**A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia**

**Abstract**

***Background***: Informal carers of cancer patients with cachexia face additional challenges to those encountered by informal carers in general because of the central role food and eating play in everyday life. Patient weight loss and anorexia, core features of cancer cachexia, are frequent causes of distress in caregivers. Identification of quality of life (QOL) issues can inform the development of interventions for both caregivers and patients, and facilitate communication with healthcare professionals (HCPs).

***Aim*:** To identify QOL issues that are relevant to carers of cancer patients with cachexia.

***Design*:** A systematic review and thematic synthesis of the qualitative literature were conducted. Reporting followed the PRISMA guidelines.

***Data sources*:** PubMed, ISI web of knowledge, EMBASE, Medline, CINAHL, PsychINFO, and PsycARTICLES were searched for publications dated from January 1980 to June 2013 using search terms relating to cancer, cachexia, QOL and carers. Papers written in the English language, featuring direct quotes from the carers of adult patients with any cancer diagnosis and cachexia or problems with weight loss or anorexia were included.

***Results*:** Five themes were extracted from the sixteen identified studies. These highlighted the impact on everyday life, the attempts of some carers to take charge, the need for HCP input, conflict with the patient and negative emotions.

**Conclusions:** The complexity of caring for a cancer patient with cachexia translates into a range of problems and experiences for informal carers. By addressing the impact of caring for a patient with cancer cachexia on carers, both caregiver and patient QOL may improve.

**Keywords**

Cancer, cachexia, quality of life, caregivers, systematic review, thematic synthesis

**What is already known about the topic?**

* There are a large number of problems and burdens related to cancer caregiving responsibilities, including physical, social and emotional difficulties, lack of information, and impact on the routines of daily life.
* For patients with cancer cachexia, conflict with carers can be an important issue.

**What this paper adds?**

* Conflict with patients is also an important issue for carers.
* Carers want healthcare professionals to acknowledge patient weight loss and provide advice.

**Implications for practice, theory or policy?**

* Management of cancer cachexia should include consideration of the needs of carers.
* Psychosocial interventions for cancer cachexia may be more effective if aimed at patients and carers together.
* Improving carer quality of life may lead to the improvement of patient quality of life.

**Introduction**

Food and eating are fundamental to human existence, both in terms of survival and also socio-culturally. Informal carers of people with cancer cachexia therefore face very particular challenges. The impact this has on caregivers’ quality of life (QOL) is explored in this paper.

There are estimated to be more than one million people in the UK providing informal care for someone with cancer, saving health and social care services nearly £12.1 billion per year 1. Informal carers or caregivers, who may or may not be family members, are non-professionals in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management2. The shifting of primary care from hospitals and health care professionals (HCPs) to the home and informal caregivers has increased the challenges faced by carers 3, 4: carers may take on the responsibility of symptom management, personal care and co-ordinating appointments, along with providing social and emotional support5. It has been suggested that the education and support required by caregivers should become part of the patient discharge plan 6. Formalising this help could be beneficial as many caregivers report having difficulty accessing HCPs, and getting the information and support they need 3. This would also be a practical step to back up governments’, advisory bodies’ and international agencies’ rhetoric on the vital role played by caregivers and the importance of addressing their needs2, 7, 8.

A recent comprehensive review listed over two hundred problems and burdens related to cancer caregiving responsibilities including physical, social and emotional difficulties, need for information, and impact on daily life 9. Given this wide range of potential problems, it is not surprising that being a cancer caregiver sometimes has a negative impact on QOL 10. One way to evaluate whether carers are receiving the appropriate support and are coping with their caregiving role is to monitor their QOL. Monitoring carer QOL can aid HCPs judge the amount of support which is required by carers and may help avoid crisis situations. These can arise when carers close to breaking point are assumed to be coping, because they do not request services 11. Tracking carer QOL may also be important because of the interdependence between caregiver and patient QOL12, with some studies providing evidence of a causal link, both from patient to carer and from carer to patient13, 14. This suggests that if a carer’s QOL declines, the same is likely to occur for the patient. Therefore, by meeting the needs of carers, and maintaining their QOL, patients could also benefit.

Along with the generic challenges faced by caregivers, there are also specific problems when patients have particular cancers, treatments or associated conditions. One such condition is cachexia. Although the precise mechanisms of how the development and progression of cancer leads to cachexia are unknown, abnormal metabolism and reduced food intake both play a role 15. Cachexia is a common problem for patients with cancer: more than 80% of those who die develop the condition 16, 17 and in an consecutive series of one thousand oncology outpatients, nearly 40% had significant weight loss 18. Involuntary weight loss is how cachexia manifests in patients. The weight loss is at least partly attributable to loss of skeletal muscle with the consequence of progressive functional impairment19.

Patient weight loss and anorexia are both sources of anxiety for carers. In a study including 115 cancer patients with self-reported anorexia and 83 carers of cancer patients with carer-reported anorexia, more carers (87%) reported anxiety consequent to the anorexia than patients (36%) 20. One reason for this distress is that patient rejection of food may induce feelings of rejection in carers, along with a sense of helplessness. A recent study found a significant correlation between the magnitude of patient weight loss and caregivers’ distress 21. Weight loss provides visible evidence of disease progression and may be perceived as symbolising the approach of death, adding to feelings of powerlessness carers may experience22-25. Food and eating have a central role in everyday life so caregivers face these problems on a daily basis. In addition, social interactions often include a food element and special occasions are frequently associated with special foods so there is an impact on social life, for both the patient and carer 26.

Issues related to patient eating and weight loss are not adequately covered by the currently available carer QOL tools. In fact, across the four instruments specifically developed to assess carer QOL, identified by a systematic review27, there is only one item, in the Caregiver Quality of Life Index-Cancer Scale28, related to patients’ eating habits. Understanding the factors which impact carer QOL can contribute to the development of interventions to help carers cope with the challenges of caregiving. This knowledge could also help HCPs start a dialogue with carers. Weight loss and eating difficulties can sometimes be taboo subjects for HCPs who fear they may upset patients and families by talking about a problem they feel unable to resolve29 or that may lead to a discussion about end-of-life issues 30. We have recently developed a model of the patient experience of cancer cachexia 31. This highlighted the importance of ‘knowledge’ on mediating the negative impact of food- and eating-related difficulties. ‘Knowledge’ encompassed the need for helpful input from HCPs and also the desire for information about the condition. For at least some patients, weight loss was not a taboo subject.

In the same patient model, ‘relationships’ also played an important role on the impact of food- and eating- related difficulties. ‘Relationships’ included the concept of carer conflict, with some patients describing feeling angry with carers, because their approach was unhelpful and made them feel under pressure. Interviewing carers can contribute to an explanation as why this conflict arises and may help with the development of strategies to limit or deal with the conflict. Interviews can also uncover the QOL issues which are relevant to these carers. There are already a number of studies which contain interviews with this carer group and can be utilized to address the review question, “What factors impact quality of life in carers of patients with cancer cachexia?” For the purpose of this review, QOL is conceptualised to be those aspects of quality of life which carers consider are affected by the patient’s cachexia and includes physical, emotional, cognitive and social components. The main aim of this study was to use a systematic review and thematic synthesis of the qualitative literature to identify the relevant QOL issues for carers of patients with cancer cachexia.

**Methods**

The methods used in this review were informed by the Centre for Reviews and Dissemination guidance for undertaking systematic reviews32, and the reporting follows the Preferred Reporting Items of Systematic reviews and Meta-Analyses (PRISMA) guidelines33. The thematic synthesis methodology was adapted from that described by Thomas and Harden34 The protocol for the review is available from the first author.

**Search strategy and selection criteria**

PubMed, ISI web of knowledge, EMBASE, Medline, CINAHL, PsychINFO, and PsycARTICLES were searched for publications dated from January 1980 to February 2015 using search terms relating to cancer (neoplasm, cancer, palliative, tumour, tumor, malignancy); cachexia (cachexia, anorexia, “anorexia-cachexia”, weight loss, systemic inflammation, food, “wasting syndrome”, appetite, malnutrition, sarcopenia, “muscle wasting”, eat\*, “nutritional assessment”, emaciation, nutrition); quality of life (“quality of life”, QOL, QL, HRQOL, HRQL, “subjective health status”, “reported outcome”, psychosocial, interview, questionnaire, emotion\*, distress\*, anxiety, fear, manage, experience\*, impact\*, perception\*, belief\*, fight\*, response\*, concern\*, challenge\*) and carer (carer, caregiver, family, partner, spouse, husband, wife, brother, sister, sibling, daughter, son, parent, mother, father, friend, relative). The Boolean operator AND was used to combine the four search term categories (cancer, cachexia, quality of life and carer) and the Boolean operator OR was used between the search terms within each set of brackets.

Two reviewers screened all titles and abstracts (SW and one other co-author). 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 one other co-author). There were no disagreements about inclusion. Mindful of the difficulty of finding qualitative research papers32, the references of all included papers were searched for additional papers.

We selected papers describing qualitative studies written in the English language, published from 1980 onwards which included direct quotes from the carers of 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’35, we accepted papers with carers of patients described as having cachexia regardless of how this was defined. We also accepted papers with carers of patients who were not described as cachectic but did have weight loss, the defining feature of cachexia19. We excluded studies focussed on the experience of using feeding tubes and also studies which explored the end of life use of medically administered nutrition and hydration. In addition, conference proceedings and abstracts were excluded.

**Quality assessment**

Assessing the quality of qualitative studies is the subject of a number of on-going debates, including whether it is even appropriate32. We chose to appraise and report on the methodological quality of the studies using the Critical Appraisal Skills Program (CASP) tool for reviewing qualitative studies36 which uses ten questions to evaluate qualitative research. 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 Harden34, carer quotes were extracted from each paper. Three judges (SW, AD and JH) independently judged whether the quotes included any information about the carer’s QOL, with disagreements resolved through discussion. They then coded the content of each QOL quote for meaning, using as many codes as was necessary. The judges met to discuss and agree the coding system. Each quote was checked to ensure that all concepts had been coded and the wording for the codes was finalised. SW then relabelled the quotes using the agreed codes and the same three judges identified themes within the codes, again independently. The judges met to discuss the themes until consensus was reached. Finally, themes were tested against the original quotes to ensure the thematic framework which had been developed was adequate.

**Results**

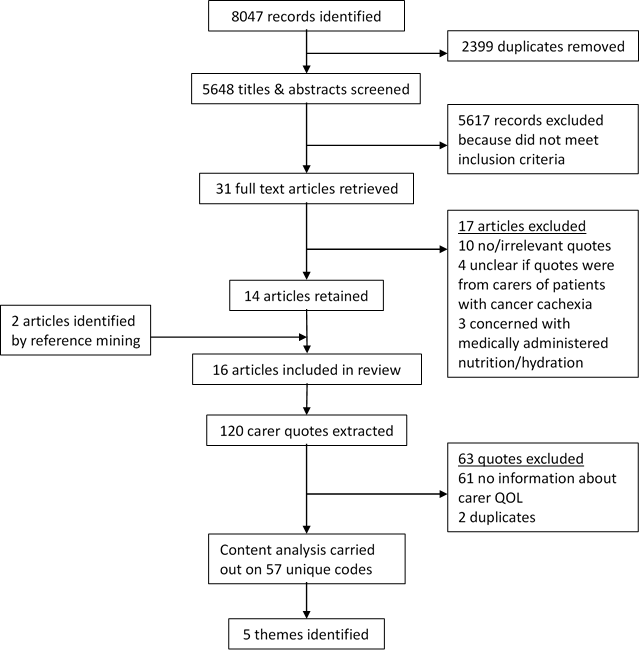
The systematic review found 16 relevant studies. A flow diagram of the review process is provided in Figure 1 and the characteristics of the 16 selected studies are shown in Table 1. Most studies were conducted in the UK and North America, with one in Sweden and one in Switzerland. The studies included interviews with a total of at least 169 carers. The precise number of carers cannot be calculated because some of the papers reported on the same interviews: the three McClement papers 37-39; the three Hopkinson papers 29, 40, 41; and the three Reid papers24, 42, 43. Despite this overlap, just two quotes were duplicated across the papers.

*Insert Table 1 about here*

As can be seen in Table 1, a variety of qualitative methodologies was 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)44. Most of the papers rated well on the CASP but all failed the reflexivity criterion because they did not report on the relationship between researcher and participants. The lower rated studies were the oldest study22 and two papers reporting results from studies, the methodology of which has been more fully described elsewhere37, 41.

Figure 1 shows that more than half the quotes were excluded because they did not contain any information about carer quality of life. Rather they covered topics such as beliefs about the importance of food and descriptions of patient’s symptoms, appearance and eating habits. Given the limited data, it became apparent that the review would identify domains of experience rather than specific QOL issues. The themes which were extracted from the 57 quotes which included information about the effect of the patient’s illness on carers themselves were impact on everyday life, taking charge, need for outside help, conflict with patient and emotions. Each of these themes is described in turn.

Figure 1: Flow diagram of review process



**Impact on Everyday Life**

Food and eating are part of everyday life for most people so when someone is having difficulty in this area, those around them are confronted with the problems on a daily basis. Carers may be constantly ‘watchful’ or aware of the patient’s appetite loss and its effects45 as they feel a profound sense of responsibility for the patient’s nutritional care23, 46.

*Every time you go shopping you look and wonder if mother’d fancy that. If we’re having something different I think I wonder if mother’d like that* 45.

Carers can spend a lot of time and energy selecting and preparing food 22, worrying about whether they are getting this right 25 and what the best strategies are to improve intake23. Carers’ time may also be taken up by going out of their way at mealtimes to make sure the patient eats.

*I came to the hospital and the trays were already gathered up. And I looked at his tray and I could see he hadn't eaten… After that I was there every day to feed him his breakfast37.*

This underlines the responsibility carers may feel for ensuring that patients’ nutritional intake is adequate.

The ongoing concern about food and eating adds to the daily stress experienced by carers. For many people, shared mealtimes provide an opportunity to talk over the day’s events but this may not be possible for carers of patients with cancer cachexia. Whereas before the onset of cachexia, patient and carers may have enjoyed eating together, carers may now eat alone because patients find it difficult to be around food.

In the extreme case, when patients cannot even tolerate cooking smells45, 47 caregivers may no longer be able to cook at home.

*He couldn’t take the smell of the food. So I was going to my sister’s place to eat. I wasn’t cooking anything. He felt sick. He didn’t like the smell of anything… [my] brother-in-law would come sit. So I would go quick, eat, come back*48.

Eating may therefore be reduced to nothing more than refuelling with a loss of the mealtimes which previously punctuated the day.

*...and dinner hour, I didn't realize until he stopped eating that there was a dinner hour, and then there was none, and it was so difficult to get through the day because what to do you do from 5 to 7? That part of your day is empty. 46*

Without mealtimes, carers may feel there is a void, time and space to be filled. Along with the loss of mealtimes, carers’ diet may also be affected, with some mirroring the decline seen in the patient.

*…We always ate together…He wouldn't eat if I didn't eat, so I stopped eating when he stopped eating...*46.

Other carers eat unhealthily or eat for comfort.

*Oh yes, I've gained 30 pounds. I never cook anymore. I eat my main meal at work at noon and then I just snack at home. I'll eat a half gallon of ice cream in front of the TV... You know, I eat like I did when I was a little girl. My mother would always feed me when I was anxious.* (This brought on a flood of tears.) 22.

Whether carers eat too little or too much, worry about the patient can result in a change in their diet.

**Taking Charge**

Some carers cope with the difficult situation they face by trying to control what is happening. They recognise that patient weight loss is a problem and set themselves the target of ensuring the patient gains weight, even if they are not sure what is achievable 41. Taking charge of food and eating may help carers assuage feelings of powerlessness and may create an outlet for the love and care that caregivers want to provide.

*I really did fuss with the food issue and it wasn't that I didn't trust them [the staff], it was more control. It was a thing that I could control. It was the one thing I could say that wasn't being done. Yeah, I could intervene. It was a power thing. I was aware of the power in me, but I was also aware that it was something I could do for her…*37.

For the carer in the quote above, taking responsibility for the patient’s nutritional care was a positive aspect of the caregiving experience. By ensuring the patient has, what the carer perceives to be, adequate nutrition, the carer is protecting the patient. Other carers protect patients and take charge by controlling conversations.

*If I were to go out to eat somewhere, to try out a new restaurant, I wouldn’t bring it up in conversation because I don’t want to make her feel ill at ease in case she was thinking about a time when she could eat and enjoy food more…*39.

Food-related topics of conversation may become taboo if carers are concerned that patients will find them upsetting. Monitoring conversation topics can be effortful and caregivers may miss the opportunity to share enjoyable experiences, a common feature of human communication 49

**Need for outside help**

Many carers talk about their need for external support, specifically from HCPs. There can be a sense of frustration when HCPs are perceived as failing to acknowledge weight loss as a problem.

*I get angry at times, you know of the idea of it happening. He said to the doctor . . . [about his weight loss] but they didn’t take it in, didn’t do anything…the doctor knew about it – but he was very lackadaisical* 42.

By appearing to ignore weight loss issues, HCPs can isolate carers through the failure to develop a common agenda for patient care. This can make carers feel powerless. If HCPs are thought to be failing to acknowledge the condition, carers may also conclude that they are not willing to help with weight loss and eating difficulties.

*We were in limbo, . . .nobody cared, we couldn’t turn to anybody. . .nobody seemed to help us. . .we just had to cope on our own. . .when he wasn’t eating and that we didn’t known whether to call for a doctor or what or who to turn to* 24.

When HCPs are considered to be failing to meet the carer’s need for information about the condition, carers can feel angry and isolated. Without the appropriate information and support, carers find themselves in the unenviable position of trying to deal with a very difficult situation for which they feel ill-prepared.

*We were panicking because he wasn’t eating and we didn’t know what to do. . .we felt it was our fault, because he wouldn’t eat and we couldn’t get him to eat* 24.

Carers want and need the support of HCPs, and they expect them to provide the information required to enable the best patient care. If this expectation is not met there can be a negative effect on the quality of the relationship between the HCP and the family.

**Conflict with patient**

Conflict and tension can arise when what a patient is able or willing to eat diverges from what the carer thinks the patient should be eating. Sometimes this relates to food quantity: family members are determined to make the patient eat more whilst the patient is unable to do so24, 38. For other carers, it is the quality and type of food that is important.

*I do go into battle sometimes…He'll eat sweet biscuits, cakes, you name it, but when it comes to actual meals, even things he used to be passionate about, he just won't eat*41.

Carers may have an expectation that patients should be following the healthy diet which is recommended for the general population, and will express their disapproval when this is not the case. The disagreements between patient and carer, both in terms of the quality and quantity of food consumed by the patient, can be viewed in terms of a clash between the carer taking charge and patient autonomy. Carers may recognise that their attempts at encouragement can have the reverse effect.

*I give her food and then she doesn’t eat it, then I feel guilty that she isn’t getting anything inside her - I was worried and sad that she wouldn’t eat and she got angry with me for nagging about food and it almost went the opposite way you see, that she would simply refuse to eat any food. 23*

This can cause feelings of guilt at both the failure to get the patient to eat enough and for upsetting the patient. In some families, carers find it hard to deal with the patient’s rejection of their efforts leading to hurtful and upsetting arguments.

*I said, ‘All right let’s get you better and [then you leave] or I’ll [leave], please yourself’. And she didn’t like that. I think she said something that really got at me…* 48

Carers feel guilty about the arguments, partly perhaps because they feel that the family should pull together in times of adversity. They may think that the patient may not have much time left and that this time should not be filled with arguments.

*And then when we did have [arguments over food], you felt terrible in yourself [participant’s eyes welled up, looks to the side, clears throat, and then re-establishes eye contact] . . . because you know why should we be having these bust ups?43*

Nevertheless, carers may be unable to suppress the anger which arises when their care is rejected.

*I made dinner, made what he liked, what he always liked. . . He said he didn’t like it, didn’t want it, which I was quite angry at* 24.

**Emotions**

Caregivers describe a number of negative emotions which are caused by the impact of caring for a loved one with cachexia. As illustrated in the quote directly above, they may feel anger when food they have spent a long time preparing is rejected. Worry and fear about the patient’s condition and the future are common emotions, which may be compounded by feelings of helplessness.

Sadness is often provoked by feelings of loss: carers are mourning for how things used to be.

*… we’ve always liked going out to eat and enjoying our food. But this last year there have been very few occasions when he has enjoyed his food and since he hasn’t enjoyed eating it isn’t any fun to invite people for dinner either, if they are going to sit and eat for several hours and he just thinks it’s a hard time and it starts to taste bad.23*

Carers can miss being in the kitchen together, going out to eat or simply eating a meal at home together.

**Discussion**

This synthesis of 16 primary qualitative studies identified five themes which describe the experience of caring for cancer patients affected by cachexia and related problems.

The five extracted themes were ‘impact on everyday life’, ‘taking charge’, ‘need for outside help’, ‘conflict with patient’ and ‘emotions’. Cachexia has an impact on everyday life above and beyond the impact of being a caregiver *per se*. This is because human beings need to eat to survive. It can be gruelling to face the daily challenge of thinking of foods to tempt the patient with, shopping and preparing food, and then having that carefully prepared food rejected, whilst watching the patient quite literally wasting away. Some carers adopt a problem-focussed coping strategy 50 by ‘taking charge’ of meals, even if the patient is in hospital, or they take on the role of the patient protector, ensuring nothing is said that might upset the patient. Nevertheless, many caregivers will want and need the help of HCPs so that they can be reassured that the care they are providing for their patient is as good as possible. As a minimum, carers want HCPs to acknowledge patient weight loss so they can feel confident that the problem is being taken seriously and it is a topic which is open for discussion.

Patient rejection of food is a common occurrence and carers may interpret this as a personal rejection of their love, care and attention24, 25. This is because of the many roles food plays beyond that of providing nourishment to the body 26. The potential conflict at the heart of the carer-patient relationship is important for cachexia: carers are determined to make their patient eat and patients struggle to eat. Conflict with patients was not one of the problems or burdens included in the comprehensive review of cancer caregiving responsibilities, described in the introduction above 9. If this conflict is being driven, to some extent, by different expectations of the amount and types of food which the patient should be consuming, better education for both patient and carer may help to avoid this conflict.

Anger, worry, fear, guilt, and helplessness are just some examples of the difficult emotions carers have to contend with, both as a direct result of conflict with the patient and because of the other pressures of caregiving. For example, if a patient is not eating, the carer may have no dining companion so the social aspect of eating is gone and this may induce a sense of loss.

Given the limited data available, these findings must be considered provisional and it would be inappropriate to use them to develop a conceptual model of the experience of caring for a patient with cancer cachexia. However, domains of experience have been identified and future studies will need to identify more specific QOL needs and issues.

All the studies included in this review are cross-sectional so there is no consideration of trajectory. Future research could explore the effects of caregiving longitudinally, perhaps mirroring a patient study in which cancer patients were interviewed two to three weeks after diagnosis with follow up interviews at three, six and twelve months after diagnosis 51. In this way, changes in the QOL of carers could be tracked, along with changes in the eating, weight and HRQOL of patients. This would help establish whether there are any triggers which have a particular impact on carer QOL.

Another future research avenue would be to shift from considering the caregiver as an individual, and instead to conceptualise the caregiver-patient dyad as the unit of analysis. In this approach, the importance of the effect that carer and patient have on each other is recognised 52. For example, the extent women psychologically adjust to the situation when one member of a married couple is diagnosed with cancer plays a key role in the wellbeing of both the woman and her spouse. This is the case whether the woman is the patient (with breast cancer) or the caregiver of her husband (with prostate cancer)12. Although all but one of the studies included in this review feature interviews with both carers and patients, findings are not generally presented in terms of the caregiver-patient dyad. The ‘conflict with patient’ theme illustrates why the caregiver-patient dyad approach is useful. Future psychosocial interventions for cachexia could profit from working with both the patient and the carer together. This approach has been found to have some benefit in, for example, patients with advanced cancer and their spousal caregivers 53 and also in women with recurrent breast cancer and their family caregivers 54.

For families affected by cancer cachexia, this review has demonstrated that patient symptoms can impact the QOL of their carer. The impact on QOL is in ways that may be amenable to intervention. For example, it may be possible to facilitate conflict resolution. There is potential for improving carer, and in turn, patient experience of cancer cachexia through attention to cachexia-related factors that impact carer QOL.

**Study Limitations**

This systematic review and thematic synthesis of the qualitative literature only included direct carer 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. The aim of the studies which contributed quotes was not to uncover all the QOL issues faced by carers of patients with cancer cachexia and many of the quotes did not include any content which could unambiguously be considered relevant to carer QOL. The themes identified in this review should therefore be considered provisional because the data set was relatively small, more than half the extracted quotes from carers did not contain any information about their own QOL and there is no indication that data saturation has been reached. We plan to address this limitation by conducting carefully designed interviews specifically aimed at elucidating the relevant QOL issues.

A second limitation is that, because we included caregivers of cancer patients with cachexia, eating or weight loss problems the samples were not homogeneous.

Finally, the studies identified in our searches were all European or North American in origin. Although there is a lack of primary evidence from the rest of the world concerning the impact of caring for a loved one with cancer cachexia, we hypothesise that there will be some overlap with the themes identified in this review. This is because of the central role food and eating play in human existence.

**Conclusion**

The complexity of caring for a cancer patient with cachexia translates into a range of problems and experiences for informal carers. However, carers can sometimes be reluctant to report on how their lives are affected and focussed research with carers is required to provide a complete list of the relevant QOL issues. By recognising and addressing the impact of caring for a patient with cancer cachexia on the carers, both carer and patient QOL may improve.

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**Table 1: Characteristics of the included studies**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country** | **Aim** | **Carer Sample Characteristics** | **Qualitative Methodology** | **Data Collection Method** | **Method of data analysis** | **How was trustworthiness ensured?** | **CASP criteria met** |
| Holden, 1991 22 | 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 female & 5 male caregivers of patients randomly selected from 4 hospice programs | Not specified | Semi-structured interviews | Not specified | Not specified | 6 |
| Meares, 1997 46 | USA | To explore the meaning of nutrition cessation in adult in-home hospice patients with cancer as described by women primary caregivers during the first year of bereavement | 12 women who had cared for terminally ill cancer patients who had ceased oral intake | Van Manen’s method for researching the lived experience 55 | Semi-structured interviews | Themes and essences were identified using Van Manen’s method 55 | Double coding of half the transcripts. Themes approved by 3 participants. | 9 |
| Wilson, 2002 48 | UK | To investigate the needs of people with cancer, and their lay carers during discharge from hospital to home, and identify the role of district nurses in meeting these needs. | 18 carers of cancer patients discharged from hospital to home | Not specified | Semi-structured interviews | Thematic analysis | Critical examination and comparative interpretation of transcripts by the research team. Presentation of copious data extracts in paper | 8 |
| McClement, 2003 38 | 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. | 13 family members of adult palliative inpatients, 10 bereaved family members whose relative had been an inpatient on the same palliative care unit (PCU) in the last year | Grounded theory | Semi-structured interviews | Constant comparison | Prolonged engagement on PCU, triangulation, systematic checking of emerging model with participants & external colleagues | 9 |
| McClement, 2004 37 | Canada | To provide a more detailed description of one of the major sub-processes of a model regarding family responses to declining oral intake and weight loss in a terminally ill relative | 13 family members of adult palliative inpatients, 10 bereaved family members whose relative had been an inpatient on the same PCU in the last year | Grounded theory | Semi-structured interviews | Not specified | Not specified | 7 |
| Orrevall, 2004 23 | 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. | 7 female and 4 male family members of patients with advanced cancer receiving palliative care | Qualitative methods | Semi-structured interviews | Constant comparison | Input from the multi-disciplinary research group | 9 |
| Souter, 2005 45 | UK | To explore the experience of loss of appetite for cancer patients and their carers | 7 carers of 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 |
| Hopkinson, 2006a 29 | UK | To develop an understanding of the manifestations, management, and meaning of eating changes in patients with advanced cancer | 23 caregivers of patients 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 |
| Hopkinson, 2006b 40 | UK | To explore the experience of and concern about weight loss in people with advanced cancer, their caregivers & nurse specialists | 23 caregivers of patients with advanced cancer & a change in eating habits since they first perceived they were unwell | Humanistic nursing theory | Semi-structured interviews | Mixed strategy for cross-case analysis | Search for disconfirming evidence. Discussion with academics & clinicians | 9 |
| Strasser, 2007 25 | Switzer-land | To discover and describe elements of eating-related distress in male patients with advanced cancer & their female partners | 19 female partners of males with advanced cancer and 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 |
| Hopkinson, 2008 41 | UK | To examine a specific cause of distress (healthy-eating messages) & the implications for nursing practice | 32 carers of patients recruited from community palliative care team clients | Hermeneutic phenomenology | Not specified | Not specified | Not specified | 5 |
| McClement, 2008 39 | Canada | To provide a more detailed description of one of the major sub-processes of a model regarding family responses to declining oral intake and weight loss in a terminally ill relative | 13 family members of adult palliative inpatients, 10 bereaved family members whose relative had been an inpatient on the same PCU in the last year | Grounded theory | Semi-structured interviews | Constant comparison techniques and open, axial and selective coding procedures. | Prolonged engagement on PCU, triangulation, systematic checking of emerging model with participants & external colleagues | 8 |
| Reid, 2009a 43 | UK | To explore the experience of cachexia & its effect on food & feeding | 6 female & 2 male family member carers of patients with advanced, incurable cancer & cachexia living at home | Heideggerian phenomenological philosophy | Unstructured interviews | Thematic & interpretative phenomenological analysis | Not specified | 9 |
| Reid, 2009b 24 | UK | To explore the lived experience of cachexia for patients with advanced cancer and their family members | 10 female & 2 male carers of patients with advanced, incurable cancer & cachexia living at home | 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 |
| Locher, 2010 56 | 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 | 21 carers of cancer patients attending outpatient clinic. NB no criterion that patients had to be experiencing difficulty with food or eating activities | Constructionist perspective & grounded theory approach | Semi-structured interviews | Constant comparison | Not specified | 9 |
| Reid, 2010 42 | UK | To investigate the perceptions of patients and family members with regard to care received for cancer cachexia | 10 female & 2 male carers of patients with advanced, incurable cancer & cachexia living at home | Heideggerian phenomenological philosophy | Qualitative unstructured interviews | Thematic for whole sample. Interpretative Phenomenological analysis on a sub-set. | Not specified | 9 |

**References**

1. IPOS Mori. More than a million. Report for Macmillan Cancer Support. 2011.

2. National Institute for Health and Care Excellence. Improving Supportive and Palliative Care for Adults with Cancer. London. 2004.

3. McCarthy B. Family members of patients with cancer: what they know, how they know and what they want to know. *Eur J Oncol Nurs*. 2011; 15: 428-41.

4. Ferrell B, Hanson J and Grant M. An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psychooncology*. 2013; 22: 1645-52.

5. Given BA, Given CW and Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol*. 2012; 10: 57-64.

6. Romito F, Goldzweig G, Cormio C, Hagedoorn M and Andersen BL. Informal caregiving for cancer patients. *Cancer*. 2013; 119: 2160-9.

7. Carers (Recognition and Services) Act. UK. 1995.

8. Harding R, Epiphaniou E, Hamilton D, et al. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Support Care Cancer*. 2011.

9. Stenberg U, Ruland CM and Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*. 2010; 19: 1013-25.

10. Kim Y and Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer*. 2008; 112: 2556-68.

11. Clark D. Evaluating the needs of informal carers. *Prog Palliat Care*. 1993; 1: 3-5.

12. Kim Y, Kashy DA, Wellisch DK, Spillers RL, Kaw CK and Smith TG. Quality of life of couples dealing with cancer: dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 2008; 35: 230-8.

13. Segrin C and Badger TA. Psychological and physical distress are interdependent in breast cancer survivors and their partners. *Psychology, health & medicine*. 2014.

14. Segrin C, Badger TA and Harrington J. Interdependent psychological quality of life in dyads adjusting to prostate cancer. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 2012; 31: 70-9.

15. Fearon Kenneth CH, Glass David J and Guttridge Denis C. Cancer Cachexia: Mediators, Signaling, and Metabolic Pathways. *Cell metabolism*. 2012; 16: 153-66.

16. Bruera E. ABC of palliative care. Anorexia, cachexia, and nutrition. *BMJ*. 1997; 315: 1219-22.

17. Tisdale MJ. Cachexia in cancer patients. *Nat Rev Cancer*. 2002; 2: 862-71.

18. Bozzetti F. Screening the nutritional status in oncology: a preliminary report on 1,000 outpatients. *Support Care Cancer*. 2009; 17: 279-84.

19. Fearon K, Strasser F, Anker SD, et al. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncology*. 2011; 12: 489-95.

20. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *J Hum Nutr Diet*. 2000; 13: 113-7.

21. Rhondali W, Chisholm GB, Daneshmand M, et al. Association Between Body Image Dissatisfaction and Weight Loss Among Patients With Advanced Cancer and Their Caregivers: A Preliminary Report. *Journal of Pain and Symptom Management*. 2013; 45: 1039-49.

22. Holden CM. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. *Hosp J*. 1991; 7: 73-84.

23. Orrevall Y, Tishelman C, Herrington MK and Permert J. The path from oral nutrition to home parenteral nutrition: a qualitative interview study of the experiences of advanced cancer patients and their families. *Clinical nutrition*. 2004; 23: 1280-7.

24. Reid J, McKenna H, Fitzsimons D and McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud*. 2009; 46: 606-16.

25. Strasser F, Binswanger J, Cerny T and Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat Med*. 2007; 21: 129-37.

26. Moore HB. The meaning of food. *Am J Clin Nutr*. 1957; 5: 77-82.

27. Hudson PL, Trauer T, Graham S, et al. A systematic review of instruments related to family caregivers of palliative care patients. *Palliat Med*. 2010; 24: 656-68.

28. Weitzner MA, Jacobsen PB, Wagner H, Jr., Friedland J and Cox C. The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1999; 8: 55-63.

29. Hopkinson J and Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage*. 2006; 31: 293-305.

30. Millar C, Reid J and Porter S. Refractory cachexia and truth-telling about terminal prognosis: a qualitative study. *Eur J Cancer Care (Engl)*. 2013; 22: 326-33.

31. Wheelwright SJ, Darlington AS, Hopkinson JB, Fitzsimmons D, White A and Johnson CD. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Supportive & Palliative Care*. in press.

32. Centre for Reviews and Dissemination. Systematic reviews: CRD's guidance for undertaking reviews in health care. York. 2009.

33. Moher D, Liberati A, Tetzlaff J and Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *J Clin Epidemiol*. 2009; 62: 1006-12.

34. Thomas J and Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008; 8: 45.

35. Argiles JM, Anker SD, Evans WJ, et al. Consensus on Cachexia Definitions. *Journal of the American Medical Directors Association*. 2010; 11: 229-30.

36. Critical Appraisal Skills Programme (CASP). Qualitative Research Checklist. 2013.

37. McClement SE, Degner LF and Harlos M. Family responses to declining intake and weight loss in a terminally ill relative. Part 1: fighting back. *Journal of palliative care*. 2004; 20: 93-100.

38. McClement SE, Degner LF and Harlos MS. Family beliefs regarding the nutritional care of a terminally ill relative: a qualitative study. *J Palliat Med*. 2003; 6: 737-48.

39. McClement SE and Harlos M. When advanced cancer patients won't eat: family responses. *Int J Palliat Nurs*. 2008; 14: 182-8.

40. Hopkinson J, Wright D and Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs*. 2006; 54: 304-12.

41. Hopkinson J. Carers' influence on diets of people with advanced cancer. *Nurs Times*. 2008; 104: 28-9.

42. Reid J, McKenna HP, Fitzsimons D and McCance TV. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer Care (Engl)*. 2010; 19: 682-9.

43. Reid J, McKenna H, Fitzsimons D and McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum*. 2009; 36: 439-45.

44. Thurmond VA. The Point of Triangulation. *Journal of Nursing Scholarship*. 2001; 33: 253-8.

45. Souter J. Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences. *Int J Palliat Nurs*. 2005; 11: 524-32.

46. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally Ill. *Oncol Nurs Forum*. 1997; 24: 1751-7.

47. Shragge JE, Wismer WV, Olson KL and Baracos VE. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med*. 2007; 21: 227-33.

48. Wilson K, Pateman B, Beaver K and Luker KA. Patient and carer needs following a cancer-related hospital admission: the importance of referral to the district nursing service. *J Adv Nurs*. 2002; 38: 245-53.

49. Sehulster JR. Things we talk about, how frequently, and to whom: Frequency of topics in everyday conversation as a function of gender, age, and marital status. *The American journal of psychology*. 2006: 407-32.

50. R. L and Folkman S. *Stress, Appraisal, and Coping.* NY, USA: Springer Publishing Co., 1984.

51. Stamataki Z, Burden S and Molassiotis A. Weight changes in oncology patients during the first year after diagnosis: a qualitative investigation of the patients' experiences. *Cancer Nurs*. 2011; 34: 401-9.

52. Fletcher BS, Miaskowski C, Given B and Schumacher K. The cancer family caregiving experience: an updated and expanded conceptual model. *Eur J Oncol Nurs*. 2012; 16: 387-98.

53. McLean LM, Jones JM, Rydall AC, et al. A couples intervention for patients facing advanced cancer and their spouse caregivers: outcomes of a pilot study. *Psychooncology*. 2008; 17: 1152-6.

54. Northouse L, Kershaw T, Mood D and Schafenacker A. Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psychooncology*. 2005; 14: 478-91.

55. Van Manen M. *Researching lived experience: Human science for an action sensitive pedagogy*. New York: State University of New York Press, 1990.

56. Locher JL, Robinson CO, Bailey FA, et al. Disruptions in the organization of meal preparation and consumption among older cancer patients and their family caregivers. *Psychooncology*. 2010; 19: 967-74.