

Anorexia-cachexia syndrome

— improving the patient experience

By Inga Andrew, MRPharmS, DipClinPharm, Colette Hawkins MRCP, MBBS, Kerry Waterfield MRCP, MBBS, Graeme Kirkpatrick MRPharmS, DipClinPharm and Stephen Williams RGN, BSc

A pharmacist-led multidisciplinary group from Durham are investigating whether standardised management and assessment strategies can improve the care of cancer patients with anorexia-cachexia syndrome.

This article describes their work



Patient leaflets form part of the Durham Macmillan Cachexia Pack

LEAFLETS DESIGNED BY JANE HOPKINSON, MACMILLAN RESEARCH UNIT

There are a number of obstacles to the effective management of anorexia-cachexia syndrome (ACS). These include inconsistency in assessment and management of patients at risk and considerable variability in understanding of the syndrome among health care staff.

In January 2005 the University Hospital of North Durham, part of County Durham and Darlington NHS Foundation Trust, secured funding from Macmillan Cancer Support to explore ways of improving the experience of ACS for patients with cancer. A Macmillan senior clinical pharmacist was appointed to run the project with the support of a consultant in palliative medicine.

The project involved:

- A review of staff understanding of ACS
- An audit of the symptoms experienced

Inga Andrew is Macmillan senior clinical pharmacist, **Colette Hawkins** is consultant in palliative medicine, **Kerry Waterfield** is staff grade in palliative medicine and **Graeme Kirkpatrick** is deputy chief pharmacist, all at University Hospital of North Durham, County Durham and Darlington NHS Foundation Trust. **Stephen Williams** is Macmillan development manager at Macmillan Cancer Support, York.

- by patients and the drugs prescribed for them
- A new protocol for the management of patients with ACS
- Development of a cachexia resource pack

Staff review

Initial work included a baseline review of how hospital staff who came into contact with cancer patients approached ACS. A questionnaire was sent to all staff in the hospital who had contact with cancer patients. This revealed a lack of awareness of the breadth of symptoms associated with the syndrome, together with variable and erratic assessment and management. This highlighted the need for tools to encourage greater consistency in assessment and management of patients with ACS, together with better staff education.

Symptoms and prescribing

An audit of patient symptoms and prescribing for ACS was undertaken in 2006. Patients who met the criteria for inclusion in the audit were assessed using the patient generated subjective global assessment tool. This assesses and scores weight loss, food intake, symptom burden and physical activity. The patients described a high number of symptoms associated with

ACS, many of which did not appear to have been managed and were active problems for them.

Review of the medicines prescribed for these patients led to a number of recommended drug changes. In most cases this involved the initiation of a new drug or increased dose of a currently prescribed drug. Discontinuation of a drug or reduction in drug dose were required less frequently.

This understanding of the symptom burden of ACS in cancer patients, and a picture of how the condition was being managed in the hospital, enabled the creation of standardised assessment and management tools. Prescribing guidelines and shared care agreements were written and approved for several of the medicines commonly used. The impact of these on symptom burden is being assessed in a research project as described in Panel 1 (p266).

Cachexia pack

Early experience of this project led to the development of the Durham Macmillan Cachexia Pack. The aim of this was to provide a tool to encourage the standardised, systematic assessment and management of the common problems encountered by patients with ACS. The pack contents have been written by a multidisciplinary group

using an evidence base wherever possible, or current best practice. Contents of the pack, which is currently being piloted locally, are summarised in Panel 2.

The pack will be launched nationally at the end of the year. A key challenge will be translating this document into a change in practice. The team are currently considering ways of achieving this, with the help of feedback from the pilot and an ongoing programme of education.

Assessment

The impact of the improved management programme on symptom burden is being assessed by a within-group study, which started in August 2006. Patients are asked to score their symptoms at each home or ward visit, ensuring that the outcome of any intervention (pharmacological or non-pharmacological) on symptoms is recorded. Although this project focuses on symptom scores, ACS is a complex physical and psychosocial experience (see p249). Therefore, on completion of this research project, a cohort of patients will be offered the opportunity to participate in a semi-structured interview with a member of the project team. The patient perspective on the impact of the standardised approach will supplement the quantitative symptom scores and data about medicine changes with qualitative information, and give a greater insight into the issues that matter to patients.

Next steps

The within-group study was due to complete as this article went to press. It will provide the evidence-base to the strategies

Panel 2: Contents of the Durham Macmillan Cachexia Pack

The Durham Macmillan Cachexia Pack has been designed for use by any health care professional. It provides a standardised, systematic approach to the assessment and management of patients with anorexia-cachexia syndrome. It contains:

- **An assessment tool** An abridged version of the patient generated subjective global assessment tool, as described in Panel 1.
- **A symptom management tool** For each symptom listed in the tool a recommendation is given for pharmacological treatment and non-pharmacological advice.
- **Nutritional strategies**
 - Two algorithms describing basic approaches appropriate for patients with either early or late ACS
 - Patient information leaflets
 - Basic information about prescribing nutritional supplements
- **Physiotherapy management pathways**
 - Two algorithms detailing simple exercise strategies with accompanying patient information leaflets
 - A patient information leaflet on managing fatigue
- **Patient and carer leaflets** Most of these are designed by the Macmillan research unit at the University of Southampton. They focus on relieving the tension ACS creates in families by educating those affected by the problem.
- **Evidence base** Where an evidence base is available it is listed here. Otherwise best practice or findings from the research project are stated.

incorporated in the Durham Macmillan Cachexia Pack. The pack will be introduced at a one-day seminar on 23 November, funded by Macmillan Cancer Support. Further details are available by e-mailing conferenceadministration.service@durham.ac.uk.

Conclusion

The research project at University Hospital of North Durham is the first pharmacist-led project aimed at improving the experience

of cancer patients with ACS. It aims to provide generic tools that can rapidly reduce the symptom burden of a large group of patients. A large proportion of patients with ACS have suffered with unrecognised or unmanaged symptoms. This project provides simple, standardised methods to improve the wellbeing of patients with ACS which, to date, have been variably managed. A novel outcome of this project is the development of strategies and tools which any health care professional will be able to access and use, regardless of background and experience.

ACKNOWLEDGEMENTS Tony Hildreth, medical statistician and deputy head of research at City Hospitals Sunderland NHS Foundation Trust and Keith Holden, principal clinical pharmacist at County Durham and Darlington NHS Foundation Trust for their input to the project.

The team from University Hospital of North Durham were awarded a Pharmaceutical Care Award for their work (*The Pharmaceutical Journal* 2007;279:10)

Suggestions for future special features

If you would like to suggest a topic for a future special feature in *Hospital Pharmacist*, or if you are interested in writing about your area of practice, please contact Hannah Pike (e-mail hannah.pike@pharmj.org.uk, telephone 020 7572 2425).

Panel 1: Assessing the impact of standardised management tools

Patients with malignancy and symptoms of anorexia-cachexia syndrome (ACS) at University Hospital of North Durham are referred to the Macmillan senior clinical pharmacist. They are reviewed by the pharmacist (on the ward or during a home visit) and the consent process for this research project is explained. Patients then complete the patient-generated subjective global assessment tool which assesses weight loss, food intake and symptom- and activity-related problems commonly encountered in these patients. Patients are also asked to complete a "symptoms and concerns checklist". This is an amended tool that asks patients to quantify how much a symptom is bothering them using the four European Organisation for the Treatment and Research of Cancer quality of life scoring techniques. A diet history, drug history and medicines use review are also undertaken by the pharmacist.

A management plan is then devised for each patient. This includes recommendations for:

- Medicines (initiated, withdrawn or dosages altered)
- Supplement drinks (in accordance with local protocol)
- Dietitian referral
- Non-pharmacological advice (for example, eating habits and oral hygiene)

This plan is then communicated to the medical and nursing teams. Patients are reviewed by the pharmacist after two and four weeks with a repeat of the symptoms and concerns checklist. These strategies are incorporated in the Durham Macmillan Cachexia Pack (see Panel 2).