sup> Considering that the understanding of cancer cachexia is evolving, the synthesis of previous qualitative

studies on weight loss and anorexia would provide information for identification of possible areas for a continued understanding of this phenomenon.

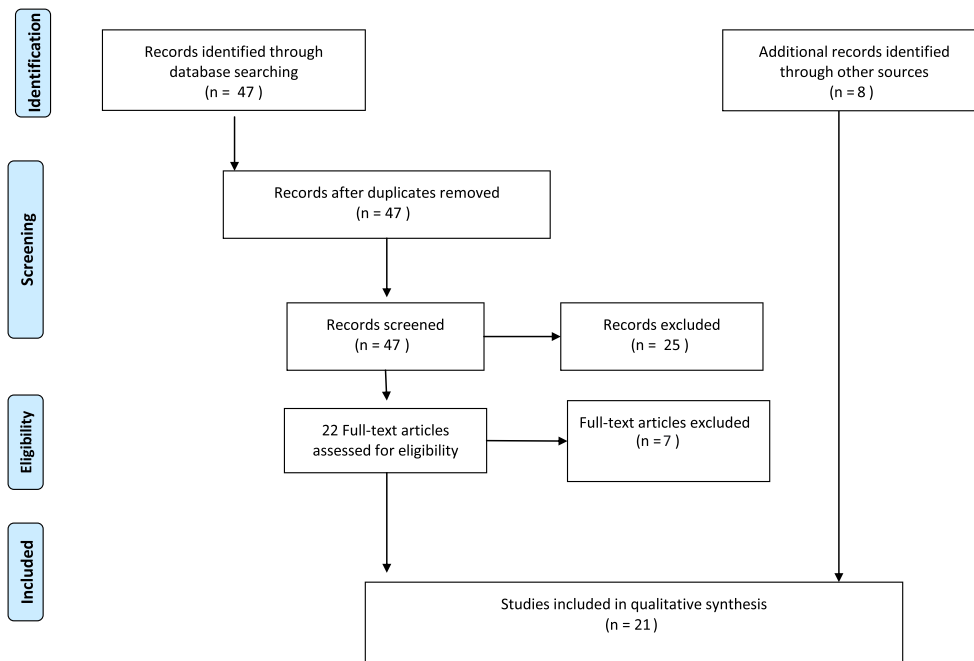
### *Literature search and selection*

A systematic literature search was undertaken using five electronic databases: Cochrane, CINAHL, EMBASE, Ovid Medline, and PsycINFO without time limits. Keywords that were used in various combinations are as follows: qualitative, cancer cachexia, weight loss, anorexia, appetite, malnutrition, food, eating, and drinking. To be eligible for this review, papers should have been primary research with qualitative methodology; focused on the experiences of weight loss and anorexia associated with cachexia and clinical management of these symptoms from the perspectives of adult cancer patients, or their caregivers, or healthcare professionals; and published in peer reviewed English language journals. Given the exploratory nature of the research question of this review, papers were included irrespective of whether cachexia and related symptoms were defined or not and how these phenomena were defined. Papers were excluded if they used mixed methods where qualitative findings could not be separated from quantitative findings, or discussed eating habits for cancer prevention or weight gain, or targeted disease-free cancer survivors. The search was supplemented by manual reference checks of all selected papers for inclusion in the review.

### *Review strategy*

The review proceeded in four stages with the inclusion and exclusion criteria applied at each stage. To minimize selection bias in the review procedure, the titles, abstracts, and data abstraction were independently conducted by two researchers (CC and SB). In the first stage of inclusion of abstracts, a total of 47 abstracts were imported and organized using EndNote software for bibliographic management and initial screening of eligibility. Twenty-five abstracts were excluded because they were not primarily focused on weight loss and anorexia experience such as eating habits for cancer prevention and weight gain or were not qualitative in nature. In stage two of retrieval of papers, full articles for the remaining 22 abstracts were obtained for further investigation of eligibility. Seven studies were excluded at this stage because of methodological issues and irrelevant to the focus of the review, and 15 studies were included in the final sample by mutual agreement of both reviewers. Additionally, an update of the literature search and hand search of reference lists of published systematic papers on cachexia further identified six papers. In the third stage of data extraction, the eligible papers were extracted for publication

Figure 1 Flow diagram of study selection process.



details. The flow diagram of the study selection process is shown in Figure 1.

**Quality assessment**

In the last stage, the publications were appraised using the critical appraisal skills programme.<sup>17</sup> The quality assessment of all selected papers was carried out by two researchers

(CC and SB) to ascertain if the researchers had clearly described the aims of the research, provided a clear description of the method and the participant characteristics and that there was coherence and consistency in their methodological approach. Table 1 presents the quality assessment results. Not all of the studies met the quality criteria, for example, ethical issues were limited or not addressed in some studies, and the issues of reflexivity were seldom mentioned in other studies. However, despite such limitations, all papers were

Table 1 Quality assessment of papers

Author/date	Clear aims	Sampling	Data collection methods	Reflectivity	Ethical issues	Accurate interpretation of the data
Holden <sup>21</sup>	Yes	Limited	Limited	No	No	No
Latham <sup>32</sup>	Yes	Limited	Yes	No	Yes	Yes
McGrath <sup>22</sup>	Yes	Yes	Yes	No	Yes	Yes
McClement <i>et al.</i> <sup>35</sup>	Yes	Yes	Yes	No	No	Yes
Orrevall <i>et al.</i> <sup>23</sup>	Yes	Yes	Yes	No	Limited	Yes
Souter <sup>25</sup>	Yes	Yes	Yes	Yes	Yes	Yes
Hopkinson and Corner <sup>20</sup>	Yes	Yes	Yes	Yes	Yes	Yes
Hopkinson <i>et al.</i> <sup>30</sup>	Yes	Yes	Yes	No	Yes	Yes
Dewey and Dean <sup>28</sup>	Yes	Yes	Yes	Yes	Yes	Yes
Hinsley and Hughes <sup>29</sup>	Yes	Yes	Yes	No	Yes	Yes
Hopkinson <sup>33</sup>	Yes	Yes	Yes	No	Yes	Yes
Strasser <i>et al.</i> <sup>26</sup>	Yes	Yes	Yes	Yes	Limited	Yes
Shragge <i>et al.</i> <sup>34</sup>	Yes	Yes	Yes	No	Yes	Yes
Wainwright <i>et al.</i> <sup>27</sup>	Yes	Yes	Yes	No	Yes	Yes
Dewey and Dean <sup>39</sup>	Yes	Yes	Yes	No	Limited	Yes
McClement and Harlos <sup>37</sup>	Yes	Yes	Yes	Limited	Yes	Limited
Reid <i>et al.</i> <sup>24</sup>	Yes	Yes	Yes	No	Yes	Yes
Reid <i>et al.</i> <sup>36</sup>	Yes	Yes	Yes	No	Limited	Yes
Reid <i>et al.</i> <sup>38</sup>	Yes	Yes	Yes	No	Yes	Yes
Muir and Linklater <sup>31</sup>	Yes	Yes	Yes	No	Yes	Yes
Millar <i>et al.</i> <sup>40</sup>	Yes	Yes	Yes	No	Yes	Yes

considered to have sufficient information provided for a better understanding of the phenomenon under investigation and therefore, remained in the final review.

## Results

Twenty-one qualitative articles were included in the review (Table 2). The largest percentage of studies focused on cancer patients with advanced disease and poor prognosis ( $n = 19$ ). Three studies included only patients after treatment for cancer. Numbers of participants varied across studies, ranging from 6 to 65.

### *Overview of the key findings from each qualitative study*

Although the findings from a qualitative study would not be generalizable in the same way as quantitative studies are,<sup>18</sup> these results may provide important information to inform or influence clinical practice in other contexts after considering theoretical and methodological issues.<sup>19</sup> Table 3 highlights what the included studies in the review add to clinical practice and future research. For example, a study by Hopkinson and Corner<sup>20</sup> reported the process of generating a conceptual model of the patient experience of living with eating changes, which were considered as theoretically relevant to guide the development of future studies.

### *Overview of synthesized findings*

There were three major findings emerging from the previous qualitative studies including 'the multidimensionality of weight loss and anorexia experience', 'patients and caregivers' responses to coping with weight loss and anorexia' and 'clinical assessment and management of weight loss and anorexia'. Each theme was divided into several subthemes of meaningful units.

## Theme 1: the multidimensionality of weight loss and anorexia experience

### *Subtheme 1: manifestations of weight loss and anorexia*

The cachexia syndrome can start in cancer patients differently, but its manifestation usually started when patients experienced anorexia described as constantly feeling the sensation of 'wanting to eat but having no desire to eat'.<sup>20–27</sup> The sensation of having 'no desire to eat' is

described as a 'fickle' experience, with patients' appetite unpredictably reduced or described as completely absent at meal times.<sup>25,26</sup> In some cases, loss of appetite was associated with the experience of feeling full quickly after eating a small amount of food (early satiety) or feeling 'disgust' when confronted with particular meals (food aversion).<sup>20</sup> In addition, there were other physical factors contributing to patients losing appetite for food and stopping to eat including fatigue, mouth ulcers, pain, nausea, difficulty with swallowing and gastrointestinal disturbance, and taste changes; many of which were attributable to treatment side effects.<sup>22,23,27</sup> Unpredictable and progressive weight loss were viewed as the most notable features characterizing cachexia in cancer patients, which were often independent of patients appetite and food intake.<sup>24,26</sup> The initial signs of losing weight occurred frequently and were highlighted to patients when their clothing did not fit anymore and they were seeing bones protruding.<sup>28–30</sup> The awareness of weight loss was heightened once patients were malnourished and began to fear dying of starvation.<sup>23</sup> As seen from the patients' perspective, severe or visible weight loss carried a more negative connotation, signifying a close proximity to inevitable death, although such a view was not accepted by family members.<sup>20,31</sup> Instead, patients held on to the belief that weight loss was a result of their reversible changes in appetite and could not be dealt with by increasing oral intake.<sup>24</sup>

### *Subtheme 2: impact of weight loss and anorexia*

Cachexia-related symptoms were found to cause a range of adverse effects on patients and caregivers, making it difficult for them to return to their previous lives.<sup>24,26</sup> The consequences of these symptoms were evident in four aspects, encompassing physical, psychological, social, and existential facets. Physically, some patients experienced muscle weakness, altered energy levels, and subsequent loss of dependence associated with their cachectic status. These symptoms would force patients to rely on family caregivers for home and social activities, which included cooking meals, transportation, and shopping.<sup>23,29,30</sup>

The psychological effects of malnutrition and weight loss were prominent in patients and caregivers and were similarly expressed in a spectrum of negative emotions, which included sadness, anger, frustration, uncertainty, fear, desperation, and helplessness.<sup>21–23,26,28,29</sup> Some patients felt down because they were unable to eat together or go out with other family members. Meals were no longer a pleasurable event to patients but were viewed as more of a survival function.<sup>21,23</sup> Family members or caregivers' primary worries and concern were due to feeling of incompetence at offering help to patients with eating when they consistently refused.<sup>21,26</sup> However, when loss of control over eating was recognized and there was a continued decline in health, patients and

Table 2 Description of the studies included in the systematic review

Author and date	Research focus	Design	Sample and setting	Key findings
Holden (1991) <sup>21</sup> USA	To explore the emotional ramifications of anorexia in the terminally ill cancer patient	Design not specified and semi-structured interviews	14 patients and their respective primary caregivers were selected from a hospice programme	Loss of appetite was a source of anxiety and conflict within the family. Patients would prefer their family members to take a less assertive approach to their eating difficulties
Latham (2001) <sup>32</sup> UK	To establish how district nurses cared for terminally ill patients with cachexia at home	Phenomenology and unstructured interviews	10 district nurses cared for terminally ill patients with cachexia	Some district nurses have little understanding of the metabolic disorders associated with cachexia, and their care activities primarily focused on advising and encouraging cachectic patients to increase food intake
McGrath (2002) <sup>22</sup> Australia	Reflects on two previous studies where nutritional issues were not the main focus but were expressed as a concern	Phenomenological philosophy using open-ended interviews	22 patients having treatment at a major metropolitan hospital with haematologic malignancies and 10 of their respective carers	Food and eating seem to be of great significance, both to patients and caregivers, for people with haematologic malignancies. The significance of food is not seen just in terms of its nutritional value but as an important quality of life issue
McClement et al. (2003) <sup>35</sup> Canada	To develop a conceptual model of family caregivers beliefs and behaviour in relation to nutritional issues	Grounded theory, unstructured interviews, and participant observation	47 participants from four groups (13 hospitalized palliative patients with cancer, 13 family members of hospitalized palliative patients with cancer, 11 healthcare providers, and 10 bereaved family members) from a palliative care unit	Under the overarching theme of 'doing what's best', there was marked variability in the ways family members respond to a dying cachectic patient, including 'fighting back', 'letting nature take its course', and 'waffling'
Orrevall et al. (2004) <sup>23</sup> Sweden	To investigate the nutritional situation prior to the introduction of home parenteral nutrition (HPN) from the perspective of patients and family members	Qualitative methodology and semi-structured interviews	13 advanced patients receiving palliative care and 11 family members	Nutritional situation prior to HPN was described as a source of distress for patients and family members, which anorexia and other eating difficulties pre-dominated. However, they saw the possibility of receiving HPN as a relief and a possible alternative to constantly having an inadequate intake
Souter (2005) <sup>25</sup> UK	To explore the experience of loss of appetite among palliative care patients and their carers supported by a specialist palliative team in the community	Phenomenology and semi-structured interviews	Seven palliative care cancer patients and their carers in the community	Six themes merged: a fickle phenomenon, the cost of caring, facing uncertainty and death, adaptations, accepting limitations, and what patients want: 'listen to me'
Hopkinson & Corner (2006) <sup>20</sup> UK	To develop an understanding of the manifestations, management, and meaning of eating changes in patients with advanced cancer	Hermeneutic phenomenology; semi-structured interviews	30 patients with advanced cancer reporting a change in eating habits, 23 caregivers, and 14 nurse-specialists	Patients experienced eating-related concerns when the reality of eating differed from the expectations of eating. They showed different preferences ranging from acceptance to engaging in self-action
Hopkinson et al. (2006) <sup>30</sup> UK	To explore the experience and concern about weight loss in people with	Hermeneutic phenomenology and semi-structured interviews	30 patients with advanced cancer with self-perceived weight loss, 23 caregivers, and 14 nurse-specialists	Visible weight loss was perceived as a proximity to death and symbolized a loss of control over

(Continues)

Table 2 (Continued)

Author and date	Research focus	Design	Sample and setting	Key findings
Dewey and Dean (2007) <sup>28</sup> UK	advanced cancer, their caregivers, and specialist nurses To explore nurses' management of patients with advanced cancer, weight loss, and eating-associated problems	Exploratory qualitative methodology and semi-structured interviews	14 nurses with 5-year experience of caring for advanced patients with weight loss	the disease, which was not routinely assessed by nurse specialists Four themes were identified: assessment of nutritional status, impact of weight loss and eating-related disorders, acknowledging weight loss, and training for nurses
Hinsley and Hughes (2007) <sup>29</sup> UK	To explore the impact of cachexia on body image of people with advanced cancer, their emotions, relationships, and social functioning To explore the management of changing eating habits in people with advanced cancer	Qualitative methodology and in-depth conversational style interview	12 palliative patients with cancer-related weight loss	Five themes were identified: visible and felt difference, rethinking, restricted life, adaptation, and becoming subsumed
Hopkinson (2007) <sup>33</sup> UK	To discover and describe elements of eating-related distress in male patients with advanced cancer and their female partners	Hermeneutic phenomenology and semi-structured interviews	30 patients with advanced cancer	Four self-action strategies were identified by patients to manage eating changes: 'taking control', 'promoting self-worth', 'relationship work', and 'distraction'
Strasser et al. (2007) <sup>26</sup> Switzerland	To investigate the process that explains how patients with advanced cancer compensate for anorexia and manage the emotional and social consequences of a decreased intake	Qualitative methodology and focus group interview	19 male cancer patients with >5% weight loss or appetite problems and their partners with whom they spent 50% of their mealtimes	Eating-related distress was a complicated issue for men with advanced cancer and their partners characterized by obstruction to eating, poor appetite, and weight loss, affecting their daily habits and relationships
Shragge et al. (2007) <sup>34</sup> Canada	To gain an in-depth understanding of patients experience of appetite loss and how this affected quality of life	Grounded theory and unstructured interviews	Nine patients with advanced cancer with self-reported loss of appetite	Shifting to conscious control was the basic social psychological process employed by participants to manage the emotional and social consequences of declining intake
Wainwright et al. (2007) <sup>27</sup> UK	To explore the management of patients with advanced cancer and weight loss cared for by nurses both in primary and secondary care	In-depth interviews using thematic analysis	11 oesophagectomy patients 3 months after surgery. Sampled from a large teaching hospital	The psychosocial aspects of eating and the stigma and embarrassment this causes. Weight loss after treatment can take on a sinister outcome, and thus, body weight is something that needs to be closely monitored. How the body remaps itself and adapts after surgery
Dewey and Dean (2008) <sup>39</sup> UK	To explore the lived experience of cachexia for patients with advanced cancer	Exploratory qualitative methodology and semi-structured interviews	14 nurses with 5-year experience of caring for advanced patients with weight loss	Many nurses used an unplanned and reactive style of nutritional management
McClement and Harlos (2008) <sup>37</sup> Canada	To examine the nutritional care experiences in advanced cancer from the perspectives of patients, families, and healthcare providers	Grounded theory, unstructured interviews, and participant observation	47 participants from four groups (13 hospitalized palliative patients with cancer, 13 family members of hospitalized palliative patients with cancer, 11 healthcare providers, and 10 bereaved family members) from a palliative care unit	Family members used when letting nature take its course and directed their efforts from nutritional care to other caring activities
Reid et al. (2009) <sup>24</sup> UK	To explore the lived experience of cachexia for patients with advanced cancer	Heideggerian phenomenology and unstructured interviews	15 advanced cancer patients with >10% weight loss in previous 6 months and 12 family members	Six themes were identified as follows: physiological changes in appetite, visibility of cachexia, weight loss

(Continues)

Table 2 (Continued)

Author and date	Research focus	Design	Sample and setting	Key findings
Reid <i>et al.</i> (2009) <sup>36</sup> UK	advanced cancer and their family members To investigate tension over food that exists between patients with advanced cancer with cachexia and their families To investigate the experience of patients and family members with regard to care received for cancer cachexia	Heideggerian phenomenology unstructured interviews	Eight patients with advanced cancer living with cachexia and eight family members	interpreted as a bad sign, response from healthcare professionals, conflict over food, and coping responses Highlighted the anxiety that surrounds eating and the distress it causes to families
Reid <i>et al.</i> (2010) <sup>38</sup> UK	To investigate the experience of patients and family members with regard to care received for cancer cachexia	Heideggerian phenomenology unstructured interviews	15 advanced cancer patients who had primary cachexia and 12 family members	Three themes emerged from the study: a lack of acknowledgement from healthcare providers about patients' reported weight loss, a lack of information about their cachexia from healthcare professionals, and a lack of appropriate supportive intervention The impact of changes in dietary intake and weight experienced by patients is not solely limited to physical malnutrition but also extends to psychological and social aspects
Muir and Linklater (2011) <sup>31</sup> UK	To explore patients' views of nutrition, to begin to understand their concerns and to determine whether such standards meet the needs of patients in the palliative care setting	Qualitative methodology and semi-structured interviews	Six hospitalized palliative cancer patients	
Millar <i>et al.</i> (2013) <sup>40</sup> UK	To explore healthcare professionals' experience, understanding, and perception of the needs of patients with cachexia in advanced cancer	Qualitative methodology, focus group, and individual interviews	34 healthcare professionals who had experience providing care to patients with cachexia in advanced cancer	Cachexia management in patients with advanced cancer can be difficult and is directed by a variable combination of the influence of knowledge, culture of the clinical area, and available resources

caregivers exhibited similar responses of helplessness to stop weight loss and reverse cachexia.<sup>24,30,31</sup> Especially for some patients, personal responsibility for weight loss implied a failure to take control of their body, which could cause distressful feelings of being a burden to family members.<sup>29,30</sup> Furthermore, changes in physical appearance resulting from losing weight were perceived as undermining patients' self-identity and self-esteem.<sup>27,29,32</sup>

The social impact of malnutrition and weight loss, including the loss of socializing, stigma, and embarrassment, was also described by some patients, although their experience varied considerably between individuals.<sup>24,25,27,29</sup> For example, some patients described the experience of stigma and loss of face when they ate out because they could only eat small portions of food or not finish the food on their plates.<sup>27</sup> Other patients reported their experience of a reduction in social interactions and withdrawal from their community mainly due to their wasted appearance and their fear of being reminded of their cancer history.<sup>24</sup>

Only one study mentioned existential distress in patients with weight loss.<sup>26</sup> They were searching for a meaning of

weight loss, since the occurrence and development of weight loss were unpredictable and uncontrollable. Some patients believed 'not eating is dying', which was a symbol of progressive weakness and death.

## Theme 2: patients' and caregivers' responses to coping with malnutrition and weight loss

When confronted with malnutrition and weight loss, patients and caregivers, as a family unit, aimed to improve the patients' food intake by adopting several coping strategies.<sup>26</sup> For example, couples actively searched for and obtained dietary information from the mass media and the Internet in order to integrate it into their dietary patterns. They also kept on trying and testing strategies to find out what ingredients, tastes, consistencies, sizes, or texture of food were suitable for meeting the patients' nutritional needs. However, patients and family caregivers had their own unique ways to deal with these symptoms.

**Table 3 Results—what these studies add to practice and key research for the future**

Author and date	What these studies add to practice and key research for the future?
Holden (1991) <sup>21</sup> Latham (2001) <sup>32</sup>	Need to be aware of the complex emotional issues surrounding food in hospices Nurses require more understanding of cancer cachexia and associated symptoms through nurse educations
McGrath (2002) <sup>22</sup>	Effective strategies should be routinely integrated into the hospital care of patients undergoing chemotherapy
McClement <i>et al.</i> (2003) <sup>35</sup>	Highlighted different ways that family members responded to patients with cachexia' eating problems
Orrevall <i>et al.</i> (2004) <sup>23</sup>	Increased an understanding of eating difficulties faced by advanced cancer patients before using home parenteral nutrition.
Souter (2005) <sup>25</sup>	An understanding of the meaning that loss of appetite holds for patients and caregivers is essential for the provision of quality care
Hopkinson and Corner (2006) <sup>20</sup>	Development of a conceptual model of the patient experience of living with eating changes and advanced cancer
Hopkinson <i>et al.</i> (2006) <sup>30</sup> Dewey and Dean (2007) <sup>28</sup>	Highlights the issue of weight loss taboo faced by advanced cancer patients This study shows the need for further views of other healthcare professionals. Also highlighted that patients' and relatives' views should be sought to find out what information and services they would like to receive
Hinsley and Hughes (2007) <sup>29</sup>	Provided an understanding of self-management of eating changes experienced by advanced cancer patients
Hopkinson (2007) <sup>33</sup> Strasser <i>et al.</i> (2007) <sup>26</sup>	Highlighted importance for psychological support for patients with cachexia Early identification of eating-related distress in cancer patient would be the first step for providing targeted psychosocial intervention to address the concern in this population
Shragge <i>et al.</i> (2007) <sup>34</sup> Wainwright <i>et al.</i> (2007) <sup>27</sup>	Development of an intervention, which could be useful in guiding clinicians Adds to the implication of the need for support and rehabilitation in oesophageal cancer patients' post-surgery
Dewey and Dean (2008) <sup>39</sup> McClement and Harlos (2008) <sup>37</sup>	Nurses play an important role in the delivery of high-quality cancer care Informational and psychological support are needed for caregivers to cope with fears and anxieties in relation to cancer cachexia Provided a deeper understanding of the concerns that palliative care patients have regarding their oral intake and weight
Reid <i>et al.</i> (2009) <sup>24,36</sup> Reid <i>et al.</i> (2010) <sup>38</sup>	Provides an insight into the tensions that exist over food between patients and their families Patients and families need information, but they also need support to cope with fears and anxieties in relation to cancer cachexia
Muir and Linklater (2011) <sup>31</sup>	Provided a deeper understanding of the concerns that palliative care patients have regarding their oral intake and weight
Millar <i>et al.</i> (2013) <sup>40</sup>	Cancer cachexia needs to be addressed from a holistic model of care to reflect the multidimensional needs of patients and their families



### Subtheme 1: patient responses

Patients expressed various attitudes and behaviours in dealing with the impact of malnutrition and weight loss throughout the disease trajectory. Maintaining a positive attitude emerged as an important coping strategy in patients, as it is related to acceptance, hope, and denial. For patients during and after treatment, they were focused on increasing their food intake and increasing body weight in order to promote recovery from disease. Consequently, they strived to eat and constantly monitor body weight.<sup>27</sup> When patients realized the terminal nature of their disease, they accepted their declining illness and attempted to live with changes in their eating habits.<sup>20,24,29,31,33</sup> Some patients accepted changes in their eating habits and did not demand any conscious self-care plans of action but were content to trust their bodies as a self-regulatory system. For the majority of patients, eating represented a means of gaining control over life and taking action to retain control over food and life in spite of eating difficulties.<sup>20,30,33</sup> The presence of hope for cure was also reported in patients, although they were aware of their prognosis and weight loss contributing towards death.<sup>24,34</sup> In some cases, denial and use of distraction appeared to be common and purposeful strategies, and patients frequently chose not to think about their weight loss.<sup>24,33</sup>

During the process of coping with cachexia, patients involved a prolonged period of physical dependency on family caregivers for support in nutritional care. They appreciated the family assistance particularly relating to food preparation and dietary advice provision.<sup>21</sup> However, some family caregivers tried very hard, for example, controlling the patients' food intake to the point of calculating calories, which became a source of conflict and tension.<sup>23</sup> Patients expected that family caregivers should take a less assertive manner or respect their wishes to cope with eating problems their way.<sup>21</sup>

Using oral nutritional supplements and seeking professional help were found as coping responses for some patients in the face of malnutrition and weight loss. Some patients reported that they felt unable to consume the supplements at home or in hospitals. This was due to their taste and smell, and a few respondents reported it was due to side effects of the supplements, including nausea and vomiting.<sup>23</sup> Others chose to consult alternative therapists to optimize their dietary habits, and some patients reported success with the side effects of cancer treatment.<sup>22</sup>

### Subtheme 2: family caregiver responses

The impressions from a number of studies were that family caregivers had actively engaged in nutritional care to help ensure that patients received sufficient oral intake.<sup>21–23,26,32,35</sup> The studies detailed the loving attention caregivers gave to selecting and preparing tasty and nutritious food, regardless

of patients being in hospital or at home. When patients were hospitalized, family caregivers used numerous strategies to improve food intake by bringing in their preferred home-made food, super-sizing the portions of hospital food, and always offering food and making it readily available.<sup>35</sup> For patients at home, caregivers felt totally responsible for patient's nutritional care and they cooked dishes, served food differently, or provided fortified food with additional nutrients.<sup>23,26</sup> There was a common fear prevailing in family caregivers that if they were not always present to prepare foods and to encourage the patient to eat, their relative would die.<sup>23</sup> In addition, family caregivers also responded differently to the impact of cachexia because of their varying belief systems. There were three coping modes that families employed when confronted with the problem of cachexia and weight loss: primarily 'fighting back', secondly 'letting nature take its course', and finally 'waffling' (between 'fighting back' and 'letting nature take its course'). Each of these three modes of family coping strategies are described below, representing their perspectives of care that they deemed optimal, but with different consequences on family–patient relationship.<sup>35</sup>

#### 'Fighting back'

Caregivers who used 'fighting back' were characterized by their insistence on forcing patients to eat.<sup>35</sup> They believed that decreased nutritional intake as opposed to disease progression was largely responsible for the patients' declining status. Therefore, providing sufficient food would reverse the patients' declining status.<sup>35,36</sup> On the other hand, patients' views of their eating difficulties were much less of a problem for them compared with their family members.<sup>21,24</sup> The contrasting beliefs between patients and caregivers indicated that caregivers may misunderstand the role of food in cachexia and over-emphasize the meaning of food for patients. Caregivers' fighting back behaviours aggravated the physical and emotional impacts of cachexia and weight loss on patients, and this could lead to decreased oral intake, emotional distress, and desperate feelings.<sup>23,35</sup> More importantly, conflicts often occurred between patients and family caregivers, and thus, patients had to use tactics such as social isolation and even lying to their family caregivers.<sup>24</sup> This coping model of family caregivers also resulted in poor relationships with healthcare providers.<sup>35</sup> For example, when caregivers' requested the initiation of artificial nutritional interventions, they felt they were not responded to in a timely manner, and they therefore accused healthcare providers of patient neglect. This was fuelled by the fear that patients would die if such measures were not instigated.<sup>35</sup>

#### 'Letting nature take its course'

Caregivers who used 'letting nature take its course' accepted that patients' weight loss could not be improved by increasing food intake. They subsequently directed their efforts away from nutritional care to other caring activities, which involved

physical care and 'being there' with their relative.<sup>35,37</sup> Meeting patients' nutritional needs were not a priority for family caregivers rather they encouraged patients to eat without engaging in any force feeding behaviours. Family caregivers stated that they trusted the patients' judgement on how much they could eat.<sup>25</sup> Consequences of this acceptance model were considered as positive, leading to fewer feelings of frustration in caregivers, reduced patient burden, and harmonization of the relationship.<sup>37</sup>

#### 'Waffling'

Some caregivers struggled with being aware of the declining intake of their cachectic patients and were defined as 'waffling' between 'fighting back' and 'letting nature take its course'. As perceived by healthcare providers, these caregivers were ambivalent, always demonstrating inconsistent responses to the nutritional care of the patients.<sup>35</sup>

## Theme 3: clinical assessment and management of malnutrition and weight loss

### *Subtheme 1: current clinical practice in malnutrition and weight loss*

From the perspectives of patients and family caregivers, there was a lack of acknowledgement from healthcare professional as patients' cachexia and related symptoms were visible.<sup>38</sup> When healthcare professionals acknowledged and offered interventions to patients, it was usually in the forms of providing dietary advice, dietetic referral, and prescriptions of drugs, which included appetite stimulants and nutritional supplements.<sup>22,28,32,38,39</sup> However, health professionals across different disciplines had their unique roles in helping patients to manage cachexia-associated symptoms. Physicians tended to provide artificial nutritional interventions such as tube feeding or parenteral nutrition when patients were unable to eat and had no other options for survival.<sup>22,23</sup> However, patients and caregivers perceived physicians focus to be on the disease and treatment outcomes, not their individual experience.<sup>22,23</sup> The nurses' roles were primarily focused on nutritional assessment and management of malnutrition and weight loss. However, they were limited as they did not perform early assessments and continuous monitoring of the patients' nutritional status. Most nutritional activities were conducted on an opportunistic basis in the hospital.<sup>28</sup> From the patients and caregivers' perspective, the work of dietitians emphasized food selection and preparation, albeit was criticized for not following patients up during their hospital stay.<sup>22,23</sup>

In addition, the information in relation to understanding and managing malnutrition and weight loss given by

healthcare professionals was perceived as inadequate for patients and caregivers. This left the nature and consequences of cancer cachexia largely unexplained.<sup>38</sup> Dietary advice provided by the dietitians was not specific to each patient's needs.<sup>20,23</sup> Family caregivers felt that healthcare professionals could not help them to cope with malnutrition and weight loss due to the lack of information they received.<sup>26,30</sup>

### *Subtheme 2: barriers to optimal management of malnutrition and weight loss*

A lack of resources, knowledge, and a culture of avoidance were identified as three major barriers for healthcare professionals to deliver quality cachexia care in clinical settings. Although many healthcare professionals were clear that cachexia was the result of an irreversible metabolic disturbance, some displayed a lack of understanding of the causation of cachexia. Other causes where knowledge was lacking included insufficient food intake and malabsorption, which consequently resulted in a failure to recognize the syndrome in clinical practice.<sup>32,40</sup> Particularly for those with nursing and nutrition backgrounds, a lack of distinct management approaches resulted in over-relying on nutritional supplements/enteral feeding despite recognizing their failure to reverse cachexia.<sup>40</sup>

Engaging in a culture of avoidance in relation to acknowledging and discussing cachexia and weight loss with patients and families was prevalent in non-palliative healthcare professionals. These professionals typically believed it would result in unnecessary distress to patients or false expectations of nutritional management outcomes.<sup>28,30,40</sup> Additionally, nurses reported that they were careful not to initiate discussions about cachexia with people affected as they believed little could be done to help.<sup>20,30</sup> In contrast, those with palliative care backgrounds tended to use a holistic care model and to communicate with patients and families about the meaning of cachexia, despite acknowledging that this was a significant challenge.<sup>40</sup> The impact of an avoidance culture in managing cachexia was explained further in relation to emphasizing the traditional biomedical model, which concentrates on curing the disease and physical dimensions.<sup>40</sup> In addition, lack of time and staff were frequently cited by healthcare professionals as barriers to effective management of cachexia and weight loss.<sup>40</sup>

## Discussion

Despite cancer cachexia remaining to be a significant clinical problem, there has been little progress in understanding cachexia and its management from the perspective of patients,

family caregivers, and healthcare professionals. Recently, several systematic reviews and integrated reviews have synthesized existing evidence on cancer cachexia beyond the biomedical perspective, with a particular focus on its psychosocial impact and quality of life, both of which being previously overlooked in the literature.<sup>14,41,42</sup> Findings emerging from these reviews have significantly advanced our understanding of this complex syndrome and highlighted the potential of incorporating psychosocial support for improving the management of cancer cachexia along with pharmacological and nutritional approaches. By collecting the selected qualitative research, the present systematic review, however, takes a broader but insightful perspective to explore how patients, caregivers, and healthcare professionals experience and manage weight loss and anorexia. Consequently, this systematic review generated a more holistic understanding of how cancer cachexia influenced people affected and identified three important findings. Firstly, weight loss and anorexia were viewed by patients as a multidimensional experience encompassing physical, psychosocial, and existential components. Secondly, although patients and caregivers were actively involved in coping efforts, cancer cachexia particularly in the later stage of disease was a greater problem to caregivers than to patients themselves. Thirdly, the existing cancer management of weight loss and anorexia remains focused on nutritional care, which was provided by health professionals in an unstructured way.

Although several definitions related to cachexia have been proposed in the literature, consensus exists on weight loss and/or anorexia as the key elements of cachexia. Additional components including muscle strength, functional status, and inflammatory markers are inconsistently reported.<sup>4,7,9</sup> A recent study also validated that weight loss and body mass index were clinically relevant to discriminate between cachectic and non-cachectic patients.<sup>43</sup> However, these findings support the perspectives from quantifiable biological and functional characteristics associated with the syndrome but fail to acknowledge the subjective experience of individuals affected. This review provided insights into the complexity of weight loss and anorexia that patients with cachexia may experience. These are multifaceted in nature and consist of physical, psychosocial, and existential impacts, which echoes current consensus that cachexia is multifactorial, and optimal management of the syndrome requires a comprehensive approach.<sup>9,41</sup> Future interventions should be developed to not only relieve the physical impact but also psychosocial aspects, which were recognized less and infrequently addressed by healthcare providers. Enabling caregivers to more fully understand the consequences of cachexia is important to help them to reduce the distress in nutritional care and therefore, meet the other aspects of patients' needs.

Another significant finding was that weight loss and anorexia caused greater distress for family caregivers than

patients themselves. Due to the significant meaning of food in patients' survival, some family caregivers particularly with the 'fighting back' coping mode tended to take an assertive approach to push patients to eat and thus, created conflict and tension with patients. Efforts to correct caregivers' false beliefs particularly with regard to 'fighting back' is important as this would help them to direct their efforts from increasing patients' oral intake to the care of achieving their optimal overall status.

Health professionals also voiced the challenges and difficulties of managing cachexia and weight loss. Inadequate knowledge, a culture of avoidance, and lack of resources were identified as major factors for them not being able to provide care for patients and caregivers. Failure to recognize the multidimensional impacts of cachexia led health professionals to feel powerless to help patients and caregivers, consequently leaving them isolated to deal with the syndrome alone. Health professionals across different disciplines should understand their important roles and responsibilities in improving the experience of cancer cachexia for patients and their families. Equipping them with necessary knowledge and communication skills would be an important step for helping them to acknowledge and effectively deliver interventions, to address the distress experienced by patients and caregivers.

### *Research gaps identified*

The research to date has predominately examined patients with advanced cancer and particularly in the palliative stages of the disease. Studies looking at cachexia at different stages, particularly early stage, are obviously lacking. Only two studies included in this review investigated cancer patients who underwent either surgery or radiotherapy, revealing a complicated process of adaptation to and recovery from weight loss and anorexia. However, none of the studies explored the experience of managing patients' cancer cachexia and weight loss at the treatment stage from the perspective of health professionals, as they are increasingly acknowledged as playing a significant role in helping patients to cope with malnutrition and weight loss either in hospital or at home. These research gaps should be further addressed in the future.

### *Limitations*

There are some limitations to be acknowledged before drawing a conclusion. There is little consensus regarding the definition of cachexia, and the majority of studies included in this review did not define the term cachexia. Cachexia was often described in relation to the experience, which included a loss of appetite, reduced oral intake, weight loss, or eating

distress. Inclusion of these studies may not fully reveal the picture of cancer cachexia and its management. Furthermore, the literature was primarily conducted in western countries, and there was no information gleaned from other sociocultural contexts, consequently limiting our understanding of comparing the meaning of food in managing cancer cachexia and related symptoms of weight loss across different cultural backgrounds.

## Conclusion

The literature review revealed that cancer cachexia was a multidimensional experience for patients and caregivers. However, it is not always recognized and managed adequately by healthcare professionals. There is a paucity of research around managing cachexia and its impact on patients in the early stages of disease. Future research in this area would be helpful for a deeper understanding of the complexity of the cancer

cachexia experience in order to move forward to developing an optimal model of supportive care for patients and caregivers.

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## Conflict of interest

None declared.

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