

# The management of nutrition for palliative care patients

Pádraig O'Hara

Faculty of Education, Health and Community  
School of Nursing and Allied Health  
Liverpool John Moores University

## Abstract

In order to improve quality of life, nutrition in palliative care must be one of the main goals when managing a patient's care. Malnutrition is a predominant factor for the palliative patient. Poor nutrition can have an impact on the patient as well as their families, as they see changes in their loved ones. The main aim of nutrition is to maximise food enjoyment and minimise food related discomfort. Guidelines are available for health care professionals. Nurses and other healthcare professionals have a vital role in the management of nutrition by providing both physical and emotional support for both the patient and their families. It can lead to ethical dilemmas and puts professionals, patients and family members in difficult positions.

## Keywords

Palliative Care, Nutrition, Malnutrition, Cancer Cachexia,

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## Introduction

The National Institute for Health and Care Excellence (NICE, 2004, p.20) defines palliative care as; "...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families." Many patients who are terminal generally experience weight loss, loss of energy and loss of appetite (Hanks et al, 2011). A study conducted by Hopkinson, Wright and Corner (2005) revealed that weight loss was a common concern highlighted by family members and carers. Patients who have cancer often are malnourished and lose weight due to a variety of mechanisms involving the tumour, the host's response to the tumour and anticancer therapies (Meyenefelt, 2006). The National Cancer Institute (NCI, 2015) suggest the close links between weight loss and poor prognosis. It has also been revealed that 80% of patients with upper gastrointestinal cancer and 60% of patients with lung cancer have already experienced substantial weight loss (NCI, 2015). Barakat, Markman and Randall (2009) explain how malnutrition can impact patients with a cancer diagnosis including increased hospital stay, poor response to treatment and decreased survival rate.

Weight loss does not just affect the patient physically but also psychologically. Patients can become conscious of their altering body image often leading to depression, anxiety and conflict between family members, which will be explored in this article (Kinghorn and Gaines, 2007).

## **Nutritional Assessment**

Nutritional screening and assessment is a fundamental aspect of nursing which is used to identify and treat patients who are malnourished or underweight (Best, 2008). Johnstone (2006, p28) stresses the importance of nutritional screening and denotes how, "failure to address the issue of malnutrition is a failure of the duty of nurses to protect the health of patients." Early identification of patients who are underweight or malnourished benefits the patient as it improves their nutritional status and avoids additional deterioration (Perry, Potter and Ostendorf, 2014).

There are various nutritional measuring tools which can be adopted. Screening tools are generally based on the patient's weight, any changes, disease, changes in food intake and symptoms (Shaw and Eldridge, 2015). Santarpia, Contolado and Pasanisi (2011) articulates how using only a body mass index (BMI) is not effective for determining a palliative patient's nutritional status as it can present normal results in patients with ascites or oedema. These screening tools, however, do not always adapt well in the palliative settings as they do not distinguish between malnutrition and cachexia (Shaw and Eldridge, 2015).

Many screening tools require the patient's weight over a period of weeks or months to identify a change, however, a barrier to this is staff attitudes. Watson et al (2010) conducted a study which explored the attitudes of staff regarding weighing patients in both a hospice and a hospital outpatient setting within the UK. The results found that 66% of patients attending hospices were rarely weighed as staff thought that it would be too upsetting for the patient. What was interesting about this study is that 96% of patients with advanced cancer did not find getting weighed upsetting. Additionally, 74% weighed

themselves at home and 89% wanted to know if their weight was changing. Weighing palliative patients is beneficial as it can determine how fast they are losing weight and whether the interventions used are effective (Ferrell and Coyle, 2010). However, sensitivity is paramount and if a patient is in the terminal stage of their disease, immobile or demented then undertaking such an assessment may be inappropriate (Cherny et al, 2015).

A full assessment should be conducted which is tailored to the patients individual needs. In palliative care the focus of eating should be based on pleasure rather than the patient getting the nutrients they need (NCI, 2015). The patient may also be referred to the dietician and the speech and language therapists who will identify the factors hindering the patient's quality of life. From this, an individual care plan can be drawn up highlighting the appropriate interventions. It is the responsibility of the entire health care team to ensure the patient's nutritional needs are met. Nurses, however, are in a unique position to ensure this as they are at the forefront of patient care (Coxall, 2007).

### **Social and Psychological Issues**

Food beliefs and eating habits stem from childhood and are associated with family and culture. Food can be highly regarded by families as it is a time where they can gather and socialise (Dillon, 2006). A palliative patient may find meal times a burden as they may feel too weak, too tired or just simply just do not have an appetite. This can cause them to feel isolated as they cannot participate which can lead to exclusion from the people they love (Holmes, 2011a). An altered body image can also hinder the patient's confidence which can cause them to feel anxious. This makes the thought of socialising and interacting with people too overwhelming (Carr and Steel, 2013). Cherney et al

(2015) explains how this can cause patients to develop a low self-esteem and potentially depression.

Food has various meanings to different people, some find hope in eating as it is the fuel that drives our body and can provide strength to battle their illness. On the other hand, some patients may resent meal times as food can cause pain and discomfort through the symptoms of their illness (Shaw and Eldridge, 2015). Families can have an active role in preparing meals for their loved ones which makes them feel like they are contributing to the healing process (Shaw and Eldridge, 2015). Martin (2010) agrees and comments on how family members are in an ideal position to help their loved ones meet their nutritional needs and assist them with eating if required. Food presentation is key, therefore, meals should be made attractive and portions should be small so the patient doesn't feel overwhelmed. The atmosphere during mealtimes remain normal to the individual family's dynamics. The family could use attractive tableware, background music or perhaps offer a small amount of alcohol to compliment the meal (Oneschuk, MacDonald and Hagen, 2012).

The Priorities of Care for the Dying Person outlines how patients should be supported to eat or drink as they wish and their choices be respected (Leadership Alliance for the Care of Dying People, 2014). However, Shaw (2011) explains how some families may advise the patient on what they should be eating to increase survival rather than focusing on food which the patient enjoys. For families food and drink can symbolise hope, strength and prosperity, therefore, the inability to eat or drink can be associated with despair (Holmes, 2011a). Oneschuk, MacDonald and Hagen (2012) explains that patients may be unable to eat or drink due to side effects of treatment or the actual illness itself, leading

to a real sense of guilt as they feel they are letting their family down. On the other hand, the patient may avoid food as a means of regaining control over their own life or to hasten death (Shaw, 2011). This can cause tension, anger and frustration between family members and the patient (Preedy, 2011). Nevertheless, the Nursing Midwifery Council (NMC, 2015) denote how professionals must respect and support a person's wishes to refuse treatment or care. Wheeler (2013) states that health care professionals cannot force a patient to eat, drink or accept medical treatment. Nurses can offer encouragement to patients and educate their families on how their illness can affect their loved ones appetite (Burton and Ludwig, 2010).

### **Nutritional Goals**

The Ambitions for Palliative and End of Life Care highlight's how goals should be clear from the beginning of treatment and should be tailored to each individual's preferences (National Palliative and End of Life Care Partnership, 2016). In harmony, the leadership alliance for the care of dying people (2014) articulate how the patient's wishes must be supported alongside the patient's choices. In order to deliver high quality palliative and end of life care a person centred approach should be adopted (Block et al, 2015).

The goals of nutrition in cancer and palliative care alter during the different stages of a patient's disease. In the early stages, during treatment, nutritional intervention is needed to help patients cope with the metabolic demands of illness, preventing infection, tissue repair and general wellbeing (Watson et al, 2009). Towards the end of life the goal is to maximise food enjoyment and diminish food related discomfort (Acreman, 2009). The rationale for this is so that patients can enjoy a higher quality of life (Cherney et al, 2015). Conflict can arise between families and the multi-disciplinary team regarding the patient's

minimal food intake, resulting in some families wishing to force feed the patient (Chochinov and Breitbart, 2009). Forcing the patient to eat does not allow the patient to live longer or feel stronger but instead may cause them to feel discomfort rather than pleasure (Arnella, 2010). Carr and Steel (2013) concur and explain how force feeding can lead to aspiration and cause the patient's condition to deteriorate. This can be an exceptionally difficult time for family members as they may have felt like it was out of love in which they were feeding their relative (Arceman, 2009).

Nurses can provide emotional support to family members and encourage them on other methods of expressing their love to their relative. The National Institute for Health Care Excellence (NICE, 2015) provide guidelines which suggest that the families of the dying person could be encouraged to provide comfort by maintaining mouth care or assisting with drinks. Nurses can also provide the necessary aids such as fluid thickener, beakers, straws and mouth care trays whilst educating and advising the families on maintaining safety (Coyle and Paice, 2015).

### **Cancer Cachexia**

Cancer cachexia can be classed as a wasting disease whereby the individual suffers from uncontrollable, unintentional weight loss and muscle wasting which is caused by abnormal metabolism and reduced diet (Del Fabbro, Inui and Strasser, 2015). Cancer cachexia increases the risk of morbidity and mortality and occurs in around 80% of patients with advanced cancer (Reid et al, 2010). Patient's families may feel like their loved one is being 'starved' by health care professionals, therefore, it is important to distinguish the difference between cachexia and starvation (Ferrell, Coyle and Paice, 2015). Cachexia and starvation is similar in that weight is lost due to a reduction in calorie

intake. However, the difference is that resting energy expenditure, protein syntheses and protein degradation are reduced in starvation whereas, in cachexia, they are all increased (Gorrol and Mulley, 2011). The configuration of weight loss is different, within starvation weight is lost preferentially from fat whereas cachexia affects skeletal muscle and connective tissue, including fat and protein (Holmes, 2011b).

The European Palliative Care Research Collaboration (EPCRC) provide recommendations in treating cachexia for patients with advanced cancer (Del Fabbro, Inui and Strasser, 2015). Conversely, Suziki et al (2013) suggests that there is limited cachexia specific research to determine the effectiveness of these recommendations due to the life expectancy of palliative patients. The management of cachexia also needs to take into consideration the patient's prognosis. Treatment for cachexia in patients with a short life expectancy may add to the disease burden without providing symptom relief and therefore be inappropriate (Suziki et al, 2013). Additionally, Del Fabbro, Inui and Strasser (2015) suggests a need for increased cachexia awareness and assessment in clinical practice which should be integrated into mainstream oncology education for health professionals.

Reid et al (2010) conducted a study in the UK on both inpatient's and outpatient's experience of cancer cachexia. The study discovered that many patients and their family members found that healthcare professionals did not give them any information or explain why the patient was losing weight. This made them feel anxious, isolated and concerned about their loved ones weight loss. The results are contrary to the guidelines suggested by the Royal College of Nursing (2015) which states how sensitive communication should take place between staff, the patient and their family. A study by Reid, Santin and Porter

(2012) revealed similar findings and family members recall feeling like nobody cared. The family members also felt like someone should have spoken to them, as a family, regarding what to expect from their loved one with cancer cachexia. Both studies, however, did not incorporate the views of healthcare professionals, therefore, this may be an area for future research.

In terms of nursing staff, a study by Millar, Reid and Porter (2013) revealed it was a lack of knowledge or outdated knowledge on cancer cachexia that led to a lack of recognition of cachexia patients in clinical practice. Similar findings were reported in a study by Churm et al (2009), suggesting it compromised professional's ability to care for patients and their families. In order to enhance practice and the experience of patients and their families more training could be arranged for nurses on cancer cachexia. Effective communication and partnership working is vital to deliver high quality end of life care. It furthermore ensures that this partnership working improves the outcomes and experience for the patient and their families (Laycock, 2011).

### **Nursing Interventions**

Symptom control in palliative nutrition is vital to enhance the patient's quality of life (Watson et al, 2009). In order to improve the patient's nutritional status the nurse can attempt to alleviate symptoms which affect a patient from eating. However, a person centred approach needs to be adopted and nurses symptom control should be individualised to the each patients' needs and wishes (Coyle and Paice, 2015). Cherney et al (2015) highlights the importance of a multi-disciplinary approach, where nurses work alongside doctors, dieticians and speech and language therapists in order to deliver safe nutrition. During a time of such vulnerability nurses hold an important role in acting as an

advocate through advising doctors on appropriate pain management and dosage to alleviate symptoms (Becker, 2009).

Kinghorn and Gaines (2007) draws attention to patients who under report their level of pain and explains how nurses can use their observational skills and their initiative to recognise and manage this. By working together the multidisciplinary team can reduce/eliminate the symptom's which prevent the patient from eating, therefore allowing them to enjoy food while improving their nutritional status (Dahlin, Coyne and Ferrell, 2016).

An audit led by the Marie Curie Palliative Care Institute Liverpool in 127 hospital trusts discovered that 91% of palliative patients had written prescriptions available to alleviate palliative symptom's including nausea and vomiting and pain, and in some trust's 100% was achieved (Royal College of Physicians, 2011). This shows that effective communication and partnership working is fundamental to delivering high quality palliative care.

Protected mealtimes is a local initiative introduced to help patients maintain and improve their nutritional status (Reed, Clarke and Mac Farlane, 2012). Results from a study conducted by Ullrich, McCutcheon and Parker (2011) highlighted that since the implication of protected meal times the nutritional status of the patients had improved. Also, a study by Taylor (2008) revealed that patients and families actually preferred protected mealtimes compared to open visiting hours. Ullrich, McCutcheon and Parker (2011) based their study on a residential care setting with a small sample making it difficult to generalise these results. The researchers could consider conducting a study based on different settings to get a deeper understanding of the impact of protected mealtimes.

Nevertheless, nurses face challenges and tensions can arise as doctors do not recognise the value of them (Tolson, Booth and Schofield, 2011). Nurses need to be assertive to ensure the focus at mealtimes is on the patient and their meal in order to maintain and improve their nutritional status (Mallik, Hall and Howard, 2009).

### **Methods of Delivering Nutrition**

There are various methods of delivering nutrition and hydration to patients. The oral route is the preferred method of delivering nutrition and patients should be advised to eat frequently and eat foods high in protein and energy (NCI, 2016). Doctors and nurses working in palliative care believe that the non-oral route for hydration and nutrition has very limited benefits at the end of life (Dean, Harris and Regnard, 2011) On the other hand, Skipper (2012) denotes how families believe that this withdrawal will cause further distress and therefore lead to an uncomfortable death. Such decisions should be based on an individual assessment, in some patients reversing dehydration can help manage symptom control in the earlier stages of the illness (Dean, Harris and Regnard, 2011).

Nasogastric tubes are effective in the short term for delivering nutrition and can be inserted during radiotherapy so long it is not painful for the patient (Bernstein and Luggen, 2010). However, it is argued that nasogastric tubes can be inserted incorrectly which could lead to aspirational pneumonia, they can also cause distress to the patient (Durai, Venkatraman and Phillip, 2009). Unlike nasogastric tubes, percutaneous endoscopic gastrostomy (PEG) tubes are for a long term basis and host less of risk of aspiration (Bernstein and Luggen, 2010). PEG tubes can be beneficial in patients with gastrointestinal cancers to provide nutritional or decompress the upper gastrointestinal tract in patients with distal bowel obstruction. It is unclear however that patients will

become totally independent of total parental nutrition, additionally it is uncertain that PEG tubes coincide with the goal of palliative care, to provide comfort (Mobily and Patel, 2015). Furthermore, Malhi and Thompson (2014) explain how nutrition through PEG tubes can cause pain, discomfort and infection, although these can be dealt with through good nursing management and care.

Doctors hold no legal obligation to provide futile treatment (General Medical Council, 2016). However, Howard and Pawlik (2009) states that doctors do have an obligation to discuss the rationale of this decision with the patient and their families whilst also advising them of the wide range of supportive care options available. A study by Efstathiou and Walker (2014) revealed that nurses lacked confidence in treatment withdrawal and felt like it impacted their ability to care for the patient. In this study however, the participants were self-selected and their motives for taking part may suggest very positive or negative experiences which can affect the accuracy of these results. Nevertheless, to improve practice training could be offered to nurses on the process of treatment withdrawal. This would be beneficial as families recall in a study by Wiegand (2008) how the decision to withdraw treatment was horrific and one of the hardest things they have ever done. Training could enable nurses to provide better support and information to patients and their families.

### **Ethical Considerations**

The most fundamental ethical aspect of nursing is the principle of respect for patients (Matzo and Sherman, 2014). This is also highlighted by the Nursing Midwifery Council (NMC, 2015, p.4) as it calls professional's to "treat people with kindness, respect and compassion." The patient's right to autonomy should be respected particularly if they

need artificial nutritional support. The patient should be educated on the benefits and the potential risks so that they can make an informed decision and give consent (Purtillo and Have, 2010). The option for artificial support may be withdrawn or withheld for some patients if it was deemed ethical for that patient. It should be effectively communicated to the patient and their families if treatment was to be withdrawn or withheld following a review of the Liverpool Care Pathway which suggested withdrawal of fluids and food was to hasten death. (Neuberger et al, 2013).

### **Conclusion**

A diagnosis of cancer or a life limiting condition can be exhausting both emotionally and physically and palliative patients and their loved ones. Nurses and the multidisciplinary team play an vital role in the management and support of palliative patients and their nutritional status. In absence of a specific screening tool to determine a palliative patient's nutritional status, a full individual assessment should be conducted and appropriate referrals made. Nutritional intervention is necessary in the early stages of palliative care, whereas, at the end of life stage the aim is to maximise food enjoyment and diminish discomfort. There needs to be effective communication between health care professionals, the patient and their families to determine the best plan of care.

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