

# Care Practices for Patients With Advanced Kidney Disease Who Forgo Maintenance Dialysis

Susan P. Y. Wong, MD, MS; Lynne V. McFarland, PhD; Chuan-Fen Liu, PhD; Ryan J. Laundry, BA; Paul L. Hebert, PhD; Ann M. O'Hare, MD, MA

**IMPORTANCE** Although maintenance dialysis is a treatment choice with potential benefits and harms, little is known about care practices for patients with advanced chronic kidney disease who forgo this treatment.

**OBJECTIVE** To describe how decisions not to start dialysis unfold in the clinical setting.

**DESIGN, SETTING, AND PARTICIPANTS** A qualitative study was performed of documentation in the electronic medical records of 851 adults receiving care from the US Veterans Health Administration between January 1, 2000, and October 1, 2011, who had chosen not to start dialysis. Qualitative analysis was performed between March 1, 2017, and April 1, 2018.

**MAIN OUTCOMES AND MEASURES** Dominant themes that emerged from clinician documentation of clinical events and health care interactions between patients, family members, and clinicians relevant to the decision to forgo dialysis.

**RESULTS** In the cohort of 851 patients (842 men and 9 women; mean [SD] age, 75.0 [10.3] years), 567 (66.6%) were white. Three major dynamics relevant to understanding how decisions to forgo dialysis unfolded were identified. The first dynamic was that of dialysis as the norm: when patients expressed a desire to forgo dialysis, it was unusual for clinicians to readily accept patients' decisions. Clinicians tended to repeatedly question this preference over time, deliberated about patients' competency to make this decision, used a variety of strategies to encourage patients to initiate dialysis, and prepared for patients to change their minds and start dialysis. The second dynamic arose when patients were not candidates for dialysis: clinicians viewed particular patients as not candidates or appropriate for dialysis, usually on the basis of specific characteristics and/or expected prognosis, rather than after consideration of patients' goals and values. When clinicians decided patients were not candidates for dialysis, there seemed to be little room for uncertainty in these decisions. The third dynamic occurred when clinicians believed they had little to offer patients beyond dialysis: when it was clear that patients would not be starting dialysis, nephrologists often signed off from their care and had few recommendations other than referral to hospice care.

**CONCLUSIONS AND RELEVANCE** These findings describe an all-or-nothing approach to caring for patients with advanced chronic kidney disease in which initiation of dialysis served as a powerful default option with few perceived alternatives. Stronger efforts are needed to develop a more patient-centered approach to caring for patients with advanced chronic kidney disease that is capable of proactively supporting those who do not wish to start dialysis.

*JAMA Intern Med.* 2019;179(3):305-313. doi:10.1001/jamainternmed.2018.6197  
Published online January 22, 2019.

← Invited Commentary page 313

**Author Affiliations:** Health Service Research and Development Center, Veterans Affairs Puget Sound Health Care System, Seattle, Washington (Wong, McFarland, Liu, Laundry, Hebert, O'Hare); Department of Medicine, University of Washington, Seattle (Wong, O'Hare); Department of Health Services, University of Washington, Seattle (Liu, Hebert).

**Corresponding Author:** Susan P. Y. Wong, MD, MS, Health Service Research and Development Center, Renal Dialysis Unit, Veterans Affairs Puget Sound Health Care System, 1660 S Columbian Way, Bldg 100, Seattle, WA 98108 (spywong@uw.edu).

Maintenance dialysis is a form of life support for patients with advanced chronic kidney disease (CKD). However, treatment with dialysis does not always have the intended effect of extending life or restoring health and quality of life for those with advanced CKD. For some patients, the potential benefits of dialysis in terms of extending life and managing signs and symptoms of uremia may be outweighed by its potential harms, which include the substantial treatment burden and prospect of a highly medicalized lifestyle<sup>1-3</sup> and risk of progressive loss of physical, social, and cognitive function.<sup>4-7</sup>

Available research on decision making about dialysis in the United States has been limited largely to patients who are receiving maintenance dialysis and suggests that dialysis is often framed to patients as a necessity rather than a treatment choice,<sup>8-12</sup> and that patients sometimes struggle with clinicians about whether and when to begin this treatment.<sup>8,11</sup> Prior work in the Veterans Affairs (VA) health care system found that it was relatively unusual for patients with advanced CKD to forgo dialysis, with only 14.5% of patients (or those making decisions on their behalf) choosing not to pursue dialysis.<sup>13</sup> Available evidence suggests that this practice may be even less common in other health care settings in the United States.<sup>14,15</sup>

To gain a deeper understanding of how decisions not to pursue dialysis unfold in the clinical setting, we conducted an in-depth qualitative analysis of the medical records of members of a cohort of VA patients with advanced CKD who decided not to pursue dialysis.<sup>13</sup>

## Methods

### Study Population

Using a previously published approach,<sup>8</sup> we conducted a qualitative analysis of the clinical notes of selected members of a national cohort of 28 568 patients with advanced CKD.<sup>13</sup> As described in detail elsewhere,<sup>13</sup> cohort members had at least 2 outpatient measures of estimated glomerular filtration rate less than 15 mL/min/1.73 m<sup>2</sup> separated by at least 90 days in the VA between January 1, 2000, and December 31, 2009, and were followed up from the date of their second estimated glomerular filtration rate of less than 15 mL/min/1.73 m<sup>2</sup> during this time frame through death or October 1, 2011. During follow-up, 19 165 cohort members were treated with dialysis based on either enrollment in the United States Renal Data System (a national registry of patients undergoing maintenance dialysis) or a dialysis procedure code in VA and Medicare files. Among the remaining 9403 cohort members, we selected a random sample of 1928 patients for in-depth review of their national VA electronic medical record to determine the treatment decision made with respect to dialysis closest to the end of follow-up. Of the patients selected for medical record review, 437 were found to have received dialysis based on documentation in progress notes despite not being registered in United States Renal Data System or having a dialysis procedure code, and 640 had not started dialysis by the end of follow-up but were discussing and/or preparing for this possibility. The analysis described here was conducted among the remaining 851 pa-

### Key Points

**Question** How do patient decisions to forgo dialysis unfold in real-world clinical settings?

**Findings** In a qualitative analysis of the medical record notes of 851 patients with advanced kidney disease who decided to forgo maintenance dialysis, 3 prominent themes emerged: (1) clinicians did not readily accept patients' wishes not to start dialysis, (2) clinicians decided particular patients were not candidates for dialysis seemingly without consideration of the patients' goals and values, and (3) clinicians seemed to believe they had little more to offer patients who would not be starting dialysis.

**Meaning** There is need for more patient-centered models of care for advanced kidney disease capable of supporting those who do not wish to start dialysis.

tients included in the medical record review for whom there had been a decision not to start dialysis made by either the patients themselves, their family members, and/or their clinicians. For the 812 patients (95.4%) who died during follow-up, the decision not to start dialysis reflected their treatment decision closest to the time of death. We used a combination of linked administrative and clinical data from VA and Medicare files to define and characterize the study cohort.<sup>13,16</sup> The institutional review boards at the VA Puget Sound Health Care System and the University of Washington approved this study and waived the requirement for informed consent for the following reasons: (1) the study was deemed to be of minimal risk to study participants; (2) this is a retrospective study in which all the patients had died by the time the study was conducted; and (3) there was no contact information within the data sources to enable us to contact legal next of kin for consent.

### Data Collection

Progress notes and other documentation in the electronic medical record are available for all episodes of care at VA facilities as Text Integration Utilities notes in the VA Corporate Data Warehouse. Using Lucene text-search software,<sup>17</sup> 1 of us (S.P.Y.W.) searched Text Integration Utilities notes for each patient's entire medical record through the end of follow-up and abstracted passages containing information relevant to decision making regarding dialysis. To ensure that all information pertaining to decisions about dialysis was reviewed, we used catch-all query terms, such as *kidney disease*, *end-stage renal disease*, and *dialysis* to locate all potentially relevant notes.

### Qualitative Analysis

Qualitative analysis was performed from March 1, 2017, and April 1, 2018. We used an inductive approach to content analysis<sup>18</sup> to analyze passages abstracted from the electronic medical record. One of us (S.P.Y.W.) reviewed all abstracted passages for each patient, openly coding for emergent themes pertaining to the decision to forgo dialysis. In parallel, another 2 of us (L.V.M. and A.M.O.) independently reviewed and openly coded abstracted passages for a random 20% sample of patients (n = 168). All 3 of us then collectively reviewed the codes

and associated passages for the 20% sample and, using an iterative and consensus-based approach, resolved differences in interpretation of passages and refined code definitions.<sup>19,20</sup> All 3 of us also reviewed the list of codes and associated passages generated by S.P.Y.W after reviewing records from all 851 patients to confirm thematic saturation based on review of the 20% sample.<sup>19</sup> Dominant themes were identified on the basis of the consistency with which they emerged in passages.<sup>21</sup> Finally, we assembled selected themes into larger thematic categories, returning as needed to the passages in the medical record to ensure that the final thematic schema was well-grounded in the data.<sup>20</sup> We used ATLAS.ti qualitative analysis software, version 8 (GmbH) to facilitate organization of codes and abstracted passages.

## Results

Of the 851 patients included in this analysis (842 men and 9 women; mean [SD] age, 75.0 [10.3] years), 567 (66.6%) were white (Table 1).<sup>8,9</sup> During a median follow-up of 0.5 years, 812 cohort members (95.4%) died, and 323 (38.0%) enrolled in hospice. In qualitative analysis, the following 3 dominant and interrelated themes emerged that were relevant to understanding how decisions to forgo dialysis unfolded: dialysis as the norm, patient not a candidate for dialysis, and having little to offer beyond dialysis.

### Dialysis as the Norm

Many of the patients included in this cohort had voiced a strong desire not to start dialysis. For example, it was not uncommon to see statements from patients recorded in clinician notes indicating that they would rather “die” than undergo dialysis treatment. In these instances, clinicians did not readily accept or fulfill patients’ preferences, and instead repeatedly questioned the patients’ decision, deliberated over patients’ competency to make decisions about dialysis, encouraged patients to initiate dialysis, and prepared for patients to change their minds and start dialysis (Table 2).

### Repeated Questioning

Although we found a few instances in which clinicians seemed to readily accept patients’ expressed wishes not to pursue dialysis (patient 1), it was more common for clinicians to question this decision, broaching the topic repeatedly over time (Table 2). Repeat questioning could come from the same or different clinicians (patient 2) and were often prompted by transitions of care (patient 3). Although repeat questioning could serve to clarify patients’ preferences (patient 4) and confirm consistency over time and/or consensus among family members (patient 5), this questioning could also be a source of frustration (patient 6) and even hostility (patient 7) for some patients.

### Consideration of Competency

When patients refused to initiate dialysis, clinicians were led to deliberate over patients’ competency to make this decision (Table 2). Concerns documented included whether pa-

**Table 1. Characteristics of Patients in Whom There Was a Decision Against Dialysis<sup>a</sup>**

Characteristic at Cohort Entry	Patient (N = 851) <sup>b</sup>
Age, y	
<65	150 (17.6)
65-74	179 (21.0)
75-84	372 (43.7)
≥85	150 (17.6)
Race/ethnicity	
White	567 (66.6)
Black	165 (19.4)
Other	119 (14.0)
Sex	
Male	842 (98.9)
Female	9 (1.1)
Burden of comorbidity	
Low	192 (22.6)
Moderate	292 (34.3)
High	358 (42.1)
Comorbidities	
Hypertension	354 (41.6)
Coronary artery disease	386 (45.4)
Congestive heart failure	354 (41.6)
Type 1 and 2 diabetes	446 (52.4)
Peripheral artery disease	142 (16.7)
Cancer	273 (32.1)
Chronic obstructive pulmonary disease	241 (28.3)
Dementia	75 (8.8)
Stroke	109 (12.8)
Cirrhosis	17 (2.0)
Nephrology care in year prior	
None	390 (45.8)
1-3 Clinic visits	301 (35.4)
≥4 Clinic visits	160 (18.8)
eGFR, mean (SD), mL/min/1.73 m <sup>2</sup>	11.7 (2.5)
Follow-up, median (IQR), mo	5.7 (1.1-17.2)
Care during follow-up	
Received palliative care consultation	439 (51.6)
Enrolled in hospice	323 (38.0)
Died during follow-up	812 (95.4)
Died in a hospital	336 (41.4)

Abbreviations: eGFR, estimated glomerular filtration rate; IQR, interquartile range.

<sup>a</sup> Further description of the cohort and ascertainment of variables have been previously reported.<sup>8,9</sup>

<sup>b</sup> Presented as number (percentage) unless otherwise specified.

tients might be suicidal or depressed (patient 8) or emotional or irrational (patient 9), or lack sufficient insight or information to be able to make informed decisions about undergoing dialysis (patient 10). When patients had a history of mental illness (patient 11), appeared to be depressed (patient 12), or had given what seemed to clinicians to be conflicting messages about their goals of care (eg, refusing dialysis treatment but also declining to not resuscitate status) (patient 13), this could

Table 2. Dialysis as the Norm: Clinicians Do Not Readily Accept Patients' Wishes Not to Start Dialysis

Patient No.	Service	Exemplar Quotes From the Medical Record
Repeated questioning		
1	Nephrology clinic	I feel that there is no need to discuss the dialysis anymore with him as he is quite determined that he would not want to accept any artificial means to sustain life, including kidney dialysis.
2	Oncology clinic	He has severe renal insufficiency and now has hyperkalemia. He refuses dialysis.
	Primary care clinic	He refuses to go onto dialysis and was told that the consequences of not going could be death. He says that he will die then.
	Nephrology clinic	He has refused to consider dialysis every time I have brought it up to him.
3	Nephrology: hospitalization 1	The patient again refused dialysis....I discussed the case with all the nephrologists at [the nephrology practice].
	Medicine: hospitalization 2	Was contacted on the phone by [the cardiologist] to discuss dialysis. He categorically refused and thought that all this has been settled during his previous admission.
4	Nephrology clinic	He seems to be willing to do dialysis, if it was a life-or-death situation, but is not too anxious to get it started before then.
	Nephrology clinic	He is unclear about whether he would do dialysis if he needed it.
	Nephrology clinic	We again discussed options of dialysis and he seems a little more resolute now that he would not agree to dialysis should it become necessary.
5	Emergency department	I called [patient's] son to again address code status and dialysis status.... He reiterated that per his father's wishes and the family's wishes, they did not want anything done. They did not want to start dialysis.
6	Inpatient medicine	The nephrology team came on rounds and readdressed the issue of dialysis. The patient seemed somewhat annoyed with them reapproaching her with the same issue and when they left she told this writer that she would appreciate it if the renal doctors do not come around to see her.
7	Nephrology clinic	Repeatedly every time asked says he will never agree to dialysis, and will die first. He gets angry, belligerent when asked this question, and says it is his right to refuse any care he chooses.
Consideration of competency		
8	Outpatient social work	Patient states he is not depressed or suicidal and would never hurt himself intentionally, but would rather die than be dependent on machinery.
9	Nephrology clinic	Patient seems scared of hemodialysis, and unable to logically explain apprehensions. Continues to state he wants things done to get better so he can continue living, yet states his life "schedule of activities" if interrupted by time spent on hemodialysis would not be worth living and he would rather die.
10	Inpatient medicine	He understands what is involved in dialysis and the consequences of his decision (death), but has made an "educated" decision not to have dialysis.
11	Ethics committee	The question centers around concern that the patient's history of schizophrenia might invalidate his prior and current expressed wishes for no hemodialysis.
12	Inpatient medicine	He has expressed his wish not to receive dialysis for a long time....He has had several personal circumstances, including the recent death of father and a son that may incite his depression and refusal of treatment. We will request psychiatry reevaluation.
13	Ethics committee	The ethical question according to [the nephrologist] is that although Veteran does not want dialysis, which is the most vital treatment, without which he will not survive, he has declined to be on Do Not Resuscitate status.
Encouraging dialysis		
14	Outpatient social work	Had numerous family meetings with patient and his family in an attempt to convince patient to accept dialysis but patient has always stated without fail that he did not want dialysis.
15	Nephrology clinic	Patient is adamant that he will not consider dialysis under any circumstances—seems to understand that the choice would be death.
16	Chaplaincy	His wife is supportive of what he decides to do, but related that she feels guilty in relation to the doctors who are urging dialysis.
17	Geriatrics clinic	He has said in past he doesn't want dialysis....I advised that he can accept this for a short time and could still decide to stop this afterwards.
18	Inpatient medicine	Willing to offer dialysis as bridge to wedding or chemotherapy...he said quite clearly that he did not want dialysis or chemotherapy, he just wanted "to be comfortable."
19	Inpatient nephrology	Patient has steadfastly refused to be placed on chronic dialysis. In terms of short-term dialysis while patient is hospitalized, this was being considered on an emergency basis only (ie, hyperkalemia or fluid overload refractory to medical management).
20	Home-based primary care	[Patient] reports that he does not really want to do [dialysis] but his wife states forcefully, "You have to"...reviewed that her yelling and "telling" him what to do were not the best ways to approach.

(continued)

**Table 2. Dialysis as the Norm: Clinicians Do Not Readily Accept Patients' Wishes Not to Start Dialysis (continued)**

Patient No.	Service	Exemplar Quotes From the Medical Record
Preparing for patients to change their mind		
21	Nephrology clinic	Still in denial about his kidney disease and his need for hemodialysis in the near future—repeat discussion with patient and wife regarding compliance.
22	Primary care clinic	Adamantly and clearly refusing dialysis, even to consider dialysis; my concern is that this may change as he begins to feel unwell.
23	Nephrology clinic	We discussed hemodialysis in some detail...he does not want access placed and does not want to pursue dialysis as a life-sustaining measure, although this will need to be discussed further, particularly if he develops an acute indication.
24	Nephrology clinic	Told him again he needs to start dialysis to prolong life. He again refused, saying he will die rather than do dialysis. Told him he may not last a month or 2 weeks or longer. He had no questions, didn't want to be bothered with me nor my mention of dialysis...would avoid fluid overload and pulmonary edema as that would force the issue of dialysis or death.
25	Outpatient social worker	Patient confirmed that he wants a referral for home hospice...he was educated that he can change his mind at any time and let us know if he wants to discontinue hospice and start dialysis.
26	Nephrology clinic	He does not want to go on hemodialysis, and does not want to have venous mapping at this point. We'll try to convince him of doing so, at least to have the information in the event we need to plan for creation of an arteriovenous fistula once he agrees.

lead clinicians to question whether patients' wishes to forgo dialysis should be honored. Clinicians might consult with mental health services and hospital ethics committees before upholding patients' wishes not to pursue dialysis.

#### Encouraging Dialysis

When patients expressed a desire to forgo dialysis, clinicians used a range of strategies to encourage initiation of dialysis (Table 2). These strategies included attempts to “persuade” or “convince” patients to start dialysis (patient 14) and to normalize dialysis treatment by framing the decision to forgo dialysis in negative terms, akin to “giving up,” or “choosing death” or their own “demise” (patient 15). Clinicians often enlisted the help of family members in discussions about starting dialysis (patient 16). Clinicians might also present dialysis as a short-term or interim treatment, offering a “trial” of dialysis (patient 17), dialysis as a “bridge” to buy time for other treatments (patient 18), or as temporary support for acute kidney injury (patient 19). We found only a few examples of clinicians who interceded on the patient's behalf when other clinicians and/or family members seemed to be pressuring patients to accept dialysis (patient 20).

#### Preparing for Patients to Change Their Minds

Patients who were refusing dialysis might be described as “difficult,” “in denial,” and “not ready” to face the “need” for dialysis (patient 21) (Table 2). Clinicians expressed skepticism that patients who said they did not want to start dialysis would actually be successful in this endeavor, expecting instead that they would eventually change their minds and go on to initiate dialysis when they became sicker (patient 22). Even when patients expressed a desire not to initiate dialysis before the need arose, clinicians tended to view these decisions as still up for discussion (patient 23) and as not final until patients reached a point where they were actually facing this need (patient 24). We found examples of clinicians reminding patients who seemed resolute about not starting dialysis that they could always change their mind (patient 25) and recommend-

ing that such patients still take steps to prepare for dialysis in case they changed their minds (patient 26).

#### Patient Not a Candidate for Dialysis

Unlike for patients described above who were refusing dialysis, we saw a different dynamic at play in situations in which clinicians did not consider patients to be “candidates” or “appropriate” for dialysis (Table 3). Determination of candidacy for dialysis seemed to hinge on particular patient characteristics or perceived poor prognosis, with little or no mention in clinician notes of the values and goals of individual patients. In these instances, clinician notes seemed to convey a high degree of certainty that patients did not stand to benefit from dialysis.

#### Determining Candidacy

Medical record notes routinely included language discussing whether patients were candidates or appropriate for dialysis (Table 3). Notions of candidacy and appropriateness tended to arise in situations in which there were pragmatic concerns about whether patients would “tolerate” (patient 27) or “comply” with (patient 28) the dialysis procedure itself or when there was concern that dialysis might not lengthen life (patient 29). Questions about candidacy and appropriateness tended to arise in the context of specific patient characteristics, such as advanced age and disability (patient 30). We found only 1 example where the patient's preference not to initiate dialysis was explicitly considered by clinicians as a reason that he was not a candidate for dialysis (patient 31). Rather, we typically found no documentation to suggest that patients' goals and values had informed this assessment.

#### Little Room for Uncertainty

When clinicians did not view patients as candidates for dialysis, their language conveyed a high degree of certainty that dialysis would not be beneficial but would rather be potentially harmful (patient 32) (Table 3). Clinician documentation also referenced patients' other serious illnesses and whether they were receiving life-prolonging treatment for these illnesses to

**Table 3. Patient Not a Candidate for Dialysis: Clinicians Viewed Patients Not to Be Candidates or Appropriate for Dialysis**

Patient No.	Service	Exemplar Quotes From the Medical Record
Determining candidacy		
27	Inpatient medicine	He will not be a candidate and he will not tolerate hemodialysis because of his poor ejection fraction.
28	Inpatient nephrology	Patient will be a poor candidate due to his longstanding history of noncompliance and refusal to allow even peripheral intravenous access.
29	Inpatient medicine	Told of poor prognosis and of the minimal benefit if any to be provided by further pursuit of possible hemodialysis.
30	Primary care clinic	The patient is 83 y of age. She has declining functional status and dementia. She is not considered to be a candidate for dialysis.
31	Inpatient medicine	Obviously he is not a dialysis candidate given his wishes/age/retroperitoneal mass/comorbidities/etc.
Little room for uncertainty		
32	Nephrology clinic	At this time or in the future the risks and complications of invasive dialysis therapy would outweigh any benefits with no improvement in survival or quality of life. Also, with extremely poor cardiac reserve, and hypotension, it is more likely than not that patient would have sudden cardiac arrest and death from arrhythmias and that risk is imminent during fluid and electrolyte shift from dialysis therapy.
33	Inpatient nephrology	Not a candidate for dialysis—demented, end-stage autoimmune deficiency syndrome (AIDS), not on highly active antiretroviral therapy (HAART), dialysis wouldn't prolong life in end-stage AIDS without HAART therapy.
34	Urology clinic	This patient's prostate cancer is not curable. Any chemotherapy would be palliative. His life expectancy is less than 5 y. In this situation, I doubt that dialysis would be recommended.
35	Primary care clinic	Has been told by [nephrologist] that dialysis would be too traumatic for his heart. Has been told that he has only 2 mo to live. Seems to be accepting of decision not to have dialysis.
36	Home-based primary care	Discussed that renal [team] had seen the patient and that he was not a hemodialysis candidate because of his comorbidities....It sounds like she had some guilt from her family about the decision that was made not to start hemodialysis during the past 3 y.

support arguments about the limited value of dialysis (patient 33), even for some patients whose prognosis could not be pinpointed (patient 34). Although patients were generally accepting of clinicians' judgements of candidacy (patient 35), family members did not always agree with this decision (patient 36).

### Having Little to Offer Beyond Dialysis

When it became clear to clinicians that patients would not be initiating dialysis—either because they were determined to forgo this treatment or because they were not viewed as being candidates for dialysis—documentation in the medical records seemed to suggest that clinicians believed they had little else to offer the patient (Table 4).

### Ending the Therapeutic Relationship

When it was clear that patients would not be starting dialysis, we found a few examples of nephrology clinicians who offered to continue to actively manage these patients' care or to make themselves available to patients on an as-needed basis (patient 37) (Table 4). More commonly, we found documentation to suggest that the nephrology team believed they “had nothing more to offer” and “signed off” from patients' care (patient 38). We also found documentation to suggest that patients also perceived nephrology services as part of the pathway to dialysis (patient 39).

### Hospice as the Only Alternative

When patients would not be starting dialysis, clinicians described a shortage of alternative treatments that could be offered to patients in place of dialysis (patient 40) (Table 4). The decision not

to start dialysis also tended to shut down other treatment options. For example, interventions that might accelerate the loss of remaining kidney function, such as surgery and cardiac catheterization, were intentionally avoided (patient 41). Instead, these patients were described as “eligible” or “candidates” for hospice care (patient 42) and were encouraged to enroll in hospice (patient 43). Although few patients (or their families) readily agreed to enter hospice care (patient 44), many patients were described as being “resistant” to entering hospice care (patient 45) or “not ready” to do so until their condition substantially deteriorated (patient 46).

## Discussion

This work among a national cohort of patients with advanced CKD in whom there was a decision to forgo dialysis provides an important window on how these decisions unfold in real-world clinical settings in a large US health system. Dialysis served as a powerful default treatment with few perceived alternatives. Patients who did not wish to start dialysis had to resist immense pressure from clinicians to do so, while patients who were not viewed as candidates for dialysis seemed to have little say in the matter.

Contemporary clinical practice guidelines favor moving away from a one-size-fits-all approach and toward a more patient-centered approach to care for patients with advanced CKD in which all clinical decisions are responsive to and uphold what matters most to individual patients.<sup>22</sup> To support a more patient-centered approach, clinical guidelines stress the importance of early and ongoing discussion of treatment options and maximiz-

**Table 4. Having Little to Offer Beyond Dialysis: Clinicians Believed That They Had Little More to Offer Patients Who Would Not Be Starting Dialysis**

Patient No.	Service	Exemplar Quotes From the Medical Record
Ending the therapeutic relationship		
37	Nephrology clinic	States he "would rather die" than go on dialysis...will honor the patient's wishes and continue to manage medically.
38	Nephrology clinic	Patient continues to refuse hemodialysis...since we cannot offer him any assistance from a renal standpoint other than hemodialysis at this stage of his disease, he will be discharged from renal clinic. Urged patient that should he change his mind about hemodialysis, to call us back to arrange this.
39	Primary care clinic	Offered to see the renal doctor, but he is not interested. He says he already saw that doctor, says the kidney doctor wanted to put him on dialysis. He does not want it.
Hospice as the only alternative		
40	Inpatient medicine	Nephrology felt that hemodialysis was not a viable option secondary to the elevated pulmonary pressure....The family was also not in favor of doing dialysis. Therefore, the team and family eventually came to the conclusion that there was nothing much that could be done for this gentleman, medically.
41	Cardiology clinic	Patient has near end-stage renal disease and is refusing to commit to beginning dialysis. Therefore, he is refusing to undergo further workup for his cardiac disease with a cardiac catheterization because of the fear of the risk of further kidney damage requiring dialysis.
42	Urgent care clinic	Hospice candidate, as patient has apparently refused dialysis.
43	Inpatient medicine	Patient's son talked with patient's brother and afterward was unsure of hospice... priority to talk to family in A.M. to address their concerns and strongly encourage hospice.
44	Inpatient social work	Spoke with patient who states he is familiar with hospice, "we had that for my wife," and he agrees to hospice services.
45	Primary care clinic	He really ought to go into hospice and I tried to impress that on him...he really does not want to until he gets to the point where he really needs that kind of help.
46	Home-based primary care	[Daughter] wants to discuss hospice, desires referral stating she's "no longer in denial"...veteran with generalized edema, dyspnea, somnolence, in fact, couldn't wake him up this morning. Some difficulty breathing. She is in agreement with palliative care. She is aware provider encouraged hospice a week ago and her mother declined and vacillated regarding the referral.

ing choice around treatment modality to include home dialysis, time-limited trials of dialysis, and palliative dialysis, as well as alternatives to dialysis, such as conservative management.<sup>23-26</sup> However, our results indicate that among this subgroup of patients with advanced CKD who did not initiate dialysis, the goals, values, and preferences of individual patients did not weigh heavily in clinicians' approaches to decision making regarding dialysis. In fact, we found examples of how some of the guideline-recommended strategies, such as continually revisiting decisions about dialysis and expanding the different options for dialysis treatment, could sometimes cross the line between preserving patient choice and undermining it when those strategies were not fully grounded in the principles of patient-centered care.

The picture that emerged from our analysis was a crisis-oriented approach to decision making for dialysis in which patients' expressed desire not to pursue dialysis was often not honored until late in the course of illness, by which time they were facing a choice between dialysis or death. Rather than create preemptive plans to support patients' wishes not to undergo dialysis, clinicians tended to initially respond with encouragement and expectation for patients to change their minds and start dialysis. These observations are consistent with the findings of several recent studies demonstrating clinicians' limited experience with conservative management of patients who chose not to pursue dialysis<sup>27</sup> and a perception of conservative care as an option of last resort.<sup>28,29</sup> This kind of approach stands in stark contrast to programs in place in several other developed countries, where formal pathways of conservative care have been established to encourage proactive decisions about dialysis before the need arises and to support

patients who do not wish to pursue dialysis.<sup>30-33</sup> In this context, available evidence suggests that, for older adults with a high burden of comorbidity, conservative care models may provide similar life expectancy<sup>34-38</sup> and quality of life<sup>39-41</sup> to that achieved with dialysis treatment. Taken together, our findings underscore the need to develop the cultural and clinical infrastructure to proactively support patients with advanced CKD who choose not to pursue dialysis.

### Limitations

This study has several limitations. First, although the VA is the largest integrated health system in the United States, our findings may not reflect care for groups not well represented in the VA, such as women, or care outside the VA. Second, the medical record permits a broad and longitudinal view of care for individual patients through documentation by multiple clinicians and in a range of settings. Nonetheless, what can be learned from the medical record is ultimately limited to what clinicians chose to document and provides only limited insight into the patient perspective or experience. Third, because documentation was not uniform across clinicians and patients, we could not reliably determine whether particular themes were present or absent in each case to measure counts. Themes identified were also complex and could not be precisely rendered into dichotomous variables. Hence, we could not estimate their prevalence or infer their generalizability. Fourth, we selected to present only dominant themes; thus, findings reported here are not exhaustive of all themes relevant to decisions to forgo dialysis. Finally, because follow-up for our study ended in 2011, it is possible that our results do not reflect contemporary practices. We believe this is un-

likely because the incidence of maintenance dialysis in the United States has not changed appreciably in more recent years,<sup>42</sup> and conservative care programs of the kind found in other developed countries remain in their infancy in the United States.<sup>43</sup>

## Conclusions

This study of a national cohort of patients with advanced CKD not treated with dialysis provides an important window on decision making regarding dialysis in a large US health

system. Our findings describe an all-or-nothing approach to care for patients with advanced CKD in which dialysis serves as a powerful default with few perceived alternatives. Regardless of whether patients had to resist clinicians' recommendations to undergo dialysis or were not considered candidates for dialysis, their goals and values did not seem to figure prominently in the decision making process. Collectively, these findings call for stronger efforts to develop more patient-centered models of care for patients with advanced CKD with the capacity to proactively support those who do not wish to pursue dialysis.

### ARTICLE INFORMATION

**Accepted for Publication:** September 17, 2018.

**Published Online:** January 22, 2019.

doi:10.1001/jamainternmed.2018.6197

**Author Contributions:** Dr Wong had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Concept and design:** Wong, Hebert, O'Hare.

**Acquisition, analysis, or interpretation of data:** All authors.

**Drafting of the manuscript:** Wong, McFarland.

**Critical revision of the manuscript for important intellectual content:** All authors.

**Obtained funding:** Wong, Liu, Hebert, O'Hare.

**Administrative, technical, or material support:** Wong, McFarland, Laundry, O'Hare.

**Supervision:** Wong.

**Conflict of Interest Disclosures:** Dr Wong reported receiving teaching honoraria from VitalTalk in the past 3 years. Dr O'Hare reported receiving speaking honoraria from Fresenius Medical Care, Dialysis Clinics Inc, The Japanese Society for Dialysis and Transplantation, the University of Alabama, and the University of Pennsylvania; receiving an honorarium from UpToDate; and participating in the Health and Aging Policy Fellows Program supported by the John A. Hartford Foundation and West Health and the American Political Science Association's Congressional Fellowship Program. No other disclosures were reported.

**Funding/Support:** This work was supported by grant 1K23DK107799-01A1 from the National Institutes of Health (Dr Wong) and grants IIR 09-094 (Dr Hebert) and IIR 12-126 (Dr O'Hare) from the Veterans Affairs Health Services Research and Development.

**Role of the Funder/Sponsor:** The funding sources had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

**Disclaimer:** The findings and conclusions in this report are those of the authors and do not necessarily represent the official position or policy of the Department of Veterans Affairs.

**Additional Contributions:** Christine Sulc, BA, and Whitney Showalter, BA, Veterans Affairs Health Services Research and Development Center, assisted with study coordination. They received salary support for their work.

### REFERENCES

- Wong SP, Kreuter W, O'Hare AM. Treatment intensity at the end of life in older adults receiving long-term dialysis. *Arch Intern Med*. 2012;172(8):661-663. doi:10.1001/archinternmed.2012.268
- Wong SP, Kreuter W, O'Hare AM. Healthcare intensity at initiation of chronic dialysis among older adults. *J Am Soc Nephrol*. 2014;25(1):143-149. doi:10.1681/ASN.2013050491
- Montez-Rath ME, Zheng Y, Tamura MK, Grubbs V, Winkelmayr WC, Chang TI. Hospitalizations and nursing facility stays during the transition from CKD to ESRD on dialysis: an observational study. *J Gen Intern Med*. 2017;32(11):1220-1227. doi:10.1007/s11606-017-4151-6
- Purnell TS, Auguste P, Crews DC, et al. Comparison of life participation activities among adults treated by hemodialysis, peritoneal dialysis, and kidney transplantation: a systematic review. *Am J Kidney Dis*. 2013;62(5):953-973. doi:10.1053/j.ajkd.2013.03.022
- Etgen T, Chonchol M, Förstl H, Sander D. Chronic kidney disease and cognitive impairment: a systematic review and meta-analysis. *Am J Nephrol*. 2012;35(5):474-482. doi:10.1159/000338135
- Jassal SV, Chiu E, Hladunewich M. Loss of independence in patients starting dialysis at 80 years of age or older. *N Engl J Med*. 2009;361(16):1612-1613. doi:10.1056/NEJMc0905289
- Kurella Tamura M, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med*. 2009;361(16):1539-1547. doi:10.1056/NEJMoa0904655
- Wong SP, Vig EK, Taylor JS, et al. Timing of initiation of maintenance dialysis: a qualitative analysis of the electronic medical records of a national cohort of patients from the Department of Veterans Affairs. *JAMA Intern Med*. 2016;176(2):228-235. doi:10.1001/jamainternmed.2015.7412
- Kaufman SR, Shim JK, Russ AJ. Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci*. 2006;61(4):S175-S184. doi:10.1093/geronb/61.4.S175
- Hussain JA, Flemming K, Murtagh FE, Johnson MJ. Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clin J Am Soc Nephrol*. 2015;10(7):1201-1215. doi:10.2215/CJN.11091114
- Ladin K, Lin N, Hahn E, Zhang G, Koch-Weser S, Weiner DE. Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions. *Nephrol Dial Transplant*. 2017;32(8):1394-1401.
- Song MK, Lin FC, Gilet CA, Arnold RM, Bridgman JC, Ward SE. Patient perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant*. 2013;28(11):2815-2823. doi:10.1093/ndt/gft238
- Wong SP, Hebert PL, Laundry RJ, et al. Decisions about renal replacement therapy in patients with advanced kidney disease in the US Department of Veterans Affairs, 2000-2011. *Clin J Am Soc Nephrol*. 2016;11(10):1825-1833. doi:10.2215/CJN.03760416
- Kurella Tamura M, Thomas IC, Montez-Rath ME, et al. Dialysis initiation and mortality among older veterans with kidney failure treated in Medicare vs the Department of Veterans Affairs. *JAMA Intern Med*. 2018;178(5):657-664. doi:10.1001/jamainternmed.2018.0411
- Salat H, Javier A, Siew ED, et al. Nephrology provider prognostic perceptions and care delivered to older adults with advanced kidney disease. *Clin J Am Soc Nephrol*. 2017;12(11):1762-1770. doi:10.2215/CJN.03830417
- Wong SPY, Yu MK, Green PK, Liu CF, Hebert PL, O'Hare AM. End-of-life care for patients with advanced kidney disease in the US Veterans Affairs Health Care System, 2000-2011. *Am J Kidney Dis*. 2018;72(1):42-49. doi:10.1053/j.ajkd.2017.11.007
- Hammond KW, Laundry RJ, O'Leary TM, Jones WP. Use of text search to effectively identify lifetime prevalence of suicide attempts among veterans. Presented at: 2013 46th Hawaii International Conference on System Sciences; January 7-10, 2013; Wailea, Hawaii.
- Krippendorff K. *Content Analysis: An Introduction to Its Methodology*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2013.
- Giacomini MK, Cook DJ; Evidence-Based Medicine Working Group. Users' guides to the medical literature, XXIII: qualitative research in health care A: are the results of the study valid? *JAMA*. 2000;284(3):357-362. doi:10.1001/jama.284.3.357
- Giacomini MK, Cook DJ; Evidence-Based Medicine Working Group. Users' guides to the medical literature, XXIII: qualitative research in health care B: what are the results and how do they help me care for my patients? *JAMA*. 2000;284(4):478-482. doi:10.1001/jama.284.4.478
- Ryan GW, Bernard HR. Techniques to identify themes. *Field Methods*. 2003;15:85-109. doi:10.1177/1525822X02239569



22. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
23. Foundation NK; National Kidney Foundation. KDOQI clinical practice guideline for hemodialysis adequacy: 2015 update. *Am J Kidney Dis*. 2015;66(5):884-930. doi:10.1053/j.ajkd.2015.07.015
24. KDIGO 2012 clinical practice guidelines for the evaluation and management of chronic kidney disease. *Kidney Int Suppl*. 2013;3(1):S1-S150.
25. Renal Physicians Association. *Shared Decision-Making in the Appropriate Initiation and Withdrawal From Dialysis*. Rockville, MD: Renal Physicians Association; 2010.
26. Grubbs V, Moss AH, Cohen LM, et al; Dialysis Advisory Group of the American Society of Nephrology. A palliative approach to dialysis care: a patient-centered transition to the end of life. *Clin J Am Soc Nephrol*. 2014;9(12):2203-2209. doi:10.2215/CJN.00650114
27. Parvez S, Abdel-Kader K, Pankratz VS, Song MK, Unruh M. Provider knowledge, attitudes, and practices surrounding conservative management for patients with advanced CKD. *Clin J Am Soc Nephrol*. 2016;11(5):812-820. doi:10.2215/CJN.07180715
28. Grubbs V, Tuot DS, Powe NR, O'Donoghue D, Chesla CA. System-level barriers and facilitators for foregoing or withdrawing dialysis: a qualitative study of nephrologists in the United States and England. *Am J Kidney Dis*. 2017;70(5):602-610. doi:10.1053/j.ajkd.2016.12.015
29. Ladin K, Pandya R, Kannam A, et al. Discussing conservative management with older patients with CKD: an interview study of nephrologists. *Am J Kidney Dis*. 2018;71(5):627-635. doi:10.1053/j.ajkd.2017.11.011
30. Okamoto I, Tonkin-Crine S, Rayner H, et al. Conservative care for ESRD in the United Kingdom: a national survey. *Clin J Am Soc Nephrol*. 2015;10(1):120-126. doi:10.2215/CJN.05000514
31. Tonkin-Crine S, Okamoto I, Leydon GM, et al. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *Am J Kidney Dis*. 2015;65(3):443-450. doi:10.1053/j.ajkd.2014.08.011
32. Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *Clin J Am Soc Nephrol*. 2015;10(2):260-268. doi:10.2215/CJN.03330414
33. Kwok AO, Yuen SK, Yong DS, Tse DM. The symptoms prevalence, medical interventions, and health care service needs for patients with end-stage renal disease in a renal palliative care program. *Am J Hosp Palliat Care*. 2016;33(10):952-958. doi:10.1177/1049909115598930
34. Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? a comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant*. 2007;22(7):1955-1962. doi:10.1093/ndt/gfm153
35. Smith C, Da Silva-Gane M, Chandna S, Warwicker P, Greenwood R, Farrington K. Choosing not to dialyze: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract*. 2003;95(2):c40-c46. doi:10.1159/000073708
36. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant*. 2011;26(5):1608-1614. doi:10.1093/ndt/gfq630
37. Verberne WR, Geers AB, Jellema WT, Vincent HH, van Delden JJ, Bos WJ. Comparative survival among older adults with advanced kidney disease managed conservatively versus with dialysis. *Clin J Am Soc Nephrol*. 2016;11(4):633-640. doi:10.2215/CJN.07510715
38. Shum CK, Tam KF, Chak WL, Chan TC, Mak YF, Chau KF. Outcomes in older adults with stage 5 chronic kidney disease: comparison of peritoneal dialysis and conservative management. *J Gerontol A Biol Sci Med Sci*. 2014;69(3):308-314. doi:10.1093/gerona/glt098
39. Da Silva-Gane M, Wellsted D, Greenshields H, Norton S, Chandna SM, Farrington K. Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clin J Am Soc Nephrol*. 2012;7(12):2002-2009. doi:10.2215/CJN.01130112
40. Yong DS, Kwok AO, Wong DM, Suen MH, Chen WT, Tse DM. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. *Palliat Med*. 2009;23(2):111-119. doi:10.1177/0269216308101099
41. Seow YY, Cheung YB, Qu LM, Yee AC. Trajectory of quality of life for poor prognosis stage 5D chronic kidney disease with and without dialysis. *Am J Nephrol*. 2013;37(3):231-238. doi:10.1159/000347220
42. United States Renal Data System. *Annual Data Report, Atlas of End Stage Renal Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institutes of Diabetes and Digestive and Kidney Diseases; 2017.
43. Scherer JS, Wright R, Blaum CS, Wall SP. Building an outpatient kidney palliative care clinical program. *J Pain Symptom Manage*. 2018;55(1):108-116. doi:10.1016/j.jpainsymman.2017.08.005

## Invited Commentary

## Active Medical Management for Patients With Advanced Kidney Disease

Keren Ladin, PhD, MSc; Alexander K. Smith, MD, MPH, MS

**Choosing a treatment** for older adults with advanced kidney disease has consequences. For many such patients, dialysis may confer limited survival benefit compared with conservative management, and often reduces quality of life and intensifies end-of-life care. A 2016 systematic review estimated the annual survival of elderly patients (>75 years) undergoing dialysis as 73.0%, compared with 70.6% for patients receiving conservative management.<sup>1</sup> Others have found no survival advantage among patients older than 80 years who choose dialysis rather than conservative management.<sup>2</sup> Nonetheless, many nephrologists in the United States do not present conservative management as an option for elderly patients with advanced kidney disease. Thus, few patients perceive the initiation of dialysis to be a choice.<sup>3</sup> Clinical guidelines have long called for shared decision making in the initiation of dialysis, as the decision is sensitive to patient

preferences. Although shared decision making is widely supported, it has not been widely adopted.

In this issue of *JAMA Internal Medicine*, Wong et al<sup>4</sup> examine care practices for patients with advanced kidney disease who forgo dialysis. Analyzing clinical encounters with 851 patients cared for in Department of Veterans Affairs medical centers, they found that shared decision making seldom occurred. Nephrologists did not consistently engage patients in decision making about initiation of dialysis. Instead, physicians relied on their intuition and clinical expertise in determining whether patients should pursue dialysis, even when this treatment directly contradicted preferences expressed by patients. This paternalistic approach is 1 of 4 approaches recently described regarding making decisions about dialysis.<sup>5</sup> In the context of making decisions about dialysis, paternalists typically view patient autonomy and the solicitation of patient values as less important than improving patient health