

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. J Pain Symptom Manage 2006;32:322–331. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

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

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Introduction

Many people with advanced cancer experience weight loss and change in eating habits.¹ The reported prevalence of these symptoms ranges from 39%–82% for weight loss and 30%–80% for loss of appetite.² Loss of appetite is one of the commonest symptoms in patients referred to palliative care services.³ 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 Plan⁴ and the National Institute for Clinical Excellence Guidelines for palliative care (2004)⁵ 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.⁶

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.^{7,8} 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.^{9,10} 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.¹¹ 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 McCarthy¹² 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.¹³ 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.^{14,15} 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.^{16–18}

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.¹⁹ 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.^{20,21} Yet Brown²² 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

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