Palliative care
Physical and spiritual wellbeing at the end of life

ALISON WHITE MB BS(Hons), MPH, FRACP

Palliative care can improve quality of life and potentially prolong survival through early management of physical symptoms and psychospiritual distress. It should be considered for any patient with a life-limiting illness, well before they require terminal care, and can be offered alongside active treatment. Every healthcare provider should have the skills to offer general palliative care, with referral to specialist palliative care services in more challenging situations.

KEY POINTS

- The prevalence of cancer and chronic noninfective disease is increasing, and approximately half of all deaths in Australia are reasonably predictable because of a diagnosis of a life-limiting illness.
- Palliative care promotes quality of life through early identification, assessment and management of physical symptoms and psychological and spiritual distress.
- Fewer patients with noncancer diagnoses are referred to palliative care, but patients with life-limiting noncancer conditions also have a high prevalence of symptoms including pain, dyspnoea, fatigue, anorexia and anxiety.
- Unmet spiritual needs can contribute to increased physical and psychological distress.
- Early integration of palliative care with other patient care, including active care, is associated with survival benefit.
- Palliative care is appropriate early in the course of life-limiting illness and in conjunction with life-prolonging therapies.

The WHO articulately defines palliative care as 'an approach which improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[1] Key features of this definition of palliative care are outlined in Box 1. Notable aspects are the use of the term 'life-threatening' rather than 'terminal' illness and the description of palliative care as applicable early in the course of illness and in conjunction with life-prolonging therapies. These highlight that palliative care is not necessarily synonymous with end-of-life care.

The palliative care population

The population who could benefit from palliative care is substantial and increasing. Almost 150,000 deaths occur in Australia annually. Up to half of these deaths could reasonably be predicted because of a previous diagnosis of a life-threatening condition.[2] In 2013, the top 10 causes of death could all be expected to have a progressively declining course. Only four of these were malignant conditions: lung, lower gastrointestinal tract, haematological and prostate cancer. The remaining six were chronic noninfective illnesses: heart disease (ischaemic heart disease and heart failure), dementia, cerebrovascular disease, respiratory disease and diabetes.[3] The proportion of deaths likely to occur as a consequence of cancer and chronic noninfective illness is predicted to increase, with the WHO estimating that these conditions will account for 70% of deaths in developed countries by 2030.[4] Palliative care is a growth industry.

MedicineToday 2016; 17(5): 22-28

Dr White is a Palliative Care Physician at Royal Perth Hospital Department of Palliative Care and St John of God Hospital, Perth, WA.

© PHOTOGRAPHEE.EU/STOCK.ADOBE.COM

From a global perspective, Australia is doing well with respect to palliative care. In the 2015 Quality of Death Index, Australia ranked second, behind the UK, in a review of 80 countries.[5] The index assesses five factors, including the provision of a palliative care framework within the healthcare environment, the availability of palliative care professionals, the affordability of care, the standard of care provided and community engagement with palliative care, including an awareness of end-of-life choices.

Australia scored well for each of these factors; however, the report noted that even the highest ranked countries do not meet the needs of every citizen.[5] The focus on curative treatments remains in many settings. A change in focus that sees quality of life ranking higher among the priorities of care will enable the provision of better palliative care through the simultaneous application of life-prolonging and supportive therapies, while also recognising dying as a normal and expected process.

Aspects of palliative care

Physical symptoms

The identification and management of physical symptoms to maximise quality of life are among the primary concerns of palliative care. The most prevalent symptoms in palliative care are listed in Box 2.[6]

Pain is a widely recognised consequence of cancer and is both common and feared by many patients. Approximately 80% of patients with advanced malignancy will experience pain, and around two thirds will require analgesic medications.[7-9] Cancer patients may, however, experience a multitude of other symptoms along with pain. Furthermore, patients with nonmalignant life-limiting conditions also have a high prevalence of pain, as well as other symptoms that are both common to terminal illnesses and unique to their specific conditions.

A recent systematic review investigated the prevalence of a range of symptoms in patients with cancer and noncancer conditions, including heart and renal failure, chronic obstructive pulmonary disease, AIDS, dementia and neurodegenerative conditions. This review found many symptoms were common across all of the disease processes examined. This was particularly true for pain, fatigue, anorexia, shortness of breath and anxiety.[10] As our population ages, patients are likely to enter their final illness with more comorbidities and complex symptoms, greater dependency and functional decline, increasing the challenge of symptom management at the end of life.[11]

Opioids have long been regarded as the go-to medications in palliative care. They remain the mainstay for management of cancer pain and have an important role in dyspnoea and cough. The International Association for Hospice and Palliative Care has developed a list of essential medications for palliative care, which includes, in addition to opioids, agents for management of neuropathic pain (e.g. amitriptyline, gabapentin), NSAIDs, aperients and antidiarrhoeal agents, corticosteroids, antipsychotics, antidepressants, benzodiazepines and antisecretory agents.[12]

To complement medical therapy, numerous nonpharmacological strategies are available to help manage symptoms. For example, walking aids, portable oxygen and advice regarding energy conservation techniques can help patients maintain independence and achieve personal goals, such as attending important events with friends and family. Multidisciplinary palliative care teams can help patients preserve function and independence, as well as support families and carers to provide safe and sustainable care.

Spirituality

The term ‘spirituality’ can be abstract and difficult to define. In a review of a number of studies exploring the concept of spirituality among patients and healthcare workers, the predominant theme of spirituality was that of relationships: with self, others, the world, nature and, for some, God or a higher being.[13]

1. FEATURES OF THE WHO DEFINITION OF PALLIATIVE CARE[1]

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- 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 in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

2. MOST PREVALENT SYMPTOMS IN PALLIATIVE CARE[6]

- Anorexia–cachexia
- Anxiety
- Constipation
- Delirium
- Depression
- Diarrhoea
- Dry mouth
- Dyspnoea
- Fatigue
- Hiccups
- Insomnia
- Nausea
- Pain
- Sweating
- Terminal respiratory congestion
- Terminal restlessness
- Vomiting

Adapted from *The Oxford Textbook of Palliative Medicine*, 5th ed.[6]

Spirituality may include the search for meaning or purpose in life, which becomes acutely more relevant when facing a life-limiting illness. Dr Paul Kalanithi, a neurosurgeon diagnosed with metastatic lung cancer at the age of 36 years, wrote extensively on this during his final two years:

‘I began to realize that coming face to face with my own mortality, in a sense, had changed both nothing and everything. Before my cancer was diagnosed, I knew that someday I would die, but I didn’t know when. After the diagnosis, I knew that someday I would die, but I didn’t know when. But now I knew it acutely … The fact of death is unsettling. Yet there is no other way to live.’[14]

Spiritual distress, also referred to as existential distress, may be challenging to identify because of the complex interplay with physical, psychological and social distress. Spiritual distress may present as fear and anxiety about death, which is often worse at night. Others may experience feelings of hopelessness, despair, anger, irritability or even guilt. A sense of loss may represent the loss of relationships, grief or loss of self with changes in appearance and function and increased dependence on others.[13] Unmet spiritual needs can lead to worsening physical symptoms such as pain and insomnia and psychological symptoms such as low mood and anxiety, and in turn increased medical resource utilisation or, on the contrary, isolation.

Patients identify an individual approach to spiritual care as vital.[13] Relationships with healthcare workers are very important, with an emphasis on compassionate and respectful patient care enabling advocacy for patient choices. Despite declining health and increasing dependence on others, patients frequently want some control over their medical care, decisions and activities. Discussions about dying, what will happen after death and involvement in funeral preparations can help to provide a sense of control and comfort for some patients. Often, a feeling of normality through maintaining care at home can be an extremely important part of spiritual care.

Crucially, patients want healthcare workers to ask about their spiritual needs, to listen, support and assist in discussions and to have meaningful relationships with them rather than to provide spiritual advice, religious or theological knowledge. Patients have reported a mismatch between their expectations for spiritual care and that provided.[13] However, time constraints on healthcare workers, with increasing work demands, make it difficult to develop relationships and discuss these sensitive issues with patients. Additionally, the provision of this type of care can be confronting and emotionally challenging for healthcare workers, particularly when they themselves are personally distressed or identify with the patient.

Depression

Depression may affect almost 40% of palliative care patients, compared with a lifetime prevalence of depression of around 16% in the general population.[15] Depression clearly reduces quality of life but may also affect decisions regarding treatments, leading to poorer survival, social withdrawal and decreased quality of relationships. Poorly controlled pain and other physical symptoms Are well recognised risk factors for the development of depression, as is unaddressed spiritual or existential distress.[12] Furthermore, depression leads to greater difficulty in the adequate management of pain and other symptoms, and an increased risk of spiritual distress.

Contributing to all of this, financial hardship is common, underappreciated and often neglected as part of medical care.[16] Distress among families is also frequent, with the provision of patient care predominantly falling to family members who have their own responsibilities and roles within the family, which may be challenged in the context of illness. For patients, a sense of anxiety within their family contributes to feelings of burden and worthlessness, which can lead to demoralisation.[6]

Integrating palliative care into patient care

In a landmark study published in 2010, the early integration of palliative care with standard oncology care for patients with metastatic non-small cell lung cancer was associated with a longer duration of survival.[17] Patients who received early palliative care, within eight weeks of diagnosis, had better quality of life and fewer depressive symptoms and received less aggressive end-of-life care. Subsequent studies have also shown improved or equal survival with early palliative care.[18,19]

Although these studies do not identify which aspect of palliative care contributes to survival, it has long been recognised that longer duration of pain and other symptoms increases the difficulty of adequate symptom management.[20,21] In addition, physical symptom burden is associated with psychological and spiritual distress, potentially decreasing motivation for health care and tolerance of side effects, as discussed above. These associations suggest that palliative care’s holistic approach is important. Palliative care is also a cost-efficient intervention, with consistent findings of lower healthcare costs associated with early involvement.[6]

It is difficult to define the appropriate timing of palliative care involvement for all patients. However, referral to palliative care should be considered for any patient when a disease is recognised as life-limiting, well before the requirement for terminal care.

Identifying patients for referral

A key challenge in the early involvement of palliative care is the identification of the 'palliative care population'. The appropriateness of referral to palliative care is often reasonably clear among patients with a cancer diagnosis. However, for patients with other life-limiting illnesses with an uncertain prognosis and nonpredictable progression, the appropriateness of referral is less clear, leading to fewer patients being referred despite their need.[22] A referral to palliative care may also represent a philosophical conundrum for the practitioner, whose mission is to heal and who may see palliative care as giving up.[23]

However, a focus on curative approaches leads to disease being viewed as its physical complications alone, without the psychological, social and spiritual context that can be so important for individual patients. The involvement of palliative care does not, and should not, demand the abandonment of hope for a longer life or a desire for life-prolonging treatment. Palliative care can, however, advocate for the patient when aggressive medical treatment may no longer be in keeping with their goals of care.

Prognostication is challenging in both malignant and nonmalignant conditions. There are multiple tools to assist in prognostication, but no one tool is ideal for every situation, and these tools are often no more accurate than the subjective judgement of an experienced clinician.[6] The 'surprise question' – 'Would I be surprised if this patient died in the next six to 12 months?' – can be a helpful adjunct in considering the appropriateness of referral to a palliative care service.[6]

Nevertheless, prognostication alone should not drive treatment plans and referral decisions. Rather, careful assessment of the patient's symptom burden, social circumstances and risk of spiritual and psychological distress should be the primary driver for considering referral to palliative care.

Generalist palliative care

Every medical specialty has at least some exposure to patients with life-limiting illnesses approaching the end of life, and general palliative care knowledge should be part of the repertoire of every doctor. Specialist palliative care does not have the capacity to be involved in end-of-life care for every patient, nor is it needed for every patient.

Generalist palliative care should be an essential component of the standard medical care provided to all patients with life-limiting illness and includes:

- provision of pain relief and other symptom management
- recognition of the dying process and withdrawal of inappropriate treatments
- consideration of advance care planning
- assistance with social and financial concerns (e.g. referral to generalist nursing services, completion of insurance and Centrelink paperwork)
- excellent nursing care.

GPs are extremely important and often best placed to provide supportive and palliative care, given their intimate knowledge of and relationship with patients, which have often developed over many years.

Specialist palliative care

Referral to a specialist palliative care service is important for the management of patients with complex symptoms, psychosocial problems and spiritual distress, along with families at risk of complex bereavement, where access to a multidisciplinary palliative care team can be vital. Specialist palliative care services include inpatient units or hospices, consultation liaison services and outpatient clinics and community palliative care teams.

Referral to a specialist palliative care service is appropriate for:

- patients with pain that is difficult to manage or requires large doses of analgesia
- patients with problematic dyspnoea, nausea or other symptoms
- socially isolated patients
- young patients
- patients with high levels of distress within the family
- patients with a history of substance abuse or mental health problems.

In addition to direct patient care, specialist palliative care teams provide support to general palliative care providers through ongoing education and availability for advice in difficult clinical situations. Specialist palliative care also needs to advocate for itself, promoting visibility of the services available to facilitate awareness among other practitioners.

With continued improvements in life-prolonging treatments, increased prevalence of chronic disease and advances in palliative care research demonstrating the benefits of supportive care, specialist palliative care teams will need to be more flexible in their referral criteria, and the work force will need to expand.

Box 3 lists some of the Australian palliative care resources available online.

3. AUSTRALIAN PALLIATIVE CARE RESOURCES

National Palliative Care Strategy

- Available at www.health.gov.au/palliativecare

Palliative Care Australia

- Available at palliativecare.org.au
- Provides a directory of specialist palliative care services in Australia

Care Search Palliative Care Knowledge Network

- Available at www.caresearch.com.au
- Provides up to date evidence on a vast range of topics in palliative medicine
- Provides printable patient information sheets
- Links to the Palliative Care Clinical Studies Collaborative (PaCCSC), which is developing high-quality randomised prospective trials
- Links to Decision Assist Palliative Care and Advance Care Planning (with a phone advisory number)

Australian and New Zealand Society of Palliative Medicine (ANZSPM)

- Available at www.anzspm.org.au

Advance Care Planning Australia

- Available at advancecareplanning.org.au

Palliverse

- Available at palliverse.com
- A forum for discussion and exchange of ideas regarding palliative care issues established by a group of Australians working or interested in palliative care

Conclusion

Palliative care focuses on quality of life by recognising and treating physical symptoms and considering psychological, social and spiritual distress. Palliative care can occur alongside active treatments aimed at prolonging life, while also attempting to recognise the goals unique to each patient. Every healthcare provider should have the skills required to provide general palliative care. Referral to specialist palliative care may be required in more challenging situations. In his book *Being Mortal*, surgeon Atul Gawande puts the spotlight on the importance of ascertaining the goals and desires of the patient and prioritising quality of life, rather than focusing on the specifics of the disease: 'The ultimate goal, after all, is not a good death, but a good life – all the way to the very end'.[24] MT

References

A list of references is included in the website version of this article (www.medicinetoday.com.au).

COMPETING INTERESTS: None.

ONLINE CPD JOURNAL PROGRAM

List factors to be considered in deciding when to offer palliative care to a patient with a life-limiting illness.

Review your knowledge of this topic and earn CPD points by taking part in MedicineToday's Online CPD Journal Program.
Log in to www.medicinetoday.com.au/cpd

© ALEXANDER RATHS/STOCK.ADOBE.COM.
MODELS USED FOR ILLUSTRATIVE PURPOSES ONLY

MedicineToday 2016; 17(5): 22-28

Palliative care

Physical and spiritual wellbeing at the end of life

ALISON WHITE MB BS(Hons), MPH, FRACP

References

1. WHO. National cancer control programmes: policies and managerial guidelines. Geneva: WHO; 2002.
2. A guide to palliative care service development: a population based approach. Canberra: Palliative Care Australia; 2005.
3. Australian Bureau of Statistics. Causes of death, Australia, 2013. Cat. No. 3303.0. Canberra: ABS; 2015.
4. Mathers CD, Loncar D. Projections of global mortality and burden of disease from 2002 to 2030. PLoS Med 2006; 3: e442.
5. Economist Intelligence Unit. The 2015 Quality of Death Index: ranking palliative care across the world. London: Economist Newspaper; 2015. Available online at: http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index (accessed May 2016).
6. Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow DC, editors. Oxford textbook of palliative medicine. 5th ed. Oxford: Oxford University Press; 2015.
7. Hui D, Bruera E. A personalized approach to assessing and managing pain in patients with cancer. J Clin Oncol 2014; 32: 1640-1646.
8. Jost L, Roila F; ESMO Guidelines Working Group. Management of cancer pain: ESMO Clinical Practice Guidelines. Ann Oncol 2010; 21 Suppl 5: v257-v260.
9. Foley KM. How well is cancer pain treated? Palliat Med 2011; 25: 398-401.
10. Moens K, Higginson IJ, Harding R; EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. J Pain Symptom Manage 2014; 48: 660-677.
11. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage 2006; 31: 58-69.
12. De Lima L, Krakauer EL, Lorenz K, Praill D, Macdonald N, Doyle D. Ensuring palliative medicine availability: the development of the IAHPC list of essential medicines for palliative care. J Pain Symptom Manage 2007; 33: 521-526.
13. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliat Med 2010; 24: 753-770.
14. Kalanithi P. How long have I got left? The New York Times Jan 24, 2014. Available online at: http://paulkalanithi.com/tag/essays (accessed May 2016).
15. Massie MJ, Lloyd-Williams M, Irving G, Miller K. The prevalence of depression in people with cancer. In: Kissane D, Maj M, Sartorius N, editors. Depression and cancer. Chichester: Wiley-Blackwell; 2012. p. 1-36.
16. Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: a systematic review of the literature. Palliat Med 2014; 28: 375-390.
17. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010; 363: 733-742.
18. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III Randomized Controlled Trial. J Clin Oncol 2015; 33: 1438-1445.
19. Zimmerman C, Swami N, Rodin G. Cluster-randomized trial of early palliative care for patients with metastatic cancer. J Clin Oncol 2012; 30 (Suppl): abstr 9003.
20. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. J Pain Symptom Manage 2002; 24: 91-96.
21. Mercadante S, Portenoy RK. Opioid poorly-responsive cancer pain. Part 1: clinical considerations. J Pain Symptom Manage 2001; 21: 144-150.
22. Mahtani-Chugani V, González-Castro I, de Ormijana-Hernández AS, Martín-Fernández R, de la Vega EF. How to provide care for patients suffering from terminal non-oncological diseases: barriers to a palliative care approach. Palliat Med 2010; 24: 787-795.
23. Feeg VD, Elebiary H. Exploratory study on end-of-life issues: barriers to palliative care and advance directives. Am J Hosp Palliat Care 2005; 22: 119-124.
24. Gawande A. Being mortal. London: Profile Books; 2014.