Advance care planning: between tools and relational end-of-life care?


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Erica Borgstrom

The way in which end-of-life care is delivered in the UK has changed dramatically over the last few years. Owing to the changes in systems and care practice promoted in the End of Life Care Strategy, more people have access to higher quality care, including advance care planning and symptom management. Drawing on the ‘best practice’ at the time, the Strategy recommended the use of several tools to facilitate identifying dying patients, communicating and planning future care, and coordinating otherwise disparate services. These changes have not gone unnoticed: in 2010, the UK was considered as the best place to die by the Economist. The use of such tools to facilitate audit of clinical practice come to subsume the very process that they record, becoming routinised over and above person-centred practice in the minds of healthcare professionals.

Previous research has noted that good intentions and positive care philosophies often unwittingly get subsumed in the routines and structures of organisations. For example, James and Field noted, back in 1992, that as hospices began to replicate a medical model of service organisation, including an emphasis on bureaucratisation and professionalism, the care they provided became routinised. Similarly, research on care homes suggests that organisational structures emphasising discrete, functional tasks can undermine the ability to provide person-centred care, even when staff value the ability to engage with people on an interpersonal level. Moreover, organisational drivers to use certain tools may encourage their adoption by staff without adequate training in understanding the purpose and design behind the procedures, as was suggested in the independent review of the Liverpool Care Pathway. Examining the structures of how care is ordered enable us to see how it has become procedural and disconnected from the values that the procedures were introduced to promote.

The logic of person-centred care often endorses the idea of autonomous individual patients who can make their wishes known and whose care is provided by others.
Relational care widens the focus of care beyond the individual, to include, for example, their family and even the environment. Importantly, relational care foregrounds care as an on-going process and relationship that is neither strictly received nor given, but forged through connection with others. Relational care, by its nature, is difficult to measure and financially incentivise within current systems of commissioning and contracting. Although end-of-life care promotes holistic care and ‘being with’ people, which should, in theory, include relational care, what it takes to provide this kind of care—time, empathy, supportive spaces—is often missing in the protocol and audited versions of ‘best practice’.

As end-of-life care policy develops and advance care planning is being openly discussed, there needs to be an emphasis on relational care and flexibility in how that care is delivered. While politicians and commissioners are interested in increasing the percentages of people dying at home, or their usual place of residence, it is clear that people are anxious about the quality of care. Reviews of care at the end of life have highlighted that people are concerned about how they are treated (or not) as persons at the end of life, including the importance of recognising and accommodating the perspectives and needs of those related to and caring for them. The concerns expressed in these reviews suggests that relational care is often lacking, in part due to ‘poor communication’ about the dying process. This is not just about adding ‘family’ to the list of those who need to be consulted about end-of-life care decision-making, although doing so may be relevant. Relational care is about finding ways to connect to people, and enabling them to continue to be part of and, perhaps, forge new, meaningful relationships.

A focus on tools and protocols may help reframe how we think about caring for the dying, and even healthcare more broadly, but they in themselves are neither care nor valid indicators of end-of-life care, if we accept the importance that service users attribute to relational aspects of their care.

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Competing interests EB is a co-convenor of the British Sociological Association, Death, Dying and Bereavement study group, and Membership Secretary for the Association for the Study of Death and Society. She has received research funding in the past from NIHR and the Foundation for the Sociology of Health and Illness.

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