

PSYCHOSOCIAL SUPPORT FOR THE PALLIATIVE CARE PATIENT

End of life is a difficult time for patients and their relatives and carers. It is important that psychosocial care is provided to palliative patients and their families in various ways through a range of medical, nursing and allied healthcare professionals.

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This case report will explore the psychosocial support needed for patients who require palliative care. The types of illnesses that are commonly seen in the field are advanced cancers, end-stage heart or renal failure, end-stage lung disease and progressive neurological disorders (eg motor neurone disease, multiple sclerosis, supra-nuclear palsy).

PALLIATIVE CARE

The World Health Organization (WHO) defines palliative care as 'the active total care of patients whose disease is not responsive to curative treatment' and states that 'control of pain, of other symptoms and of psychological, social and spiritual problems is paramount' with the goal to 'achieve the best quality of life for patients and their families' (WHO, 1990). This reflects the view that attending to a patient's psychosocial needs, and those of their family, is an integral part of caring for someone in accordance with this approach.

Psychosocial care is specifically 'concerned with the psychological and emotional wellbeing of the

patient and their family/carers, including issues of self-esteem, insight into and adaptation to the illness and its consequences, communication, social functioning and relationships' (Dix and Glickman, 1997). It is important to define what is meant by psychosocial support for the palliative care patient and how this can be provided in practice.

CONSEQUENCES OF DIAGNOSIS

The psychological and social consequences of a diagnosis of life-limiting illness on the patient needs to be considered.

A diagnosis of this kind may provoke a range of emotional responses in the patient or family member. These include:

- ▶▶ Fear of physical deterioration/dying; pain/suffering; losing independence; the consequences of illness or death on loved ones
- ▶▶ Anger at what has happened or what may have caused/allowed it to happen; unsuccessful treatment
- ▶▶ Sadness at approaching the end of life; restriction of activities due to illness
- ▶▶ Guilt/regret for actions; in some cases for contributing to the development of the illness

- ▶▶ Changes in sense of identity, adjusting to thinking of themselves as unwell/dependent (*all above from Lloyd-Williams, 2008*)
- ▶▶ Loss of self-confidence, sometimes related to loss of physical functioning/changes in appearance
- ▶▶ Confusion about what has happened; the future and choices available.

These psychological concerns also overlap with spiritual anxieties. These might be fears about what happens after death or existential questions about the meaning of life. This is often common when someone is facing the end of their life or that of someone close to them (Williams 2006 as cited in Lloyd-Williams 2008).

Additionally, the patient's illness may have a number of social consequences for themselves and those close to them (Sheldon, 1997; Monroe, 1999; Hearn et al, 2008; Lloyd-Williams, 2008). The illness may impact on the patient's ability to perform everyday social tasks such as shopping, cleaning, laundry, paying bills, and may necessitate the involvement of carers (often paid or unpaid family members or friends) in these activities of daily living. The illness

may render the patient unable to perform previous social roles such as parenting, caring for a sick/elderly relative or maintaining paid employment.

Serious illness can have a number of financial consequences. Some of these are related to the inability to perform social roles (unemployment or having to pay for someone else to look after the children) and some are not (higher fuel bills because of prolonged periods at home, feeling the effects of the cold more keenly after chemotherapy treatment, parking charges at hospitals).

Patients may find that their accommodation is not suitable to their altered physical needs, necessitating a house move or adaptations to the living environment such as moving a bed downstairs and fitting rails or other equipment. Patients and their family members may need to be involved in planning for the future, such as taking steps to make a will or discussing and deciding who will look after any dependent children.

A life-limiting illness often has a profound impact on relationships between patients and their family or friends, which, therefore, need to be renegotiated. Patients' relationships with their partners might be affected by personal care tasks (such as washing or feeding) that partners have to perform. In the author's experience it is not uncommon for carers to say they wish they could go back to being 'wives or sisters' to patients rather than having to care for them as well.

When personal care has to be performed by relatives there may

be less time for the activities they had previously taken part in, such as eating out, going to the pub, or other leisure activities.

Patients' sense of their sexuality and their ability to feel attractive or experience intimacy may also be affected by their illness and could impact on relationships with partners. For example, a patient with a stoma may feel self-conscious and wish to avoid that area being seen/touched.

In the author's opinion, it is these psychological and social consequences, which could be described as the 'non-medical needs' of palliative care patients that psychosocial care seeks to address. These psychosocial needs cannot be entirely separated from physical needs, as people's psychological/social circumstances can impact upon their physical symptoms and vice versa. For example a patient's distress or anxiety can exacerbate his or her experience of pain. Likewise, a patient's physical symptoms (pain or vomiting) may impact on his or her psychological wellbeing, giving rise to feelings of fear, anxiety or depression. These physical symptoms could also affect a person's social situation, for example, his or her ability to work or the level of care they need.

FEATURES OF PSYCHOSOCIAL CARE

The care taken to address the psychological and social concerns of patients in palliative care might involve:

- ▶▶ Helping patients understand their illness and/or symptoms
- ▶▶ Helping patients to understand their options and plan for the future

- ▶▶ Advocating on behalf of patients/those close to them to ensure they have access to the best level of care and services available
- ▶▶ Enabling patients and those close to them to express their feelings and worries related to the illness, listening and showing empathy, providing comfort through touch as/when it is appropriate, e.g. holding a patient's hand or putting a hand on his or her shoulder. Also, complementary therapies such as massage
- ▶▶ Helping the patient or family member access any financial aid they may be entitled to (including benefits, but also charitable trusts/grants where applicable)
- ▶▶ Practical help with daily activities like grocery shopping
- ▶▶ Arranging personal/social care and organising aids for daily living — setting up a care package, installing hand rails or other adaptations
- ▶▶ Carer support such as making arrangements for respite
- ▶▶ Signposting the patient/those close to them to relevant resources like local support groups
- ▶▶ Exploring spiritual issues and ensuring the patient is able to continue his or her religious practices
- ▶▶ Referring the patient or family member to specialist psychological/social support where appropriate (Sheldon, 1997; Monroe, 1999; Hearn et al, 2008; Lloyd-Williams, 2008; Burtzotta and Noble, 2010).

CASE STUDY

'Alena' was a 45-year-old female teaching assistant who was diagnosed with advanced metastatic breast cancer. Alena

was divorced and lived with her two school-aged children.

Alena's breast cancer was widespread and incurable. The oncologist at the hospital discussed her options in terms of palliative treatment, helping her to understand the benefits and drawbacks of each so that she could make an informed decision. With Alena's agreement, the oncologist also referred her to the community palliative care team.

The palliative care community nurse specialist (CNS) advised Alena about the management of her symptoms (particularly the pain, which made it difficult for her to look after the children). Alena was unable to work due to her ill health and worried about how she would support herself and the children. The CNS helped her apply for the benefits she was entitled to. Alena had also become quite lonely since she had stopped work, but the CNS put her in touch with a local support group for women living with cancer.

Alena consulted a palliative care social worker about how to explain her illness to her children and how she could help them cope. With the support of the social worker, she made plans for the care of the children after her death. Alena was sad that she would not see her children grow up and felt guilty that she may have contributed to her illness by smoking. She was often low in mood and was referred to a counsellor.

As Alena's disease progressed she grew increasingly tired and weak. An occupational therapist visited to advise her on fatigue management

(ways to conserve her energy and arranges for the installation of some grab rails. A community social worker organised a carer to visit twice a day to help Alena get washed and dressed in the morning and ready for bed at night.

In discussion with her palliative care nurse, Alena decided that she would like to be cared for at the hospice when she reached the final stages of her illness, and was eventually admitted there for terminal care. The nurses and healthcare assistants at the hospice allowed Alena to express her concerns and fears about dying, which helped her to feel less isolated. They gave her information and choice about her treatment, which enabled her to retain a sense of control. She was seen by a complementary therapist for reflexology to increase her relaxation. One of the healthcare assistants also helped Alena make a telephone call to her brother in Australia when she was too weak and fatigued to manage this by herself, and she took great comfort in hearing his voice.

After Alena's death the hospice bereavement service continued to support her family and friends.

CONCLUSION

As this case study illustrates, psychosocial care can be provided to palliative patients and their families in various ways through a range of medical, nursing and allied healthcare professionals (AHCPs). While it may be necessary to enlist a specialist social worker, psychologist, counsellor or psychiatrist if a particular need arises (for example, in the case of clinical

depression/anxiety), psychosocial care can be provided at every stage of a patient's illness. It could be argued that psychosocial care not only can, but also should be provided by everyone involved in a patient's treatment, as this is the only way to achieve holistic, palliative care. **WE**

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