

Paradigm Shift: Dialysis as a Terminal Condition



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Five-year survival among patients on dialysis in the United States is approximately 40%¹; however, clinicians rarely consider end-stage renal disease to be a “terminal” diagnosis and typically involve palliative care only when such patients are very close to death.² This raises the question of whether the cohort of patients, for whom mortality is 60% at 5 years, has been adequately prepared for the end of life, precisely the question that Russwurm and colleagues sought to investigate.³

In their study, Russwurm *et al.*³ surveyed patients on dialysis to determine how often and with whom they discussed their end-of-life wishes. They found that about half of patients contemplate their mortality, but fewer than 10% of patients on dialysis discuss their end-of-life wishes with their nephrologist. Even when these discussions occur, it is not clear that typical advance care planning adequately prepares people for death, especially when time is scarce. An older tradition of approaching preparation for death as a lifelong practice called the *ars*

moriendi, or “art of dying” has wisdom to offer those with a terminal prognosis, which is ultimately a universal human condition.

Extending Life or Delaying Death? Challenges of Medicalization

Patients on dialysis are not the only ones ill-prepared for death. In the West at least, where most aspects of life have become medicalized, patients and doctors have elected to also medicalize the dying process.

As I describe in my book, “The Lost Art of Dying”, during the aftermath of the mid-1300s Bubonic plague, the *ars moriendi* literary tradition developed to help ordinary people anticipate and prepare for death. The genre circulated for more than 500 years but lost favor in the 1920s, as the world rebounded from the first world war and the global influenza pandemic.⁴ The discovery of antibiotics and then chemotherapy, combined with the advent of cardiopulmonary resuscitation, the mechanical ventilator, and hemodialysis, gave the illusion that death could be avoided. In the United States these discoveries appeared alongside an explosive growth in hospitals, from fewer than 200 in the 1870s to more than

6000 by 1920.⁵ Those with access to sophisticated medical treatments grew accustomed to the idea that a miraculous cure sits around the next corner, if we can only avoid death.

Nevertheless, this illusion has perplexed living and dying for patients and doctors alike. For example, rather than seeing dialysis as a kind of miracle and not something to be taken for granted, modern patients have come to expect dialysis as a fix for chronic kidney disease. And even though mortality is high, clinicians indulge expectations of patients, often without preparing them for the inevitable. My own uncle, who started dialysis during the COVID-19 pandemic, was shocked that he would have arteriovenous fistula complications. He fully expected dialysis to extend his life a couple of more decades. Although the numbers tell a different tale, his doctors did not warn him.

We see the impact of medicalization in our own hospital as well, where patients suffer setback after setback, each attended to with some intervention or another. We have machines to pump hearts, administer artificial nutrition and hydration, and substitute for kidneys. Patients dependent on such interventions can experience prolonged hospital stays in the order of months to more than a year, because ongoing complications prevent stabilization and discharge. Even though they require a heart transplant, or cannot eat for themselves, or are dialysis-dependent, we do not consider them to have terminal conditions, and we fail to help them prepare for death. As the authors rightly note, current nephrology guidelines omit palliative care for end-stage renal disease.⁶

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Limitations of Advance Care Planning

Russwurm and colleagues sought to investigate, among German patients on dialysis, the frequency of precautionary planning directives, consideration of end-of-life wishes, and treatment plans concordant with the patient's goals. Although they found that only a minority of patients on dialysis engage their nephrologists in end-of-life discussions, the question is whether that minority benefits and whether the majority misses out. The answer may not be so obvious.

Some American physicians are not persuaded that advance care planning has yielded expected results. Morrison and colleagues highlight "a substantial body of high-quality evidence" that fails to demonstrate that advance care planning affects medical decision making at the end of life improves goal-concordant care, or enhances patient and family perceptions of quality of care.⁷ Clinical practice rarely provides the conditions necessary for advance care planning to achieve its desired outcomes. They highlight 8 steps for successful planning, including the following: (i) patients articulate their values and goals in a variety of hypothetical scenarios; (ii) clinicians ask about those values; (iii) patient preferences are documented, and (iv) documentation is available when needed; (v) surrogate decision-makers act in accordance with patient wishes; (vi) clinicians attend to and integrate the documentation, and (vii) honor patient wishes; and (viii) health care systems prioritize the support of goal-concordant care. Even when circumstances are optimized, the emotions and complexity involved in treatment toward the end of life can confound the clearest documentation.

If not advance care planning and conversations about the end of life,

what do Morrison and colleagues recommend? They suggest encouraging patients, while they are able, to appoint a trusted medical decision-maker, and then studying the outcomes; they also recommend further research on actual discussions of end-of-life decision-making. These solutions, though constructive, will take longer to bear fruit. The *ars moriendi* offers a time-tested alternative.

Lessons From the *Ars Moriendi*

The *ars moriendi* handbooks developed to help people acknowledge their finitude and prepare for death over the course of a lifetime. The idea was simple: if you want to die well, you must live well, and one of the tasks of a life well lived is to attend to the lifelong work of living well to die well. For the *ars moriendi*, this meant living with mortality in sight, investing in community and mending broken relationships, cultivating cultural and religious practices, participating in ritual, and examining core beliefs. These activities were never carried out in isolation or without the end in sight. Life (and death) had meaning, and communities pressed into this claim.

In contrast to how we approach advance care planning today, *ars moriendi* practices were not one-off events, but they were incorporated into the warp and woof of daily existence. Perhaps if we approached planning for our own mortality as a regular practice, nephrologists would have more advance-care-planning conversations with their patients, and patients would receive more goal-concordant care as they die.

The data suggest that mortality is high for patients on dialysis, and I suggest that we should view dialysis as a terminal condition. However, the truth is that despite

enormous advances in medical science, mortality remains high for all of us. In fact, human mortality has always been 100%. Because this is the case, perhaps an even broader paradigm shift is in order: it is not only patients on dialysis who have terminal conditions but it is also everyone else.

DISCLOSURE

LSD receives royalties, honoraria for talks related to the book named in this manuscript, and HER travel expenses are usually covered as well.

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