

Nutritional considerations for the palliative care patient

Clare Shaw and Lucy Eldridge

Weight loss and poor nutrition is a common concern among palliative care patients and their carers (Hopkinson et al, 2005). Weight loss may be identified by many as symbolising progression of the disease, loss of control over the patient's own body and both physical and emotional weakness. It may also symbolise proximity to death and is often associated with physical weakening, fatigue and reduced quality of life. This article explores the nutritional issues faced by palliative patients, the ethical issues supporting decision-making and the methods of nutritional support available.

Nutritional issues

Patients in palliative care often describe nutritional problems as their disease progresses. Poor nutritional status has been associated with reduced survival in terminally ill cancer patients (Shaw, 2011), and in one study, 71% of patients were deemed malnourished (Sarhill et al, 2003). Progressive forms of neurological conditions such as Parkinson's, motor neurone disease and multiple sclerosis, as well as later stages of chronic obstructive pulmonary disease (COPD) and HIV, are also often associated with nutritional difficulties (Gandy, 2014).

A range of symptoms and barriers, often caused by the condition or the treatment can effect nutritional intake. Patients may experience a loss of interest in food, a decreased appetite, nausea, vomiting, diarrhoea or constipation, or a physical obstruction within the gastrointestinal tract.

For some patients, malnutrition and weight loss develops into cachexia as the effects of malnutrition and advanced disease interact. Cachexia is defined by Fearon et al (2011) as 'a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support'. In 2011, a panel of experts agreed on a definition and classification of the stages of cancer cachexia (Sarhill et al, 2003). They classified cachexia into the stages of pre-cachexia, cachexia and refractory cachexia,

Abstract

Many palliative care patients experience nutritional problems as their conditions progress. This includes those with progressive neurological conditions, chronic obstructive pulmonary disease (COPD) as well as advanced cancer. Nutritional issues not only impact patients physically but also psychologically and can also have an effect on those caring for them. It is important that patients are screened appropriately and that one identifies what symptoms are potentially affecting their intake. Decisions should always be patient-centred. Nutritional interventions range from food modification and nutritional supplements, to more intense methods such as enteral or parenteral nutrition, and these may have ethical and legal considerations. This article explores the nutritional issues faced by palliative patients, the ethical issues supporting decision-making and the methods of nutritional support available.

Key words: Palliative care ● Nutritional supplements ● Weight ● Nutrition screening ● Food ● Nutrition

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as shown in *Figure 1*. Studies have shown that almost half the number of all patients with advanced disease have cachexia demonstrating an interaction of malnutrition with metabolic and physiological changes. Cachexia is also seen in other long-term progressive conditions such as COPD, HIV and end-stage heart disease.

In addition to the physical effects of weight loss, malnutrition and cachexia, there are psychosocial aspects of these changes in body composition and function. Studies into the experience of changes in nutrition in advanced cancer patients have indicated that many people have concerns about weight loss. These concerns particularly occur when the reality of eating and drinking is different from the individual's expectations (Hopkinson and Corner, 2006), for example, when a person is making efforts to eat well but actually continues to lose weight and deteriorate. For some, this visible weight loss and depletion in physical function will symbolise proximity to death, a loss of control and emotional weakness.

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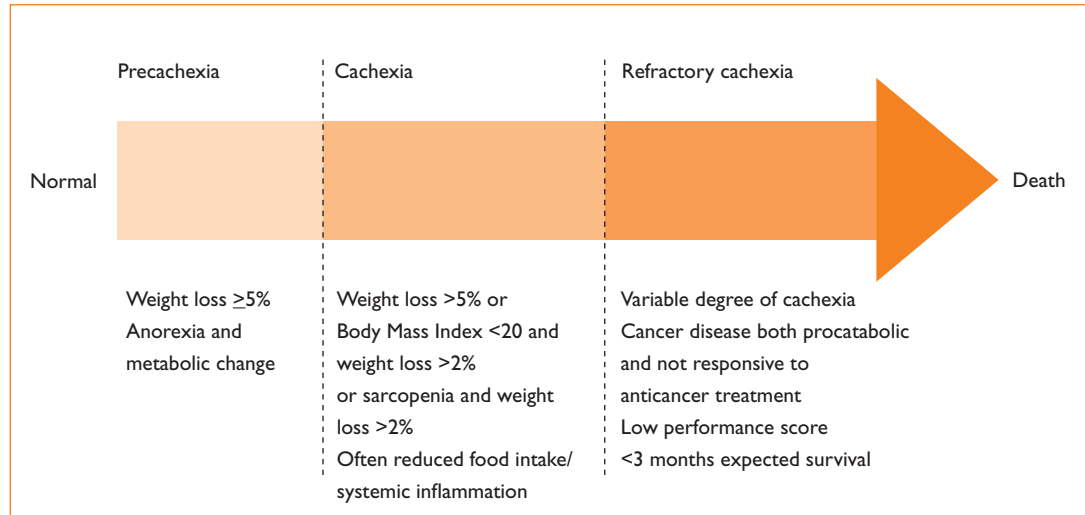


Figure 1. Stages of cancer cachexia (Fearon et al, 2011)

The consequences of a poor nutritional status can directly correlate with a reduced performance status in palliative care patients and have been shown to negatively impact on quality of life.

Identification of malnutrition

Nutrition screening and assessment of patients is a mandatory requirement of all health-care providers in the UK. Identifying patients who are struggling with eating, drinking and who have experienced changes in their nutritional status, allows appropriate action to be implemented, usually with the aim of improving nutritional status or preventing further decline. Many nutrition screening tools are available, some of which are aimed at particular diseases such as cancer (Shaw et al, 2014) or at certain age groups, such as the elderly (Isenring et al, 2012). Most are based on the patient's weight, weight changes, disease, changes in food intake and symptoms (Kondrup et al, 2003). The European Society of Parenteral and Enteral Nutrition (ESPEN) has outlined the necessary criteria for an effective nutrition screening tool, providing a framework for how to identify nutrition risk and predict future changes (Kondrup et al, 2003) (see Table 1). The majority of screening tools require the patient's weight or knowledge of weight changes in recent weeks or months which have met with some barriers in the palliative care setting. These screening tools do not distinguish between malnutrition and cachexia, generally because of historical lack of a definition of cachexia with clear diagnostic criteria.

The measurement of body weight is not universally undertaken in the palliative care and hospice setting. Watson et al (2010) identified that some 23% of hospices did not own a set of working scales and 10% 'never' weighed

patients. Health professionals may feel that it is not necessary to weigh a patient for whom continued weight loss is likely to be taking place as their disease progresses or their condition worsens. Attitudes to weighing patients were surveyed by Watson et al (2010), and the results indicated that over half the number of health professionals surveyed believed that weighing patients might cause distress. This opinion was particularly predominant among nurses, who felt that weighing patients was distressing for the patient and would not change the management of their condition. In contrast to the opinion of health professionals, the overwhelming majority, (96%) of patients did not mind being weighed in the hospital setting (Watson et al, 2010). Many patients in the survey weighed themselves regularly at home and wanted to know if their weight was changing, which could be a measure of 'things getting better or worse'. In addition, patients wanted to know if anything could be done about their weight loss.

Health professionals may also have additional barriers to screening or assessing nutritional status. There is a belief that weight loss is inevitable in patients with progressive disease and that nothing can be done about it. This deters some health professionals, from mentioning this seemingly difficult subject (Hopkinson et al, 2005).

Nutritional screening in palliative care is an important aspect of holistic care, identifying those who are experiencing difficulty with eating or drinking, to enable these issues to be discussed and practical suggestions to be explored. Nutrition screening tools do not always transfer well to the palliative setting, and there are barriers to using body weight in the screening process. There are also additional clinical issues such as

Table 1. The main principles of a nutrition screening tool

	Principle	Definition
1	What is the condition now?	This includes measurement of height, weight and body mass index (BMI). If it is not possible to measure these, then other anthropometric measurements such as mid-arm circumference may be appropriate.
2	Is the condition stable?	This includes measurement of weight loss over previous weeks and months.
3	Will the condition worsen?	Identification of food intake and recent changes are required.
4	Will the disease process accelerate malnutrition?	This may be influenced by decreasing appetite and possible metabolic changes in advanced diseases.

Source: Kondrup et al, 2003

fluid changes, particularly increased fluid retention, which may adversely affect the use of weight as an objective measure. Studies have identified that questions on symptoms and food intake are particularly useful in identifying nutritional issues (Hopanci et al, 2011; Khalid et al, 2007). Psychosocial aspects of food intake are not identified by the screening tools, and questions asked to patients should also include discussion about the experience of food intake, any barriers to intake, the role of family and carers and the importance of food to the individual (Hopkinson et al, 2008).

Ethical considerations in the provision of nutrition

Once nutritional issues have been identified, these should then be addressed by the health-care team. The main aim of nutritional care in the palliative setting is to ensure that the patient's needs are met and that all care is in the patient's best interest. Offering food and fluids via an oral route is deemed basic care and should always be provided unless actively resisted by the patient. However, patients have the right to refuse food and fluid, but it is essential that health professionals address any physical or psychological causes for this (General Medical Council (GMC), 2010). The desire to eat and drink diminishes towards the end of life and this should be acknowledged and discussed. Food and fluids should frequently be offered and the decision to decline these should always be that of the patient rather than clinical staff. Relatives' concerns that food and fluid had been withdrawn to hasten death was raised in a recent independent review of the Liverpool Care Pathway (Neuberger et al, 2013). When looking at nutrition from an ethical perspective, one can use Gillon's model of ethical principle (1994), which considers autonomy, non-maleficence (avoiding harm), beneficence

(doing good) and justice. Patients need autonomy, wherein they are given all options that would be suitable for their needs with the benefits and burdens having been addressed and a patient's individual goals always considered. Moreover, the potential harm a nutritional intervention may bring should always be considered. Questions such as whether nutritional intervention would provide false hope, or if it would keep a patient in hospital when they could be at home or if it exacerbates symptoms should all be considered prior to commencing such support.

In the UK, artificial nutritional support such as enteral tube feeding or parenteral nutrition, is considered a medical treatment. The potential benefits and burdens of these treatments should be considered and discussed within Gillon's framework. If it is unclear whether the patient will benefit from such support, then a time-limited trial may be helpful, with clearly documented aims against which nutrition can be assessed. In addition, such support may be withheld or withdrawn from a patient if this is in the best interests of the patient, for example, where it may put the patient at risk of fluid overload, infection or deranged organ function (British Medical Association, 2007; GMC, 2010). However, nutrition is seen as a source of life and can therefore have strong emotional attachments for individuals, making such discussions difficult (Ferrell and Coyle, 2006). Concerns that the patient is starving rather than deteriorating owing to a progressive illness are common and distressing for both patients and carers (Neuberger et al, 2013).

What does food represent to patients and carers?

Food has many meanings; it is the fuel with which our bodies need to function, but it also represents so much more. For patients, food can become a symbol of hope—as long as they have good nutrition, it is aiding life and can be comforting. For some, the burden of symptoms means food can be associated with pain and discomfort, resulting in the individual fearing meal times. They may feel guilt associated with not eating the food prepared by loved ones.

It is essential that the cultural, spiritual and religious meanings of food are accounted for when addressing the nutritional needs of patients (McCracken, 2013). At the end of life it is ideal for the normality of food and drink to be maintained where possible, and the aim should be to continue oral intake if possible (Royal College of Physicians, 2010).

Families are often the main carers for those with life-limiting disease, and provision of food

Table 2. Oral nutritional supplements available for palliative care patients

Type of supplement	Indications for use (UK Advisory Committee on Borderline Substances (ACBS) criteria)	Practical usage in palliative care	Examples of supplement
Nutritionally complete/supplementary			
<ul style="list-style-type: none"> Whole protein, milk-based supplements containing vitamins and minerals Usually 1.5–2.4 kcal/ml and 6–10 g protein/100 ml Some may contain dietary fibre 	Standard criteria: Disease-related malnutrition, intractable malabsorption, pre-operative preparation of malnourished patients, dysphagia, proven inflammatory bowel disease, following total gastrectomy, short-bowel syndrome, bowel fistula	Usually liquid and available in a bottle. Milkshake or yoghurt style. Used to increase energy and protein intake. Used in addition to food or as main source of nutrition, e.g. in dysphagia	Fortisip Compact, Fortisip Bottle, Fortisip Yoghurt Style (Nutricia), Ensure Plus (Abbott), Fresubin Protein Energy Drink (Fresenius Kabi) Resource (Nestlé)
<ul style="list-style-type: none"> Fruit juice style supplements. Whole protein, generally low in fat Not full complement of vitamins and minerals, usually low in fat-soluble vitamins 	Standard criteria (as above)	Liquid available in a bottle. Used to increase protein and energy intake. Used in addition to food. Can be used in recipes, e.g. jelly, and can be blended with other drinks, e.g. lemonade, ginger ale, soda water and tonic water	Fortijuice (Nutricia) Ensure Plus juice style (Abbott) Resource Fruit (Nestlé)
High protein and energy			
<ul style="list-style-type: none"> Protein and carbohydrate supplement Usually small volume, e.g. 30 ml 	Biochemically proven hypoproteinaemia	Liquid available in bottles or sachets. Can be drunk as a 'shot' or added to food and drinks	ProSource Liquid, ProSource Plus (Nutrinovo)
Protein and fat			
<ul style="list-style-type: none"> Protein and fat supplement. Usually taken as a small volume, e.g. 40ml Contains vitamins and minerals 	Disease-related malnutrition, malabsorption states, or other conditions requiring fortification with a high fat or carbohydrate (with protein) supplement	Can be drunk as a 'shot' or added to food and drinks	Calogen Extra, Calogen Extra Shots (Nutricia)
Protein, fat and carbohydrate			
<ul style="list-style-type: none"> Protein (cow's milk), fat and carbohydrate supplement as a powder Not full complement of vitamins and minerals 	Disease-related malnutrition, malabsorption states or other conditions requiring fortification with a high fat or carbohydrate (with protein) supplement	Usually presented as a powder which is reconstituted with whole milk and provides approximately 2 kcal/ml. Often, sweet flavours and made into a milkshake, but manufacturers' recipes include ice-cream, fortification of soup, desserts and cakes. Some savoury flavours available.	Calshake (Fresenius Kabi) Enshake (Abbott) Complian Shake, Scandishake (Nutricia) Vitasavoury (Vitaflo)

and nutrition is a role they take on. Food preparation is a way of being involved, of expressing love and contributing to the healing process. Families can find it very difficult to acknowledge when nutrition and hydration is no longer required, and are often more concerned with weight loss and a poor intake than the patient is (Poole and Froggatt, 2002). In particular, family

members can become distressed with regard to the provision of artificial nutrition and its potential withdrawal at end of life (van der Riet et al, 2008). It is essential that there is clear communication at all times with all concerned (Scott and Robinson, 2009).

Food can become a form of control, especially in palliative care when conventional treatment

has been shown not to be effective. Individuals might turn to complementary or alternative diets as a means of improving their quality of life and to provide hope (Austin, 1998). It is important for health professionals to be aware of any nutritional or herbal supplements a patient might be taking to ascertain if they would interact with conventional medication (Werneke et al, 2004).

Some patients may retain motivation to eat without an appetite. This may involve shifting to conscious control and rationalising that food is required to sustain life (Shragge et al, 2007). Others may refuse food and/or fluid as a means of hastening their death, of having the ultimate control of the situation they are in. In food avoidance, it is essential that psychological distress and physical symptoms be explored (Shragge et al, 2006; GMC, 2010; Eldridge and Power, 2014).

Evidence for nutritional interventions in palliative care

When patients are identified as being malnourished or at risk of malnutrition, the initial nutritional approach is usually the provision of dietary advice. This may take the form of written or verbal advice aimed at improving dietary intake and include information on meal pattern, food choice and fortification of food (Durrieu et al, 2011). Symptoms affecting food intake and contributing to malnutrition are very common in the palliative setting; these include loss of appetite, fatigue, changes in bowel habits, nausea and vomiting, taste changes, oral pain and dysphagia (Labori et al, 2006). Such symptoms, particularly loss of appetite, have been identified as the main causes of distress in patients, contributing to poor quality of life. If dietary advice alone is insufficient or people have particular needs such as in dysphagia, then oral nutritional supplements may be considered as a means of improving dietary intake. The types of products available and indications for their use are outlined in *Table 2*. As products vary in nutritional composition, it is necessary to consult the manufacturer's product literature for a detailed analysis. Many manufacturers provide recipes and information on how the supplements may be used to maximise palatability.

Often the strategies to improve oral intake through dietary advice have not been tested in the palliative setting, although there is some emerging evidence in the cancer treatment setting. A study of patients receiving radiotherapy treatment for colorectal cancer demonstrated that individualised dietary advice provided by a registered dietitian was superior to oral nutri-

tional supplements and standard care, with respect to maintaining nutritional status, quality of life, radiotherapy toxicity and mortality (Ravasco et al, 2012). This study provided intensive advice and support for the duration of radiotherapy treatment with a long-term follow-up of a median of 6.5 years to assess the longer term outcomes. However, the evidence that dietary counselling can improve similar outcomes in palliative care patients is lacking.

Studies in palliative care have generally been of a much shorter duration, often with outcomes of nutritional status, dietary intake or quality of life. Some studies have addressed a number of strategies and interventions at the same time. For example, a study undertaken by Herrmann et al (2012) assessed the influence of a multi-professional team approach to providing dietary advice, oral supplementation, enteral tube feeding or parenteral nutrition to meet the nutritional needs of palliative patients with solid tumours (Herrmann et al, 2012). Such support with regular monitoring, review and amendments to the method of support resulted in an improvement of hand-grip strength and quality of life with a stabilisation of nutritional status. While this study demonstrated good use of the methods of nutritional support available, there is variation in the use of the more invasive methods of artificial nutrition support in different countries. The UK is more likely to use parenteral nutrition only in cases of intestinal failure, whereas other countries may use it as a supplement to oral nutrition or enteral tube feeding (National Collaborating Centre for Acute Care, 2006; Bozzetti et al, 2009). However, this raises interesting questions about the appropriate use of these methods, especially if studies continue to demonstrate that support, such as parenteral nutrition, may contribute to improved quality of life. Such support is expensive and requires specialist teams to manage its use safely, support patients and caregivers and ensure it is effective (Penner et al, 2012). Future research should include cost-benefit analysis as an integral part of any outcome measures.

A randomised study of patients receiving palliative chemotherapy combined with dietary advice and/or oral nutritional supplements was undertaken for a period of 6 weeks, commencing as early as possible before the start of chemotherapy (Baldwin et al, 2011). Follow-up data was collected at 3, 6 and 12 months but failed to demonstrate that this period of nutritional intervention influenced survival or quality of life. Nutritional status at 26 weeks post-chemotherapy was comparable between the groups although a difference in nutritional status was seen at 1 year, with those

Malnourished patients are most likely to benefit from oral nutritional supplements.

‘Nutritional support has been shown to have a positive effect on quality of life, particularly in those who are malnourished.’

who had received dietary advice having a significantly heavier body weight. The numbers at this time were small so the results should be interpreted with caution.

The use of oral nutritional supplements has increased in recent years and has been supported by an increased availability of flavours and the introduction of more energy-dense liquids, which enable people to take smaller volumes of liquid. They may be purchased by patients or, in some countries, can be prescribed by doctors, potentially reducing the cost to the patient. Supplements may also be used extensively in health-care organisations including hospitals, nursing homes and hospices. Some oral nutritional supplements but not all, are categorised as ‘nutritionally complete’, indicating that if sufficient volume was consumed they would provide an adequate dietary intake. However, the majority are used in conjunction with an oral diet to supplement intake, either to meet nutritional requirements or promote weight gain. Use of these supplements is controversial as they can be expensive and use financial resources in both the community and hospital setting.

Malnourished patients are most likely to benefit from oral nutritional supplements. A randomised intervention study using dietary advice or oral nutritional supplements in malnourished care-home residents suggested that overall health-care costs were not significantly different between the two groups (Parsons et al, 2012). The oral nutritional supplements were effective at improving the quality-adjusted life years of malnourished patients, although it is difficult to extrapolate these results to palliative care patients.


A systematic review of nutritional interventions in malnourished patients with cancer looked at studies where nutritional interventions had been compared with standard practice (Baldwin et al, 2012). From these, six studies compared dietary advice with routine care, three compared oral nutritional supplements with routine care and seven compared dietary advice plus supplements if required, with routine care. All studies aimed to improve nutritional status in the participating patients and the follow-up periods varied, although the majority were less than 6 months. The review showed that there was no influence of nutritional interventions on mortality although there was a beneficial effect on global quality of life measures, assessed primarily via the questionnaire from the European Organisation for Research and Treatment of Cancer (EORTC) which was the outcome measure used in the majority of studies (EORTC,

2014). In addition, the questionnaire indicated that nutritional supplements had a beneficial effect, particularly on ‘physical functioning’ and ‘emotional functioning’. Nutritional interventions were reported as improving energy intake when compared to those receiving routine care although there was heterogeneity between the studies examined. When this was accounted for, the difference diminished and was deemed to be not statistically significant. This highlights that measuring nutritional parameters alone may not be the most relevant outcome measure.

Use of omega-3 fatty acids in oral nutritional supplements

Specialist nutritional supplements containing eicosapentanoic acid have been formulated to address the inflammatory aspects of cachexia, in addition to providing energy and protein to promote weight gain. These supplements have been compared with isocaloric oral nutritional supplements in advanced cancer patients, and while small studies report benefit, larger randomised trials have failed to demonstrate any additional benefit in terms of weight gain or change in body composition (Ries et al, 2012). Although the adverse effects of these supplements are few, they include abdominal discomfort, fish belching and fish aftertaste, which have been reported to have a negative effect on quality of life.

Summary

Nutritional support in the form of dietary advice or oral nutritional supplements has not been universally demonstrated to positively impact on morbidity or mortality in palliative care. Nutritional support has been shown to have a positive effect on quality of life, particularly in those who are malnourished. However, studies in this patient group have often been limited owing to the short periods of intervention and because they have failed to address the main concerns of patients with advanced and progressive disease. Food has a complex role in both health and disease, and future research must acknowledge this to assess any benefits that nutrition may bring to patients with life-limiting conditions. 

Declaration of interests:

The authors have no conflicts of interest to declare.

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