

What ‘a good death’ means for bereaved family carers

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Commentary on: Holdsworth LM. Bereaved carers’ accounts of the end of life and the role of care providers in a ‘good death’: a qualitative study. *Palliat Med* 2015;29:834–41.

Implications for practice and research

- Care providers are not always aware of the complex ways in which they can shape end-of-life experience.
- Beyond good medical and nursing support, social aspects of care shaped by care providers can have a long-lasting effect on bereaved carers.
- The interpersonal impact care providers can have on bereaved carers, especially when considering that care provision is terminated after the patient’s death, needs to be further and more systematically explored.

Context

There is a growing body of evidence exploring end-of-life experience and the attributes of a ‘good death’ with general consensus being reached on the complexity of managing dying due to its multidimensional nature.^{1–2} Such complexity has been argued to result in care providers prioritising medical aspects of care over non-clinical aspects such as the social and psychological experience of dying, a critical issue that the study by Holdsworth seeks to address.

Methods

The purpose of the study was to explore the way bereaved carers conceptualise ‘good death’ and the impact that care providers might have on shaping such conceptualisations. The study used in-depth interviews with bereaved family carers from a hospice population in the South East of England following a pragmatic, applied approach to qualitative inquiry as introduced by Snape and Spencer.³ Out of a sample of 270 carers identified and invited by letter to take part in the study, 44 participated in the interviews. An interpretative thematic analysis using the framework approach was employed for data analysis.

Findings

Attributes of a good death, as conceptualised by bereaved carers, were classified into six main themes. These themes comprised social

engagement and connection to identity, carer provider characteristics and actions, carer’s confidence and ability to care, preparation and awareness of death, presentation of the patient at death and support after death for protected grieving in all of which care providers were observed to play a key role. The findings suggest that the role of care providers in shaping end-of-life experience extends beyond medical and nursing support into more social aspects of care.

Commentary

This study focused on bereaved carers’ accounts of what constitutes a ‘good death’ to determine the extent to which care providers can influence non-medical aspects of the dying experience. Although the impact of social support and the ways to improve such support for patients and carers have been systematically examined, research on the role of the care providers has largely focused on medical management with no explicit consideration of the role they can play in shaping social aspects of death.^{4–5} This study indicates that the boundaries between care providers and the social network of patients and their families can be blurred as care providers are increasingly becoming part of this network. Furthermore, Holdsworth demonstrates that the role of care providers in shaping end-of-life experience is by no means limited to providing good medical and nursing support, as considered so far, but extends into more social aspects of care especially when considering the extent the input of care providers increases as death approaches.

The importance of this study lies in the recognition that in the complex process of managing dying, care providers play a multidimensional role that exceeds good medical and nursing support. By increasingly becoming part of the social network surrounding the patients and their families, care providers can considerably affect end-of-life experience by shaping social aspects of care in complex ways of which they may occasionally be unaware. These aspects are seen to have a long-lasting impact on bereaved carers and their experience of the dying process. In this respect, not only care providers need to become aware of the wide ranging influence they have on patients and their families but also this influence has to become explicit in future recommended frameworks for professional practice.

Competing interests None declared.



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