



Invited Commentary | Nephrology

Stopping Dialysis, Good Deaths, and Social Justice

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One of the greatest challenges in modern medicine is that there are so many things that can be done to help people live longer, such as dialysis. This amazing therapy effectively replaces the work of the kidney and allows people who would otherwise have died of kidney failure a chance to continue living. A major challenge, one not unique to dialysis, is knowing when it is the right time to stop pursuing these aggressive, organ-replacement therapies and instead pursue an aggressive approach focused on high-quality palliative and end-of-life care. In the study by Richards et al,¹ the authors conducted an elegant analysis of multiple data sets to explore the association of stopping dialysis and receipt of hospice services with end-of-life care measures, such as quality of care. Overall, they found that only 28% of patients stopped dialysis prior to death. Of those, 58% received hospice services. Of the remaining 72% of patients who continued dialysis, only 18% received hospice services prior to death. Compared with patients who continued dialysis, families of patients who chose to stop dialysis were more likely to rate the quality of end-of-life care as excellent (46% vs 56%). Of patients who continued dialysis, choosing to receive hospice services was associated with a markedly higher proportion of family members rating the quality of care as excellent at the end of life compared with those who did not receive hospice services (61% vs 40%). Put another way, patients who continued dialysis and did not receive hospice services had lower family member ratings of quality of care at the end of life.

Readers should understand that linking all the disparate data sources used in the study by Richards et al¹ was no small task. By doing this difficult work, the authors have given us a gift of highly credible evidence. However, 2 cautions should be considered in interpreting these results. First, the US Department of Veterans Affairs (VA) is quite different from non-VA health systems in terms of options at the end of life. Patients in the VA have the option of pursuing treatments, such as chemotherapy and dialysis, while they pursue hospice services. In contrast, patients in the Medicare fee-for-service system often must forgo expensive, life-prolonging therapies at the time they begin receiving hospice services simply because of the payment model. Second, and more importantly, the study by Richards et al¹ provides evidence of an association, not causation. One should not conclude that stopping dialysis leads to better quality of care. Indeed, the fact that those who continued dialysis but received hospice services had the highest ratings of care at the end of life suggests there is a lack of a causal link. An alternative interpretation would be that people who stopped dialysis or received hospice services were very different than the larger group of people who continued dialysis and did not receive hospice services. This article highlights several important questions about death. Death is inevitable, but what is a good death?

A good death is an ideal that suffers from a lack of clarity and constantly shifting definitions. In the 1960s and 1970s, the term *good death* was synonymous with physician-assisted death or euthanasia.² The dominant attitude was that decisions of life and death were solely the concern of the physician, and the patient had little or no agency. This paradigm began to shift in the 1980s when the definition of a good death began to evolve to include ideas of symptom management and patient preferences for treatment decisions.³ Though still underused, this shift directly coincided with the increasing use and popularity of hospice services in the United States. Yet, while we have embraced patient preferences in some respects, today's unspoken paradigm of medicine instructs students to view death as a failure rather than a natural process that all of us are fated to experience. To add to the convoluted, modern conceptions often oversimplify a good death as one that occurs at home

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with hospice services and a bad death as one that occurs in a health care facility.⁴ All permutations of a good death are heavily criticized, and rightly so.⁴

The finding in the study by Richards et al¹ of higher quality-of-care rating at the end of life among families of patients who stopped dialysis or received hospice services does not tell us if these deaths were good. We will never know, because we cannot know what services those patients were offered and how those discussions occurred. This highlights the underlying problem with all definitions of a good death, which is that they fail to consider the heterogeneity of patients' individual needs and desires. However, there is concerning evidence that the US health care system fails to navigate this challenge. First, use of hospice services is relatively low with only 50% of decedents receiving hospice services prior to death, and one-third of those patients receive hospice services for less than 7 days.⁵ Second, the study by Richards et al¹ reported important differences between groups in that patients who stopped dialysis were less likely to be black or live in the South Atlantic region. Third, this same research group published another 2019 study⁶ in which they reviewed the health records of patients who chose not to start dialysis and found significant documentation that clinicians felt the patients were violating some kind of social norm, questioned their competency, and used repeated strategies to convince the patients to start dialysis.

While *good death* as currently envisioned may not be the best construct, rather than abandon the term, we should reimagine it as a social justice issue. John Rawls⁷ conceptualized social justice as each person having an equal right to the most extensive basic liberty compatible with a similar liberty for others. Considering a good death from a Rawlsian perspective would mean that all individuals are entitled to define what a good death means to them and possess the information, agency, and opportunity to choose what helps them achieve their definition of a good death. This is consistent with the fundamental American ideals of liberty, equality, and equity. To achieve this, clinicians must inform patients of their options and respect their decisions, and we must ensure that those options are available to them. For example, a black patient receiving dialysis in the southern United States may indeed choose to continue dialysis and avoid hospice services. However, if that choice was made because no one ever introduced the options of stopping dialysis or receiving hospice services, then that patient had no option to have a good death.

ARTICLE INFORMATION

Published: October 11, 2019. doi:10.1001/jamanetworkopen.2019.13110

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Conflict of Interest Disclosures: None reported.

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