

# End-of-life care

## Introduction

A concern with issues associated with the care of people at the end of their life has run throughout the first 7 years of *Mortality*, with at least one paper on this topic in each volume. The early papers were informed by an interest in palliative care, drawing upon the concerns of the hospice and palliative care movement about how best to provide ‘holistic care’ that addresses social, psychological and spiritual needs as well as the management of physical symptoms. Since 2000, papers on this topic have taken a wider view, looking at end of life care for older people, technology and death policy, bioethics, and the use of do not resuscitate orders.

The continuing concern with hospice and palliative care was signaled in the first volume (published in 1996) by an invited contribution from Cicely Saunders on ‘Hospice’.[1] Saunders described the influences that led her to establish St Christopher’s Hospice in London and then identified current aspects and future challenges for hospice care: that physical and emotional problems must not ‘drown the spirit’, the importance of clinical competence in winning support for hospice care, attending to bereavement and the ‘unceasing need’ to educate physicians and nurses and to ‘enlighten the general public (that) opioids properly used do not lead to drug dependence and addiction. She also saw the need to respond to, and resist, pressures around the world for physician assisted suicide and active euthanasia. A substantive discussion of the role of Cicely Saunders and the establishment of St Christopher’s Hospice in the development of the modern hospice movement is provided by David Clark.[2] Clare Humphreys[3] provides a analysis of the first hospices in London to provide care for the dying and their recognition the special medical, nursing and spiritual needs of these patients. These two papers are reviewed in the virtual issue containing Historical papers.

Other papers relating to hospice and palliative care, but not addressing end of life care directly, are Katherine Froggatt’s discussion of Rites of passage and hospice culture[4] (2: 123 – 136), Allan Kellehear’s proposal for ‘healthpromoting palliative care’[5] and Sheila Payne’s discussion of dilemmas in the use of volunteers to provide hospice bereavement support in New Zealand’.[6]

Three papers have been concerned with spiritual care at the end of life. In the same issue as Saunders’ paper, Louis Heyse-Moore discussed spiritual pain in the dying.[7] His starting point is that suffering, death and the spirit are intertwined; spirituality is common to all people regardless of belief. In his paper he discusses what constitutes spiritual distress through a consideration of the spirit as a life force and as an essence and the relationships between spirituality, immortality, consciousness and religion. He then suggests how spiritual pain might be recognized and what might be done to alleviate it. In his view effective help depends upon establishing a relationship with the sufferer that enables them to find meaning (through dialogue and contemplation) of their life’s experience. Pam

McGrath discussed a different approach to spirituality in her paper on the Karuna hospice service in Brisbane.[8] She argues that the Buddhist philosophy which underpins this service, with its emphasis upon compassion and wisdom, willingness to serve and a duty to do no harm, is compatible with the ideals of hospice care. Barbara Carroll brings a phenomenological perspective to her discussion of hospice nurses' conceptions of spiritual care.[9] Her qualitative study found that the nurses she interviewed had 'integrated their spirituality' into their nursing role and that the spiritual dimension 'infiltrated all dimensions of (their) nursing care'. Those readers also interested in the role of spiritual beliefs in bereavement should look at Richard Golsworthy and Adrian Coyle discussion of spiritual belief and the search for meaning among older adults following the loss of a partner.[10]

'Hope' is often linked to spirituality. Like spirituality, it is a nebulous concept that is difficult to define and whose role in end of life care is difficult to establish with any precision. Rod Macleod and Helen Carter attempt to address these issues in their literature review of health professionals' perceptions of hope.[11] They outline the various frameworks proposed for maintaining hope among those who are critically ill or dying and comment upon the importance of inspiring hope in maintaining the quality of life of those who are dying. The important elements of hope are identified as effective relief from distressing symptoms, meaningful relationships between staff and patient, perception of a positive future for the patient and/or their family, feeling valued and a redefinition of goals as the illness progresses. The major threat to hope is a patient's loss of control over their circumstances.

There has been much discussion about what constitutes a 'good death', with the recognition that what professionals regard as a good death may differ from the perceptions of patients' and those close to them. In his study John Masson used qualitative interviews with hospice patients and relatives of hospice patients in order to identify what they saw as the core features of a 'good death'. [12] The 'core features' he found are consistent with those found in other studies, but he reports that patients identified a more limited range of features than relatives, probably reflecting their different expectations. Respondents acknowledged there was inconsistency between their ideals and the practicalities of managing dying and placed their ideas about dying within the context of how lives had been lived. Mason sums up the attitudes of his respondents as 'flexible realism' in addressing the important issues of the place of death and the management of pain.

Although death in contemporary 'advanced' modern societies is most likely to occur in old age there has been remarkably little research or discussion about end of life care for older people. Basiro Davey's report of the use of 'do not resuscitate decisions' (DNRs) in an English hospital[13] was written in response to a media 'scare story' claiming that doctors were inappropriately using DNRs to let older people die who could be saved. She found that communication between staff and

with patients about DNR was poor and that patients' views were rarely sought. Ward nurses felt that rather than too many DNR orders these were in fact too few and often too late to protect their patients from futile and harmful resuscitation attempts. There was no direct evidence of ageism, although age was certainly a factor in arriving at a DNR decision. Liz Lloyd discusses the nature of health and social care interventions in the care of older people dying in Britain.[14] She points to increasing evidence of age-related rationing in health care that discriminates against older people, reflecting an ageist social context. She argues for a primary care led tertiary prevention approach to improve the coordination of end of life care. Drawing upon palliative care this would promote noninstitutionalized services, encourage openness about dying, enable choice and control by older people over care interventions, minimize their fear of death and maintain their family and social networks. In their commentary on ageism and euthanasia in the Netherlands [15] Sjaak van der Geest and Ann-Marie Niekamp suggest that 'older people who request euthanasia are taken less seriously and are thus the victim of another type of ageism'.

Another paper that addresses the practice and policy of end of life care is Robert Blank's discussion of technology and death policy.[16] Blank identifies two central conceptual and practical aspects: the interpretation of death in the context of medical technology and the appropriate clinical tests to use to determine that a patient is dead. Current practice and policy is to use definitions of higher brain functioning, which might lead to the inclusion of patients in a persistent vegetative state or end stage Alzheimer's in the ranks of the dead. This has critical implications for public policy and the disposal of 'dead' bodies that are still 'breathing human forms'.

From time to time *Mortality* publishes short commentaries. One of these, drawing upon the experiences of two doctors, Simon Dein and Rob George, considered the effect of significant life events upon when people die.[17] Although the literature is inconclusive, Dein and George argue that the timing of death may be related to personally significant anniversaries and events and that this has clinical implications for end of life care. They suggest that such symbolic dates should be elicited and 'mapped' when taking a medical history.

The origins of the hospice and palliative care movement lie in Christianity (as Humphrey's paper shows) and there is concern in the UK that people from other faiths and cultural backgrounds are not using these services to the extent that might be expected. Advanced modern societies are characterized by cultural diversity and it is sometimes difficult from health professionals to know how to provide appropriate and culturally sensitive end of life care to patients in multiethnic communities. Leigh Turner addresses this issue through a discussion endof-life care in multi-ethnic settings in Canada and the USA. He observes that most of the contemporary literature in bioethics stresses the importance of truth telling, the principles of autonomy and patient choice and the value of advanced care planning. However, these principles run counter to beliefs and values of many

cultural groups in these societies. He reviews literature about the plurality of attitudes as to what constitutes appropriate communication at the end of life and discusses the tension between the biomedical values and ethical codes that guide health professionals and the need to provide end of life care that respects other values and beliefs.

Debates about what constitutes good end of life care will continue to be significant and contentious. We hope that *Mortality* will continue to publish papers that will contribute to that debate.

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