

Qualitative study - other

Without adequate nursing support for families, dying at home threatens the values of a good death

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Commentary on: Hoare S, Kelly MP, Barclay S. Home care and end-of-life hospital admissions: a retrospective interview study in English primary and secondary care. *Br J Gen Pract* 2019;69(685):E561–9.

Implications for practice and research

- ▶ Families providing end-of-life care in the home urgently require well-resourced community nursing services.
- ▶ Future research should explore the perspectives of people who choose, for whatever reason, not to take on formal and intimate caregiving roles for their dying family members.

Context

The idea of *home* as a preferred location to achieve a 'good death' has become popular within end-of-life care discourse. So popular that hospital death is a measure of failed palliative care.¹ Less attention is paid—with notable exceptions²—to critically examining the challenges of home care at end of life.

Methods

The focus of this study³ was on understanding why some patients receiving end-of-life care at home do not die there. Interviews were conducted with healthcare staff (community and hospital), as well as family members. All participants were involved in the care of specific 'case-patients' (a person receiving end-of-life care at home but who ultimately transferred to hospital within 3 days of death).

Findings

The two most significant findings concern the challenges that families face in home-based palliative care and the under-availability of nursing resources to support these families. The authors illuminated crucial aspects of the family caregiving experience in home end-of-life care. For example, the fact that patient and family preferences for location of death can diverge, that nursing support in this context is radically under-resourced and that family members who take on caregiving duties do so at risk to their health, which is sometimes already fragile. The authors present a powerful story of a patient and family member found together on the floor of their home. They had both fallen hours before,

when attempting to use the bathroom, and did not have the strength to get back up. The authors' findings are in line with previous research that elaborates the challenges of supporting quality palliative care in the home environment,² and that nuances the simplistic idea of home as the default preferred location for end-of-life care.⁴

Commentary

Noteworthy is that of 33 participants, most were physicians. Only three were family members, and only one was a nurse. Given the article focuses on challenges faced by families and the limitations of nursing care, the analysis would obviously have benefited from a higher proportion of family and nurse participants. Nevertheless, this article makes a valuable contribution to the literature, significantly through the authors' critical stance towards ideas about families who are 'unable' or 'unwilling' to achieve the romanticised home death. Their paper encourages readers to adopt a strengths-based attitude towards such families. We should consider the enormity of what families face when they accept responsibility for home-based caregiving. We should also be critical of a policy context that relies on families, as well as unregulated carers, to do this work without adequate nursing support. A limitation of the study, acknowledged by the authors, was that unregulated carers who support palliative home care were not included.

Nurses contribute to ethical practice when they resist damaging discourses that marginalise the perspectives of family members in end-of-life care. As Colin Murray Parkes observed over four decades ago, "*Home can be the best place or the worst place to die*" (Parkes, p.26).⁵ And as the authors of this study highlight, "*Pejorative assessments of the association between family care and end-of-life hospital admissions obscures the significant undertaking of lay carers to support patients at home*" (Hoare, p.566).³ Future research should explore, from the perspectives of family and from nurses, the details of this undertaking and its ethical implications. For example, what right do families have, for whatever reason, to protect their home space from being transformed into a location of clinical end-of-life care,² and to reject the identity of *de facto nurse* during their loved one's final days? What role should nurses play in supporting such families, whose choices are transgressive in the face of the received view that home is the 'best' place to die?

Competing interests None declared.

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