CARERS’ INFLUENCE ON DIETS OF PEOPLE WITH ADVANCED CANCER

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The Macmillan weight and eating studies (MWES) 2003–2007 are investigating ways of helping people with advanced cancer live with symptoms of weight loss and loss of appetite. These can cause distress for both patients and carers, and can be a source of conflict between them. The aim of this study was to examine a specific cause of distress (healthy-eating messages), and the implications for nursing practice. Data for this article is taken from a mixed-method exploratory case study carried out in 2003 and a pilot study for a trial in 2005. Carers are committed to helping patients and believe it is important to encourage them to eat. However, the influence of healthy-eating messages can lead to inappropriate feeding and cause distress for both groups. Nurses can help by assessing carers’ concerns about patients’ eating habits and providing information about eating well in advanced cancer.

INTRODUCTION
This article provides evidence that family members can influence patient food intake and their experience of eating. It draws on research about people with advanced cancer who have symptoms of cancer cachexia syndrome. This condition is a constellation of symptoms that include weight loss and anorexia. The syndrome is caused primarily by tumour-induced metabolic change (Tisdale, 2002).

Up to 80% of people with advanced cancer have symptoms of weight loss and loss of appetite. People with advanced cancer troubled by weight loss and anorexia require different support from those earlier in their cancer journey who have potentially curable disease.

The current lack of evidence that feeding people with advanced disease can lead to sustained weight gain or improved survival should inform nursing care.

The purpose of nursing assessment should be to identify whether patients perceive weight loss and eating as problems. Only if the symptoms are causing distress is intervention appropriate.

There is a spectrum of response to weight loss and changing eating habits in people with advanced cancer, ranging from acceptance to self-action (Hopkinson and Corner, 2006).

Patients who engage in self-action can improve their nutritional intake without needing to increase the amount they eat (Cancerbackup, 2007). However, the majority of people with advanced cancer and a small appetite place value on enjoyment rather than nutritional content of food, and eating what they enjoy is likely to optimise patients’ nutritional intake.

AIM
The aim of this study was to examine a specific cause of distress for both patients and carers (namely, healthy-eating messages), and the implications for nursing practice.

METHOD
MWES is a series of mixed-method studies informed by hermeneutic phenomenology. This report draws on data from two projects – a mixed-method exploratory case study conducted in 2003 and a pilot study for a trial carried out in 2005. Participants were clients of two community palliative care teams in the South of England.

The main method of data collection for both projects was semi-structured interviews. These interviews were transcribed verbatim, then analysed using content and thematic approaches. This study draws on a subset of the interviews – the 32 patient-carer pairs of interviews generated by the two projects.

Two local research ethics committees approved the study, which conformed to local healthcare organisations’ research governance requirements. All participants gave written consent.

RESULTS
Without exception, carers wanted to help patients with their problems. However, many expressed uncertainty about how best to help when patients were losing weight and had a small appetite.

Carers typically felt a sense of responsibility for patients’ food intake. Effort to encourage them to eat was often described. However, while carers wanted to

IMPLICATIONS FOR PRACTICE

• While dietitians are the professional group with expertise in nutritional support, nurses have contact with all patients, so are in a prime position to offer first-line assessment and intervention or referral to specialist services if appropriate.

• Nursing assessment should include questions on carers’ concerns about what patients are eating. Depending on the carer’s concerns, it may be important to offer information and advice about the disease-induced changes in eating habits often experienced by people with advanced cancer.

• It may also be worth pointing out that a healthy diet (that is, low-fat, high-fibre foods, and five portions of fruit and vegetables daily) has no proven benefit for people with advanced cancer.
do something to help patients and saw feeding as a way of helping, few were confident that what they were actually doing was appropriate.

Paula’s husband was focusing on his wife’s nutritional intake, for example counting her daily calorie intake but without knowing what a realistic goal might be: ‘I think we can, from a diet point of view, strengthen her. I can’t help thinking she has had such a rapid weight loss in a few months… really we need to stop that and try to put some of that weight back. I don’t know how much, I’m in out of my depth here.’

Beryl had a different concern. Her husband had lost weight and was weak. He was able to eat just one-quarter of his pre-illness intake. She was uncertain if doing things for him was helpful (enabling him to conserve energy) or unhelpful (as exercise is needed to maintain muscle mass).

In the absence of any guidance, carers did what they believed sensible and in the patient’s best interests. However, well-intentioned comments and action could contribute to patients’ eating problems. In some cases, this was even seen as uncaring, when it was felt to show that the carer had little insight into the experience of living with a poor appetite. Emma explained: ‘Mum will go through, “Would you like this? Or would you like that?” The end product is that it is even harder for me to try and stomach something.’

Colin’s problem was different. He found his wife’s encouragement to eat troubling because it implied he was to blame for his weight loss, when it was outside his control.

Healthy-eating messages were one source of information that carers drew on when deciding what was in patients’ best interests. These messages, disseminated to the general population, are about avoiding the risk of disease.

Carers described urging patients to eat fruit and vegetables. They were proud of their achievements in encouraging, persuading, cajoling and sometimes forcing patients to eat these foods.

Fruit, vegetables and other foods considered good for patients were perceived to have the potential to strengthen the body and/or to arrest or cure the cancer.

Mike’s wife said: ‘We haven’t been told but I presume that a healthy diet is good for your body no matter what the cancer tries to do to it. It [the body] can fight back and you need somebody to encourage you to eat sometimes.’

When patients were unable to eat foods perceived as healthy by carers, tensions could arise. There was also conflict over what should be eaten. Of the 32 patient-carer pairs, 10 described at least one disagreement arising from the perception that the patient was eating unhealthy foods.

**DISCUSSION**

The MWES have found that carers can unintentionally compromise the well-being of a person with symptoms of cancer cachexia syndrome. This article draws attention to one possible explanatory factor – healthy-eating messages.

Carers want to help people with advanced disease manage weight loss and appetite change. They take for granted that encouraging or even forcing food is important to patients’ well-being, yet there is no proven benefit for people with advanced cancer. Engaging in feeding activity can contribute to suffering as the end of life approaches. These findings suggest that working with carers is important in improving the lives of people in this situation.

Evidence that a diet high in fibre, fruit and vegetables can protect against cancer (Shaw and Lewis, 2005) and other diseases has generated an industry around promoting good foods to eat. The messages are targeted at the general population.

However, healthy-eating messages do not take into account the special dietary needs of people with disease or particular illness-related problems. Patients with advanced cancer and cancer cachexia syndrome are a special group. If they experience unintentional weight loss and loss of appetite, then selecting high-energy and high-protein foods from those that are enjoyed is the way to eat well. Many such foods are “prohibited” foods, labelled as unhealthy for the general population. It is easy to assume that they will be particularly harmful for those who have already succumbed to disease – when, in fact, for someone who has a small appetite they are a way of optimising nutritional intake (Nutrition Advisory Group for Elderly People of the British Dietetic Association, 2001).

**Study limitations**

The limitation of this study lies primarily in its cross-sectional design. It examines interviews conducted at one point in time and relies on individuals’ accounts of events to draw its conclusions. The claims would be strengthened by further work examining change in patient symptom experiences and associated carer behaviour over time.

In addition, the transferability of the findings is limited by the sample, as black and minority ethnic groups were poorly represented. The findings may not translate to all community care contexts.

**CONCLUSION**

While only some people with advanced cancer see a dietitian, all see a nurse. Nurses are therefore in an ideal position to provide information and advice on how to eat well when living with advanced cancer. For resources to support nursing practice, see nursingtimes.net.