Facilitating better end-of-life care

How to help your patients die well

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doi: 10.5694/mja12.10889

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All health professions aim to provide the best care they can for their patient. However, achieving this is easier said than done. In this issue of the Journal, Horey and colleagues document the implementation of a care pathway aimed at facilitating care at the end of life (EOL) in 14 residential aged care facilities (RACFs),[1] while Thompson and Brown's letter raises the problem of resuscitation often being the default position when elderly patients deteriorate rapidly, even though the survival rate is poor and most older people do not want that option.[2]

Older people in hospital often have conditions where deterioration to death is a likely consequence.[3] Therefore, while deterioration to death may be rapid, it is frequently not unexpected. Thompson and Brown show that recording the wishes of patients regarding resuscitation is not routine, or couched in consistent, easily understood language.[2] This reflects a broader problem — there is little evidence of whole-of-system planning for the inevitable deaths that will occur as inpatients. In the United Kingdom, Seymour identified confusion about the goals of care, reactive and crisis-led treatment, and care that poorly met needs, right up to the time of death.[4] Initiating EOL planning can be a real problem in hospitals, particularly if care is provided by multiple teams. It is essential that someone takes responsibility for EOL planning. If this does not happen, if no one is prepared to take the initiative, then unwanted, largely fruitless resuscitation attempts or inappropriate admission to intensive care units are the inevitable result.[5]

The human dimension of medical professionals is also on display in this setting. There is an inevitable clash between medical training, which promotes the preservation of life, the inevitability that we all must die of something, and concern about being seen to fulfil a duty of care to the patient. Being clear and realistic about the aims of care (cure/control, palliation, and/or EOL care) is essential, as is acceptance that death is not an adverse outcome when the final stages of an illness are reached. It is essential that medical professionals do not take upon themselves decisions regarding the degree to which prolonging life is pursued — the impact of a disease on quality of life is a call that patients themselves must make.[6]

There are concerted efforts to bring the patient perspective more clearly into the decision-making process. In particular, national efforts have produced advance health directives in every Australian state. A recent study reported the positive impact of the Respecting Patient Choices program, which has sought to document the choices of patients in Australian hospitals and should lead to the completion of an advance health directive.[7]

Not pursuing curative treatment does not mean the absence of active care. The Liverpool Care Pathway for the Dying Patient (LCP) outlines active treatment measures to provide comfort to patients, and deals with the needs of the carers in the last days of life.[8] However, discussion with the patient about the goals of care, and subsequent care planning, should take place long before the LCP is triggered. Framing this discussion as "hoping for the best but preparing for the worst"[9] may be a useful way of initiating this discussion.

Death is a constant visitor to RACFs and, again, most deaths are predictable. Horey and colleagues found that the introduction of the LCP, modified to suit RACF conditions, reduced the rate of unnecessary transfers to hospital (where residents are returned immediately from hospital to the RACF) from 14% to 2%. However, the uptake of the pathway ranged from 10% to 68% of eligible patients.[1]

Why has there been such disappointing recording of EOL plans in hospitals? Why was uptake of the LCP pathway so patchy in RACFs?

Embedding an innovation is a complex process and people take varying times to adopt change.[10] Having four of 14 RACFs using the LCP routinely at the end of this time-limited study was a very good outcome. The sites that most successfully implemented the intervention had incorporated the pathway into RACF policy and had clear general practitioner support. This points to the importance of system-wide adoption in supporting innovation, and the importance of participant buy-in.

Leading from the front — at the level of national health policy, as Australia has done[11] — is a very important step. However, we can do a lot better in converting the principles of palliative care to a broader policy on care at EOL, particularly in care planning for the frail aged and in cases of far-advanced chronic disease.[12] It is now time to move to policy adoption at the hospital level, and thence to individual clinician practice. At the clinical level, "hoping for the best but preparing for the worst" is a simple catchcry that provides a framework for promoting care planning and facilitating best-practice care of people likely to die from any cause.[9] It is time to embed this sort of thinking into all levels of the health care system.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed.

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