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


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

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 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 Strategy recommended the use of several tools to facilitate identifying dying patients, communicating and planning future care, and coordinating otherwise disparate services. 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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 suggest 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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