

# End-of-Life Decision Making

By Vanessa Grubbs

“If you really want to do something, you’ll find a way. If you don’t, you’ll find an excuse.”

—Jim Rohn, American entrepreneur, author, and motivational speaker

Arguably, the biggest problem facing end-of-life decision making in elderly patients with advanced and end stage renal disease is that conversations about the end of life simply don’t happen often enough. In one survey of dialysis patients, fewer than 10 percent reported having a conversation about end-of-life issues with their nephrologist in the past year. Moreover, fewer than 10 percent reported that any physician had ever discussed prognosis with them (1). This despite evidence that patients and family members want to be given information about life expectancy even if the prognosis is poor, and those engaged in shared, informed decision making are more likely to make decisions about renal replacement therapy and end-of-life care consistent with their personal values—often resulting in preferences for less aggressive care and greater use of conservative management (2–4).

One explanation often given for the dearth of end-of-life conversations is nephrologists’ lack of training to have them. In a 2003 survey, nephrology fellows reported that they had received little training on end-of-life issues and felt less prepared to take care of dialysis patients at the end of life compared with other practice skills (5). Ten years later, a similar survey of nephrology fellows gave nearly identical results (6). Without meaningful incorporation of palliative care into nephrology training, another survey in 2023 would undoubtedly yield nearly the same results yet again. Perhaps nephrology fellowships have not made significant progress in this area because the nephrologists doing the training aren’t comfortable teaching the subject. Therefore, the key to true reform of nephrology training may lie in a requirement that practicing nephrologists obtain training in palliative and end-of-life care, similar to how many states in this country began requiring continuing medical education in pain management for licensure in the early 2000s.

It is also commonly assumed by nephrologists that there is not enough time to discuss end-of-life issues with patients and families. There is no way around the reality that talking through how we hope to live out the remainder of our lives usually takes time, often repeatedly. Many nephrologists turn to dialysis social workers and nursing staff to have these conversations, but patients and families prefer to have end-of-life discussions with their doctors (1, 3). Although dialysis social workers and nursing staff may be tasked with following up with end-of-life discussions, the assignment of health care proxies, and the completion of living wills, nephrologists must remain primarily responsible for discussing prognosis and goals of care with patients and families. Improved expertise in the area would allow nephrologists to facilitate such discussions with greater ease and efficiency. Perhaps a system-level realignment of financial incentives for achieving metrics, such as meaningful elicitation of patient goals and use of appropriate services near the end of life, would allow nephrologists to restructure their time allocation.

Finally, a lack of prognostic certainty is also con-

sidered a major barrier to end-of-life conversations. It is not surprising that we nephrologists are uncomfortable with diagnostic uncertainty, given that the field is rife with equations. There are equations to calculate deficits of free water, bicarbonate, and sodium; more equations to calculate fractional excretion of sodium and urea; and still more to calculate creatinine clearance and glomerular filtration. Although tools to estimate prognosis among dialysis patients exist and those to estimate prognosis among patients with advanced kidney disease are in development, without a crystal ball it is doubtful that any tool will ever have enough precision for clinicians to feel assured of accuracy for any patient before them. But compared with the vast majority of patients and families who have only their “n of 1” experience with illness, our clinical knowledge and experiences with similar patients is invaluable and should be shared.

The penalty for not having end-of-life conversations is that the default for our elderly patients is intensive care patterns focused on prolonging life, when survival alone may not be the only thing that matters to them. Currently, many older adults in the United States being treated with maintenance dialysis continue to receive aggressive care focused on life prolongation toward the end of their lives. Almost half (45 percent) of older dialysis patients in the United States die in a hospital setting, compared with 35 percent of older patients with other severe chronic illness, including congestive heart failure, advanced liver disease, dementia, and chronic obstructive pulmonary disease (7). The rates of hospitalization (76 percent) and intensive care unit (ICU) admission (49 percent) during the final month of life are also substantially higher than those reported for other older Medicare beneficiaries, including those with cancer (of whom 61 percent are hospitalized and 24 percent are admitted to an ICU) and heart failure (of whom 64 percent are hospitalized and 19 percent are admitted to an ICU). Additionally, older dialysis patients spend twice as many days in the hospital during the last month of life, compared with older patients with cancer (9.8 versus 5.1 days) and are three times more likely to undergo intensive procedures like mechanical ventilation, feeding tube placement, and cardiopulmonary resuscitation (29 percent versus 9 percent). By contrast, the rates of palliative care and hospice use among dialysis patients at the end of life are extremely low (7). Compared with hospice use in patients with terminal cancer (55 percent) and heart failure (39 percent), the use of hospice is only 20 percent among dialysis patients and is often initiated only within the last days of life (7–9).

Inasmuch as dialysis may be life-saving treatment in many circumstances, it seems to lull us—clinicians, patients, and families alike—into a false sense that acute events are temporary, when the truth is that dialysis cannot change the reality that the trajectory of kidney failure is continuous and is characterized by acute illnesses and setbacks where recovery is never back to baseline functional sta-

tus and ends in death (Figure 1) (10). Perhaps if we could embrace this fact we could take action to help our patients prepare for the inevitability of death with the same vigor that we apply to helping them prepare for renal replacement therapy.

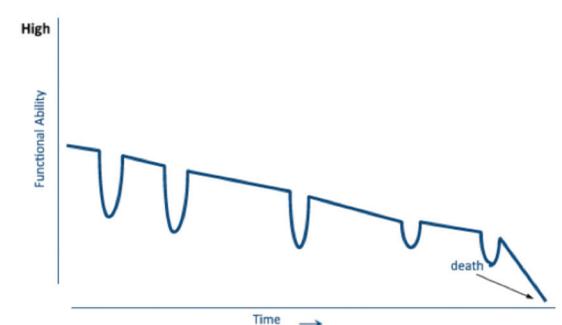
More than 1 in 5 of our patients die every year. The onus is on us to move beyond pointing out the reasons why we fail to act in ways that ensure these deaths are aligned with our patients’ values. ●

Vanessa Grubbs, MD, MPH, is an Assistant Professor at the University of California, San Francisco School of Medicine.

## Reference

1. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 2010; 5:195–204.
2. Visser A, et al. Accepting or declining dialysis: considerations taken into account by elderly patients with end-stage renal disease. *J Nephrol* 2009; 22:794–799.
3. Fine A, et al. Nephrologists should voluntarily divulge survival data to potential dialysis patients: a questionnaire study. *Perit Dial Int* 2005; 25:269–273.
4. Holley JL, et al. Failure of advance care planning to elicit patients’ preferences for withdrawal from dialysis. *Am J Kidney Dis* 1999; 33:688–693.
5. Holley JL, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. *Am J Kidney Dis* 2003; 42:813–820.
6. Combs SA, et al. Palliative and end-of-life care training during fellowship: national survey of second-year US nephrology fellows. *J Am Soc Nephrol* 24; 2013:54A.
7. Wong SP, et al. Treatment intensity at the end of life in older adults receiving long-term dialysis. *Arch Intern Med* 2012; 172:661–663; discussion 663–664.
8. Murray AM, et al. Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 2006; 1:1248–1255.
9. O’Connor NR, et al. Survival after dialysis discontinuation and hospice enrollment for ESRD. *Clin J Am Soc Nephrol* 2013; 8:2117–2122.
10. Holley JL. Advance care planning in CKD/ESRD: an evolving process. *Clin J Am Soc Nephrol* 2012; 7:1033–1038.

**Figure 1. Illness trajectory of kidney failure—despite dialysis**



Adapted from reference 10