Book Review

Cohen, J. and Deliens, L. (eds.)

A Public Health Perspective on End of Life Care


255pp

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In recent years discussion of both the social and clinical aspects of experiences of death and dying has found a more prominent place in a range of literature - academic, policy documents, autobiography and journalistic commentary in the press. The increase in writing about death, as both social and personal, can be seen as part of a wider discourse that positions death and dying as a public health issue. The argument that death is now managed by clinical professionals, with specialist skills and knowledge in end-of-life care, has been powerfully made by a number of commentators. For example, the ideas of Australian sociologist, Allan Kellehear, have been particularly influential in moving the debate about what might be termed a 'good death' from a mainly clinical/professional domain to a public health arena, wherein families and communities can 'reclaim' skills to enable them to care for their dying. It is this cultural shift that is at the core of this fascinating edited collection.

In drawing out some of the chapters for particular attention, I have in fact started from the end, so to speak. Allan Kellehear contributes the final chapter (before the editors' conclusion) in which he discusses how families in many contexts do want to care for their dying but, this is often characterised by high levels of stress, limited practical information and, in some cultures, by stigma and taboo. The chapter highlights that end-of-life care in families and within communities is experienced as complex, contingent and uncertain.

The book is organised into five main parts - clinical and social context of death and dying; end-of-life care: provision, access and characteristics; end-of-life care settings; inequalities at the end of life: under-served groups; end-of-life care policies. Each part has a number of chapters that focus specifically on discrete aspects of the part's overall theme and this is useful for the reader. Terms, context and some key literature are identified to give each chapter both theoretical and empirical boundaries.

The chapters that I found most useful appear in the parts on End-of-life-care: Provision, Access and Characteristics and the part on Care Settings. Linda Emanuel's chapter (8) on communication between patient and caregiver discusses how communication is central to shared decision-making that is culturally appropriate and person-centred. She highlights the concepts of 'creative adaptation' and 'integration' as holistic techniques to support the wishes of the dying person. Where, for example, verbal communication is impeded by end stage disease, adapting to written forms can enable the dying person to retain an acceptable state.
of mind. 'Integration' is akin to life review that entails bringing one's personal story to closure. Elsewhere (see Watts, 2009) I have argued that life review is contested with potentially negative as well as positive outcomes for the dying person. This dualism is not referred to by Emanuel. However, her claim that 'integration involves vesting parts of the dying person in the surviving people', in terms of 'wisdom's', values, role transfers and memorabilia, extends thinking in this area.

Because most people in the West continue to die in acute hospitals, I was particularly interested in the ideas of Kelley and her colleagues (chapter 11) about approaches to the delivery of palliative care in this setting. The data in the chapter about the overall growth of palliative care services in hospitals illustrates that this is not evenly spread and that this is particularly limited in many countries in Africa, South-East Asia and Eastern Europe. This returns us to the precept promoted by the World Health Organisation that access to quality end-of-life care is a basic human right. It seems that the setting of death continues to be a key determinant in achieving this.

Overall, this is a very accessible text that draws out current thinking on this important topic. Its international focus on diverse approaches that promote a 'good enough death' takes into account the burgeoning global population, the AIDS crisis in sub-Saharan Africa and the problem in the west of so many people 'living too long'. A useful and focused book, the introductory and closing chapters written by the editors skilfully draw out key ideas and challenges and I would suggest reading both of these first before embarking on the other chapters. Because of its multiple perspectives, this book will be helpful reading for clinicians, academics, students and policy-makers concerned with 'how people die' in the context of both the developed and the developing world.

REFERENCE