Enabling Patient Choice: The "Deciding Not to Decide" Option for Older Adults Facing Dialysis Decisions

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Dr. Smith, a psychiatrist, and Dr. Anderson, a nephrologist, share a common patient, Mr. Johnson. He is 77 years old, has ischemic cardiomyopathy, and an eGFR of 20 ml/min per 1.73 m^2. The buzzing of his arteriovenous fistula reminds him of the prospect of a future life on dialysis. Although he had the arteriovenous fistula placed 2 years ago, he is unenthusiastic about dialysis, not aware of alternatives, and has recurring thoughts of suicide. When Dr. Smith spoke with Dr. Anderson about ligating the fistula, Dr. Smith was told the patient would need it for dialysis.

Nearly a decade ago, the American Society of Nephrology's Choosing Wisely Campaign recommended shared decision making before dialysis initiation for older people with CKD. Yet decision making about RRT remains suboptimal, because genuine shared decision making is rarely incorporated.[1,2] Dialysis is often presented as the default option,[3] although Medicare data show that more than half of those >65.5 years initiating dialysis die within 12 months,[4] and dialysis confers limited survival advantage in older, frail people.[5]

Both patients and nephrologists report being emotionally burdened by RRT decision making.[2,6] Many patients are ambivalent about their RRT choices, and want more time to finalize a decision.[2] Similarly, many nephrologists feel uncomfortable not offering dialysis for reasons that are poorly understood, but may include prognostic uncertainty and discomfort with death.[6,7] To foster shared decision making, we propose that nephrologists discuss the standard options—transplantation, home or in-center dialysis, and active medical management without dialysis—along with a fourth option, "deciding not to decide" (DND), which intentionally defers the decision and lets patients revisit RRT choices at a mutually agreeable time. This fourth option is patient centered and supported by psychologic theory and research that shows many older patients with CKD prefer a "wait and see" approach, taking one day at a time, and focusing on living well in the present, rather than planning for the future.[2] In this Perspective, we lay out a proposed framework for the DND option.

Several reasons compel us to advocate for the DND option in older patients: first, kidney function often declines more slowly with age, and it may be appropriate to delay dialysis for some older patients with CKD until a very low eGFR. Second, patients often feel a power imbalance in RRT decision making that manifests as a perceived lack of choice and "immense pressure" to start dialysis.[2] This "choiceless choice" could lead them to acquiesce to unwanted vascular access surgery (as was the case with Mr. Johnson).[2,3,8] In one study of 3418 patients, 37% of patients aged ≥75 years who underwent a procedure for dialysis preparation died before dialysis initiation.[9] The DND approach represents an additional option to help patients maintain some control. Third, few patients see active medical management without dialysis and dialysis as mutually exclusive; rather, they want active medical management without dialysis throughout the disease course, with the flexibility to start dialysis if they wish.[10] Lastly, failing to offer patients the freedom of DND compromises the ethical principle of respect for patient autonomy. Therefore, to ensure a discussion of all options, we call on the nephrology community and all who treat people with advanced CKD to offer all options, including DND.

We expect the DND option will be welcomed by older patients not ready to commit to a particular treatment option.[2,3] We acknowledge that some patients seemingly choose this option

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Table 1. Pros and cons of deciding not to decide

Pros and Cons of the Deciding Not to Decide Option
Pros
(1) Provides more control for patients and families and facilitates a "wait and see" approach for those who prefer it; it takes into account the patient's stage of readiness to engage in the decision-making process and aligns with the Renal Physicians Association's Shared Decision Making Guideline recommendation that patients ultimately have choices throughout their disease course, and the role of the clinician is to present patients with options and help them choose from these options on the basis of their preferences and goals.
(2) Delays and/or prevents unwanted disruption in day-to-day life.
(3) Offers the potential for fewer unnecessary procedures.
(4) Focuses on quality of life.
(5) Allows more time to fully appreciate options and contemplate choices.
(6) Recognizes choices may be revisited, particularly if preferences change.
Cons
(1) May increase potential for more emergency dialysis initiations for patients who decide to start dialysis late in the disease course.
(2) May increase the number of patients who initiate dialysis with a catheter with attendant risks.
(3) May result in a missed opportunity to have subsequent decision-making conversations if the patient unexpectedly becomes overtly uremic.

by not keeping appointments, or by deferring these decisions when physicians broach the topic. However, such passive decision making is rarely "informed" and "shared" between patients and physicians. By making DND an explicit option, the physician can present the patient and family with the pros and cons of all four options (Table 1), along with the evidence regarding the potential effect on quality and quantity of life. We propose the DND option includes the following:

(1) For an older adult (*e.g.,* aged ≥75 years) with advanced CKD, who is not a candidate for kidney transplantation, the clinician informs the patient (and family) the time has arrived to start thinking about RRT decisions, while acknowledging that treatment preferences often change.
(2) The patient (and family) agrees to hear more.
(3) In addition to the other options, the physician also shares the DND option, where the focus is on preserving kidney function and maintaining or improving quality of life. It gives patients and families a "time out" from the clinician-preferred focus on the future and planning for dialysis.[2] It also allows patients to actively control the pace of the decision-making process, depending on their readiness to engage and commit to a choice.
(4) The nephrologist also offers to discuss both end-stage kidney failure risk and overall prognoses and involve in advance care planning, depending on the patient's readiness.
(5) If patients choose the DND approach, the clinician accepts their decision, while letting them know they can reconsider their options at a mutually agreeable time, or when they feel ready to re-engage in the decision-making process.
(6) When patients choose the DND approach, the nephrologist documents this choice in the chart. At this point, in addition to usual CKD management, the patient's quality of life is maintained or enhanced by either their primary clinician, or a palliative care specialist.
(7) When the patient's eGFR declines significantly (*e.g.*, <10 ml/min per 1.73 m^2), or they develop early uremic symptoms, or experience any major change in life (*e.g.*, hospitalization, decreased functional status, acute kidney injury superimposed on CKD, change in goals), or are ready to commit to a particular treatment option, the clinician and patient discuss the RRT options, including palliative dialysis, a time-limited trial of dialysis, and active medical management without dialysis. Once a patient commits to a choice (*e.g.*, dialysis), we encourage prioritizing permanent access placement.

We recommend offering the DND approach to patients regardless of race, age, ethnicity, sex, sexual orientation, gender identity, insurance, education, or other potential correlate of health disparities. We acknowledge that, as with all RRT options, the DND approach has advantages and disadvantages (Table 1). Still, it warrants careful consideration because it expands and strengthens patient-centered care through informed patient engagement. It does not force patients to choose a particular RRT modality before they have been informed of all of the options, nor does it subject them to dialysis access procedures in advance of their readiness to settle on a particular treatment option.

In this context, let us again consider the case of Mr. Johnson. It seems he was given little time to reflect on his treatment choices and life goals. He felt conflicted and anxious about starting dialysis, feared losing bodily integrity, and eventually underwent surgery without fully informed consent. The sensation of the fistula became a constant reminder of impending dialysis, a looming threat, that elicited thoughts of suicide.

"How well did the present decision-making approach of the healthcare system do for Mr. Johnson?" we ask. The DND option gives older persons with advanced CKD, many of whom may experience limited or no benefit from dialysis, more time and space to consider how they want to live the rest of their lives. We urge those who care for these patients to consider adding the DND option to the range of discretionary choices they offer patients and their family members.

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AUTHOR CONTRIBUTIONS

P.R. Duberstein, K.A. Fiscella, A.H. Moss, and F. Saeed conceptualized the study; K.A. Fiscella provided supervision; F. Saeed wrote the original draft; and P.R. Duberstein, K.A. Fiscella, and A.H. Moss reviewed and edited the manuscript.

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