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Nutrition support in palliative care


Aims and intended learning outcomes

This article aims to provide an overview of nutrition support in palliative care. After reading this article you should be able to:

- Discuss the importance of nutrition in early palliative care.
- Identify nutritional support goals during the progression of cancer and motor neurone disease.
- Understand the ethical and legal issues relating to nutrition in palliative care.
- Outline the necessity for hydration and nutrition towards the end of life.

Introduction

The aims of nutritional support in palliative care will change as the disease progresses. In the early stage, when the patient is undergoing active treatment, the aim is to ensure that the patient receives sufficient nutrition to restore or maintain his or her nutritional status to:

■ Cope with the metabolic demands of the illness and treatment.
■ Repair tissue and prevent infection.
■ Promote a sense of wellbeing and quality in the patient's life.

Towards the end of life the aims of nutrition support will change. Patients must be offered food, but the emphasis is on quality of life and relief of suffering rather than active nutritional therapy.

Palliative care is the total care of patients whose conditions do not respond to curative treatments. The goal of palliative care is to promote the best possible quality of life for patients and their families (WHO 2002). Palliative care includes physical care, symptom management, psychosocial and spiritual care. It involves the active and co-ordinated involvement of members of the multidisciplinary team, the patient and family in all care decisions.

The World Health Organization's (2002) definition states that palliative care:

■ Affirms life and regards dying as a normal process.
■ Neither hastens nor postpones death.
■ Provides relief from pain and other distressing symptoms.
■ Integrates the psychological and spiritual aspects of patient care.
■ Offers a support system to help patients live as actively as possible until death.
■ Offers a support system to help the family cope during the patient's illness and following bereavement.

Those responsible for the clinical management of patients with cancer have contributed a large proportion of the literature on palliative care, particularly in the terminal phase. Some of this information can be used to help other patients with similar problems but different diagnoses. Palliative care encompasses more than the terminal care of cancer patients. Early palliative care can be as much about helping a patient in cardiac failure to maintain his or her weight, despite breathlessness, as it is about managing cachexia (a complex metabolic state that involves anorexia, weight loss, fatigue and muscle wasting) in patients with cancer or acquired immune deficiency.

In brief

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Summary
Nutrition is an important aspect of caring for patients with life-threatening illness. Good nutrition support is essential, not only for meeting the body's physical requirements but also because of associated social, cultural and psychological benefits for patients. The author uses examples from cancer and motor neurone disease to illustrate the nutrition needs, legal and ethical issues and specific symptoms that affect dietary intake in patients receiving palliative care.

Key words
- Nutrition and diet
- Palliative care

These key words are based on subject headings from the British Nursing Index. This article has been subject to double-blind review.

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TIME OUT 1
What is meant by early and late palliative care? Can you think of patients in your care who fit these categories?

Early palliative care is the period when the patient has been diagnosed with a disorder or disease that cannot be cured. It might be a life-threatening diagnosis, but death is not likely to be imminent. The patient might have a week, months or even years of life and, with good clinical management, his or her quality of life might also be good.

The term late palliative care implies that the patient’s condition has reached a stage where quality of life is harder to maintain. The patient is progressing towards the end of life. It is a continuum brought about by the patient’s condition, and his or her physical, mental, social and spiritual response to it.

At each stage of the palliative care continuum there is a need to assess, plan care and anticipate the consequences of the disease and any clinical decisions. Palliative care requires a sound understanding of the ethical and legal issues involved in making decisions to minimise difficulties and enhance quality of life. Decisions to be made include those related to nutrition and its administration.

Nutrition is not solely concerned with refuelling the body with appropriate nutrients: it also has an important psychological, social, spiritual and cultural role. It can be a pleasurable experience, which helps to promote psychological comfort, communication and social interaction. Eating might also help patients to maintain a sense of autonomy and normality within their lives, and should be viewed as a therapy in itself. Nutrition is important, particularly in the early stages of palliative care, as it can give the patient energy and reduce the risk of infection or poor tissue repair.

The term nutrition support is frequently limited to artificial methods of feeding a patient. This does not take account of other skills and interventions the multiprofessional team can consider in the care of these patients (Box 1). In this article, nutrition support refers to the use of a variety of skills and methods to enable a patient to meet nutritional requirements appropriate to his or her needs.

Importance of nutrition in palliative care

The body requires a well-balanced diet to survive, repair tissues and meet the energy demands of activity. If the body is unable to prepare, digest, and absorb nutrients, nutritional status can be impaired. Malnutrition results in poor resistance to infection, poor wound healing and fatigue (Wilkes 2000). Deficiencies in particular nutrients can have detrimental effects on health and result in focal or systemic disorders such as night blindness, peripheral neuropathy or diarrhoea. Poor nutrition can also affect mental wellbeing, since a drop in essential amino acids or glucose can adversely affect the nervous system and behaviour (Kolb and Wishaw 1990).

In early palliative care, nutrition should be seen as a priority. It will enhance recovery where healing is possible and contribute to the patient’s overall sense of wellbeing. During this period, staff might wish to address issues that could affect a patient’s ability to maintain independent nutrition so that he or she can consider possible options before problems arise.

TIME OUT 2
Think about the places in which you eat and describe what makes them everyday or special. Describe how you would feel if you were not able to eat the foods you like in an environment of your choice.

What is meant by early and late palliative care? Can you think of patients in your care who fit these categories?

TIME OUT 1
Change diet or medication to reduce symptoms
Change pattern of eating to a time when the patient is experiencing less fatigue, pain or nausea
Use a combination of feeding methods: for example, part oral, enteral or parenteral
Use eating aids to assist independent eating, such as uni-valvular straws (which keep the fluid at the last level reached)
Provide fortified, energy dense foods
Avoid favourite foods during chemotherapy or radiotherapy so that if food aversions develop they are not for foods that they would really miss
Offer a choice of eating environment
Change the method of food preparation: for example, use boil in the bag or microwaved foods to avoid odours
Offer nutritional supplements in different ways, such as ice lollies, mousses and soups

TIME OUT 2
Think about the places in which you eat and describe what makes them everyday or special. Describe how you would feel if you were not able to eat the foods you like in an environment of your choice.

Eating and drinking have psychological and social functions, such as going out for a meal, meal-time behaviour, celebrations and festivals, which are influenced by the individual’s social, cultural and religious background. Inevitably, the patient’s experience of palliative care will consist of a series of losses that need to be confronted. Among these
are the ability to taste, chew, swallow and digest food, absorb nutrients and eliminate waste products independently. This can lead to loss of confidence and self-esteem, social isolation and depression. Skilled palliative care nursing can help not only to attenuate the pain of each loss, but it can also ease the transition from self-care to dependence on others to maintain the activities of daily living.

Several factors influence the decision-making process when considering nutrition in palliative care (Box 2). Management of nutrition should be consistent with the aims of palliative care and the patient’s wishes. Regular liaison between members of the multidisciplinary team will help to ensure that nutritional care is appropriate to the patient’s individual needs. Nurses need to plan the patient’s nutritional care with his or her immediate and long-term needs in mind. It is important to prepare for the consequences of the disease process, as well as to meet immediate goals, for example, the patient might be able to swallow and speak now, but might not later. The benefits and potential adverse effects or complications of various methods of nutritional support should be evaluated and discussed with the patient before they are commenced. It is also important to consider what effect they might have on patient comfort and autonomy.

Patients with intravenous infusions, drainage catheters and offensive-smelling discharges experience feelings of isolation and might also feel nauseous, which will reduce their appetite. A patient might wish to eat at a dining table with other patients, but reactions to his or her illness could lead to further isolation and also loss of appetite. Depression, isolation, fear and anxiety can all lead to reduced food intake. Ensuring that patients receive a nutritious diet in a setting that is pleasant and psychologically comfortable is one of the most important challenges in nursing.

TIME OUT 3
Before reading on, try to answer the following questions:
- Why do cancer patients frequently have unexplained weight loss?
- What is the body’s response to a malignant tumour?
- Should nurses strive to improve the nutritional status of patients in the early palliative stage of disease?

Nutritional needs of the cancer patient

Anorexia-cachexia is a complex metabolic response to cancer, the extent of which depends on the type and site of the tumour. It is at its most severe in gastrointestinal and head and neck cancers, and least in pelvic and breast cancers (Laviano and Meguid 1996, Nixon 1996). In patients with cancer, anorexia-cachexia leads to a number of metabolic responses (Box 3). Anorexia in cancer patients is a cytokine-mediated response. It is thought to be due to a modulation of areas of the hypothalamus responsible for feeding behaviour, especially in the paraventricular and ventromedial nuclei (Pita-Salaman 1996). The principal cytokines that induce anorexia are interleukin-1, interleukin-6 and tumour necrosis factor (Laviano et al 1996). The condition is sufficient to induce malnutrition, but can be worsened by fear, local and systemic effects of the tumour, metastases and treatment. Chemotherapy, radiotherapy and surgery all exacerbate malnutrition in cancer patients. A better understanding of the body’s response to malignancy raises further questions. For example, if the tumour deprives the body of its energy supplies, thus altering the host’s metabolism (Laviano and Meguid 1996), then should nutritional support be regarded as feeding tumour growth? The current view of clinicians is that the benefits of encouraging optimum nutritional status to support patients through the therapeutic stages of disease outweigh any possible advantage to the tumour (Laviano and Meguid 1996).

Nutritional support might change as curative care progresses to palliative care. Patients might have increasingly distressing symptoms such as pain, nausea and vomiting, fatigue, swallowing difficulties (dysphagia), dry mouth (xerostomia), altered taste (dysgeusia), mucositis, diarrhoea or constipation. Many therapies can manage symptoms, but some affect appetite and digestion: opiates, for example, which can increase nausea and cause constipation. At this stage patient preference and the provision of small, well-presented meals or snacks that patients enjoy and are able to tolerate can positively influence intake. The goal of palliative care is to maximise the patient’s quality of life and minimise suffering.

For this reason, aggressive or invasive nutritional support, such as enteral or parenteral feeding, might not always be appropriate within palliative care.

TIME OUT 4
You are caring for a patient who is about to undertake a course of cytotoxic chemotherapy and radiotherapy as part of the treatment for carcinoma of the tongue. Make a list of the symptoms this patient is likely to experience that will affect his or her nutritional status. Write notes on how you will manage each of these symptoms.
CONTINUING PROFESSIONAL DEVELOPMENT

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Distressing symptoms that affect nutritional status

Distressing symptoms need to be treated, but the impact of certain treatments on the patient’s appetite, and subsequent nutrient intake, also needs to be incorporated into planning care. Side effects of therapy such as dysgeusia (an abnormal or impaired sense of taste), xerostomia and mucositis occur in many patients with cancer. These conditions are particularly common in patients with head and neck cancer, in haematological cancers following chemotherapy and radiotherapy, and those with advanced AIDS (Barker 1996).

Symptom distress needs to be assessed regularly. This should involve professional assessment, but also give patients an opportunity to report on their perceptions of the severity and treatment of symptoms. A number of assessment instruments have been tested for their validity and reliability, such as the Symptom Distress Scale (McCorkle and Young 1978) and the Rotterdam Symptom Distress Checklist (de Haes et al 1996). They use Likert-type scales which record degrees of agreement or disagreement with statements regarding the presence or absence of different symptoms in a specific time period. Some assessment scales used in clinical practice were first designed for research.

Symptom management is an important part of the holistic care of patients and should not be treated in isolation. Drugs used to alleviate one symptom can provide another. For example, opiates prescribed to manage pain can result in nausea and constipation. One of the greatest skills of palliative care is to use drugs when essential, and to find other therapeutic methods where possible. For example, a patient’s diet could be altered to prevent constipation before prescribing aperients. Some patients prefer to try complementary therapies to relieve nausea before taking anti-emetics.

Complications that develop in patients with oral cancer are distressing and effective treatment can help to promote comfort and relieve stress and anxiety. There is evidence that sucking ice before being treated with 5-fluorouracil in patients with cancer, other than head and neck cancer, can help to prevent mucositis (Clarkson et al 2000). Established mouth ulcers can be treated with benzylamine spray or mouthwash, or choline salicylate gel. Viral ulcers can be treated with antiviral agents such as aciclovir (Regnard and Tempest 1998).

If a patient has xerostomia, cool drinks, sips of water, ice cubes and moist food will help to keep the mouth and lips moist. Some patients find that pineapple or lemon flavoured drinks stimulate saliva production, when there is little rather than no saliva present (Davies 2000, Twycross 1997). However, patients with mouth ulcers find sharp tastes like lemon very painful. Artificial saliva and oral pilocarpine are other useful alternatives to saliva (Reke et al 1995).

Nausea and vomiting can be treated most successfully once the cause has been identified. It might be opiate-induced nausea and vomiting, gastric distraction, or poor peristalsis resulting in constipation and bloating. Nausea and vomiting might also have a psychological component – patients might be frightened or upset. To work effectively, anti-emetics should be targeted at the appropriate parts of the vomiting reflex: in the intestine, liver or brain. If there is chemical stimulation of the chemo-receptor trigger zone in the brain stem by drugs or uraemia, metoclopramide or haloperidol are the drugs of choice. Odansetron may be used if vomiting is induced by chemotherapeutic agents which stimulate serotonin (5-HT) production from the enterochromaffin cells in the intestinal wall. Non-pharmacological methods include reducing noxious sights, sounds and smells, changing position slowly, keeping the eyes closed when being wheeled on a trolley and sucking sugar cubes if hungry but nauseated (Hawthorn 1995). Encouraging patients to eat small amounts of non-odorous foods and to eat slowly can help to reduce nausea and vomiting. If patients are feeling nauseous and cannot tolerate food, they should be encouraged to sip water.

Dysgeusia occurs when the taste buds are damaged, leading to an abnormal or impaired sense of taste. One way to combat this problem is to identify types of food the patient can tolerate. It is important to remind the patient that this problem often improves some time after the completion of chemotherapy. Broberg and Bernstein (1987) suggested that patients who are about to undergo chemotherapy or radiotherapy that is likely to affect the taste buds should be given sweets. This followed research where children had been given sweets to act as a scapegoat for food aversion. The rationale was that it is better that children dislike sweets than other more nutritious foods. Thus, sweets became the scapegoat.

Motor neurone disease

Motor neurone disease is a progressive disease, which leads to muscle wasting and loss of muscle function. In the later stages the muscles of swallowing and speech are affected. The patient finds...
it increasingly difficult to chew and swallow food, and the muscles of the arms become unable to support the movement of food to the mouth. Public assessments of the patient's swallowing and eating skills will ascertain whether there is any deterioration. The nurse can help by changing the patient's position, offering an altered-texture diet and monitoring the patient's weight and swallowing safety. Speech becomes increasingly difficult for patients, but their minds remain clear and active. It is, therefore, important to obtain patients' views on nutrition support options before their condition deteriorates.

**Hussein is 67 years old. He is a retired bank clerk and has motor neurone disease. He is a practising Muslim. His wife and two daughters care for him. During re-assessment at a hospice he is found to have lost weight and to have increasing weakness in his limbs and in the muscles involved in speech and swallowing. The disease is progressive and it will be only a matter of time before Hussein will be unable to swallow safely. It is also likely that his speech will be seriously affected. Identify the options available to Hussein and make notes on the ethical and legal consequences of these options.**

**TIME OUT 5**

**Ethical and legal issues**

The British Association of Parenteral and Enteral Nutrition (BAPEN) (Lennard-Jones 1998, 1999) and the British Medical Association (BMA) (1999) have drawn up guidelines on the ethical and legal issues related to nutrition support. Key statements included in the ethical and legal guidance are listed in Box 4.

Hussein has been gradually losing the ability to swallow and the consultant responsible for his care in the hospice has brought him in for assessment by the multidisciplinary team, including the speech and language therapist and dietitian. The assessment shows that it will not be long before Hussein will not be able to eat or drink safely because of difficulties in swallowing. Hussein and his wife wish to discuss with the team the options open to him.

Ethical and legal principles to be considered when planning the clinical management of nutrition in competent adult palliative care patients include:

- Patient choice and informed decision making.
- Methods of feeding that should enhance quality of life and not prolong dying.
- The right to quality of life and a dignified death.

The option chosen by Hussein was to have a gastrostomy, but he required reassurance that the tube feeds would not contain animal products. His wife offered to liquidise family meals to ensure that he only had halal meat and that no pig meat would be used. This raises issues for clinical practice because the current focus is on the administration of commercially prepared feeds as an alternative to oral diet. Liquidised feeds are discouraged because of the need to ensure that all the nutrients are present in the feed and because the risk of infection is minimised on using manufactured products.

If the patient is not receiving a commercial diet, it might be necessary to insert a larger gastrostomy tube, to prevent blockage as a result of liquidised foods. Inserting a larger gastrostomy tube is a more complex clinical decision. However, Hussein needs to know that his beliefs will not be compromised and that a method of feeding will be found that optimises his nutritional status. Dialogue needs to continue with commercial feed companies to ensure that patients whose religious beliefs prohibit the use of specific foods do not receive them inadvertently.

By discussing his views, Hussein felt more in control of the situation. He felt comfortable that his decisions embraced his religious beliefs and that his family and professional carers understood and respected his wishes. Patients need to know that, even if speech becomes impossible, communication aids are available to assist them to express their opinions and decisions on their care.

It is important that health professionals and carers are aware of the patient's views and that close family, partners and friends are involved in care decisions throughout the patient's illness.

As the disease progresses and patients become less able to make their own decisions, relatives and friends often feel unable to help their loved ones at this stage of illness. Some family members might be shocked at the prospect of patients refusing to eat and might find the sight of severe weight loss distressing. They might demand that the patient is fed artificially and commenced on intravenous fluids because they cannot bear to see his or her condition deteriorate.

However, it is important to distinguish between the patient's suffering and that of carers and friends, so that dietary management is appropriate to meet the patient's needs and maximise comfort. Each patient should be individually assessed to evaluate the most appropriate dietary support for them. Terminally ill patients should not be made to feel guilty for not eating and if they no longer wish to eat, offering regular nutritional fluids might be more appropriate than commencing invasive nutritional therapy.
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Box 5. Arguments against hydration

- Deeply unconscious patients do not suffer pain or thirst
- Less fluid leads to reduced load on the heart and lungs
- Less fluid leads to less acidity and oedema, which are distressing
- Less fluid can lead to less nausea and vomiting
- Dehydration reduces micturition problems and possibly incontinence
- Dehydration facilitates loss of consciousness and decreases suffering

(MacDonald and Faisinger 1996)

TIME OUT 6

Describe the patient’s nutritional and hydration needs in the terminal phase of illness.

Nutritional and hydration requirements at the end of life

The arguments for and against hydration at the end of life remain controversial (MacDonald and Faisinger 1996). The arguments offered by those against hydration are outlined in Box 5 and the arguments for hydration in Box 6.

Health professionals should consider the reaction of family members to the withdrawal of food and fluids – many would like to do something for the patient and feel helpless: they often become distressed by what they perceive as starving a patient to death. Sometimes a decision is made to give the patient subcutaneous fluids (normal saline) and the reasons for this should be discussed with the patient and family members. Many patients lose interest in food and fluids during the last 48 hours of life (Adam 1997). Food might be offered, but is usually refused. Decisions related to the withdrawal of nutrition support have been outlined in the section on ethical and legal decision-making.

Conclusion

The primary goal of palliative care is to achieve the best quality of life for patients and their families through the management of physical symptoms, and psychological, social and spiritual care. Palliative care involves more than terminal and cancer care, and in the early phase of illness it might involve adaptation and lifestyle changes. Distressing symptoms that affect nutritional status include fatigue, nausea, vomiting, dysphagia, dysgeusia, xerostomia, mucositis, diarrhoea and constipation. Ethical and legal decision making requires foresight and planning. Health professionals should use the BMJ’s (1999) guidance on withholding or withdrawing life-prolonging medical treatment to guide clinical practice. Nutrition and hydration at the end of life are controversial, but it would appear that patients might benefit from having less food and fluids at the end of life (MacDonald and Faisinger 1996).

Health professionals should adopt an approach to nutrition that embraces the principles of palliative care and promotes quality of life for patients. The goals of dietary management in a palliative care setting are different from those for patients in other areas of health care. Involving patients and their families in nutrition support, combined with sensitive and skilled nursing care, will help to make eating and drinking as pleasurable an experience as possible for patients receiving palliative care.

TIME OUT 7

Now that you have completed the article, you might like to write a practice profile. Guidelines to help you are on page 55.

REFERENCES


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