Challenges in end-of-life care: what the VOICES survey tells us

Every minute someone in England dies, but there is an increasing body of evidence to suggest that, although some people are able to benefit from exemplary care and support when they are approaching death, too many still aren’t getting the right care at the end of their lives.

The third National Survey of Bereaved People, also known as the VOICES (Views of Informal Carers – Evaluation of Services) survey, which asks bereaved people for their views on the quality of care provided to a relative or friend in their last three months of life, was recently published by the Office for National Statistics.1 In all, 22,661 completed responses were received from informants, from a sample of 49,607 deaths. This is the latest major study to highlight where things are going right, as well as wrong, in end-of-life care in England.

There has been some encouraging progress, particularly in the dignity and respect shown by nurses to dying patients and families, but it is really concerning that many people still appear to be failed by the health- and social care system when they are approaching death. The latest VOICES survey shows that, once again, end-of-life care in many hospitals is falling short. This should be a particular concern, given that almost half of the people covered by the survey died in hospital, even though only 3% of those who had expressed a wish regarding their place of death said that this was where they wanted to die.

It is also worth reflecting on the finding that, according to the respondents, less than a third of people (32%) had expressed a preference regarding their place of death. This confirms the ongoing need for what Baroness Neuberger, in the independent review into the Liverpool Care Pathway, described as a ‘national conversation about dying.’ Although, thanks to the Dying Matters Coalition, there has been some real progress in this area, we still have a long way to go.

The third VOICES survey shows that perceptions of the overall quality of care have not improved since 2011, when the first survey was conducted. It is especially concerning that people from deprived areas appear to be receiving poorer care.

Regarding the co-ordination of care, people who die in care homes are the most likely group to experience care as fragmented, as opposed to well co-ordinated. Co-ordination of care appears to be getting worse, not better, for those dying at home. And there has also been a significant worsening of care co-ordination for those who die in hospital, which must be explored and addressed as a priority.

The VOICES survey indicates how far there is to go if we are to ensure that people who choose to be cared for and die at home receive the support and treatment they need: it seems that pain is still significantly less likely to be relieved at home than in any other setting. Generally, it also appears that pain relief is far less available at home and in hospital than in care homes and hospices. However, if meaningful choice is to be provided for people at the end of life, we need to ensure that appropriate support is available across all settings.

Through capturing perceptions and experiences of end-of-life care, surveys such as VOICES help us to understand what is going wrong, as well as what is going right, in how we care for people at the end of life. The challenge now is to transform the way in which we care for people who are dying, so that everyone receives the care that is right for them based on their wishes and needs. It is simply unacceptable to have so much inconsistency, with the quality of care varying depending on where you are and what your condition is.

All those involved in end-of-life care must see this as a priority. This requires strong leadership at a local level – including from hospital boards, clinical commissioning groups, local authorities and health and wellbeing boards – as well as nationally. It also requires the right training and support for staff, so that they understand what is expected of them and how to best deliver excellent end-of-life care. We only have one chance to get end-of-life care right for an individual, and at present this chance is sadly being missed on too many occasions.

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