Managing cancer-related fatigue in palliative care

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Cancer-related fatigue is the most frequently experienced symptom in palliative care patients suffering from cancer, and has a profound effect on their quality of life. This article explores the current literature relating to the assessment and management of this complex and distressing symptom in patients with advanced cancer.

Fatigue is a common, distressing and debilitating symptom experienced by people with cancer. In those receiving palliative care it is probably the most frequently reported symptom (Pedersen et al, 2003) and is experienced by more than 90 per cent of these patients (Stromgren et al, 2002). However, it represents the most commonly unrelied cancer symptom (Smets et al, 1993).

Much of the research into cancer-related fatigue explores the experience and management of patients undergoing chemotherapy or radiotherapy (Ahlberg et al, 2003). Far less attention has been paid to those with advanced cancer in the palliative care setting, although fatigue is well recognised by health care professionals as a significant problem during end-stage disease (Krishnasamy, 1997). This article reviews the literature on the assessment and management of cancer-related fatigue in the palliative care setting. The primary focus of palliative care should be on comfort and support (Billings, 1998), which should include meticulous symptom control, psychosocial and spiritual care, as well as a personalised management plan that ensures patients have the best quality of life possible (Billings, 2000). However, studies have shown that cancer-related fatigue can significantly impair quality of life (Curt et al, 2000).

Fatigue is a subjective experience, and evidence of its impact on an individual’s quality of life must be determined by qualitative studies (Krishnasamy, 1997). Cancer-related fatigue is also a multidimensional phenomenon, and can have a number of causative factors that can be difficult to establish. However, despite these complexities, advancing research will help to promote the problem as a palliative care symptom that can be assessed and managed.

Defining cancer-related fatigue

Cancer-related fatigue is a complex phenomenon with physical, cognitive and affective modes of expression (Pedersen et al, 2003; Cella et al, 1998). A clear understanding of what it constitutes is essential before it can be assessed and managed, or health care professionals are able to discuss it with patients and colleagues (Ream, 1999).

After exploring fatigue from the perspective of patients, Richardson and Ream (1996) derived the following definition: ‘a subjective, unpleasant symptom which incorporates feelings ranging from tiredness to exhaustion, creating an unrelenting overall condition which interferes with individuals’ ability to function to their normal capacity’.

Causes and effects

The pathogenesis of cancer-related fatigue is still unknown, and lack of success in treating it at the end of life stage is in part due to this lack of knowledge (Ahlberg et al, 2003). There may be multiple aetiological factors relating to the underlying disease, accompanying factors or other concurrent diseases, psychosocial factors and the use of centrally acting drugs (Pedersen et al, 2003; Barnes and Bruera, 2002).

Quality of life is related to symptoms, functioning, and psychological and social well-being, while during end-of-life care, spirituality and existential issues become increasingly prominent (Kaasa and Loge, 2003). As patients become too tired to participate fully in the roles and activities that

Learning objectives

Each week Nursing Times publishes a guided learning article with reflection points to help you with your CPD. After reading the article you should be able to:

- Know what cancer-related fatigue is;
- Understand the causes and effects of fatigue;
- Recognise the issues surrounding management of fatigue in palliative care;
- Know how patients perceive this condition;
- Understand the nursing management priorities for patients with this condition.

REFERENCES


Loge, 2003). As patients become too tired to participate fully in the roles and activities that
make life meaningful, fatigue therefore significantly affects their quality of life (NCCN, 2004).

In a number of studies, people with cancer have rated fatigue as the symptom with the most severe negative impact (Curt et al, 2000; Portenoy and Itri, 1999; Ross and Alexander, 2001). Potter (2004) found that for some the spiritual aspects of fatigue caused the most distress as they tried to cope with feelings of hopelessness and struggled to find meaning.

Patients’ perceptions

One of the barriers to treating fatigue at the end of life may be patients’, families’ and clinicians’ perception of it as an avoidable, untreatable symptom (Johnson, 2004).

Many people experience fatigue, but qualitative studies have shown that fatigue experienced by patients with cancer is more rapid in onset, more energy-draining, more intense, longer-lasting, more severe and more unrelenting when compared with ‘typical’ fatigue (Holly, 2000; Magnusson et al, 1999).

Interventions can only be developed and tested if health professionals and researchers understand the subjective experience of fatigue from the patients’ perspective in addition to the language they use to describe it, and their expectations of treatment (Potter, 2004).

The meanings that patients attribute to fatigue can determine their reaction to it, especially in advanced cancer where it is intertwined with the process of adjusting to a diagnosis of cancer and living with a terminal illness (Potter, 2004). Patients often use metaphors instead of the term fatigue to describe how they feel (Magnusson et al, 1999) and ultimately fatigue may become a metaphor for death (Krishnasamy, 1997).

The experience of fatigue in cancer patients has a considerable impact on role function, family dynamics and perceptions of suffering. Magnusson (1999) found three major categories in patients’ perceptions (Box 1).

Potter’s (2004) study of cancer-related fatigue in patients with advanced cancer identified five interconnected themes that described their experience in terms of physical, psychological, social and spiritual consequences, and unhelpful coping strategies. The phenomenological method used by Potter enables the researcher to investigate subjective phenomena and may reveal the ‘lived experience’, giving a rich and meaningful insight into patients’ perceptions (Streubert and Carpenter, 1999).

Krishnasamy (2000) used a case study approach, and a number of data sources to ensure that objective and subjective data was collected to enable an understanding of the fatigue as well as patients’ experiences of this symptom.

This approach, providing a holistic perspective, was greatly valued by the patients who took part in the study as it gave them an opportunity to talk about their fatigue. Potter (2004) also concluded that time spent listening to patients could help to alleviate some of their psychological distress by channelling their fears into meaningful discussion about fatigue.

Nursing assessment

Since it is a common symptom among patients with cancer, it is essential to incorporate measurement of fatigue into nursing assessment. Patients will often not inform health care professionals of its presence unless asked, as they assume nothing can be done about it (Pedersen, 2003).

Magnusson et al (1997) found that Swedish nurses failed to use a systematic framework to help them recognise and assess patient fatigue, while a survey of nurses in a cancer centre using a structured survey questionnaire (Knowles et al, 2000) confirmed that this was the case in a UK cancer centre.

While the nurses acknowledged problems associated with fatigue, assessment tools were not widely used. The majority of nurses in this survey reported that they would benefit from further education on the subject.

Assessment of fatigue should identify the factors that exacerbate or relieve it, determine the degree to which it interferes with the activities of daily living, and identify potential causes, including the underlying disease, treatments, intercurrent systemic disorders, psychological disorders, and

**Box 1. Patients’ perceptions of the impact of fatigue**

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**References**


This article has been double-blind peer-reviewed.

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REFERENCES


Guided reflection

Use the following points to write a reflection for your PREP portfolio:

- Outline where you work and why this article is relevant to you;
- Think about a patient you have nursed who had cancer-related fatigue;
- List what the article says about patients’ perception of this condition;
- Describe how this article has helped you understand the experience of fatigue;
- Write about how you can apply this to your work.

Measuring cancer-related fatigue

There is the potential for confusion in the measurement of fatigue because of its close association with other factors such as depression, muscle weakness and functional status. Because cancer-related fatigue differs from that in healthy people, instruments should be designed specifically for, or at least validated for use with, patients with advanced disease and short life expectancy (Kaasa et al, 2003; Fillion et al, 2003).

Cancer-related fatigue has subjective and objective features that are not easily quantified (Schwartz, 2002), but only by adequate monitoring will health professionals develop more appropriate treatment strategies, whether palliative or curative. Schwartz (2002) reviewed a variety of tools for assessing fatigue, several of which have been validated in patients with cancer. However, these are difficult to use in the clinical setting, owing either to their complexity or the length of time required to administer them (Mendoza et al, 1999; Yellen et al, 1997).

Nevertheless, researchers have noted the availability of shorter versions of original instruments that allow for easier completion in clinical settings while maintaining solid psychometric properties (Schwartz, 2002).

Portenoy and Itri (1999) suggest the use of three questions in screening for fatigue (Box 2). A simple unidimensional tool, such as the Brief Fatigue Inventory (Ross and Alexander, 2001), could be used in the clinical setting to rapidly assess fatigue, using a numeric or verbal rating scale (Mock et al, 2000). However, Krishnasamy (2000) warns that there is increasing evidence of the limitations of evaluating individuals’ experience by using measurement tools as they ‘reduce experience to a series of subscales and numerical values’.

Nurses must listen carefully to patients’ own descriptions (Magnusson et al, 1997) as these are the best measure of their fatigue (Ahlberg, 2003), and the most sensitive indication of successful fatigue management may be patients’ perception of their quality of life (Clark and Lacasse, 1998).

Management

Studies have demonstrated the problems and challenges faced by health care professionals trying to manage fatigue in patients who have advanced cancer (Potter, 2004). However, the key to managing cancer-related fatigue is recognising that it is a multicausal, multidimensional problem (Stone, 2002).

The related science is developing rapidly and some evidence-based clinical practice guidelines for fatigue management are now available (Mock et al, 2000). However, little is known about the mechanisms or causes of end-of-life fatigue, and few interventions have been developed or tested in terminally ill patients (Johnson, 2004).

Very few nurses believe they have received adequate training on fatigue management (Knowles et al, 2000), but awareness of the significance of this disruptive symptom is increasing among health professionals (Ahlberg et al, 2003).

Management strategies are typically divided into those that are aimed at treating the underlying cause of fatigue and those aimed at treating fatigue directly.

Treating underlying causes

Before a patient’s fatigue is simply attributed to the cancer or its treatment it is important to identify and treat easily reversible underlying physiological and psychological causes of fatigue (Stone, 2002). For example, this may involve reducing non-essential medications, treating infections, correcting hypercalcaemia and electrolyte disorders or treating pain, depression, sleep disorders or anaemia (Pedersen et al, 2003).

Potter (2004) found a link between fatigue, sleep and anxiety. In many patients with cancer, no cause for fatigue can be readily identified, and the approach to management is a general one (Ahlberg et al, 2003).

Treating fatigue directly

In palliative care, efforts are directed at alleviating symptoms, as well as toward preventing or treating the underlying cause when that is possible or reasonable (Ross and Alexander, 2001). Potter (2004) suggests that interventions should begin with the promotion of sensitive communication, giving patients the opportunity to discuss their fatigue in the context of living with a terminal illness and its impact on their lives.
Krishnasamy (1997) found that enabling patients to talk about their fatigue both facilitated professional assessment and helped them to explore the meaning of the cancer and fatigue experience for themselves, and for their family and friends. This exploration can help patients regain a sense of control and freedom to focus on other important aspects of their lives, so restoring their self-esteem (Holly, 2000).

Patient and family education can be of great value in understanding cancer-related fatigue. Family members may interpret fatigue as a sign that the patient is ‘giving up’, when it is actually beyond her or his control.

Krishnasamy (1997) concludes that the fundamental basis for nursing intervention aimed at minimising the impact of fatigue in advanced cancer appears to rest on three core elements:
- Facilitating the expression of symptoms of fatigue through in-depth assessment;
- Supporting patients and carers as they struggle to find meaning in something so disabling;
- Shifting the focus of patients and carers from managing the symptom of fatigue to facilitating the process of living with the fatigue of dying.

To be effective, interventions for fatigue in patients with advanced cancer need to incorporate a range of strategies that should be tailored to meet the changing needs of each individual (Ream, 1999).

Complementary medicine embodies the principles of palliative care (Zappa and Cassileth, 2003) by helping to ease the physical, psychosocial, and spiritual effects of illness. It aims to control symptoms and to enhance quality of life for patients and their families.

Relaxation, visualisation, massage and aromatherapy are currently being evaluated as part of a global intervention known as Beating Fatigue. There is already evidence of the beneficial effect of massage and aromatherapy on depression and other symptoms including fatigue (Fellows et al, 2004). Meanwhile Post-White et al (2003) have found that ‘healing touch’ lowered fatigue. Both therapies lessened mood disturbance.

Further multicentre studies are required, making use of rigorous research designs, with larger sample sizes and greater standardisation of interventions – to facilitate replication and increase validity – before complementary and alternative therapies can truly be integrated into a patient’s plan of care.

**Conclusion**

Despite the high prevalence of cancer-related fatigue among patients in palliative care, its treatment is less successful than treatment for other symptoms at the end of life (Ross and Alexander, 2001). The aetiology of fatigue in patients with advanced cancer is often unclear, multiple factors may be responsible and little is known about its pathogenesis (Barnes and Bruera, 2002).

The specific goals of palliative care are to improve the quality of the last stages of patients’ lives, control symptoms, provide support to family members and to pay attention to patients’ perceptions of ‘purpose’ and ‘meaning of life’ (Kaasa and Lodge, 2003). The experience of cancer-related fatigue has a major impact on patients’ motivation as it means they are unable to undertake physical activities and that they lose interest in activities and life in general (Holly, 2000). Efforts to improve their quality of life may therefore depend on the development of effective interventions for fatigue (Johnson et al, 2004).

Although it is difficult to conduct research on patients who are highly distressed, have severe symptoms or who are dying, there is the potential for such research to have a therapeutic benefit for those taking part (Conner, 1996).

Providing patients with advanced cancer with an opportunity to discuss their feelings associated with symptoms such as fatigue provides information necessary to develop understanding and can also help patients to make sense of their experiences (Krishnasamy, 2000). Future research should focus on determining effective solutions – including alternative and complementary therapies – rather than on reasserting need.

More focused fatigue assessment tools and targeted fatigue interventions for patients at the end of life are required, as is training in fatigue management so that health professionals are knowledgeable and skilled in assessing and managing fatigue.

By drawing together the physical, psychosocial and emotional components of an individual’s experience of advanced cancer, palliative care research demonstrates that health professionals can facilitate patients’ adaptation to living with cancer-related fatigue.

Such intervention can empower patients to maintain control over decisions relating to their care and can assist them to understand and find meaning in their fatigue.

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**REFERENCES**


