

Nursing Practice Review End-of-life care

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Death/Service delivery

A review was undertaken to pull together the findings from a variety of research studies into the quality, organisation and delivery of end-of-life services

Better endings: a review of end-of-life services

In this article...

- › Overview of recent research on end-of-life services
- › Nationwide variations in care and common misconceptions
- › How to identify areas for improvement

Authors Tara Lamont is deputy director, NIHR Dissemination Centre, Wessex Institute, Southampton; Alison Richardson is clinical professor of cancer nursing and end-of-life care, University of Southampton and University Hospital Southampton Foundation Trust.

Abstract Lamont T, Richardson A (2016) Better endings: a review of end-of-life services. *Nursing Times*; 112: 12/13, 16-18. The NHS has undertaken research on the organisation and quality of end-of-life services, which provides valuable insights for those planning and delivering care for people approaching the end of life, and their families. The review of the findings, structured around the right care in the right place at the right time, highlights what is already known, and how research that is currently underway will address key gaps and uncertainties for frontline staff and clinical leaders. This article summarises the findings outlined in that review.

Providing good care for people who are dying is a priority for the NHS – but it is hard to do well. This matters for the district nurse making home visits to a patient with heart failure, the nurse in a care home wondering whether to call an ambulance for a very frail patient, or a senior nurse in a hospice inpatient unit juggling demands for beds.

Research on the organisation and quality of care at the end of life was funded by the National Institute for Health Research (NIHR) and a review of the findings was compiled (Box 1). Findings from research undertaken since 2010 – published in 2015 by NIHR – provide

insights into what works and also identifies gaps in our knowledge; this article highlights some of the key findings from that report.

Why focus on end-of-life care?

Improving the quality of end-of-life care is a priority for the NHS and those who work in the service.

There is also increasing demand as it is predicted there will be a 15% increase in the number of people dying each year between now and 2035 (Choice in End of Life Care Programme Board, 2015). These people will be older, they will have lived for longer and will have complex conditions.

The healthcare needs in the last months of life are uncertain for people with advanced life-limiting disease (Murray, 2013). This means the job of caring for people in their final months will become more difficult for a range of staff in different care settings:

5 key points

1 The annual number of deaths is expected to increase significantly over the next 20 years

2 Policies are being implemented to help people to die in the place of their choice

3 Better evidence is needed to inform service decisions

4 Research has shown that care is inconsistent and access to specialist services is unequal

5 Conversations between staff and patients about end-of-life arrangements often take place too late



Nurses working in end-of-life care must prepare for people living longer and dying older

BOX 1. THE NIHR REVIEW

The *Better Endings* review was brought together with the help of an expert group comprising nurses, doctors, researchers, managers and carers from different organisations, as well as the national clinical director for end-of-life care. It complements policy initiatives, such as the recent Ambitions framework (Endoflifecareambitions.org.uk) and relevant clinical and quality guidelines from the National Institute for Health and Care Excellence (2015).

Our aim was to make the NIHR review accessible and relevant to key audiences. It includes quotations from frontline staff, such as community and hospital nurses, on what the evidence means to them. Examples are also given of service innovations that are being evaluated, from rapid-response community end-of-life services in Kent to volunteer-led support of family caregivers in Southampton. We have summarised key findings and identified questions arising from this evidence, which can be asked by hospital and community organisations to identify areas for improvement.

Many of the full research studies can be accessed at: Journalslibrary.nihr.ac.uk/collections/end-of-life-care

- » *Community services* – there will be more pressure on these services, particularly if we support more people dying at home;
- » *Care homes* – research shows most people with dementia now die in care homes (Sleeman et al, 2014), so these will face greater demands;
- » *Hospitals* – these will experience more pressure. One study featured shows that as many as one-third of all hospital inpatients have palliative care needs (Gott et al, 2013). General staff need time, training and support to do end-of-life care well;
- » *GPs and community nurses* – these professionals provide much day-to-day care for people who are dying, but most people have two or more emergency hospital admissions in their last year of life (Public Health England, 2012). This is costly and some admissions could be avoided.

What could we do better?

Right care

We know (largely from cancer studies) that people who receive specialist palliative care tend to do better than those who do not (Higginson and Evans, 2010), but not everyone has the same chance of accessing this care and spend varies greatly across the country. Services are not always matched to need and integration between general and specialist services varies. Evidence is not clear about the most cost-effective models of specialist palliative care. New research funded by NIHR will help to identify the patients who will benefit most from specialist palliative care and target resources appropriately.

More support and tailored services are needed to care for people with dementia

and very old people at the end of life. Research highlights the uncertain trajectories of these patients, as well as the need for close working over time between care home staff and those in primary care and specialist palliative care (Goodman et al, 2015).

Right place

One of the most important studies featured in the NIHR review was the largest-ever population-based analysis of place of death in England (Gao et al, 2014), which reviewed more than 13 million deaths registered between 1984 and 2010. It showed that more people with cancer are now able to die in their place of choice, usually home or hospice, but this is not true for people with conditions other than cancer and there are persistent inequalities in who dies where. Other studies showed that patient preferences change over time (Pollock and Wilson, 2015) and place of death may not be the most important factor for many (Gomes et al, 2011).

There is variation in out-of-hours cover and many patients experience fragmented care, with fewer than one-in-five areas having effective systems to share information about patients across organisations (Addington-Hall et al, 2013). Coordination of care appears to be better for those people with cancer than those without (Murray et al, 2013).

Right time

Given limited resources, it is not always easy to know when to refer people at the end of life to specialist teams. The NIHR review suggests findings from studies on early referral to integrated breathlessness services are promising in terms of

BOX 2. QUESTIONS TO ASK: WHAT DOES THIS MEAN FOR ME?

The Better Endings review raises questions that you and your organisation may want to consider to identify areas for improvement.

Right care?

- How do we identify patients who need palliative care in the community and in hospital?
- What kind of staff training do we provide?
- Who currently uses our specialist palliative care services – for instance, what proportion have a diagnosis other than cancer? What actions are we taking to reduce inequalities in access to these services?
- What services do we have for people with dementia – and their carers – at the end of life? What kind of ongoing support is there for care homes?

Right place?

- What proportion of our population dies in hospital? How does this compare with stated preferences, national trends and benchmarking?
- What plans do we have to coordinate and integrate services 24/7, including community nursing, pharmacy, hospital, general practice, hospice, care homes, voluntary and social care? Are we evaluating any of these new approaches?
- What arrangements do we have to share information about what individual patients and carers want across these agencies? Is there a designated lead for end-of-life care in these partner organisations?

Right time?

- Looking back, how many patients who died in our care were identified as having palliative care needs at the right time?
- What are we doing to support staff in discussing with patients and families plans for their next phase of care?
- How can we ensure that the expressed wishes of patients and families about when they want to stop invasive treatments or not be resuscitated are known and acted on by local hospitals, ambulance services and others?

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Some nurses may find it difficult talking about patients' future plans for end-of-life care

better management of symptoms, reduced distress and increased quality of life (Higginson et al, 2014). Other ongoing research will help to show when best to refer people for specialist palliative care and the impact of brief palliative care interventions.

Much good end-of-life care centres on communication. A qualitative study showed how difficult staff find it to talk to patients about future plans, especially if there are uncertainties about prognosis and disease trajectories (Pollock and Wilson, 2015). The NIHR review also shows variation in the forms used to record Do Not Attempt Cardiopulmonary Resuscitation orders (Freeman et al, 2015). However, there is emerging good practice, including more structured forms of decision-making on admission and extending decision-making to include overall goals of treatment.

Conclusion

The NIHR (2015) review highlights many important issues for those delivering and planning services. We know there are persistent inequalities and variations in care, with poorly coordinated services and limited access to specialist palliative care for those with conditions other than cancer. Increasing numbers of people are now

dying from longer term, life-limiting conditions with uncertain trajectories, which can make planning ahead difficult.

Other research has challenged commonly held notions, suggesting place of death is not always the top priority for patients and families, and that patient preferences are not static but can change over time.

New research will help us to target specialist care more effectively and tell us more about the most cost-effective mode of delivering care, from hospice-at-home services to forms of integrated 24/7 care. Given increasing demands on services, it is important that nurses and doctors in all settings know how and when to get specialist help, and have the time and support to care well for people at the end of life. Box 2 highlights questions health professionals can ask their organisations to identify where service improvements are needed. **NT**

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- Perceptions of a "good death" in acute hospitals
- [Bit.ly/NTGoodDeath](http://bit.ly/NTGoodDeath)



NEXT ISSUE...

... we look at the role of the volunteer in end-of-life care within the acute hospital setting.