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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 Strategy¹ 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 Intelligence Unit,² and recent UK data released as part of Dying Matters Awareness week suggest people are more comfortable talking about death and dying now than they were 10 years ago.³ Yet, end-of-life care has been described as 'failing', in a 2015 Parliamentary and Health Service Ombudsman's report, particularly in terms of discussing dying and documenting patient preferences.⁴

A theme appears to be emerging from the history of attempts to scale up hospice-style care into acute and mainstream health services. It may be that focusing on the tools and documents of advance care planning risks undermining the discussions and relational care they are intended to support.

This is evident in observations on how advance care planning

documents and tools, such as the Preferred Priorities of Care, among others, have been used in daily clinical practice. The tools advocated by policy are often document or software based and create another, new process that staff and patients must follow before clinical decisions can be put into practice. In an ethnographic study on advance care planning, staff across the medical and social care spectrum often viewed the planning documents as something that 'had to be done'.⁵ They suggested that the tools structured the advance care planning conversations into another task that had to be navigated as part of their job, rather than simply being a prompt for discussions, as potentially originally designed and advocated. Instead, staff felt pressured to document-specific details in limited time and non-private spaces, and with patients who may be perceived as uncooperative, as part of a commitment to 'best practice'. Consequently, some people have begun to question the validity of the approach and its usefulness in providing care.

Desires to audit the use of these documents, such as care plans, add weight to the idea that institutions are interested in the tool and the process of collecting patient preferences, rather than the ways in which care is delivered. This sentiment was supported in this year's Dying Matters annual debate on whether a good death is possible: the speakers noted that clinicians are often judged on the boxes they tick, and not given the time to talk and, more importantly, to listen to patients. The focus on using tools can consequently unintentionally reduce personalised and relational

care, by demonstrating a commitment to 'best practice', rather than to the individualised care of the patient in front of them.

The use of such tools to facilitate care has come from a desire to provide more person-centred care. However, another important factor is the requirement of modern healthcare provider organisations to demonstrate quality assurance to their own governing bodies as well as statutory regulators. It is possible that documents designed to facilitate audit of clinical practice come to subsume the very process that they record, becoming prioritised 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 Field⁶ noted, back in 1992, that as hospices began to replicate a medical model of service organisation, including an emphasis on bureaucracy 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.⁷ 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.⁸ 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.⁷

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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.^{8 9} 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.

Twitter Follow Erica Borgstrom at [@ericaborgstrom](https://twitter.com/ericaborgstrom)

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