

## To Dialysis and Beyond: The Nephrologist's Responsibility for Advance Care Planning



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The need to plan defines nephrology as a medical specialty. In caring for patients with non-dialysis-dependent chronic kidney disease (CKD), one of the most common diagnoses with which we deal as nephrologists,

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we take it for granted that many of our patients will reach a point in their trajectory at which we would be remiss to not discuss planning for end-stage kidney disease (ESKD). The safest, smoothest transition to kidney replacement therapy (KRT), or the conscious decision to not initiate it, requires months or even years of planning. That we so often get to engage our patients in this planning is a testament to how successful we have become in prolonging life for many of them. In few other scenarios in medicine will the clinician and patient spend such an extended period together planning for a particular transition point.

However, because of epidemiologic shifts, how and for what we plan have both come under scrutiny. Year after year, people 75 years or older have the highest incidence of ESKD in the United States.<sup>1</sup> By virtue of their age, they are also at extremely high risk for death,<sup>1</sup> hospitalization,<sup>1</sup> frailty,<sup>2</sup> and cognitive and functional decline<sup>3</sup> on dialysis. Given that the number of older adults with advanced non-dialysis-dependent CKD who rank maintaining independence as their top health outcome priority exceeds the number who rank staying alive as their top health outcome priority,<sup>4</sup> we cannot assume that dialysis is the right choice for everyone. Despite this, dialysis has become the default treatment for ESKD in the United States, even for the very elderly and multimorbid. In their description of the quality of and experience with advance care planning among older adults with non-dialysis-dependent CKD stages 4 to 5, in this issue of *Kidney Medicine*, Oskoui et al<sup>5</sup> hint at some reasons for why we default to dialysis and how we might do otherwise.

Oskoui et al found that their elderly patients (average age nearing 80 years) with non-dialysis-dependent CKD generally thought that their clinicians knew their treatment preferences and understood their values, although a very small minority recalled having discussed with their clinicians treatment options, including in the case of life-threatening illness, and what matters to them as they make health care decisions. It is not entirely clear which clinicians that patients were thinking of when they answered these questions—was it always the same clinician, and was that clinician the patient's nephrologist? In addition, patient recall is bound to be imperfect, and care partners reported discussing more elements of advance care planning with clinicians than the respective patients did.

Notwithstanding these limitations, the disconnect revealed in this study is striking, to put it mildly. To the patients, it begs the question, "How can your doctor know and understand what you and your doctor have not discussed?" However, this question unfairly implies that the burden of ensuring that these discussions happen should rest on the patient, who often is already burdened enough. Instead, the question for the clinicians is, "Do you know and understand your patients as well as they think you do?" That patients believe their clinicians know their treatment preferences and understand their values in the absence of recollected discussions implies a tremendous amount of trust in clinicians. This level of trust is made explicit in the study; more than two-thirds of the patients said that their clinician definitely cares about them, listens to what they have to say, and gives them enough attention. But as we enjoy the privilege of our patients' trust in us, we must pair that privilege with the responsibility to have sensitive, honest conversations with our patients about prognosis, values, and treatment preferences, including but not limited to dialysis. That is, we must engage them in advance care planning, not just KRT planning.

It is easy to understand how nephrologists might believe that KRT planning can substitute for advance care planning in the case of a patient who does not protest the idea of dialysis. From the perspective of the nephrologist focused on KRT, the way forward is clear: refer for modality education, if someone other than the nephrologist provides it; if the patient chooses dialysis, refer to a surgeon for access; and follow up frequently in the office to monitor for indications to start. Why bring up prognosis, values, and treatment preferences if the patient is progressing as expected down the path toward initiation of dialysis, a life-sustaining procedure?

The problem of course is that so often patients do not progress "as expected," and the older and sicker they are, the more likely they are to deviate from the intended path. Until they reach an estimated glomerular filtration rate of 15 mL/min/1.73 m<sup>2</sup>, patients 65 years and older are more likely to die than they are to develop ESKD,<sup>6</sup> so the nephrologist who addresses only dialysis and not death could be subjecting his or her patients to unnecessary access procedures while missing an opportunity to convey prognostic information that patients with advanced non-dialysis-dependent CKD generally say they want to hear.<sup>7-9</sup> Moreover, elderly patients who survive to start dialysis will learn what life with ESKD looks like, with all the aforementioned hospitalizations and cognitive and functional decline, and some might regret their decision.

Even more problematic for the KRT-focused nephrologist are patients who opt for conservative management, often after overcoming objections and questions about their decision-making capacity from the health care team.<sup>10</sup> Few nephrologists in the United States have much experience in conservative management,<sup>11,12</sup> and some nephrologists doubt that they have anything to offer to patients not doing dialysis.<sup>10</sup> Furthermore, patients forgoing dialysis are probably the ones most likely to also wish to forgo other invasive end-of-life interventions such as mechanical ventilation and cardiopulmonary resuscitation, both of which could become indicated from complications of ESKD. How many nephrologists, though, are willing or able to broach do-not-resuscitate orders with their patients, especially stable-seeming outpatients?

The barriers that nephrologists perceive to their participation in advance care planning are well documented,<sup>8,12-15</sup> especially the lack of training in how to conduct effective conversations about end of life, lack of time necessary to conduct these conversations, lack of incentive for having these conversations and then for conservatively managing patients who opt against dialysis, and lack of support from the rest of the health care system. Indeed, it might be idealistic to expect any group of people who lack training, time, incentives, and support to do something that can be difficult and uncomfortable just because it seems like the right thing to do. Make no mistake, however; it is the right thing to do, and so we need to figure out how to help all nephrologists do it, not just the ones who are already inclined.

It is important for nephrologists to realize that though they must take a role in advance care planning beyond KRT planning, they do not have to do it alone. Primary care providers can and should partner with nephrologists on advance care planning for elderly patients with non-dialysis-dependent CKD. Access to specialist palliative care services outside of hospice is improving in the United States,<sup>16</sup> though palliative care referral alone does not absolve the nephrologist of the need to also participate in advance care planning.

Methods to improve nephrologists' skills and comfort in the communication portion of advance care planning are an area of active study. A validated nephrology-specific palliative care communication curriculum now exists for institutions or fellowship programs that have the resources to implement it.<sup>17</sup> Less resource intensive is a communication tool,<sup>18</sup> currently the subject of a multicenter clinical trial,<sup>19</sup> designed for nephrologists to involve their elderly patients with non-dialysis-dependent CKD in shared decision-making about dialysis initiation and palliative care referral. Finally, to which the authors of this study allude, the growth of value-based care models within nephrology that the Advancing American Kidney Health Initiative is accelerating means that in the near future, nephrologists might find themselves additionally incentivized to engage their elderly patients with non-dialysis-dependent CKD in advance care planning. It seems likely that for the next few years, innovation in this area will abound.

Regardless of the assistance available to us, we as nephrologists must continue to excel at planning but expand our vision of how and for what we plan, especially when caring for elderly patients with advanced non-dialysis-dependent CKD. As this study demonstrates, we already have their trust. Now we need to use it to together develop the best individual plan for each one of them.

## ARTICLE INFORMATION

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