

The Durham Macmillan Cachexia Project: Improving the Experience of the Anorexia-Cachexia Syndrome for Patients with Cancer

Colette Hawkins, Macmillan Consultant in Palliative Medicine
Inga Andrew, Senior Clinical Pharmacist
University Hospital of North Durham
colette.hawkins@cddft.nhs.uk

Background

Patients with cancer and their carers face many challenges. But living with Anorexia-Cachexia Syndrome (ACS) seems particularly demoralising. The effects impact on both patients and carers in many different ways.

Cachexia has no agreed definition, but is often described as the presence of involuntary weight loss.¹ Percentage weight loss compared with pre-illness weight, speed of weight loss over time and preferential loss of muscle and visceral protein are variably described.¹⁻³ Cachexia is driven by a complex of abnormal metabolic, neuro-endocrine and immunological pathways, which also have yet to be fully defined. Although cachexia is commonly recognised once patients have lost significant weight, the underlying pathophysiology is established before weight begins to fall.

Cachexia is common; it has been shown to be present in up to 80% of patients with advanced solid malignancy.⁴ It is already established at first presentation in 80% and 60% of patients with primary upper gastrointestinal malignancy and lung malignancy respectively.⁴ Cachexia rarely occurs in isolation - rather a symptom complex occurs including anorexia, early satiety, chronic nausea and fatigue, amongst others.⁵⁻⁸ ACS is a term used to encompass the breadth of symptoms commonly seen alongside a weight-losing process. ACS reflects a symptom pattern, but not necessarily a common etiology.

The psychosocial impact of ACS is also increasingly appreciated. Social consequences include strained family dynamics over meals coupled with pressure to eat, and guilt on all sides. Anxiety around eating is common particularly amongst carers and for some, this is their greatest source of anxiety.⁹ Both patients

and staff describe a sense of hopelessness and helplessness around anorexia and weight loss in cancer¹⁰ with a tendency to avoid raising the subject. This has been described as the 'weight loss taboo'.¹⁰ Relentlessly progressive, the weight loss provides a permanent visible reminder of incurable illness.

The Durham Macmillan Cachexia Project was defined with the impression that awareness, assessment and management of ACS were generally inadequate leaving a significant area of physical and psychosocial distress which warrants attention.

The Project

Macmillan Cancer Support funded a three year project based at the University Hospital of North Durham (UHND), with the overarching aim of improving the experience of ACS for patients with cancer. The philosophy of the project centred on an acceptance of the current inability to reverse or reliably retard the progression of ACS together with the ambition to improve care of patients with problems related to ACS. Several research projects and an audit were designed and undertaken.

Baseline investigations included a questionnaire survey of trained medical and nursing staff in various clinical areas within UHND.¹¹ The aim was to ascertain understanding of ACS and approaches to its management. One hundred questionnaires were completed (86% response). Key findings included a wide range in understanding and awareness of cachexia, common symptoms inconsistently screened (especially relating to mouth problems and early satiety) and considerable variability in approach to the three most commonly reported symptoms: dry mouth, early satiety and poor appetite.

An audit of the prevalence of unmanaged symptoms associated with ACS in patients in the palliative care setting, together with medication prescribed to this group was also undertaken.¹² Active symptoms reported by the 23 patients within the audit are detailed in Table 1.

Table 1 Symptom Profile of Patients with ACS; audit results

Symptom	Number of patients reporting symptom (%)
Dry mouth	21 (91)
No appetite	17 (74)
Feel full quickly	16 (70)
Nausea or vomiting	14 (61)
Constipation	12 (52)
Altered taste	11 (48)
Problems swallowing	10 (43)
Mouth sores	9 (39)
Diarrhoea	5 (22)
“Smells bother me”	4 (17)

Eighty nine recommended changes to prescribed medication were suggested by the project pharmacist. Thirty eight per cent of these recommendations were to manage dry mouth and 17% involved prokinetic antiemetics, mostly initiating or increasing the dose of metoclopramide.

The baseline studies confirmed initial impressions that patients with ACS have a considerable burden of physical symptoms for which assessment and management is haphazard. The need for education of staff and the potential value of a standardised assessment and management tool were clear and work commenced on the Durham Cachexia Pack.

The main research project undertaken was a within-group study to quantify the impact of our standardised assessment and management tools on the symptoms reported in ACS.¹³ Forty of the 79 patients referred to the project were recruited (most non-recruitments were because patients were too unwell). Key findings from this project included recognition that patients were identified very late in their disease journey, with a considerable burden of unmanaged symptoms. Staff are primarily aware of weight loss whereas patients report other symptoms (early satiety and dry mouth) as their greatest concern. Simple advice and strategies (non-pharmacological and pharmacological) used according to the pre-written management strategy significantly reduced symptom burden over the 4 week duration of the project (figure 1).

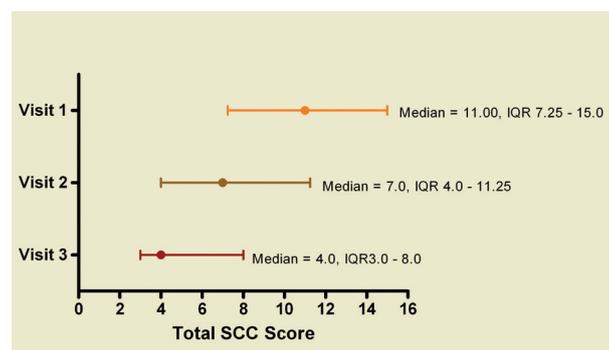


Figure 1 Sequential Total Symptom Scores from the Symptoms and Concerns Checklist

The Pack

The Macmillan Durham Cachexia Pack (MDCP) has been developed as a consequence of experience and evidence accumulated during the 3-year project. The multi-disciplinary team behind the pack evaluated the evidence base and current best practice when developing the strategies within the pack. However, with local variation in prescribing guidelines and access to services, it is adaptable for local use. It is intended for use by any healthcare professional, irrespective of experience with

this group of patients. The aim is to provide a standardised assessment tool to be used at any stage, and repeatedly in a patient's cancer illness. The pack is promoted for use in all patients with metastatic malignancy and in patients with lung or upper gastrointestinal cancers regardless of stage. It is not intended for use only if patients have clear weight loss, rather as a means to identify ACS at an earlier stage, when treatments may have greater impact.

The pack includes a short assessment tool (patients can complete this if they are able), algorithms for management of dietary and exercise needs according to patients' fitness, symptom management advice and a number of patient/carer information sheets addressing the practical and psychological issues they face (see box 1).

Box 1. Information Leaflets for Patients and Carers in the MDCP

- Eating well
- Helping someone to live with changes in their eating habits
- Helping yourself live with changes in eating
- Living with change in eating habits
- Living with disagreements about food
- Living with change in the smell of food
- Living with taste changes
- Living with change in the texture of food
- Pacing and daily activities
- Storage and use of nutritional supplements
- Recipe ideas for nutritional supplements
- Adapting meals to prevent weight loss (Focus on Food)
- Exercise programmes
- Mouth care
- I need advice about benefits and financial support

The pack was adopted by Macmillan Cancer Support and launched nationally in 2007. It is the first national set of guidelines for the management of ACS.

The pack is accessible on the CDDFT intranet site (via 'Cancer Services', 'Palliative Care', then 'Guidelines').

The Future

There is considerable research effort invested in identifying ways of manipulating the underlying pathophysiology of ACS, thus retarding or reversing the process. Modest progress has been made with some agents, including eicosopentanoic acid, melatonin and thalidomide, apparently reducing the speed of progression of ACS in some patients. Nevertheless there is no sign yet of a predictable attack on the complex of abnormal pathways leading to ACS and until this is achieved, it is imperative to improve the experience of living with ACS in any way possible. This will entail education to increase awareness of ACS and the wide ranging problems it causes. In addition, a new culture of assessment is required to encourage identification of ACS at the earliest possible stage. Further research to develop a stronger evidence base for management strategies would be important, and would enable a bolder shift towards standardised approaches.

The Durham Cachexia Project and MDCP raise the profile of the breadth of problems these patients face and the potential for improvement by simple, systematic strategies which are within the capabilities of all healthcare professionals.

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