**A systematic review to establish health-related quality of life domains for intervention targets in cancer cachexia**

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**ABSTRACT**

**Objectives**

To develop a model of the impact of cancer cachexia on patients by identifying the relevant health related quality of life (HRQOL) issues and to use the model to identify opportunities for intervention.

**Methods**

Standard systematic review methods were followed to identify papers which included direct quotes from cancer patients with cachexia or problems with eating or weight loss. Following thematic synthesis methodology, the quotes were coded, and themes and meta-themes were extracted. The meta-themes were used to develop a model of the patient experience of cachexia.

**Results**

18 relevant papers were identified which, in total, contained interviews with more than 250 patients. 226 patient quotes were extracted from the papers and 171 codes. 26 themes and 8 meta-themes were formulated. The model developed from the meta-themes demonstrated both a direct link between eating and food problems and negative emotions and also a link mediated by the associated physical decline. These links provide opportunities for interventions.

**Conclusion**

There are a vast number of HRQOL issues associated with cancer cachexia as identified from patients’ own words. The model generated from these issues indicates that relationships, coping and knowledge of the condition are important components of new psychosocial interventions.

**INTRODUCTION**

The potential of patient reported outcomes measures (PROMs) to improve routine clinical practice is gaining credence [1]. PROMs provide a measure of patients’ health from the perspective of the patient, and may address symptoms, functional status and health related quality of life (HRQOL). HRQOL refers to those aspects of quality of life which patients consider are affected by disease and treatment [2] and includes physical, emotional, cognitive and social components. The assessment of HRQOL is particularly important for those conditions in which disease outcomes, such as survival, are inappropriate measures of treatment success because the disease is incurable. One such condition is refractory phase cancer cachexia, but HRQOL is also an essential component in the evaluation of therapeutic interventions across the cachexia spectrum because patients must perceive a benefit if a treatment is to be considered successful [3 4]. In addition, identification of HRQOL issues can inform the content of interventions by pinpointing what concerns are most significant to patients with cancer cachexia.

Patients with cancer cachexia present with involuntary weight loss. Since the weight loss is attributable to loss of skeletal muscle (with or without loss of fat mass) cachexia leads to progressive functional impairment [5]. Cachexia is caused by the combination of reduced food intake and abnormal metabolism and the pathophysiology of cachexia is characterised by a negative protein and energy balance [6]. Cachexia is conceptualised to have three phases: pre-cachexia, cachexia and refractory cachexia [5]. For patients with refractory cachexia, who usually have less than three months to live, therapeutic interventions are concerned with palliation of symptoms and other disease-related problems. Prior to the refractory phase, cachexia may be reversible to some degree so if cachexia therapy was started early, and ran in parallel with antineoplastic therapy, patients’ progression along the cachexia continuum might be curtailed. This is why the focus of cachexia therapy research is now switching to the point of cancer diagnosis [3]. Unfortunately, cachexia therapies have, so far, had limited success [3 7]. These disappointing results have partly been attributed to the unimodal nature of the trials and it is now recognised that therapeutic interventions for cachexia will likely require a multimodal approach [3 7].

For cancer cachexia, a multimodal approach should include a psychosocial component [8]. The importance of psychosocial factors for oncology patients has long been recognised [9] but with the increasing complexity of the medical management of cancer patients, clinics consistently overrun [10] and clinicians have little time to discuss psychosocial issues [11]. In addition, patients may feel that it is not the physician’s role to deal with psychosocial issues or they may withhold information so as not to burden their physician [12]. Although psychosocial support for cancer cachexia patients may address the consequences of the condition, such as distress, it is important to stress that it can also tackle the causes of the condition. For example, psychosocial support may help to maximize nutritional intake and also support uptake and compliance with new therapies [8].

A previous review of the qualitative literature informed the development of a model of the psychosocial effects of cancer cachexia [13]. The review included data from patients, carers and healthcare professionals (HCPs). We decided to focus on patients alone and took the novel approach of concentrating on HRQOL issues. By identifying very specific HRQOL issues, a more detailed understanding of how cancer cachexia affects patients can be obtained. This information can be used in the both the development of interventions and also the assessment of outcomes, both in everyday clinical practice and also for more targeted interventions.

Hence the review question addressed in this study was “What factors impact quality of life in patients with cancer cachexia?” The main aim of the study was to use a systematic review and thematic synthesis of the qualitative literature to identify the relevant HRQOL issues and to develop a model of the impact of cancer cachexia on patients. A further research question to be addressed is whether opportunities for intervention can be identified in the model.

**METHODS**

The methods used in this review were informed by the Centre for Reviews and Dissemination guidance for undertaking systematic reviews [14], and the reporting follows the Preferred Reporting Items of Systematic reviews and Meta-Analyses (PRISMA) guidelines [15]. The thematic synthesis methodology was adapted from that described by Thomas and Harden [16] The protocol for the review is available from the first author.

**Search strategy and selection criteria**

ISI Web of Knowledge, PubMed, EMBASE, Medline, CINAHL, PsychINFO and PsycARTICLES, were searched from January 1980 to May 2012 using search terms relating to cancer (neoplasm, cancer, palliative, tumour, tumor, malignancy), cachexia (cachexia, anorexia, weight loss, systemic inflammation, food, wasting syndrome, appetite, malnutrition, sarcopenia, muscle wasting, eating, nutritional assessment, emaciation, nutrition) and quality of life (“quality of life” OR QOL OR QL OR HRQOL OR HRQL OR “subjective health status” OR “reported outcome” OR psychosocial OR “qualitative research” OR interview OR questionnaire OR emotion OR “emotional impact”). We selected papers written in the English language, published from 1980 onwards which included direct quotes from adult patients with any cancer diagnosis who had cachexia or problems with weight loss or anorexia. Because of the historical lack of a consensus definition for ‘cachexia’ [17], we accepted papers with patients described as having cachexia regardless of how this was defined and patients did not have to be described as cachectic to be included. Conference proceedings and abstracts were excluded.

Two reviewers screened all titles and abstracts (SW and AW). If either reviewer felt that the citation could match the inclusion criteria, the full paper was obtained. Full papers were also screened by two reviewers (SW and AW). There were no disagreements about inclusion. Mindful of the difficulty of finding qualitative research papers [14], the references of all included papers were searched for additional papers and papers already known to the authors were also included.

**Quality assessment**

Assessing the quality of qualitative studies is the subject of a number of on-going debates, including whether it is even appropriate [14]. For completeness, we chose to appraise and report on the methodological quality of the studies using the Critical Appraisal Skills Program (CASP) tool for reviewing qualitative studies [18]. However, we decided, *a priori*, to retain all the identified studies, whatever the quality, because we anticipated there would be very few.

**Thematic synthesis**

Following the approach described by Thomas and Harden [16], two judges ( SW and one from AD, JH and DF) extracted direct patient quotes from each paper. Five judges (SW, CJ, DF, AD and JH) each independently coded the content of each quote for meaning, using as many codes as was necessary. Following discussion amongst the judges, SW rationalised the codes to ensure consistent wording. The same five judges then extracted themes from the codes, again independently. Discussion of the proposed themes led to revisions, with further revisions after the original quotes were tested against the themes. Meta-themes were developed through discussion. A model based on the meta-themes was developed by SW and AD which led to a final revision of the meta-themes.

**RESULTS**

The systematic review found 18 relevant studies. A flow diagram of the review process is provided in Figure 1 and the characteristics of the 18 selected studies are shown in Supplementary Table 1. Most of the studies were conducted in the UK (n=11), with five studies from North America and one each from Sweden and Switzerland. The studies included interview with at least 252 patients. It is not possible to compute the exact number of patients included because some of the papers report on the same interviews: Hopkinson and colleagues used the same patient interviews in three reports [19-21] and these interviews were later used again in combination with interviews from a pilot trial [22]. However, across these studies, there was only one repeated quote (see Figure 1). Similarly, the patient interviews described in one paper by Reid and colleagues [23] were drawn from those reported in another[24]. Since the focus of these two papers was different, there was no overlap in patient quotes.

As can be seen in Supplementary Table 1, a variety of qualitative methodologies were used, and a number of data collection and data analysis techniques were employed across the studies, which improves the richness of the data set (triangulation)[25]. Only one study scored the CASP maximum of ten [26]. All the 15 studies which scored nine lost a point for the reflexivity criterion because they did not consider the relationship between researcher and participants. The two low scoring studies were the oldest study [27] and a very concise report of some results from a study [22], the methodology of which has been more fully described elsewhere [19-21].

The flow diagram in Figure 1 shows that eventually 171 codes were extracted from the data and these contributed to 26 themes, which can be grouped into eight meta-themes. Most of the 171 issues were included in just one theme but nine issues contributed to two themes: significance of weight loss and one other. The high number of themes demonstrates the wide-ranging concerns of patients with cancer cachexia. The multi-dimensional nature of these concerns is confirmed by examination of Table 1, which lists the themes along with a patient quote to illustrate each theme, and the lists of codes is available in the online supplementary material. Figure 2 shows how the 26 themes can be organised into eight meta-themes: ‘food and eating’, ‘loss of control’, ‘physical decline’, ‘emotions’, ‘identity’, ‘knowledge’, ‘relationships’ and ‘coping’. Each theme contributes to a single meta-theme.

The meta-themes were used to develop a model to conceptualise the patient experience of cancer cachexia and to inform the development of future interventions (Figure 3). The starting point for the model is ‘food and eating’ and the endpoint is ‘emotions’. Problems with food and eating contribute to the physical decline experienced by patients which in turn affects the patient’s identity (both in terms of physical appearance and role played in life). The physical decline and identity changes both impact the patient’s emotional well-being. ‘Identity’ and ‘emotions’ are also directly affected by ‘food and eating’. The extent to which this occurs is mediated by the patient’s relationships, how they cope with the situation and their knowledge of cachexia.

There are two points identified in the model where interventions would be most potent. The first, at site A in Figure 3, is reducing the risk that problems with food and eating will result in physical decline. This means maximising nutritional intake using appropriate interventions such as appetite stimulants, nutritional supplements and psychosocial interventions to increase consumption. Interventions at Site B in Figure 3 are concerned with the direct link between food and eating, and emotions. Psychosocial and education interventions for both patients and their informal carers would be most appropriate at this site, with the goals of improving knowledge of cachexia, coping strategies and family relationships.

**DISCUSSION**

This synthesis of 18 primary qualitative studies identified 26 themes (or HRQOL domains) and eight meta-themes which describe the experience of cancer patients affected by cachexia and related problems. The meta-themes were used to develop a psychosocial model to conceptualise the patient experience of cancer cachexia, including suggestions for where interventions are most likely to be beneficial.

In the discussion of the model which follows, the details were obtained from the themes in Table 1 and Figure 2, and the codes listed in the online supplementary material. The model starts with ‘food and eating’. Most patients with cachexia report that they have a poor appetite and eat relatively little. Along with alterations in the taste and texture of food, preferences may have changed, sometimes to the extent that there is a strong aversion to formerly enjoyed foods. Eating is no longer a pleasurable activity but rather a chore with meals taking too long. All these food and eating problems contribute to the physical decline experienced by patients. They describe issues with weight loss, fatigue and weakness. The physical decline can have a negative impact on body image and patients sometimes struggle to recognise themselves in the mirror, or they may even avoid mirrors altogether. These issues contribute to the identity meta-theme, which also encompasses the idea that patients’ role in life may change as a result of their condition. For example, patients who were previously responsible for the provision of family meals may no longer be able to fulfil that responsibility. Following on from the identity meta-theme are the two connected meta-themes of ‘loss of control’ and ‘emotions’. ‘Loss of control’ refers to both body – the patient feels that eating and weight are unrelated and weight loss is out of control – and mind, with the loss of autonomy and independence. Some patients feel a sense of failure at not being able to control their weight loss and eating, both in terms of quantity and the types of food they are able to consume. Negative emotions, such as fear, depression and frustration are commonly experienced. Some patients describe their situations as hopeless whereas others cling on to the chance of a miracle.

Along with the link between problems with food and eating and negative emotions mediated by physical decline, there is also a direct link. This implies that even if the physical decline could be minimised, there would still be negative emotions associated with the cachexia. This is because the role of food is more than just nourishment [28]: the preparation and sharing of food has a central role in daily life, special occasions are often associated with special foods and providing food can be an expression of love or caring. The model identifies three meta-themes which have a significant impact on whether difficulties with food and eating lead to negative outcomes: ‘relationships’, ‘coping’ and ‘knowledge’. Looking at the themes which are included in the relationships meta-theme illustrates how relationships may be both beneficial and harmful to the patient’s well-being. For example, conflict with carers, such as feeling pressured, and feeling isolated have a negative impact, whereas feeling supported and maintaining a social life result in positive emotions.

The knowledge meta-theme underlines the importance of health care professionals taking the time to explain more about the condition and how to deal with it. Patients want advice and information. Sometimes the knowledge they want is not available, e.g. precise prognostic predictions based on weight loss, so it is important to be aware of this and manage expectations. Sometimes all that is required is acknowledgement of the weight loss by health care professionals.

The coping strategies patients use can also influence the impact of food and eating on emotions. Some patients are able to accept and adapt to their new situation, others ignore it (“ostrich phenomenon”) and others cope by trying to control the effects of cachexia, by forcing themselves to eat for example. The importance of coping strategies was also identified in the previously developed psychosocial model of cachexia mentioned in the introduction [13].

The psychosocial model [13] was developed from a systematic literature search which had the research question “What are the various aspects of the psychosocial effects of cancer cachexia?”. In that model, mechanisms which lead to psychosocial effects, identified as negative emotions, are listed. These mechanisms include inability to eat, awareness of weight loss and changed cooking and eating habits. Adverse reactions, namely force feeding, patient withdrawal and hunger strike, are associated with escalating psychosocial effects. Decreasing psychosocial effects are associated with coping strategies, specifically letting nature take its course, finding other ways to care and patient driven feeding. The model does not make explicit the direction of causality in either of these two associations. It is also not clear how “psychosocial effects” is being conceptualised since the review included data from patients, carers and healthcare professionals. Do the authors mean patients and carers together, or perhaps the psychosocial effects refer to either patient or carer? This is important because sometimes patients and carers have different responses. For example, more carers are anxious about patient anorexia than patients [29].

The advantage of the model presented in the present study is that it was systematically generated from the patients’ own voices and it integrates into a single model the HRQOL issues which need to be addressed by a cachexia intervention. The development of a detailed model, with specific HRQOL domains, provides clinicians with the information they need to treat patients with cancer cachexia more effectively. Although the necessity of taking a biopsychosocial approach to cancer cachexia has already been emphasised [8], this review brings together for the first time the information required to underpin this approach. In the biopsychosocial approach, health concerns are framed in terms of the functional interdependence between physical, psychological and social functioning [30]. Recognition of the limitations of the biomedical model is leading to a shift from the biomedical to the biopsychosocial approach throughout medicine, which is already demonstrable in the USA [31]. This shift is partly driven by a change in the leading causes of death from infectious diseases to chronic disease, with the consequent augmented role of behaviour in disease aetiology, prevention and management.

The two intervention sites identified in the model are consistent with the biopsychosocial approach. The goal for interventions at the first site is to reduce physical decline associated with cachexia. A recently suggested treatment plan [3] which advocates first targeting the tumour, then systemic inflammation, next normalising energy and substrate intake and finally encouraging exercise, is appropriate for this site. The research effort to improve the therapy for this intervention site is clearly warranted. It is important that this effort explores the use of psychosocial interventions, particularly in the context of increasing intake and exercise, along with biomedical agents.

Even if the physical aspects of cachexia are treated successfully, it is likely that there would still be a psychosocial impact of the condition. This is because eating plays such a significant part in everyday life and food has very significant emotional, social and cultural roles [32]. It is therefore vital to develop effective interventions at the second site, to address the emotional impact of the condition. This site is particularly important for patients with refractory cachexia, for whom the primary treatment goal is the overall increase of well-being and the alleviation of cachexia-related symptoms [33]. The model presented here suggests that there are three elements which contribute to the emotional welfare of the patient: their relationships, how they cope and their knowledge of the syndrome. These three elements should be incorporated in any psychosocial intervention for patients with cancer cachexia. The only interventions we are aware of in this area are the Macmillan Approach to Weight and Eating (MAWE) and the Family Approach to Weight loss and Eating (FAWE) [34 35]. Although these nurse-led psychosocial interventions for weight- and eating-related distress in people with advanced cancer and their carers implicitly address the three elements, they have not yet been fully validated. Future research is required to develop fully validated, easily accessible interventions, which can be tested against the new theoretical insights provided by the model presented here.

**Study Limitations**

This systematic review and thematic synthesis of the qualitative literature only included direct patient quotes. Although this approach is not reliant on the authors’ interpretation, it has the disadvantage that the number of quotes available for analysis is limited and selected. We are addressing this limitation, along with European collaborators, by conducting semi-structured interviews with cancer cachexia patients to ensure that all HRQOL issues have been identified. This work contributes to the development of a cachexia module to supplement the EORTC QLQ-C30, the core quality of life questionnaire of the European Organisation for the Research and Treatment of Cancer Quality of Life Group [36].

A second limitation is that, because we included cancer patients with cachexia, eating or weight loss problems the samples were not homogeneous. In addition, the studies identified in our searches were all European or North American in origin so the cultural generalizability is limited.

**CONCLUSION**

Patients with cancer cachexia describe many HRQOL issues, drawn from a wide range of domains. The model generated in this review underlines the necessity of clinicians using a biopsychosocial approach to tackle both the physical decline associated with cachexia and its emotional consequences. Relationships, coping and knowledge of the condition are important components of new psychosocial interventions.

**ETHICS**

No study approval as our study is based on a systematic review of the extant literature.

**COMPETING INTERESTS**

Jane Hopkinson is on the Scientific Board, Cachexia Hub, Helsinn Healthcare. All remaining authors have declared no conflicts of interest.

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**Table 1: Themes**

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| --- | --- |
| **Themes** | **Example patient quote** |
| Acceptance & adaptation | I’m accepting what I’ve got and I’m quite happy with it. Whether that’s correct in dietary terms is another matter. Doesn’t mean a thing to me [28]. |
| Appetite | You want to eat but you can’t eat. I could go with a wee taste of soup of something, but I’ve no real appetite [24]. |
| Body image | My sport is swimming… I’m embarrassed to go swimming because I look at my body and say what the hell has happened to me [26]? |
| Carer conflict | She worries too much. She tries to force me to eat when I don't want to. It is really a source of conflict and it is driving me nuts [27]. |
| Change in experience of eating | I take soups but I don’t enjoy anything... I have no feeling of hunger at all and no appetite [19]. |
| Change in identity | See when I look in the mirror and see [myself] the face that looks back at me, it’s not me [24]! |
| Concern for others | I am glad she does this for me (i.e. brings me two to three meals a day)...I worry about her, though [45]. |
| Continuum of hope | I know I am going to die soon; there is nothing anybody can do to help me [20]. |
| Eating as pleasure | Yes, food is important as a source of pleasure, as a pleasurable experience [28]. |
| Food aversion | It’s just you cannot force it inside you because I know if I force it I will be sick – you don’t want to see it or smell it. In fact, sometimes I go in the kitchen and its horrible [21]. |
| HCP input | Nobody mentioned it to me at the hospital, I do get weighed at the hospital though, one time ten stone seven, the next ten stone four, but no talk of the weight loss from them [23]. |
| Isolated | I don’t feel comfortable meeting people. . . [puts heads down and looks at floor] you know what their reactions are gonna be [24]. |
| Knowledge to understand | No one explained why you lose weight. You would then not have to destroy yourself psychologically with: I must eat, even if I am not hungry, if I don’t like the taste [42]. |
| Loss of control of body | I know the cancer is eating away at me…I always felt I was in control. You know you are not going to be in control but subconsciously you don’t believe it, then you get the physical evidence. You can see you are losing weight fast [20]… |
| Loss of independence | You got no control. Basically, it’s like being a kid again [21]. |
| Negative emotions | I’m getting fed up with myself. It gets you down, you think, “Oh my God! How much longer am I going to be like this?” You know, like this. And it doesn’t seem possible. And you can’t see any way at the end of the tunnel. Strange, strange how your life could come to this [39]. |
| Nutritional support | One thing that (my specialist nurse) put me on to was this energy drink. That’s absolutely magic. (..) I feel as though I couldn’t do without it. I have one of those every day [19]. |
| Sense of failure | I feel that I’m useless because I can’t eat, and I feel quite weak as well [26]. |
| Significance of weight loss | I suppose it’s all tied up with the cancer thing, which is very scary, very scary. So I think it’s all tied up with that ‘cos I can’t bear the thought of cancer. When I look at myself, it reminds me of why I’m looking, why I’ve lost weight [39]. |
| Social life | Taking liquidized food is not the sort of thing you want to do with family and friends [19]. |
| Social support | Almost everybody brought their version of chicken soup—and, it was wonderful [45]. |
| Symptoms | Also, I have lost the ability to walk....But, not eating is not allowing me to gain my muscle strength back [43]… |
| Taking control | You know you are doing something yourself, as well as other people helping. It enables you to keep going. You know you are looking after yourself [21]. |
| The ostrich phenomenon | I’m trying to cope with it. . .put it out of my mind [24]. |
| The unexpected | I always thought cancer patients lost weight because they had it in the stomach and they couldn’t eat [20]. |
| Waste | Well, in the end there was no point in it. It was meaningless to eat. Cooking every day and eating just to go and put it down the toilet is a waste of effort, I think, a waste of money [38]. |

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C:\Users\jsb1f08\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.Outlook\4RKSOPAT\Fig2.tifFig 2

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Fig 3

Supplementary Table 1: Included study characteristics

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country** | **Aim** | **Patient Sample** | **Qualitative Methodology** | **Data Collection Method** | **Method of data analysis** | **How was trustworthiness ensured?** | **CASP total score** |
| [27] | USA | To explore the ways in which terminally ill cancer patients and their primary caregivers view and respond to the patient's loss of appetite | 9 males & 5 females randomly selected from 4 hospice programs. | Not specified | Semi-structured interviews | Not specified | Not specified | 6 |
| [37] | Canada | To develop a beginning substantive theory aimed at uncovering the social processes inherent in family interactions with patients and health care providers around the issue of nutritional care in a palliative context. | 3 male & 10 female patients on palliative care unit (PCU). | Grounded theory | Semi-structured interviews | Constant comparison | Prolonged engagement on PCU, triangulation, systematic checking of emerging model with participants & external colleagues | 9 |
| [38] | Sweden | To investigate the nutritional situation prior to the introduction of home parenteral nutrition (HPN) from the perspective of patients with advanced cancer and their family members in order to understand the factors contributing to their decision to accept HPN. | 8 male & 5 female patients with advanced cancer receiving palliative care. | Qualitative methods | Semi-structured interviews | Constant comparison | Input from the multi-disciplinary research group | 9 |
| [32] | UK | To explore the experience of loss of appetite for cancer patients and their carers | 7 patients supported by a specialist palliative care team in the community. | Phenomenological | Semi-structured interviews | Hermeneutical analysis & poetic transcription | Double coding of a subset of text. | 9 |
| [20] | UK | To explore the experience of and concern about weight loss in people with advanced cancer, their caregivers & nurse specialists | 16 males & 14 females. All but 1 with reported weight-loss. | Humanistic nursing theory | Semi-structured interviews | Mixed strategy for cross-case analysis | Search for disconfirming evidence. Discussion with academics & clinicians | 9 |
| [19] | UK | To develop an understanding of the manifestations, management, and meaning of eating changes in patients with advanced cancer | 16 males & 14 females with advanced cancer & a change in eating habits since they first perceived they were unwell. | Hermeneutic phenomenology | Semi-structured interviews | Mixed strategy for cross-case analysis | Dialogue with cancer patients, clinicians and academics. Search for disconfirming evidence | 9 |
| [39] | UK | How does altered body image arising from cachexia impact on people's emotions, social functioning & relationships? How do other people's reactions to an altered body image impact on people's lived experience of the illness? | 6 males & 6 females with cancer related weight loss. | Not specified | In-depth conversational style interviews | Thematic | Not specified | 9 |
| [21] | UK | To explore the management of changing eating habits in people with advanced cancer | 16 males & 14 females with advanced cancer | Hermeneutic phenomenology | Semi-structured interviews | Mixed strategy for cross-case analysis | Dialogue with cancer patients, clinicians and academics. Search for disconfirming evidence | 9 |
| [40] | Canada | To investigate the process that explains how patients with advanced cancer compensate for anorexia & manage the emotional and social consequences of declining intake. | 7 male & 2 female patients with advanced cancer & self-report loss of appetite. | Grounded theory | Up to 3 unstructured interviews per participant | Constant comparison | Verification strategies based on[41] | 9 |
| [42] | Switzer-land | To discover and describe elements of eating-related distress in male patients with advanced cancer & their female partners | 19 males with advanced cancer with weight loss (≥5%, 6 months) or appetite problems. | Qualitative methodology supported by related quantitative data | Focus groups for couples, one couple interviewed individually | Grounded theory coding and constant comparison methods | Results approved by patients, partners and professional, to whom findings were presented | 9 |
| [22] | UK | To examine a specific cause of distress (healthy-eating messages) & the implications for nursing practice | 23 males & 9 females | Hermeneutic phenomenology | Not specified | Not specified | Not specified | 5 |
| [43] | USA | To examine the social factors that may contribute to under eating in older adults with cancer. | 13 male & 17 female patients >70 years. | Constructionist perspective & grounded theory approach | Semi-structured interviews | Thematic with constant comparative method | Not specified | 9 |
| [24] | UK | To explore the lived experience of cachexia for patients with advanced cancer and their family members | 8 males & 7 females with advanced, incurable cancer living at home, >10% weight loss in previous 6 months, weight loss progressive, involuntary & problematic & not due to reduced oral intake. | Heideggerian phenomenological philosophy | Inductive format interviews with non-directive, open-ended questions | Thematic for whole sample. Interpretative phenomenological analysis on a sub-set of 8. | All authors contributed to the analysis | 9 |
| [44] | UK | To explore the experience of cachexia & its effect on food & feeding | 4 male & 4 female patients with advanced, incurable cancer living at home, >10% weight loss in previous 6 months, weight loss problematic, no secondary causes of cachexia. | Heideggerian phenomenological philosophy | Unstructured interviews | Thematic & interpretative phenomenological analysis | Not specified | 9 |
| [45] | USA | To analyse the social organisation of caring as gendered work as it relates to meal preparation & consumption activities surrounding older adult cancer patients & their caregivers | 13 male & 17 female patients >68 years. NB no criterion that participants had to be experiencing difficulty with food or eating activities. | Constructionist perspective & grounded theory approach | Semi-structured interviews | Constant comparison | Not specified | 9 |
| [23] | UK | To investigate the perceptions of patients and family members with regard to care received for cancer cachexia | 8 males & 7 females with advanced, incurable cancer living at home, >10% weight loss in previous 6 months, weight loss problematic & not due to explainable clinical cause. | Heideggerian phenomenological philosophy | Qualitative unstructured interviews | Thematic for whole sample. Interpretative Phenomenological analysis on a sub-set. | Not specified | 9 |
| [28] | UK | To explore patients' views of nutrition, to begin to understand their concerns & to determine whether such standards meet the needs of patients in the palliative care setting. | 4 male & 2 female inpatients in specialist palliative care unit. | Qualitative approach | Semi-structured interviews | Miles & Huberman's (1994) framework for qualitative data analysis[46] | Not specified | 9 |
| [26] | UK | To acquire a deeper understanding of cancer patients' experiences with the physical manifestations of weight loss or gain, the consequences of these changes on their psychosocial life and their self-management strategies | 54 cancer patients with weight-change issues. | A longitudinal qualitative approach used to obtain indepth exploratory descriptive data | Semi-structured interviews | Thematic with constant comparative method | Followed criteria established by [47] and [48] | 10 |