Editor’s choice

Bill Noble

Jane Maher’s editorial on the Palliative Care Funding Review gives it a broad welcome. The initiative aims to create a patient mechanism to meet the needs of the approximately 457,000 people who need palliative care every year in England. Drawing on the Australian experience, the review goes a long way in designing a transparent system to assign resources to patients at the end of life. We are looking forward to seeing the ideas piloted, not least because the estimates of the cost of care at the end of life vary by such a wide margin throughout the country; £186–£6213 being the range of average spends by primary care trusts. However, we should not forget the results of a recent survey into the expenses associated with a death in the family. When all is added up, including the funeral and legal services, families in the UK now face an average bill of about £7200. So if dying sounds expensive, being dead is certainly no cheaper.

Following some controversy in the press last year, over the way the Liverpool Care Pathway (LCP) is being put into practice, Maureen Gambles and others report findings from the UK national audit of the LCP. The data provided by 155 hospitals from 3893 patients indicated that 51% of patients received sedative medication for agitation or restlessness in the last 24 h of their lives. She highlights the finding that median doses were low, suggesting that there is no ‘blanket’ policy associated with a death in the family. When all is added up, including the funeral and legal services, families in the UK now face an average bill of about £7200. So if dying sounds expensive, being dead is certainly no cheaper.

In September 2009, a meeting of 19 experts in Milan, Italy, produced recommendations on how to assess and classify cancer pain. They recommended a strategy for the further development, validation and implementation of an international cancer pain classification and assessment. In this issue, we present their proceedings as a feature. It represents an important body of opinion and a potential basis for international cooperation. In other papers on pain, we hear about the relative merits of different formulations of transmucosal fentanyl by comparing patients’ views of the placebo version of the medication and consider the evidence which suggests that acupuncture has the potential to produce a rapid and effective analgesia for breakthrough pain in cancer.

A paper by Alison Chapple and colleagues on the preferred place of death for patients with pancreatic cancer reports the results of their qualitative study. Preferences were affected by their perceptions and previous experiences of care available at home, in a hospice or hospital. Preferences were also shaped by fears about possible loss of dignity or fears of becoming a burden. Some people thought that a home death might leave bad memories for other members of the family. This paper seems to portray a picture of patient preferences common to many patient groups. A related and rather thorny question for policy makers is, ‘How important is place of death, in relation to other factors that go to make a good death?’ Melanie Young and her coauthors conclude that overall, it comes in at number six, below pain and symptom control, not being a burden and affairs being in order. Her survey of 120 patients with cancer challenges the importance of place of death as a mark of quality in palliative care.

The paper by Sue Hall et al reports the findings from a randomised phase II trial of dignity therapy reports no effect on their primary outcome of ‘dignity-related distress’. However, they appear to have detected a significant and potentially important effect on one of their five secondary outcomes, hope.

We have another paper on the nature of narratives produced within dignity therapy by Glendon Tait and others. The dignity interview’s resonance with the eulogy and dissonance from the traditional medical interview, appear to facilitate a sense of agency, a key effect of this intervention. Three narrative types emerged, each containing several themes. Evaluation narratives create a life lived before illness, overcoming adversity. Transition narratives describe a changing health and its meanings. Legacy narratives discuss the future with parables and messages for loved ones. The commonality of narrative structures suggests that patients draw on the eulogy and the medical interview to create their narrative while dying.

The first of this issue’s republished papers from the British Medical Journal concerns international guidelines on the palliation of amyotrophic lateral sclerosis. The second concerns the UK law on assisted suicide, a constant subject of debate in our parent journal.

Mairi Harper, Rory O’Connor and Ronan O’Carroll’s paper about mortality of bereaved parents is that most important category of scientific report, an empirical observation that confirms what we all thought we knew, that mothers and fathers might die of a broken heart. The magnitude of the relative risk is higher than expected by most, particularly for mothers, whose risk of death is four times their compatriots with all their children living over 15 years. Poet’s corner in this issue is occupied by a new poem from John Birtwhistle with something to say on this very subject. Strike-a-Light describes the memory of a dead child symbolised by a medieval grave artefact; a quartzite pebble for making sparks to set kindling alight. It is an affecting and powerful evocation of the experience of profound loss, an experience that we share with our most ancient ancestors.

Correspondence to Dr Bill Noble, Academic Unit of Supportive Care, University of Sheffield, Sykes House, Little Common Lane, Sheffield S11 9NE, UK; bill.noble@sheffield.ac.uk

Competing interests None.

BMJ Supportive & Palliative Care 2011;1:277.

doi:10.1136/bmjspcare-2011-000155