Original Article

The Prevalence of Concern About Weight Loss and Change in Eating Habits in People with Advanced Cancer

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Abstract
Weight loss and anorexia are commonly reported symptoms in people with advanced cancer. Little is known about patient experience of these phenomena, in particular whether they find them of concern. In this study, the prevalence of weight loss and eating-related concern was evaluated in patients with advanced cancer receiving specialist palliative homecare. The survey was a component of a larger study exploring the potential for helping patients and their families live with weight loss and change in eating habits. Patients were under the care of two specialist palliative homecare teams in the south of England in 2003. The questionnaire was distributed to the total eligible caseload of 233 patients with advanced cancer. The response rate was 85%. More than three-quarters of the 199 patients who returned the questionnaires reported weight loss (79%) and/or eating less (76%). Excluding the 32 patients (16%) who had sought help from a family member or friend to complete the questionnaires, more than half (52%) reported concern about weight loss and/or eating. Concern about weight loss or eating was found irrespective of proximity to death. Weight loss and eating-related concerns are commonly experienced by people with advanced cancer receiving palliative homecare. Further work is needed to establish if concerns are amenable to interventions that translate into meaningful outcomes for patients and their families.

Key Words
Weight loss, anorexia, prevalence, survey, advanced cancer, palliative care

Introduction

Many people with advanced cancer experience weight loss and change in eating habits. The reported prevalence of these symptoms ranges from 39%–82% for weight loss and 30%–80% for loss of appetite. Loss of appetite is one of the commonest symptoms in patients referred to palliative care services. Yet
little is known about patient experience of these symptoms, in particular whether they find them to be of concern.

In the UK, the National Health Service Cancer Plan and the National Institute for Clinical Excellence Guidelines for palliative care (2004) place importance on the need for improvement of palliative care services. Emphasis has been placed on strengthening the evidence base for symptom management and establishing outcomes of treatment and care that reflect the concerns of patients and their families.

This paper reports findings from a study of weight loss and change in eating habits of people with advanced cancer. The overall purpose of the research was to explore the potential for helping patients and their families live with these symptoms by developing interventions that lead to outcomes that they value. In this paper, we report data on the prevalence of the symptoms and the extent to which patients perceived them to be of concern.

**Background**

The study of weight loss and loss of appetite in people with advanced cancer has been undertaken in the context of biomedical research that has sought therapy for cancer cachexia syndrome. Cancer cachexia has been conceptualized as having both primary and secondary causes. Primary cachexia is caused by metabolic changes in response to the host tumor. Secondary cachexia is caused by factors that contribute to primary cachexia by reducing food intake. Examples include swallowing difficulties, depression, taste changes, nausea, and food aversions.

Pharmacological and nutritional interventions have been trialled for their effectiveness in treating cancer cachexia. However, such interventions have only been found to be of temporary benefit. Future management is seen to lie in combining therapies for both primary and secondary cachexia.

Increasingly, there are calls for research to examine outcomes that are meaningful to patients and their caregivers, such as increased quality of life, in addition to the traditional outcome measures of survival and morbidity. This surmises that weight loss, loss of appetite, and other symptoms of cancer cachexia syndrome can impact negatively on the quality of life of patients. In general, the presence or intensity of a symptom does not correlate with self-reported distress associated with the symptom. Thus, patients with weight loss and experiencing a decline in food intake may not necessarily perceive the symptoms to impact on their quality of life and well-being.

Few studies have looked at patient perception of weight loss and appetite loss. However, researchers have used caregivers, as proxies for patients, to assess the distress caused by loss of appetite. Addington-Hall and McCarthy conducted a survey with bereaved relatives and found that 50% reported that the deceased patient had experienced anorexia, and 23% reported that the patient had been distressed by the symptom. Morita et al. reported a survey of Japanese bereaved family members and found that 78% of those who noted appetite loss in a patient also reported a high level of distress in response. Exploratory work has similarly demonstrated loss of appetite to be perceived by carers as being distressing for patients. Using proxies for patients has limitations, however, in particular when the focus of interest relates to the meaning of the illness experience for the patient.

A structured literature review of electronic databases (PubMed 1966–2006/01; CINAHL 1982–2006/01; EMBASE 1980–2006/01; CancerCD 1990–2003/09) revealed three sources of information on patient experience of loss of appetite and weight. These sources were studies that look for a relationship between quality of life and appetite or weight, data from trials, and data from symptom assessment studies in palliative care populations.

Improved appetite alongside improvement in other symptoms has been shown to be associated with improved quality of life. Also, quality-of-life scores have been found to be lower in patients who have lost weight as compared with those whose weight remains stable. Yet Brown conducted a systematic review of evidence related to cancer-related anorexia and cachexia, and concluded that increasing food intake does not improve quality of life. This seems to imply that if anorexia and cachexia impact negatively on quality of life, this effect cannot be reversed by feeding.

Trials that have tested the effects of nutritional and pharmacological interventions
have reported conflicting results on the association between appetite, weight, and quality of life. Some provide supporting evidence that loss of appetite can impact negatively on quality of life, whereas others present seemingly contradictory findings. For example, attenuation of weight loss with thalidomide did not lead to significant difference in quality of life between intervention and control groups.

The surveys that have inquired about patients’ own perception of weight loss and loss of appetite indicate that these phenomena are troublesome to people with advanced cancer. Hawkins conducted a survey of 145 hospice and hospital inpatients and homecare patients referred to a palliative care service and found that 36% reported anxiety associated with anorexia. Seligman et al. asked 71 patients entering hospice care what symptoms bothered them and loss of appetite was ranked fourth. In addition, studies of symptom profiles of palliative care populations may provide insights into whether patients find the symptoms problematic. For example, Bradley et al. used the Edmonton Symptom Assessment Scale (ESAS) with palliative radiotherapy outpatients to demonstrate that 51% of patients reported moderate or severe distress in response to a question about their appetite. Like other symptom scales, the ESAS may be recording the presence or absence of appetite change rather than perception of the symptom as problematic, as the patient is asked to circle a number that best describes their appetite on a scale from best to worst possible. Furthermore, the response can be given with help from a health care professional or family member, who may influence the score. A scale that does invite patients to record how distressing or bothersome they find loss of appetite and weight loss is the Memorial Symptom Assessment Scale Short Form. Patients report the presence or absence of lack of appetite and then, using a five-point Likert scale, respond to the question “How much did it distress or bother you?” Of a sample of 156 inpatients and outpatients with advanced malignancies, 76% of those who lacked appetite also reported bother or distress from the symptom. Lack of appetite correlated with quality of life, overall symptom distress, and other symptoms that included weight loss.

It is widely assumed that loss of appetite and weight loss are troublesome to people with advanced cancer, yet limited research-based evidence supports this claim. No previous work has looked at the symptoms in a population of patients receiving specialist palliative homecare. If the symptoms are perceived by patients as distressing, there is an important implication. A new avenue for addressing cancer cachexia emerges, which is the potential for enhancing quality of life by developing psychosocial interventions that can mitigate distress.

Methods

The study was a cross-sectional survey of the total caseload of two specialist community palliative homecare teams typical of those delivering services across the UK. Patients referred to the service were over 18 years of age and were experiencing at least one symptom that required management by a specialist palliative care clinician. Together, the teams served a population of over one million people living in the South of England in 2003.

The survey was one of the methods of data collection adopted within a larger exploratory study of the experience of weight loss and eating difficulties for people with advanced cancer and their caregivers. Additional findings are reported elsewhere. The purpose of the survey was to elicit self-reported concern about weight loss and/or decline in food intake. All patients under the care of the participating homecare teams were invited to take part, with the exception of those judged inappropriate by their nurse specialist (NS). The patients excluded from the study by NSs were inpatients, those who died before they were approached, those unable to give informed consent, those living in complex social circumstances, those on holiday, and those in the process of discharge from palliative care during the period of questionnaire distribution.

The questionnaire was distributed by NSs in the course of their everyday practice to 67% (n = 233) of the total caseload across the two study sites over a two-week period. During a home visit, the nurse would describe the study to the patient and invite them to take part by completing the questionnaire. The patient was given a letter from the researcher and a questionnaire. All patients were also given
a stamped addressed envelope in which to return the questionnaire, and were offered the option of returning it to their NS in person. Nurses made telephone calls to the small number of patients whom they were visiting infrequently, requesting permission to mail the letter and questionnaire.

The questionnaire asked participants to consider their current weight and eating habits as compared to when they first considered that they were unwell. Questions invited a yes/no response to questions such as “I have concerns about eating” (see Appendix). The questionnaire was designed to be simple to minimize burden to patients, as this was thought important to accrual and minimizing the likelihood of missing responses. Questions were developed following a review of nutritional screening tools and consultation with the project steering group, which included people affected by cancer. The focus was on relevance and acceptability to patients.

Of the questionnaires returned, one had missing data and was subsequently not included in the analysis relating to weight loss. Analyses of the data were conducted using Statistical Package for Social Scientists version 12.0. Tests of significance for cross-tabular comparisons were performed using the Pearson Chi-squared test of independence, with significance being set at the 5% level.

The study was approved by two Local Research Ethics Committees (LREC no. 427/02/w) and conformed to local National Health Service research governance requirements.

**Results**

**Sample Characteristics**

Of the total patient population (n = 345) across the two study sites during the two-week study period, 272 (79%) were eligible for inclusion in the study. There were no statistically significant differences in the distributions of gender (P = 0.7), age group (P = 0.34), or diagnostic group (P = 0.07) in eligible participants across the two study sites. The sample was 48% male and ranged in age from 24 years to 97 years. Diagnoses were breast cancer (n = 40, 15%), lung cancer (n = 50, 18%), gynecological cancer (n = 17, 6%), gastrointestinal cancer (n = 47, 17%), head and neck cancer (n = 23, 9%), and other cancers (n = 94, 35%) (Table 1).

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Patient Characteristics (n = 272)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age, years (range)</td>
<td>67 (24–97)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>130 (48)</td>
</tr>
<tr>
<td>Women</td>
<td>142 (52)</td>
</tr>
<tr>
<td>Diagnosis, n (%)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>40 (15)</td>
</tr>
<tr>
<td>Lung</td>
<td>50 (18)</td>
</tr>
<tr>
<td>Gynecological</td>
<td>17 (6)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>47 (17)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>23 (9)</td>
</tr>
<tr>
<td>Other</td>
<td>95 (35)</td>
</tr>
</tbody>
</table>

**Questionnaire Completion**

Of the 272 patients eligible to participate, 39 were not invited to take part. The reason was that 25 were judged by their NS to be too ill, and 14 were under the care of two nurses whose ability to distribute the questionnaires was compromised by large caseloads and annual leave during the data collection period.

The questionnaire was completed by 199 patients and there were 34 nonresponders (response rate 85%). Responders did not differ from nonresponders in terms of gender, age or diagnostic group. Patients who were unable to complete the questionnaire independently were encouraged, in a letter, to seek the help of a relative, or their nurse specialist. Almost half (47%) of the patients self-completed the questionnaire. The other patients could be classified into two further groups, those who completed the questionnaire with the assistance of their nurse and those who used the assistance of a relative.

**Prevalence of Weight Loss or Decline in Food Intake**

More than three-quarters of the responders reported weight loss or decline in food intake. The figures, with confidence intervals (CIs) were as follows: weight loss was reported by 156 patients (79%; 95% CI = 73%–85%) and eating less was reported by 151 (76%; 95% CI = 70%–82%). There were no statistically significant differences in these percentages across the three groups of “self-completion”, “nurse-assisted completion”, and “family-assisted completion.”
Prevalence of Concern About Weight Loss or Decline in Food Intake

In contrast to the reporting of actual weight loss or decline in food intake, the response rates registering concern about these symptoms did appear to be affected by whether or not the questionnaire completion had been assisted by a relative. Family-assisted questionnaires reported concern about weight loss more frequently as compared with either self-completed or nurse-assisted questionnaires. Table 2 shows that this difference is statistically significant ($P = 0.01$). In contrast, there were no statistically significant differences between the concern rates reported by the self-completed and nurse-assisted groups. It is, therefore, possible that when family members or friends aided completion of the questionnaire, they could incorrectly report the patient to be concerned; while they were able to report the observable symptoms of weight loss and eating less, they may have been less able to report the patient’s feelings.

In view of the potential bias in the family-assisted questionnaires, questions related to concern were evaluated after excluding this group. More than one-third who completed the questionnaire without the aid of a family member reported that weight loss was of concern ($n = 60, 36\%$; $95\%$ CI $= 29\%$–$43\%$). More than one-third of these patients also reported eating less to be of concern ($n = 72, 43\%$; $95\%$ CI $= 36\%$–$51\%$). Overall, more than half of the respondents who completed the questionnaire without the aid of a family member reported concern about one or both of the symptoms ($n = 87, 52\%; 95\%$ CI $= 44\%$–$60\%$).

Six patients were concerned about their eating, although neither had they lost weight nor had their eating habits changed. There were no statistically significant differences in the reporting of concerns about eating across gender ($P = 0.95$) or concern about weight across gender ($P = 0.56$).

Difference Across Age Groups

For those respondents who reported weight loss, there appeared to be a trend toward decreasing concern about weight with advancing age (Table 3). But the trend in proportions did not reach statistical significance (Cochran-Armitage Trend Test $P = 0.08$). Similarly, a pattern, of decreasing concern with advancing age, emerged with reports of concern about eating less (see Table 4) but, again, the trend was not statistically significant (Cochran-Armitage Trend Test $P = 0.12$).

Proximity to Death

The respondents were followed-up between 18 and 22 months after they had completed the survey. It was found that $19\%$ ($n = 37$) remained alive or had been discharged from the palliative care services and $81\%$ ($n = 162$) had died from between less than a week and 85 weeks after completing the questionnaire (median time to death $= 17$ weeks). The survival time of the 101 deceased participants who had completed the questionnaire without the aid of a relative or friend was charted, with a distinction made between those who had reported concern about weight loss (Fig. 1; a narrow vertical line is drawn for each patient and the patients have been arrange on the x-axis in rank order of proximity to death.) and concern about eating less (Fig. 2).

Certain patterns appear to emerge in Figs. 1 and 2, such as higher incidence of weight loss and eating-related concern as death approaches. However, analysis has not established any as statistically significant at the 5% level. However, in another respect, the data are interesting as they demonstrate that respondents could report concern about weight loss and/or eating less irrespective of proximity to death. Concern about weight loss or eating was a problem for some patients at any point in their disease trajectory.

**Table 2**

<table>
<thead>
<tr>
<th>Patient Concern About Weight Loss and Eating Reported by Patient vs. Patient Assisted by Family Member in Completing Questionnaire</th>
<th>Self-completion, % (n)</th>
<th>Family-assisted completion, % (n)</th>
<th>$\chi^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient concern about weight loss</td>
<td>34 (32)</td>
<td>59 (19)</td>
<td>$= 0.01$</td>
<td></td>
</tr>
<tr>
<td>Patient concern about eating less</td>
<td>44 (42)</td>
<td>53 (17)</td>
<td>$= 0.38^*$</td>
<td></td>
</tr>
</tbody>
</table>

*Not significant.*

Discussion

This study revealed the point prevalence of concern about weight loss and/or eating to
be more than 50% in a population of people with advanced cancer. This is approximately two-thirds of patients who had experienced actual weight loss or decline in food intake, and is a measure of the extent to which the observable symptoms translate into concern. This is the first research-based evidence that the symptoms are problematic to a large proportion of people receiving palliative homecare services.

One of the limitations of this study is its cross-sectional design. It is possible that a higher proportion of patients experience weight loss and eating-related concerns at some point during the disease. This would be the case if there is intermittency in experiencing such concerns, or if concerns evolve as death approaches.

The extent to which the results can be generalized may be limited by the focus on people receiving palliative homecare, although this is a group of patients who have previously received scant attention, as the majority of palliative care research has been conducted with inpatient groups. Placing emphasis on minimizing patient burden to maximize participation in the study limited the information that could be gathered from each participant. As a consequence, many characteristics of the participants are unknown, such as ethnicity, functional status, economic status, cohabitants, and psychological health, which may all be important to the perception of weight loss and loss of appetite as problematic. Furthermore, even though much attention had been paid to developing a questionnaire that could be completed by frail patients with poor concentration, 32 questionnaires were completed with the help of a family member. This subsample was excluded from some of the analysis because it seemed that the responses may be a reflection of the relative’s or friend’s perception rather than the patient’s. Therefore, the findings exclude a subgroup of patients who may be more dependent on their caregiver than those included in the analysis.

Very little previous work has examined the experience of weight loss and eating for patients with advanced cancer. The exploratory work that has been conducted provides evidence that declining food intake is of greater concern to caregivers than patients.\(^{26,31}\) The difference in results obtained by this study between self-completed questionnaires and questionnaires completed with the assistance of caregivers is consistent with the earlier observations. This raises the question of whether interventions should be targeted at caregivers, as opposed to patients. However, this study demonstrates that change in eating habits is of concern to many patients. It might be that it is important to address both patient and carer concerns, either independently or together, in order to mitigate weight- and eating-related concern.

In populations of people with advanced cancer, Hawkins\(^{26}\) found the prevalence of anxiety about loss of appetite to be 36% and Chang et al.\(^ {29}\) found the prevalence of bother or distress to be 76%. These reported findings

### Table 3

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Concerned about weight loss</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 Years</td>
<td>70% (7)</td>
<td>100% (10)</td>
</tr>
<tr>
<td>50–59 Years</td>
<td>35% (8)</td>
<td>100% (23)</td>
</tr>
<tr>
<td>60–69 Years</td>
<td>50% (19)</td>
<td>100% (38)</td>
</tr>
<tr>
<td>70–79 Years</td>
<td>39% (16)</td>
<td>100% (41)</td>
</tr>
<tr>
<td>&gt;80 Years</td>
<td>24% (4)</td>
<td>100% (17)</td>
</tr>
</tbody>
</table>

Number of patients appears in parentheses.

### Table 4

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Concerned about eating</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 Years</td>
<td>54% (6)</td>
<td>100% (11)</td>
</tr>
<tr>
<td>50–59 Years</td>
<td>48% (16)</td>
<td>100% (33)</td>
</tr>
<tr>
<td>60–69 Years</td>
<td>49% (22)</td>
<td>100% (45)</td>
</tr>
<tr>
<td>70–79 Years</td>
<td>36% (19)</td>
<td>100% (53)</td>
</tr>
<tr>
<td>&gt;80 Years</td>
<td>36% (9)</td>
<td>100% (25)</td>
</tr>
</tbody>
</table>
contrast with the findings of this study, where 43% of patients reported concern about decline in food intake and 36% of patients reported concern about weight loss. Possible explanations for differences across the studies include the differing cultural and patient populations, and the use of different concepts (concern vs. anxiety vs. bother vs. distress) to try to capture negative emotion in response to symptoms.

Concern was studied because of its everyday usage and the assumed importance of selecting a concept that would be easily understood and not interpreted as an inquiry about mental health problems. But concern may be a precursor of distress. Perhaps intervention for concerns could prevent more debilitating emotional change, such as psychological distress. Distress as a consequence of symptoms can precipitate admission to secondary care services and preclude the possibility of patients dying at home. In the UK, more than 50% of people with cancer express a preference for home death, yet a majority dies in hospitals or other institutions. If patients are troubled by weight loss and decline in food intake, psychosocial intervention to mitigate this concern may be important in enabling them to achieve their preferred place of death.

**Implications**

Weight-losing patients have previously been shown to have poorer quality of life and greater symptom distress than weight-stable patients. As this survey was cross-sectional, it cannot show if concern about weight loss changes over time. It is perhaps the case that only patients who were losing weight at the time of completing the survey reported concern. Sarna et al. found symptom distress to fluctuate over time and to be greatest in those who had lost the most weight, but this does not mean that weight loss causes distress. It is interesting that there were examples of people expressing concern irrespective of their proximity to death, demonstrating that weight loss and eating can be troublesome for patients regardless of their location on their advanced cancer journey. Longitudinal work is needed to test the hypothesis that patients only...
become troubled by weight loss when they are losing weight and that concern is, therefore, an intermittent but recurring problem that contributes to overall symptom distress for people with advanced cancer.

In health, weight is dependent on dietary intake. Patients may believe that the solution to the weight loss in advanced cancer is to increase food intake and their concerns may, in part, arise out of efforts to achieve this goal. However, the weight loss that can accompany cancer cannot be explained by reduction in food intake alone. Weight-losing patients have been found to have a higher energy intake per kilogram body weight than weight-stable patients. Enhanced food intake has not been found to improve survival time, nutritional status or lead to sustained weight gain, although there may be benefits still to be recognized. Addressing patients’ concerns about their weight loss and change in eating habits may need to include education on the likely costs and benefits of working at optimizing food and nutritional intake when living with advanced disease.

**Conclusion**

This study has found that weight loss and eating-related concerns are commonly experienced and previously unresearched as problems for people with advanced cancer receiving specialist palliative homecare services. Exploratory work, conducted in parallel with the survey report here, has revealed that some of the reasons for patients’ concerns may be amenable to intervention. Further work is needed to establish if concerns are amenable to interventions that translate into meaningful outcomes for patients and their families in terms of improving their quality of life.

**References**


35. Ovesen L, Hannibal J, Mortensen EL. The inter-relationship of weight loss, dietary intake, and quality of life in ambulatory patients with cancer of the...


Appendix

The Macmillan Weight Loss and Eating Concerns Questionnaire

Please read the following statements and then circle YES or NO next to each statement.

My weight has changed since I first became unwell.…………… YES/NO
I weigh less now than before I first became unwell……………. YES/NO
I am concerned about my weight. …………………….. YES/NO
My family is concerned about my weight. …………………….. YES/NO
My eating habits have changed since I first became unwell. …… YES/NO
I eat more now than before I first became unwell.……………… YES/NO
I eat less now than before I first became unwell.……………… YES/NO
I have concerns about eating. …………………….. YES/NO
My family is concerned about my eating habits………………… YES/NO
My friend/relative helped me to complete this questionnaire. … YES/NO
My nurse/carer helped me to complete this questionnaire……… YES/NO
I am willing to consider being interviewed by Research Nurse, Jane Hopkinson, about my weight and eating habits. ……….. YES/NO
Name……………………..Address……………………………... Tel……..