Meeting end-of-life care needs for people with chronic disease: palliative care is not enough

… but what should a system that successfully combines interventional and palliative approaches look like?

Teresa A Burgess
GradDipNursing Management, MPHC, Senior Lecturer, Discipline of Public Health, School of Population Health

Annette J Braunack Mayer
BMSc(Hons), PhD, Head, School of Population Health

Gregory B Crawford
MB BS, MD, FAChPM, Mary Potter Associate Professor of Palliative Medicine

Justin J Beilby
MB BS, MD, FRACGP, Executive Dean, Faculty of Health Sciences

University of Adelaide, Adelaide, SA.

teresa.burgess@adelaide.edu.au

doi: 10.5694/mja12.11058

Perspective p 188

Considerable efforts have been made, both nationally and internationally, to address the growing "epidemic" of chronic disease. Chronic disease accounts for more than half of all Australian deaths,[1] treatment of chronic disease in Australia accounts for almost 70% of total health expenditure[2] and hospitalisations associated with chronic disease are a major component of this expenditure (see the Box for a definition of chronic disease as used in the context of this article). Systematic processes to prevent and manage chronic disease have been developed, and all incorporate the concept of a continuum of care from prevention and early intervention, through disease management to the end of life.[2] While there is a strong focus on systematic care, health education, chronic disease self-management and regular review, comparatively scant attention is paid to the actual care required as people approach the end of their life.

In Australia, to date, the need for end-of-life care for people with advanced chronic disease has been addressed by recommending referral to a specialist palliative care service or by developing closer links between these services and specific disease services and primary care.[5] It is assumed that a referral to palliative care can, and will, provide the most appropriate care for people dying with a chronic disease. However, often this process is poorly handled, and general practitioners and primary care clinicians are left to manage an uncoordinated and challenging situation. Inadequate and inappropriate end-of-life care has significant and costly implications: unnecessary hospitalisations; prolonged intensive interventions in acute care settings; patients dying in intensive care units rather than in their preferred place of death; poor symptom management; little opportunity for patients and their families to discuss issues around death and dying; and increasing stress on staff who are not trained in the provision of palliative care.

Originally, palliative care developed to provide support for people dying with cancer, with a trajectory of relatively predictable deterioration requiring intensive support over a fairly short period of time. Chronic disease tends to follow a much slower and more unpredictable trajectory that includes progressive functional decline, poor quality of life and increasing dependency on both formal and informal caregivers as well as the health system. Many people with chronic disease have multiple comorbidities, so it is vital they have access to active and systematic disease management.[3] However, there is a concurrent need for supportive and palliative care to effectively control distressing symptoms and to provide emotional, spiritual and psychological support for the patient and his or her family as the patient's condition slowly deteriorates.[5] Referral to specialist palliative care can mean that patients may not continue to have access to active disease management. A system that not only allows but actively supports the provision of active and palliative care is required.

Disease-focused health professionals and palliative care professionals may sometimes differ in their philosophical understanding of the basis of care provision. Many health professionals still view death as a defeat rather than accepting that death is an inevitable part of living;[6] and palliative care may erroneously be seen as relevant only for the last days of life and as being "exclusive of life prolonging treatments".[7] The term "a palliative approach" is increasingly being used to describe care that allows continuation of active interventions while introducing elements of palliative care (Box), but there are few models of care that successfully combine chronic disease management (CDM) and palliative approaches. For CDM and palliative models of care to blend successfully, both need to be expanded to accommodate understandings that recognise their differing perspectives.

The practice of referring patients to palliative care suggests that there is a clear transition from active disease management to an approaching end-of-life period that triggers the referral. However, there is growing evidence that there is no clear transition for patients with chronic disease, but rather, a slow period of decline, where both interventional care and a palliative approach are required.[8,9] Indeed, there is currently no common understanding in the Australian context of the term "end of life". Palliative Care Australia's definition of end of life (Box) is not specific enough to indicate when a referral should be triggered.[3] The End of Life Care Strategy in the United Kingdom defines the end-of-life period as the last 12 months of a person's life;[10] however, this raises the issue of how to prospectively identify the last 12

Definitions

Chronic diseases[2]

- Have complex and multiple causes
- Usually have a gradual onset, although they can have sudden onset and acute stages
- Occur across the life cycle, although they become more prevalent with older age
- Can compromise quality of life through physical limitations and disability
- Are long term and persistent, leading to a gradual deterioration of health
- While usually not immediately life threatening, they are the most common and leading cause of premature mortality

Palliative approach[3]
A term that has been used to describe care that aims to improve the quality of life for individuals with an eventually fatal condition, and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs

Patient-centred care[4]
Health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of patient-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care

End of life[3]
That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown ◆

months for people with advanced chronic disease. The generic "surprise" question (ie, "Would I be surprised if this patient died in the next 6 to 12 months?") can be useful,[9] but it is increasingly being recognised that needs and symptoms should dictate care, rather than prognosis.

It has been suggested that the responsibility for end-of-life care in Australia should lie with general practice;[9] however, people with advanced chronic disease who are approaching the end of their lives often receive a complex array of medical services from a range of service providers.[8] As people experience exacerbations of disease, care may be centred around acute care hospitals and outpatient departments. These patients may have a private specialist, see their GP regularly or use a combination of health care providers. In these situations, the role of GPs is quite unclear. While a number of GPs have considerable experience in the provision of end-of-life care, current funding mechanisms and practice structures mean that many GPs are unable to allocate the time and resources required. Many people with advanced chronic disease use their GPs for prescriptions and minor care and do not see them as their main health service provider.[8] Even if GPs have developed care plans for their patients with chronic and complex diseases, patients may still not see them as their care coordinator.[8] In this situation, who makes initial contact with a palliative care service? And how is ongoing patient support coordinated? In the UK, systems such as the Gold Standards Framework (with associated infrastructure) allow health professionals to support patients as they approach the end of life (http://www.goldstandardsframework.org.uk). This framework was developed to facilitate the coordination of end-of-life care through primary care, but no infrastructure currently exists in Australia to support a similar process.

The way forward

Patient-centred care

The first step in establishing a model of best practice end-of-life care for people with advanced chronic disease is to adopt a patient-centred approach[10] (Box). If care is patient-centred, it follows that it must be based on patient needs and symptoms rather than prognosis, allowing such care to be introduced much earlier in the trajectory of illness. In 1999, Kellehear outlined five foundational principles that guide palliative care from a public health and health-promotion perspective and provide a clear framework for supporting patient-centred end-of-life care.[11] For care to be truly patient-centred, people must have access to education and information about end-of-life care issues. In the UK, programs such as *Dying matters* (http://www.dyingmatters. org) are fostering community conversations around death and dying.

Leadership

Strategic leadership is vital at all levels of the health system. Chronic disease and palliative care policies need to be revised to allow greater recognition of the importance of end-of-life care in chronic disease and to facilitate articulation between palliative care and chronic disease strategies and policies. Increased funding is required to support flexibility of service provision, particularly around eligibility requirements, and to build infrastructure to support service provision across specialties.

> "It may be that the term "palliative care" allows end-of-life care to be perceived as someone else's business"

Workforce education

Recognising and prioritising the ongoing professional development and education of all health professionals in the principles of person-centred and palliative care is vital to allow them to provide appropriate care at the end of life.[5] There are programs in place for undergraduate education (eg, an Australian palliative care curriculum for undergraduates, http://www.pcc4u.org/index.php/about-pcc4u); however, this is a long-term strategy and other educational opportunities for existing health professionals are required.

The role of specialist palliative care

Specialist palliative care plays a vital role in ensuring access to best-practice end-of-life care for people with advanced chronic disease. The Australian National Palliative Care Strategy suggests that specialist palliative care services have ongoing roles in education and consultation as well as providing expert care for people with particularly complex conditions.[5] The patient-centred, holistic approach of specialist palliative care means that it is well placed to support better integration of end-of-life care into the ongoing management of chronic disease in both primary and secondary care.

There has been minimal consideration of how the current health care system can accommodate, integrate and implement the strategies required for quality end-of-life care for people with chronic diseases. In the absence of a clear policy framework and appropriate funding, palliative care services have been attempting to support people with chronic disease, but the growing magnitude of the population requiring care and recognition of their differing needs means they will not be able to continue to do so. It may be that the term "palliative care" allows end-of-life care to be perceived as someone else's business — the domain of specialist palliative care doctors and nurses. End-of-life care must become part of the routine continuum of care, and the remit of both chronic disease management and end-of-life care services. Using the term "end-of-life care" rather than "palliative care" could help to change health professionals' attitudes to the skills and training they require to meet the needs of people with chronic disease as they approach the end of their life.

Competing interests: No relevant disclosures.

Provenance: Not commissioned; externally peer reviewed.

1 Australian Institute of Health and Welfare. Australia's health 2010. (AIHW Cat. No. AUS 122.) Canberra: AIHW, 2010. http://www.aihw.gov.au/publication-detail/?id=6442468376 (accessed Sep 2012).
2 National Health Priority Action Council. Health priorities: National Chronic Disease Strategy. Canberra: Australian Government Department of Health and Ageing, 2006.
3 Palliative Care Australia. Palliative and end of life care. Glossary of terms. Edition 1. Canberra: PCA, 2008.
4 Australian Commission on Safety and Quality in Health Care. Patient centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC, 2011. http://www.safetyandquality.gov.au/wp-content/uploads/2012/03/PCC_Paper_August.pdf (accessed Feb 2013).
5 Australian Government Department of Health and Ageing. National Palliative Care Strategy 2010. Canberra: Commonwealth of Australia, 2010.
6 Callahan D. End-of-life care: a philosophical or management problem? *J Law Med Ethics* 2011; 39: 114-120.
7 Philip J, Gold M, Brand C, et al. Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals. *Intern Med J* 2012; 42: 816-822.
8 Crawford G, Brooksbank M, Brown M, et al. The unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. *Intern Med J* 2013; 43: 183-190.
9 Mitchell G, Johnson K, Thomas K, Murray S. Palliative care beyond that for cancer in Australia. *Med J Aust* 2010; 193: 124-126.
10 UK Department of Health. End of life care strategy. Promoting high quality care for all adults at the end of life. London: NHS, 2008. http://www.endoflifecare.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf (accessed Feb 2013).
11 Kellehear A. Health promoting palliative care. Melbourne: Oxford University Press, 1999. ❑