

Routine integration of palliative care: what will it take?

Palliative care is an essential component of quality care in advanced illness

"our society
determinedly
avoids
discourse
around dying,
focusing
instead on
'staying
positive' and
'fighting hard'"

alliative care has substantial benefits for patients with advanced disease, including improved symptom relief, quality of life, and communication around health care goals. These benefits extend to the patient's family, improving caregiver quality of life and bereavement outcomes. Palliative care is also associated with cost savings with reduced hospitalisations and emergency department presentations, and greater likelihood of death at home. 1.4

Despite these proven benefits, there is variability in access to palliative care and many patients are not referred in a timely manner. Although 62% of patients with metastatic lung cancer in Victoria are engaged with palliative care services by the time of death, most are referred in the final hospital admission, during which they die.⁵ These patterns are reflected nationally and internationally, with a median survival following admission to palliative care programs of 22–54 days,^{3,6} suggesting late referral.

The timing of referral to palliative care or adoption of a palliative approach appears to be important in achieving benefits.^{2,4,7} Late referral leaves little time to establish confidence in community-based care, or to undertake complex communication tasks, such as exploring values and establishing goals for care. Barriers to timely engagement with palliative care include limitations in workforce and service models, availability of services, failure to recognise poor prognosis or patient needs, and fear of destroying hope or upsetting patients.89 Indeed, when referral to palliative care is raised, some patients are distressed but they also report interest in its components, namely access to symptom control, psychological and family support, and assistance with decision making.¹⁰ Bereaved carers report a wish for earlier engagement with palliative care in their relative's illness.11

So how may we improve routine integration of palliative care in advanced illness? A whole-of-system approach has been advocated, involving quality-improvement strategies that identify and respond to specific gaps in care, coupled with measures of achievement and accountability. Yet, even in systems without barriers to palliative care, there remain two clinical tasks that appear critical to its successful integration: recognition of the possibility (and need) for palliative care, and sensitive communication.

A number of prompts have been proposed to ensure the task of recognition occurs. These include disease specific prognostic tools, measures of need both symptomatic and psychosocial, and clinical prompts such as "would I be surprised if this patient died in the next 6 months?". An alternative approach based on service use, such as

increasing frequency of admissions, or the development of a nominated disease complication such as metastatic disease, may offer an administrative prompt that occurs routinely and requires a response, rather than initiation, by the physician.

Once recognised, there remains the task of communicating with the patient and family around issues of worsening disease, disability and death. Yet, our society determinedly avoids discourse around dying, focusing instead on "staying positive" and "fighting hard". The media reinforces this language and focus, offering few stories of those whose illness progresses. This silence is also present in the clinic, and so instead we frequently find it easier to offer a further round of treatment rather than discuss the implications of failure of the last. By failing to engage patients and their families in such discussion until death is imminent, we limit opportunities of patients to realise choices in the final phase of life.

Given these significant barriers, how do we promote palliative care to patients and their families? Perhaps patients themselves offer the solution. When asked, patients are clear about what is important at the end of life, and much of this revolves around successful communication and subsequent planning.¹³ They want a holistic approach to their care that embraces their hopes for living even as they die. They want to be free of pain and other symptoms, so that they may realise goals in the personal realm. Palliative care represents a philosophy of care that facilitates these goals and should be explained to patients in these terms, as a set of practices oriented towards achieving their nominated wishes.

Successful integration of palliative care in the future will therefore require not just access to quality services, but also recognition of the final phase of life and a willingness by physicians to have this difficult conversation with patients. This conversation should include a careful exploration of the patient's understanding of the disease, a discussion of possible outcomes, establishing the goals of care, and then, as appropriate, an explanation of tasks of palliative care and how these might be relevant to these goals. Without engagement with this communication, any future possibility for integrated quality care based on patients' preferences for the end of life will likely be lost.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed.

© 2015 AMPCo Pty Ltd. Produced with Elsevier B.V. All rights reserved.

References are available online at www.mja.com.au.

Jennifer Philip PhD, FAChPM, MMed

Anna Collins MHealthPsych, BSci(Psych)

St Vincent's Hospital, Melbourne, VIC.

jennifer.philip@svha. org.au

doi: 10.5694/mja15.00994

Editorials

- Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care — translating data in oncology into practice. N Engl J Med 2013; 369: 2347-51.
- 2 Dionne-Odom JN, Azuero A, Lyons KD, et al. Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: outcomes from the ENABLE III randomized controlled trial. J Clin Oncol 2015; 33: 1446-1452.
- 3 Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. Soc Sci Med 2003; 57: 465-475.
- 4 Hui D, Kim SH, Roquemore J, et al. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer* 2014; 120: 1743-1749.
- 5 Philip J, Hudson P, Bostanci A, et al. Metastatic non-small cell lung cancer: a benchmark for quality end-of-life cancer care? Med J Aust 2015; 202: 139-143. https://www.mja.com.au/ journal/2015/202/3/metastatic-non-small-cell-lung-cancerbenchmark-quality-end-life-cancer-care
- 6 Good PD, Cavenagh J, Ravenscroft PJ. Survival after enrollment in an Australian palliative care program. J Pain Symptom Manage 2004; 27: 310-315.
- 7 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.
- 8 Le BH, Mileshkin L, Doan K, et al. Acceptability of early integration of palliative care in patients with incurable lung cancer. J Palliat Med 2014; 17: 553-558.
- 9 Johnson C, Paul C, Girgis A, et al. Australian general practitioners' and oncology specialists' perceptions of barriers and facilitators of access to specialist palliative care services. J Palliat Med 2011: 14: 429-435.
- 10 Philip J, Collins A, Brand CA, et al. "I'm just waiting ...": an exploration of the experience of living and dying with primary malignant glioma. Support Care Cancer 2014; 22: 389-397.
- n Collins A, Lethborg C, Brand C, et al. The challenges and suffering of caring for people with primary malignant glioma: qualitative perspectives on improving current supportive and palliative care practices. BMJ Support Palliat Care 2014; 4: 68-76.
- 12 Schenker Y, Arnold R. The next era of palliative care. *JAMA* 2015; Sep 3 [Epub ahead of print]. doi: 10.1001/jama.2015.11217.
- 13 Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-2482.

