

What has philosophy got to do it? Conflicting views and values in end of life care

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In this issue of the journal, philosopher Frances Kamm analyses and criticises in detail a set of highly influential US documents/guidelines and research studies relating to end of life care and advanced care planning.¹ These documents, written by a diverse group of experts working in and around palliative care, were designed to address widely-recognised problems in care of the dying in the US. Writer and surgeon Atul Gawande, has powerfully described what he calls the “modern tragedy” of a “system of technological medical care [that] has utterly failed to meet the needs” of dying patients.²¹

The documents analysed by Kamm aren’t the sort of thing that usually elicit ethical analysis. They aren’t endorsing withdrawal of artificial nutrition and hydration at the end of life. They don’t delve into elective ventilation, terminal sedation or assisted suicide or other controversial choices at the end of life. Instead, the various documents attempt to identify and recommend evidence-based initiatives in end-of life care. Several of them focus on ways to encourage and improve patients’ conversations about their preferences for medical treatment towards the end of life. We might be tempted to wonder what could be wrong with that? What does philosophy have to contribute to these topics?

However, as Kamm makes clear in her paper, documents like these are sometimes ambiguous about the concepts that they invoke and they make assumptions that could be challenged. They also lead to (though do not always appear to recognize) potential conflicts between different values or perspectives. She argues, persuasively, that philosophy can help to identify and clarify these concepts and questions.

For example, one of the key tensions in provision of end of life care is between the view that it is important to respect patients’ choices about treatment and the view that certain ways of dying are objectively better than others. In some places, the documents appear to encourage neutrality about patient preferences – for example one states “Don’t judge: A “good” death means different things to different people”.¹ In other places, the documents appear to specifically endorse certain ideas of a good death – in particular, that a good death is one that eschews unnecessary medical intervention, is peaceful, and is associated with an attitude of acceptance.¹ One way of interpreting this (as highlighted by Robert Truog in a commentary in response to Kamm³) is as yet another example of the conflict between the ethical principles of autonomy and beneficence/non-maleficence – respecting what a patient wishes will sometimes mean pursuing a course of action that will be harmful for the patient. That may be particularly significant in cases concerning children, as the recent case of Charlie Gard makes clear.⁴ It also raises important questions in value theory about what makes for a good life, or in this case a good death. Is a good death one that is associated with the least pain, one that is consistent with the patient’s preferences, or one that promotes certain objective values (such as dignity, peacefulness or non-invasiveness)? Our answer to that depends in part on whether we are drawn to hedonism, desire-based, or objective list theories of the good.⁵

Kamm doesn’t indicate her own views about what would constitute a good death. She does, however, argue in favour of using neutral language when asking patients about their preferences. She finds it problematic that some of the questions encouraged in conversations about end of life preferences appear to be phrased or framed in ways that would nudge patients towards certain answers. In response, palliative care physicians Yael Schenker and Robert Arnold argue that complete neutrality in counselling is neither possible

¹ Gawande is also co-author of one of the documents analysed by Kamm.

nor desirable.⁶ They argue (as I have previously) that given existing bias in favour of life-prolonging treatment, provide information or questions in a way that is skewed in favour of comfort measures may actually serve to redress the balance.⁷

But what should we think about the question of the value of a particular way of dying? Is there an objective sense of a good death? Do doctors have special knowledge about what a good death is? A full answer to that question is beyond the scope of this commentary. However, here are some preliminary thoughts. First, given that death and dying relates to some of our most important and deeply felt values, and given the variability between people in the content and source of those values, it is highly unlikely that we could arrive at a single conception of a good death. There are good deaths, not a good death, and it may not be possible to say that some of these are better or worse than others. However, (to paraphrase Isaiah Berlin) pluralism about dying is not relativism about dying. There are, unquestionably, bad deaths, ways of dying that are bad on any reasonable account of what matters. Imagine, for example, if someone elected to die by torture – not for any reason, not because it would bring them pleasure or for anyone else's benefit, but simply because that was their preferred way of dying. That seems a terrible way to die. We shouldn't simply shrug our shoulders and say – "death by torture was his preferred death, so it was a good death for him". Of course, this is a highly unrealistic example. Yet, at least some of the deaths that occur in the setting of high-technology medicine appear dangerously close to "death by torture".

Perhaps it is here that the evidence of views of physicians might be relevant. Health professionals, who have seen many deaths, may not be able to say for sure what a good death is – but we have all seen bad deaths. Truog describes a child who developed severe air hunger and distress when his sedation was reduced prior to dying³. Gawande described an older man with disseminated cancer, (who had previously expressed a strong wish not to die on a ventilator), but who elected to have major surgery on his spine despite his physical frailty and terminal illness. He developed multiple complications, never recovered from the surgery, and died in the intensive care unit 2 weeks later.⁸

Faced for requests for treatments at the end of life that lack benefit or risk substantial suffering, doctors shouldn't remain neutral. They should be prepared to explain what is at stake, and why it is that a particular course of action risks a bad death. It is important that they engage with the patient's values and do not simply extrapolate from their own preferences, but they should engage in a rational dialogue with the patient about what would be in their best interests.⁹ For adults (though not necessarily for children), doctors might ultimately agree to provide the patient's request, accepting that the patient has the right to decide about treatment. However, good end of life care requires more than just providing a menu of options. It requires professionals to engage with some of the most profound ethical questions – the meaning and value of our lives and our deaths.

That is why philosophy is essential for good palliative care.

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