

Is there a role for end-of-life care pathways for patients in the home setting who are supported with community palliative care services?

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The concept of a “good death” has developed immensely over the past few decades and we now recognise the important role of palliative care services in healthcare for the dying, our most vulnerable population. [1-3] In palliative care, end-of-life care pathways have been developed to transfer the gold standard hospice model of care for the dying to other settings, addressing the physical, psychosocial and practical issues surrounding death. [1,4] Currently, these frameworks are used in hospitals and residential aged-care facilities across Australia. [1] However, there is great potential for these pathways to be introduced into the home setting with support from community palliative care services. This could help facilitate a good death for these patients in the comfort of their own home, and also support their families through the grieving process.

Although there is no one definition of a “good death”, many studies have examined factors considered important at the end-of-life by patients and their families. Current literature acknowledges that terminally ill patients highly value adequate pain and symptom management, avoidance of prolongation of death, preparation for end-of-life, relieving the burden imposed on their loved ones, spirituality, and strengthening relationships with health professionals through acknowledgement of imminent death. [2] Interestingly, the Steinhäuser study noted a substantial disparity in views on spirituality between physicians and patients. [3] Physicians were found to rank good symptom control as most important, whilst patients considered spiritual issues to hold equal significance. These studies highlight the individual nature of end-of-life care, which reflects why the holistic approach of palliative care can improve the quality of care provided.

It is recognised that patients with life-limiting illnesses have complex needs that often require a multidisciplinary approach with multiple care providers. [1] However, an increased number of team members also creates its own challenges, and despite the best intentions, care can often become fragmented due to poor interdisciplinary communication. [5] This can lead to substandard end-of-life care with patients suffering prolonged and painful deaths, and receiving unwanted, expensive and invasive care, as demonstrated by the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). [6] Temel *et al.* also demonstrated that palliative care can improve the documentation of advanced care directives. [7] For terminally ill patients, this is essential in clarifying and enabling patients’ wishes regarding end-of-life to be respected.

In 2010, Temel *et al.* conducted a randomised controlled trial in patients with newly diagnosed metastatic non-small-cell lung cancer, comparing the effect of palliative care and standard oncologic therapy, to standard oncologic therapy alone. [7] Results demonstrated that palliative care intervention improves quality of life and reduces rates of depression, consistent with existing literature. [7] Furthermore, despite receiving less aggressive end-of-life care, the additional early involvement of palliative care services resulted in a significant prolongation of life, averaging 2.7 months ($p = 0.02$). [7] This 30% improved survival benefit is equivalent to that achieved with a response to standard chemotherapy regimens, which has profound significance for patients with metastatic disease. [7] This study thereby validates the benefits of early palliative care intervention in oncology patients. In addition, early palliative intervention encourages advance care planning, allowing treating teams to elicit and acknowledge patient preferences regarding end-of-life care.



Many physicians often find it difficult to discuss poor prognoses with patients, potentially leaving patients and their families unaware of their terminal condition, despite death being anticipated by the treating team. [1,4] Many health care professionals are uncomfortable discussing death and dying, citing lack of training and fear of upsetting the patient. [8] Regardless, patients are entitled to be informed and supported through this difficult time. In addition, terminal patients and their caregivers are often neglected in decisions about their care, [9] despite their fundamental legal and ethical right to be involved, and studies indicate that they often want to be included in such discussions. [1,10,11] With the multitude of patient values and preferences for care, it can often be difficult to standardise the care provided. End-of-life care pathways encourage discussion of prognosis, facilitating communication that allows patients’ needs to be identified and addressed systematically and collaboratively. [1]

End-of-life care pathways provide a systematic approach and a standardised level of care for patients in the terminal phase of their illness. [1] This framework includes documentation of discussion with the patient and carers of the multi-disciplinary consensus that death is now imminent and life-prolonging treatment is futile, and also provides management strategies to address the individual needs of the dying. There is limited evidence to support the use of end-of-life care pathways, however we cannot discount the substantial anecdotal benefits. [1,12] The lack of high-quality studies indicates a need for further research. [1,12] When used in conjunction with clinical judgment, these pathways can lead to benefits such as: improved symptom control, earlier acknowledgement of terminal prognosis by the patient and family, prescription of medications for end-of-life, and aiding the grieving process for relatives. [1,12,13] As such, end-of-life care pathways are highly regarded in palliative care, transferring the benchmarked hospice model of care of the dying into other settings, [14] and have been widely implemented nationally and internationally. [1]

The most recognised and commonly used end-of-life care pathway is the Liverpool Care Pathway (LCP), which was developed in the United Kingdom to transfer the hospice model of care for the dying to other care settings. [13,15] It has been implemented into hospices, hospitals and aged care facilities, and addresses the physical, psychosocial and spiritual needs of these patients. [1,13,15] In 2008, Verbeek *et al.* examined the effect of the LCP pre- and post-implementation on patients from hospital, aged care and home settings. [13] Results demonstrated improved documentation and reduced symptom

burden as assessed by nurses and relatives, in comparison with the baseline period. [13] Although increased documentation does not necessarily equate to better care, high-quality medical records are essential to facilitate communication between team members and ensure quality care is provided. In this study, staff also reported that they felt the LCP provided a structure to patient care, assisted the anticipation of problems, and promoted proactive management of patient comfort. [13] The LCP has significantly increased the awareness of good terminal care, and has provided a model for the end-of-life care pathways currently in use in hospitals and institutions throughout Australia. [1,4]

Community palliative care services support terminally ill patients at home in order to retain a high quality of life. Recognising the holistic principles of palliative care, these multidisciplinary teams provide medical and nursing care, counselling, spiritual support and welfare supports. In the Brumley trial, which evaluated an in-home palliative care intervention with a multidisciplinary team for homebound terminally ill patients, results demonstrated that the intervention group had greater satisfaction with care, were less likely to visit the emergency department, and were more likely to die in the comforts of their own home. [16] These results infer that the community palliative care team provided a high standard of care where symptoms were well-managed and did not require more aggressive intervention. This prevented unnecessary emergency presentations, potential distress for the patient and family, and allowed better use of resources. This study demonstrates that community palliative care services can significantly improve the quality of care for patients living at home with life-limiting illnesses, however, there is still scope for improvement in the current healthcare system.

End-of-life care pathways are regarded as best practice in guiding care for patients where death is imminent. [1] In Australia, there are a number of these frameworks that have been implemented in hospitals and aged-care facilities, demonstrating an improvement in the quality of care in these settings. However, there are also many terminally ill patients who choose to reside in the comfort of their own home, and are supported by community palliative care services. End-of-life care pathways support a high standard of care, which should be available to all patients, irrespective of where they choose to die. As such, there may be a role for end-of-life care pathways in the home setting, supported by community palliative care services. Introducing already implemented local end-of-life care pathway into the community has great potential to reap similar benefits. Initially, these frameworks would be implemented by the community palliative care team, however, caregivers could be educated and empowered to participate in the ongoing care. This could be a useful means to facilitate communication between treating team members and family, and also empower the patient and family to become more involved in their care.

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The potential benefits of implementing end-of-life care pathways into community palliative care services include those currently demonstrated in the hospital and aged-care settings, however there are potentially further positive effects. By introducing these frameworks into the homes of terminally ill patients, caregivers can also be encouraged to take a more active role in the care of their loved ones. This indirect education for the patient and family can provide a sense of empowerment, and assist them to make informed decisions. Additional potential benefits of these pathways could include a reduction in the number of hospital admissions and emergency department presentations, which would reduce the pressures on our already overburdened acute care services. Empowered family and carers could also assist with monitoring, providing regular updates to the community palliative care team, which could potentially lead to earlier detection for when more specialised care is required. The documentation within the pathways could also allow for a smoother transition to hospices if required, and prevent unnecessary prolongation of death. This may translate to prevention of significant emotional distress for the patient and family in an already difficult time, and promote more effective use of limited hospital resources. Integrating end-of-life care pathways into community palliative care services has many potential benefits for patients at home with terminal illnesses, and should be considered as an option to improve the delivery of care.

Palliative care can significantly improve the quality of care provided to patients in the terminal phase, which can be guided by end-of-life care pathways. Evidence validates that these pathways encourage a multidisciplinary change in practice that facilitates a "good death", and supports the family through the bereavement period. In the community, this framework has the potential to empower patients and their caregivers, and assist them to make informed decisions regarding their end-of-life care, thereby preventing unwanted aggressive intervention and unnecessary prolongation of death. However, there is a need for further high-quality studies to validate the anecdotal benefits of these pathways, with potential for a randomised controlled trial investigating the use of end-of-life care pathways in the home setting in Australia. In conclusion, the introduction of end-of-life care pathways into community palliative care services has great potential, particularly if supported and used in conjunction with specialist palliative care teams.

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Conflicts of interest

None declared.

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