

# research

## managing dying in the acute care setting— the role of the end-of-life care pathway

Dying was once accepted and embraced as a natural part of life. However, the advent of various medical, technological and pharmacological advances has resulted in dying increasingly becoming a medical event.

In Australia, over half (54%) of the 144,000 people who die annually spend their last days or hours of life in an acute hospital. Few Australians have their care managed by specialist palliative care teams (doctors, nurses, allied health and volunteers), with only 20% of people dying in hospices. Even fewer people (16%) are now dying at home, while a smaller proportion (10%) of people die in residential aged care.<sup>1</sup>

The focus of our hospitals has traditionally been on 'curing and prolonging life'. Given this focus it is inevitable that there can be tensions and challenges reorientating care towards palliative care as patients' needs change and families require more support as the end-of-life approaches.<sup>2</sup> Failure of health care teams to facilitate this transition frequently results in patients and families' experience sub-optimal care. The delivery of suboptimal end-of-life care contributes to increased health care costs and causes unnecessary suffering, especially when clinically futile treatments are administered or symptoms are poorly managed.<sup>3</sup>

The end-of-life care pathway was originally developed for use within the acute care setting to better manage the care of people dying from cancer but is now widely used in a variety of care settings to manage end-of-life care for a variety of conditions across 20 countries.<sup>6</sup> In the UK the end-of-life care pathway is now used in over 1000 care organisations.<sup>7</sup>

The global adoption of various end-of-life care pathways has occurred despite a lack of robust evidence for their use.<sup>8</sup>

A recent systematic review found no randomised controlled trial evidence, confirming that the uptake of the end-of-life care pathway had occurred without supporting evidence.<sup>9</sup> A recent integrative review found only low levels of evidence to support the use of the end-of-life care pathway in the acute care and/or hospice settings.<sup>8</sup> And while the existing qualitative and quantitative data suggests that implementing an end-of-life care pathway can improve end of life care in the acute care setting,<sup>8</sup> the absence of randomised control trial data precludes definitive recommendations and underscores the importance of ongoing research.<sup>8</sup>

Since these reviews were completed, a cluster randomised control trial to determine the effectiveness of the end-of-

---

"The global adoption of various end-of-life care pathways has occurred despite a lack of robust evidence for their use."

---

Consumer concerns over inadequate end-of-life care currently account for over half of all hospital complaints in the UK.<sup>4</sup> The most frequent complaints of patients and families regarding end-of-life care are that: they were not provided with the information they required at the time they needed it; symptoms were poorly managed; they had inadequate access to psychological and social support; there were few opportunities to plan for the future; and the care provided at the end-of-life was inappropriate or inadequate.<sup>5</sup>

During the past decade various integrated end-of-life care pathways have emerged largely in response to these shortcomings. These end-of-life care pathways have been promoted as a tool to better manage care of the dying in a variety of care settings. Pathways endeavour to detail the essential elements of care required to manage the last days or hours of life and ensure that the best available evidence is systematically integrated into care of the dying, whilst also providing a framework for auditing and benchmarking care.

care pathway for dying cancer patients in hospital has commenced in Italy.<sup>6</sup> The results of a pragmatic clinical trial will provide important evidence as to whether or not the end-of-life care pathway improves care of people dying of cancer in the acute care setting.

A national roll out of an integrated care pathway across the Australian primary, acute and aged care sectors has been identified in the recently released *National Palliative Care Strategy 2010*.<sup>1</sup> This action has been identified as required to ensure that *appropriate and effective palliative care is available to all Australians based on need*.<sup>1</sup> Further details about this national roll are yet to be provided, but if implemented will have potential implications for all Australia public and private health care services.

Integrated end-of-life care pathways appear to have a role in helping to better manage the care of those who are dying of cancer in the acute care setting. As one potential tool to enhance care of the dying they ought not to be used in isolation. Their implementation is best managed

jane phillips  
cunningham centre for palliative care & professor palliative  
nursing university of notre dame, australia

by a skilled facilitator working collaboratively with a multi-disciplinary team and supported with ongoing education. Actively engaging the patient and their family in this implementation decision making process is critical, as is clinician flexibility to respond to patient's changing needs or circumstances.

Building the integrated care pathway evidence-base through pragmatic clinical trials is an important priority—the current Italian study may well deliver critical data to assist Australian health policy makers with their planning.

Ensuring that public policy responds to emerging evidence, will help to guarantee that all Australians have access to appropriate and effective palliative care based on the best available evidence.

Address correspondence to:

Jane L. Phillips, RN, BA Sci (Nur), PhD,  
School of Nursing, The University Notre Dame Australia,  
Sydney – The Cunningham Centre for Palliative Care, 160  
Oxford Street, Darlinghurst, New South Wales 2010, Australia.  
E-mail jane.phillips@nd.edu.au



Jane Phillips

#### References

1. Australian Government. Supporting Australians to live well at the end of life: National Palliative Care Strategy 2010 Canberra Department of Health and Ageing; 2010.
2. Gibbins J, McCoubrie R, Alexander N, Kinzel C, Forbes K. 2009; Diagnosing dying in the acute hospital setting - Are we too late? *Clinical Medicine, Journal of the Royal College of Physicians of London.* 9(2):116-119.
3. Davidson PM, Phillips JL. 2010; Facing the inevitable – death from chronic illness. *EoL – Towards quality care at the end of life: The policy forum of Palliative Care Australia.* Winter:14-15.
4. Al-Qurainy R, Collis E, Feuer D. 2009; Dying in an acute hospital setting: The challenges and solutions. *International Journal of Clinical Practice.* 63(3):508-515.
5. Weissman DE, Meier DE. 2011; Identifying patients in need of a palliative care assessment in the hospital setting a consensus report from the center to advance palliative care. *Journal of Palliative Medicine.* 14(1):17-23.
6. Costantini M, Ottonelli S, Canavacci L, Pellegrini F, Beccaro M, The LCP Randomised Italian Cluster Trial Study Group. 2011; The effectiveness of the Liverpool care pathway in improving end of life care for dying cancer patients in hospital. A cluster randomised trial. *BMC Health Services Research.* 11(1):13.
7. Ellershaw J. 2007; Care of the dying: What a difference an LCP makes! *Palliative Medicine.* 21(5):365-368.
8. Phillips JL, Halcomb EJ, Davidson PM. In press - accepted June 2010; End-of-life care pathways in acute and hospice care: an integrative review. *Journal of Pain and Symptom Management.*
9. Chan R, Webster J. End-of-life care pathways for improving outcomes in caring for the dying (Review). *The Cochrane Collaboration;* 2010.