

End-of-life decisions in acute hospitals

Simon Conroy

Care of the dying is a core business for hospital clinicians. Typically, 56% of deaths occur in hospital, which equates to around 1,000 deaths per annum in a typical district general hospital (DGH). Before 2000, however, there were very few studies on death and dying in hospital, and relatively little policy or practice guidance. In the world literature between 1946 and 2000 there were 63 relevant published papers. Since the turn of the millennium, however, there has been an impressive academic and clinical practice focus on palliative care, with 96 papers published between 2001 and 2009.

The SUPPORT study was one of the first to examine the dying process in the hospital environment. It was carried out in the USA in the 1990s, at the same time that legislation embedding individuals' rights to choose came into force (the Patient Self-Determination Act). SUPPORT was a well-conducted, multi-centre randomised controlled trial that used dedicated nurses to promote the use of advance directives in hospitalised, sick adults. Nurses facilitated communication among patients, surrogates and physicians about preferences for end-of-life care and outcomes of treatment alternatives and, when clinically appropriate, to encourage completion and use of advance directives (ADs). In brief, the study demonstrated an increase in AD discussions (35% *v* 78%), but no actual increase in the actual completion (21% in both groups). Nor was there any difference in do not resuscitate (DNR) decisions between the two arms. The conclusion was that nurse-led end-of-life care discussions had little influence over medical care.

Meanwhile in the UK, clinicians were faced with conflicting pressures to increase DNR and end-of-life discussions, yet finding themselves increasingly exposed to media criticism for attempting to do so.¹ Eventually UK guidelines were revised in such a way that such a discussion was not mandatory if, for example, cardiopulmonary resuscitation was unlikely to be required, or of it was clinically inappropriate for it to be offered (revised joint guidelines October 2007, BMA).

A more pragmatic approach to end-of-life care in acute hospitals was finally realised with the introduction of the Liverpool Care Pathway (LCP), which attempted to standardise a patient-centred approach to the last days of life. The LCP used a structured pathway to optimise the initial assessment, any ongoing assessments and care after death.

A series of national audits of the LCP have shown increasing uptake, and good adherence to the pathway. In 2009, 155/214 eligible hospitals contributed data, showing

that of people dying in hospital, most were old (mean 81 years) and 61% had a non-cancer diagnosis (including stroke, heart failure, chronic obstructive pulmonary disease and dementia). The mean period spent on the LCP was 30 hours; 90% had a medication review and more than 80% had 'inappropriate interventions' stopped (fluids, antibiotics, blood tests). There was good discussion – 50% of patients were aware of being on the pathway, as were 75% of relatives. DNR decisions were made in 94%, and physical symptoms were being alleviated in the majority (pain 77%, agitation 76%, respiratory secretions 75%, nausea and vomiting 79%, dyspnoea 76%, and mouth care 79%). Though impressive, there was still room for improvement in areas such as attending to spiritual needs and communication with GPs. So it appears that care of the dying in hospital is improving, but what of the ambition to prevent hospital deaths in the first place?

In the UK, there has been a concerted policy drive to try and reduce deaths in hospital, underpinned by the belief that many can be anticipated, and that dignity and quality of life is best served by a death at home – a concept supported by the public.^{2,3} Advance care planning (ACP) is one proposed mechanism by which individuals' wishes and preferences may be better respected, especially in end-of-life care where the loss of decision-making ability is common. Policy and guidelines promote the use of ACP with varying levels of caution,^{4,5} but what is the evidence that ACP will actually achieve its intended outcomes?

There have been surprisingly few controlled trials of ACP conducted thus far, and none yet from the UK. One of the more robust studies was carried out in large Canadian care homes (typically 200–300 residents), and looked at the ACP process and its ability to improve care and reduce hospital deaths.⁶

Using a structured AD proforma ('Let me decide'), which contained both instructions and allowed for the appointment of a proxy (similar to the Mental Capacity Act provision in England and Wales), care home staff were encouraged to discuss ACPs with residents. In a multicentre, cluster randomised controlled trial, the effect of a concerted effort to increase the completion of ADs was uncertain, though there was an increase in proxy statements (72% *v* 80%). This resulted in a reduction in resource use in the intervention arm over an 18-month follow-up – mean 0.27 *v* 0.48 hospitalisations, length of stay 2.61 *v* 5.86 days, and total costs \$3,490 *v* \$5,239. Importantly there was no difference in satisfaction or mortality. So it appears that in large Canadian care homes there is some evidence that a concerted programme

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of education and training may reduce health-associated resource without adversely affecting care. It is presumed, but not clearly established, that by doing so, the quality of care is improved.

So what does this mean for the UK? It may well be that there is a role for ACP, for example in large care homes with well trained staff. It is possible by extrapolation, to anticipate that ACP may improve outcomes for community dwelling older people. However, the literature suggests that ACP will only be taken up by a minority of individuals to whom it is offered (approximately 11–14%), and as ACP is only for use with people with capacity, it is unlikely to lead to a major impact on the main users of acute care – namely frail older people with cognitive impairment.

Despite policy exhortations, practice experience is that ACP is a relatively low volume affair, practised by enthusiasts, and has yet to fully attract the widespread support seen, for example, for the LCP. No doubt future efforts will be directed at better understanding the ‘who, how, where and when’ of ACP in the UK.

References

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Concise guidance

Advance care planning – national guidelines

Prepared by the British Geriatrics Society, Royal College of Physicians, Royal College of Nursing, Royal College of Psychiatrists, Royal College of General Practitioners, British Society of Rehabilitation Medicine, Alzheimer’s Society, Help the Aged and the National Council for Palliative Care.

At the core of current health and social care are efforts to maximise individuals’ autonomy, promote patient-centred care, and offer choice and the right to decide one’s own treatment or care. This can be difficult to achieve when an individual has lost capacity – the ability to make their own, informed decision. Advance care planning (ACP) is one method of enhancing autonomy, not only where an individual has lost capacity, but also by focusing discussion on the individual’s values and preferences throughout the time they are in contact with health or social care professionals.

This concise guidance is primarily aimed at professionals in England and Wales, and will be relevant to all doctors involved in ACP, especially geriatricians, psychiatrists, general practitioners, general physicians and acute medicine specialists. ■

The guidelines in this document are:

- When and with whom should I be considering ACP discussions?
- The discussion
- Will ACP work?
- Individuals with progressive cognitive impairment
- Recommendations for training and implementation of ACP

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