

Health Outcome Priorities of Older Adults with Advanced CKD and Concordance with Their Nephrology Providers' Perceptions

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ABSTRACT

Background Older adults with advanced CKD have significant pain, other symptoms, and disability. To help ensure that care is consistent with patients' values, nephrology providers should understand their patients' priorities when they make clinical recommendations.

Methods Patients aged ≥ 60 years with advanced (stage 4 or 5) non-dialysis-dependent CKD receiving care at a CKD clinic completed a validated health outcome prioritization tool to ascertain their health outcome priorities. For each patient, the nephrology provider completed the same health outcome prioritization tool. Patients also answered questions to self-rate their health and completed an end-of-life scenarios instrument. We examined the associations between priorities and self-reported health status and between priorities and acceptance of common end-of-life scenarios, and also measured concordance between patients' priorities and providers' perceptions of priorities.

Results Among 271 patients (median age 71 years), the top health outcome priority was maintaining independence (49%), followed by staying alive (35%), reducing pain (9%), and reducing other symptoms (6%). Nearly half of patients ranked staying alive as their third or fourth priority. There was no relationship between patients' self-rated health status and top priority, but acceptance of some end-of-life scenarios differed significantly between groups with different top priorities. Providers' perceptions about patients' top health outcome priorities were correct only 35% of the time. Patient-provider concordance for any individual health outcome ranking was similarly poor.

Conclusions Nearly half of older adults with advanced CKD ranked maintaining independence as their top health outcome priority. Almost as many ranked being alive as their last or second-to-last priority. Nephrology providers demonstrated limited knowledge of their patients' priorities.

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CKD, common in older adults,¹ is associated with multimorbidity,¹ decreased quality of life,^{2,3} and increased mortality.⁴ For older adults with CKD, death is more likely than progression to ESRD until very late in the disease course.⁵ In those whose CKD progresses to ESRD, maintenance dialysis initiation may contribute to disability^{6,7} and lower satisfaction

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with life⁸ and may not confer a substantial survival benefit.^{9–12} Moreover, patients with ESRD appear to receive high-quality end-of-life care less often than their counterparts with cancer, dementia, or other chronic illnesses.^{13,14} Given these findings, national nephrology organizations have advocated for a patient-centered approach to treatment decisions in advanced CKD.^{15,16} It remains unclear, however, whether nephrologists devote enough time to understanding their patients' values before making treatment recommendations to older adults with advanced CKD.^{17–19}

Advance care planning involves discussions between patients, the important people in their lives, and their clinicians about possible clinical trajectories and personal values in order to inform treatment decisions.²⁰ Older patients with advanced CKD and multimorbidity are likely to have lived experiences that have shaped their health outcome priorities, which might include control of pain and other symptoms, maximizing life expectancy or independence, or minimizing treatment burden for both themselves and their caregivers. In pursuit of these priorities, trade-offs are inevitable.²¹ Ideally, advance care planning conversations increase concordance between patients' health priorities and providers' perceptions of these priorities, because lack of concordance may drive care that is inconsistent with patients' values. Yet few studies have characterized patient health outcome priorities and concordance with their providers' perceptions of these priorities in CKD.

To that end, in this study we elicited the health outcome priorities of older adults with advanced non-dialysis-dependent CKD. We then examined the association between patients' priorities and self-reported health, as well as the association between priorities and acceptance of common end-of-life scenarios. Finally, we measured concordance between patients' priorities and providers' perceptions of these priorities and assessed patient-level predictors of concordance.

METHODS

Study Setting and Participants

We approached older adults (age ≥ 60 years) with non-dialysis-dependent CKD stages 4–5 who were seen in follow-up by a nephrology provider at an academic clinic in the southern United States from November of 2016 to January of 2018 to participate in research examining their health values and communication with their nephrology providers. As described in previous related studies,^{19,22} we excluded patients with dialysis dependence, prior kidney transplant, and possible AKI, as well as patients on their initial visit with a particular nephrology provider. In this clinic, it is the standard of care to refer patients for education in CKD and renal replacement options when they reach CKD stage 4.

Of 293 patients approached, 16 (5.5%) declined to participate and 6 (2.0%) found the health outcome prioritization measure distressing, asked to skip the assessment, and were therefore excluded from this analysis. We report results for the

Significance Statement

Although older adults with advanced CKD carry a substantial burden from symptoms and disability and often have to accept trade-offs in their treatment, little is known about these patients' health outcome priorities or their nephrology providers' perceptions of these priorities. This study found that more of these patients prioritize maintaining independence over staying alive. Furthermore, these priorities are associated with what patients would find acceptable toward the end of life. Nephrology providers, however, tend to show limited awareness of which health outcomes their individual patients value most. This discordance raises questions regarding nephrology providers' readiness to participate in patient-centered decision-making about initiation of maintenance dialysis and other medical interventions.

remaining 271 participants. We also enrolled nephrology providers who deliver outpatient CKD care at this clinic. All 13 attending physicians and one advanced practitioner at the clinic chose to participate. We obtained written informed consent from patients and providers. Patients were permitted to skip any measure. The Vanderbilt University Medical Center Institutional Review Board approved this study.

Health Outcome Prioritization

Before patients prioritized their health outcomes, the trained research staff (all physicians) asked several related questions to determine whether the patients had discussed their health values and priorities with a doctor in the past, how well they thought their caregivers knew their goals of care, and whether they had advance care planning documents. Patients then completed a previously validated health outcome prioritization tool.²¹ The four outcomes were (1) "maintaining independence"; (2) "keeping you alive"; (3) "reducing or eliminating pain"; and (4) "reducing or eliminating dizziness, fatigue, shortness of breath" (see Supplemental Material). We adapted the instrument script to a sixth-grade reading level but otherwise maintained its content and general format.

On the instrument, patients ranked the four health outcomes from highest to lowest priority using an enlarged visual analog scale (VAS), with 100 representing the highest priority and 0 the lowest priority. Patients could not rank two priorities equally. When patients were ranking pain and symptom relief, the staff asked them to imagine they were experiencing pain or symptoms at that moment. The staff then confirmed the patients' rankings by reporting back the order of priorities on the VAS and allowing the patients to make adjustments if necessary. Because the health outcome priorities demonstrated excellent reliability on prior testing but the VAS scores demonstrated substantial variation, we *a priori* chose to capture rank orderings only.²¹

Using the same VAS, the nephrology providers ranked a patient's health outcome priorities according to their perception of them immediately after the same visit in which the patient completed the study instruments. Providers could opt to respond that they had no insight on the patient's

priorities. To minimize biases, patients' priorities and providers' perceptions of those priorities were gathered after the completion of the clinic visit, so as not to prompt a discussion regarding priorities if it was not already planned, and providers were not allowed to view patient responses at any point during this study.

End-Of-Life Scenarios

We used a publicly available advance care planning workbook to capture patient preferences in common end-of-life scenarios.²³ Research staff introduced the material, spoke about the importance of understanding the patients' responses should their illness worsen, and asked patients to carefully consider their values and preferences when answering the items. Each item prompted the patients to judge whether they would find life in a described condition "difficult but acceptable," "worth living, but just barely," or "not worth living." The research staff reminded the patients to consider each of the described scenarios as permanent. Patients were permitted to respond "Can't answer now" if they were unable to provide a response or found the questions distressing. Patients could also skip items they found distressing, in which case the research staff would provide emotional support if the patients appeared upset. For data analysis, we chose to collapse the responses "difficult but acceptable" and "worth living, but just barely" into a single category, because both convey that the patient would find life worth living in that state.

Subjective Health

We assessed patients' self-rated health by asking, "In general, would you say your health is excellent, very good, good, fair, or poor?" The answer to this question has previously been shown to identify patients with CKD at high risk of disease progression and death.²⁴

Patient Characteristics and Other Measures

Upon enrollment, patients completed a brief questionnaire to collect information on sociodemographics and medical conditions. We also performed manual chart reviews and structured data abstraction to supplement this information with documented comorbidities and common clinical measurements (e.g., vital signs, lab values, etc.) from the prior 12 months. With information on comorbidities, we calculated a Charlson comorbidity index for each patient.²⁵

We measured independence in activities of daily living (ADLs) and instrumental ADLs with the Katz²⁶ and Lawton²⁷ indices, respectively. Scores on the Katz index range from 0 to 5, whereas Lawton index scores range from 0 to 8. On both scales, higher scores indicate greater independence. We used the Palliative care Outcome Scale Symptoms Renal to assess patient symptoms.²⁸ This self-administered questionnaire captures the presence and severity of 17 symptoms experienced over the prior week using a five-point scale ranging from "absent" (0) to "overwhelming" (4). The individual symptom scores are summed to generate a total score, ranging from 0 to 68.

Statistical Analyses

We present patients' characteristics as medians and interquartile ranges (IQR) for continuous variables and counts with percentages for categorical variables. We report all agreements as absolute agreement and weighted κ statistics with 95% confidence intervals (95% CIs). Absolute agreement occurred when the patient and provider assigned the same ranking to a specific priority. The degree of overall agreement between patients and providers for all priorities simultaneously was summarized with the weighted κ statistic using rank-difference weights. A weighted κ score of 1 indicates perfect agreement; 0 indicates the level of agreement expected by chance alone; a negative score indicates agreement worse than chance. We also calculated a weighted κ statistic for each specific priority by treating patients as a single rater and providers as a second rater. We analyzed summary measures of patient-provider concordance with a cumulative probability proportional odds model including patient age, sex, race, marital status, education, income, insurance, body mass index, and comorbidities. We tested the association between categorical variables with chi-squared statistics. *P* values of <0.05 are considered statistically significant. We performed all analyses using R (version 3.4.4).

RESULTS

A total of 271 patients, 45.4% women, with median age 71 years (IQR, 66–77), enrolled in the study (Table 1). The median eGFR at enrollment was 22.6 ml/min per 1.73 m² (IQR, 17.0–28.2) by the Modification of Diet in Renal Disease equation.²⁹ Almost half of patients had diabetes mellitus, whereas 43.2% had a history of cardiovascular disease, 24.4% had a history of heart failure, and 24.7% had a history of cancer.

Approximately half of patients (*n*=133; 49.1%) selected maintaining independence as their top health outcome priority (Figure 1, Supplemental Table 1), significantly more than the next most common choice, staying alive (*n*=96; 35.4%; *P*=0.002). Comparatively fewer patients chose reducing pain or reducing other symptoms as their top health outcome priority (9.2% and 6.3%, respectively). Notably, almost three-quarters of the patients (*n*=202; 74.5%) ranked maintaining independence as their first or second priority, and nearly half of the patients (*n*=132; 48.7%) ranked staying alive as their last or next to last priority (Supplemental Table 2). There was no significant relationship between patients' self-rated health and top priority ranking (*P*=0.33) (Table 2).

Patients' top health outcome priorities according to their acceptance of common end-of-life scenarios are shown in Table 3. In general, patients who prioritized maintaining independence were more likely to say life is not worth living (i.e., not acceptable) in the hypothetical scenarios. Specifically, top priority and scenario acceptance were associated for "No longer can think or talk clearly" (*P*<0.01), "No longer can respond to commands or requests" (*P*<0.01), "Are in severe

Table 1. Demographic and clinical characteristics of the patients

Characteristic	n=271
Age, yr	71 (66, 77)
Women	123 (45.4)
Race	
Black	50 (18.5)
Nonblack	221 (81.5) ^a
Marital status	
Married	175 (64.6)
Divorced	31 (11.4)
Widowed	48 (17.7)
Single/other	17 (6.3)
Highest education level	
Less than high school diploma	29 (10.7)
High school diploma or equivalent	68 (25.1)
Some college	59 (21.8)
College degree or higher	115 (42.4)
Yearly household income ^b	
<\$20,000	42 (15.5)
\$20,000–39,999	67 (24.7)
\$40,000–59,999	54 (19.9)
\$60,000–79,999	43 (15.9)
\$80,000–99,999	16 (5.9)
≥\$100,000	46 (17.0)
Insurance type	
Private	75 (27.7)
Medicaid/medical assistance	11 (4.1)
Medicare	185 (68.3)
ADL score	5 (5, 5)
iADL score	8 (7, 8)
POS-S Renal score	9 (5, 15)
eGFR, ml/min per 1.73 m ^{2c}	22.6 (17.0, 28.2)
BMI, kg/m ²	30.2 (25.9, 35.2)
Charlson comorbidity index	5 (3, 6)
Specific comorbidities	
Hypertension	265 (97.8)
Diabetes mellitus	134 (49.4)
Coronary artery disease	86 (31.7)
Cerebrovascular disease	50 (18.5)
Peripheral vascular disease	31 (11.4)
All cardiovascular disease	117 (43.2)
Heart failure	66 (24.4)
Cancer	67 (24.7)
Chronic lung disease	38 (14.0)

Continuous variables expressed as median (IQR); categorical variables expressed as n (%). iADL, instrumental ADLs; POS-S Renal, Palliative care Outcome Scale—Symptoms Renal; BMI, body mass index.

^a218 white, three other.

^b268 responses, because 3 (1.1%) declined to answer.

^cAs calculated using the Modification of Diet in Renal Disease Study equation.²⁹

discomfort most of the time” ($P=0.04$), “No longer can control your bladder or bowels” ($P=0.01$), “Live in a nursing home permanently” ($P=0.004$), and “Are an emotional or financial burden to family” ($P=0.001$). Although more patients whose top priority was maintaining independence reported that life would not be worth living if dependent on dialysis,

overall there was no significant relationship between top priority and acceptance of this scenario ($P=0.22$).

Nephrology providers’ perceptions of their patients’ top health outcome priorities were only correct in a minority of cases (35.2%; 95% CI, 29.7% to 41.2%) (Table 4), with an expected chance agreement of 25%. Notably, in 18.0% (95% CI, 11.9% to 24.7%) and 20.3% (95% CI, 14.2% to 27.0%) of cases, providers ranked the patient’s top priority as the perceived third or fourth priority, respectively. For top-ranked health outcome priority, the weighted Cohen’s κ for patient-provider concordance was 0.10 (95% CI, -0.21 to 0.40). The overall measure of patient-provider concordance considering each priority simultaneously yielded a weighted Cohen’s κ of 0.10 (95% CI, 0.04 to 0.15). Patient-provider concordance for any individual health outcome priority was similarly poor (weighted $\kappa < 0.1$ for all four health priorities at any rank; Table 5).

Although the 14 providers ranked health outcome priorities for variable numbers of patients, from as few as one patient to as many as 51 patients, nine providers assessed at least ten patients, and five providers assessed at least 25 patients. Even for the providers who saw the most patients, the highest weighted κ for any priority at any rank was 0.18, and all other weighted κ s were ≤ 0.1 (data not shown). No patient characteristic (including sociodemographics and comorbidities) was significantly associated with concordance in health outcome priority rankings (data not shown).

DISCUSSION

In this study, we found that nearly half of our cohort of older patients with non-dialysis-dependent advanced CKD ranked maintaining independence as their top health outcome priority, and almost as many ranked staying alive as their last or second-to-last priority. Yet their nephrology providers’ knowledge of their priorities was poor, and patients’ impression of their own health did not predict their top health outcome priority. These priorities appear to have important implications for advance care planning, because patients’ stated acceptance of many common end-of-life scenarios was significantly associated with their top health outcome priority.

Our study population’s ordering of top priorities (maintaining independence, staying alive, reducing pain, reducing other symptoms) mirrors that seen in the sample of older adults with multiple chronic diseases in whom the health outcome priorities tool was validated.²¹ Also identical in the two samples is the most common lowest priority of staying alive among those who ranked maintaining independence as their top priority. Approximately 70% of people in the health outcome priorities tool study, drawn from senior centers and a senior living facility, had four or more chronic conditions. Despite sample recruitment in different settings, the basic similarity in health outcome priorities in the two studies suggests that older age and multimorbidity likely drive health priorities more than any particular medical problem does.

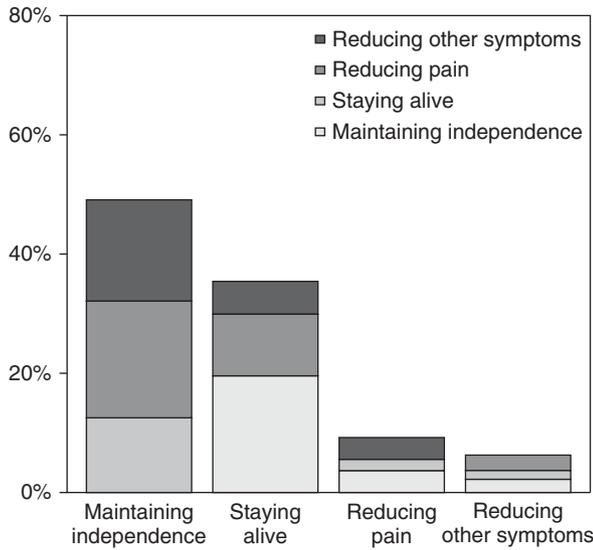


Figure 1. Patients' first and second choices for health outcome priorities. The proportion of patients who designated a particular outcome as first priority is displayed as a main bar; the proportion of those patients who designated a particular outcome as second priority is displayed as a sub-bar.

That many patients prioritized maintaining independence above all else is of particular interest in light of prior research suggesting that, among the elderly, initiation of maintenance dialysis is associated with worsening functional dependence,^{6,7} decline in executive function,³⁰ and prolonged periods spent in hospitals or skilled nursing facilities.³¹ Given the growing body of evidence showing that maintenance dialysis might not repair or even preserve the aspects of patients' lives most important to some of them, nephrologists must be aware of their patients' health outcome priorities to adequately counsel their older advanced CKD patients regarding the benefits and burdens of initiating maintenance dialysis. The lack of a significant relationship between top priority and acceptance of maintenance dialysis in our study perhaps speaks to patients' lack of education on likely trajectories after dialysis initiation and our somewhat limited sample size. Further data regarding symptom burden, quality of life, and survival with maintenance dialysis versus conservative management would aid United States nephrologists as they try to

tailor treatment recommendations to their patients' health outcome priorities.³²

Although some studies in patients with ESRD suggest that avoiding death is a lower priority than maximizing daily well-being,³³ the choice to forego maintenance dialysis in favor of conservative management of advanced CKD is uncommon in the United States. This apparent contradiction likely results from multiple factors, with low patient-provider concordance in health outcome priorities being one of them. Our findings reinforce previous research that has shown that patient-provider communication in the period leading up to maintenance dialysis initiation is suboptimal.³⁴⁻³⁷ In at least one study, many patients suspected that their nephrology providers might not have time for in-depth discussions,³⁷ and nephrologists have confirmed that they do not feel incentivized to engage in such discussions.³⁸ Moreover, effective communication about topics such as health outcome priorities requires training and, despite growing recognition of the need for such training, nephrology fellows in the United States report they are still not receiving enough of it.^{39,40} Communication skills training designed for nephrologists has demonstrated the potential to improve capabilities in this area⁴¹; whether it could increase patient-provider concordance in health outcome priorities remains to be seen. Although this study dealt with CKD patients not yet on dialysis, provider awareness of patient health outcome priorities remains pertinent even for patients who start maintenance dialysis. After a patient becomes acquainted with the lived experience of dialysis, perhaps in a time-limited trial, the conversation on whether to continue can center upon whether dialysis is helping to achieve a particular prioritized health outcome, and whether the patient's priorities are in fact evolving.⁴²

Along the same lines, a discussion of priorities should start but then not end the shared decision-making process. If the destination in such a process is the patient living and dying in circumstances that match his or her preferences as much as possible, then health outcome priorities should be viewed as guideposts toward that destination. At times, though, the patient's chosen path might not clearly follow those guideposts. In this study, even among patients who ranked maintaining independence as their top health outcome priority, when they had to provide specific preferences on a different instrument, 45%, 46%, and 29% responded that life would still be worth living if they required 24-hour care, permanently resided in a

Table 2. First-choice health outcome priority, according to self-rated health status

Self-Rated Health Status	Maintaining Independence (n=133)	Staying Alive (n=91)	Reducing Pain (n=25)	Reducing Other Symptoms (n=17)
Excellent (n=3)	2 (66.7)	1 (33.3)	0 (0)	0 (0)
Very good (n=39)	20 (51.3)	16 (41.0)	2 (5.1)	1 (2.6)
Good (n=100)	56 (56.0)	27 (27.0)	11 (11.0)	6 (6.0)
Fair (n=102)	46 (45.1)	34 (33.3)	12 (11.8)	10 (9.8)
Poor (n=22)	9 (40.9)	13 (59.1)	0 (0)	0 (0)

n=266 (five patients missing because they did not answer self-rated health question). Numbers expressed as n (%). Percentages are from row totals. Chi-squared test of overall association: P=0.18.

Table 3. First-choice health outcome priority and acceptance of common end-of-life scenarios

Common End-of-Life Scenario	Maintaining Independence (n=130)	Staying Alive (n=82)	Reducing Pain and Other Symptoms (n=42)	P ^a
No longer can recognize or interact with family or friends				0.19
Difficult, but acceptable/Worth living, but just barely	55 (42.3)	48 (58.5)	20 (47.6)	
Not worth living	55 (42.3)	24 (29.3)	14 (33.3)	
Can't answer now	20 (15.4)	10 (12.2)	8 (19.0)	
No longer can think or talk clearly				0.01
Difficult, but acceptable/Worth living, but just barely	59 (45.4)	52 (63.4)	22 (52.4)	
Not worth living	60 (46.2)	22 (26.8)	11 (26.2)	
Can't answer now	11 (8.5)	8 (9.8)	9 (21.4)	
No longer can respond to commands or requests				0.01
Difficult, but acceptable/Worth living, but just barely	46 (35.4)	46 (56.1)	18 (42.9)	
Not worth living	68 (52.3)	26 (31.7)	14 (33.3)	
Can't answer now	16 (12.3)	10 (12.2)	10 (23.8)	
No longer can walk but get around in a wheelchair ^b				0.28
Difficult, but acceptable/Worth living, but just barely	109 (84.5)	74 (90.2)	35 (83.3)	
Not worth living	10 (7.8)	1 (1.2)	2 (4.8)	
Can't answer now	10 (7.8)	7 (8.5)	5 (11.9)	
No longer can get outside and must spend all day at home				0.22
Difficult, but acceptable/Worth living, but just barely	108 (83.1)	75 (91.5)	34 (81.0)	
Not worth living	8 (6.2)	2 (2.4)	1 (2.4)	
Can't answer now	14 (10.8)	5 (6.1)	7 (16.7)	
Are in severe untreatable pain most of the time				0.14
Difficult, but acceptable/Worth living, but just barely	52 (40.0)	43 (52.4)	18 (42.9)	
Not worth living	62 (47.7)	25 (30.5)	16 (38.1)	
Can't answer now	16 (12.3)	14 (17.1)	8 (19.0)	
Are in severe discomfort most of the time (such as nausea, diarrhea) ^b				0.04
Difficult, but acceptable/Worth living, but just barely	73 (56.6)	59 (72.0)	23 (54.8)	
Not worth living	43 (33.3)	13 (15.9)	11 (26.2)	
Can't answer now	13 (10.1)	10 (12.2)	8 (19.0)	
Are on a kidney dialysis machine to keep you alive ^b				0.22
Difficult, but acceptable/Worth living, but just barely	77 (59.7)	61 (74.4)	28 (66.7)	
Not worth living	32 (24.8)	11 (13.4)	7 (16.7)	
Can't answer now	20 (15.5)	10 (12.2)	7 (16.7)	
Are on a breathing machine to keep you alive				0.18
Difficult, but acceptable/Worth living, but just barely	37 (28.5)	34 (41.5)	10 (23.8)	
Not worth living	76 (58.5)	37 (45.1)	24 (57.1)	
Can't answer now	17 (13.1)	11 (13.4)	8 (19.0)	
Need someone to take care of you 24 h a day				0.15
Difficult, but acceptable/Worth living, but just barely	59 (45.4)	52 (63.4)	23 (54.8)	
Not worth living	52 (40.0)	23 (28.0)	14 (33.3)	
Can't answer now	19 (14.6)	7 (8.5)	5 (11.9)	
No longer can control your bladder or bowels				0.01
Difficult, but acceptable/Worth living, but just barely	60 (46.2)	56 (68.3)	25 (59.5)	
Not worth living	51 (39.2)	15 (18.3)	10 (23.8)	
Can't answer now	19 (14.6)	11 (13.4)	7 (16.7)	
Live in a nursing home permanently				0.004
Difficult, but acceptable/Worth living, but just barely	60 (46.2)	59 (72.0)	20 (47.6)	
Not worth living	52 (40.0)	15 (18.3)	15 (35.7)	
Can't answer now	18 (13.8)	8 (9.8)	7 (16.7)	
Are an emotional or financial burden to family				0.001
Difficult, but acceptable/Worth living, but just barely	42 (32.3)	46 (56.1)	16 (38.1)	
Not worth living	69 (53.1)	21 (25.6)	16 (38.1)	
Can't answer now	19 (14.6)	15 (18.3)	10 (23.8)	

Numbers expressed as n (%). Total n=254 (17 of the 271 participants with health outcome priorities were enrolled before inclusion of the end-of-life scenarios tool), except where indicated.

^aTest of association between first priority and scenario responses. P value calculated using chi-squared test.

^bn=253.

Table 4. Patients' (columns) and their providers' (rows) first choices for health outcome priorities

Provider Choice	Patient Choice				Total
	Maintaining Independence	Staying Alive	Reducing Pain	Reducing Other Symptoms	
Maintaining independence	50 (18.5)	31 (11.4)	9 (3.3)	4 (1.5)	94 (34.7)
Staying alive	50 (18.5)	38 (14.0)	9 (3.3)	10 (3.7)	107 (39.5)
Reducing pain	15 (5.5)	9 (3.3)	3 (1.1)	2 (0.7)	29 (10.7)
Reducing other symptoms	12 (4.4)	15 (5.5)	3 (1.1)	1 (0.4)	31 (11.4)
Provider unsure	6 (2.2)	3 (1.1)	1 (0.4)	0 (0.0)	10 (3.7)
Total	133 (49.1)	96 (35.4)	25 (9.2)	17 (6.3)	271 (100)

Numbers expressed as n (%).

nursing home, or were dependent on a breathing machine to stay alive, respectively. Many observers would say that patients in such conditions could not be considered independent. One possibility is that terms such as “maintaining independence” and “24-hour care” mean different things to different people. For example, some individuals are accustomed to extensive assistance with instrumental ADLs not because of poor health but because of family habits; they may see themselves as independent despite the presence of a family caregiver nearly around the clock. It seems more likely, however, that as in other areas of life, people do not always make choices that are consistent with their stated priorities. In such cases, the poor concordance between patients' health outcome priorities and their nephrology providers' perceptions of such is hardly surprising. Rather than finding frustration in this inconsistency, we would suggest that providers forge ahead in the shared decision-making process, asking whether the priorities serving as guideposts are really the ones pointing to the patient's preferred destination, and then selecting new guideposts and paths as needed.

Our study had several strengths. First, patient and provider participation rates were high, limiting selection bias, and the number of patients enrolled was relatively large compared with other published research on this subject. Second, the health outcome prioritization tool we used was specifically developed for older adults with multimorbidity, and the patient-based subjective health assessment measure we used has demonstrated predictive validity in the CKD population.²⁴ Third, we specifically targeted older patients with advanced stages of CKD, for whom the process of health outcome prioritization is most pressing and for whom evidence suggests the likely stability of end-of-life preferences over time and with changes in health status.⁴³

We also acknowledge several limitations. First, this was a single-center study of a clinic population with a relatively high

level of educational attainment, perhaps limiting generalizability. Second, the clinical implications of the limited concordance between patients and providers in health outcome priorities require further investigation. Although studies examining end-of-life care in advanced CKD indicate that patients may receive care that is not consistent with their stated values and preferences, it remains to be seen whether improving concordance would improve the quality of end-of-life care. Third, our study dealt with only patients, not their surrogates, even though it is surrogates who are often tasked with making the weightiest decisions toward the end of life. Fourth, older patients with advanced CKD frequently have cognitive impairment, which may have limited patients' ability to understand and respond to the health outcome prioritization tool. Notably, however, the presence of dementia in our patient sample was quite low (data not shown). Finally, patients' responses to hypothetical situations may not reflect how they would respond to the same situation in real life. Advance care planning exercises, including the ones described in this cross-sectional study, must be paired with longitudinal studies to assess the durability of preferences over time and through crises. Although many United States nephrology providers express skepticism that patients who initially voice a preference to forego dialysis will maintain that preference as they get sicker, data from other Western countries suggest durability of this preference.^{10,11} We do acknowledge that ever-changing cultural norms influence these decisions, though.

Taken together, the findings from this study raise the possibility that engaging older adults with advanced CKD in an explicit health outcome prioritization process might enrich their nephrology providers' understanding of what matters most to them, enhancing the care experience for patients and providers alike.

Table 5. Absolute agreement and weighted κ values for patient-provider concordance for health outcome priorities

Health Outcome Priority	Absolute Agreement, % (95% CI)	Weighted κ^a (95% CI)
Maintaining independence	31 (26 to 37)	-0.02 (-0.23 to 0.19)
Staying alive	26 (21 to 31)	0.01 (-0.20 to 0.21)
Reducing pain	30 (24 to 35)	0.01 (-0.18 to 0.20)
Reducing other symptoms	27 (22 to 33)	-0.07 (-0.47 to 0.32)

^aCalculated by treating patients as one rater and providers as another rater.

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A poster presenting these findings will be presented at the American Society of Nephrology Kidney Week, October 23–28, 2018 in San Diego, California.

H.S. and K.A.-K. designed the study; N.N.M., H.S., and K.A.-K. collected the data; A.B. and T.G.S. analyzed the data; all authors participated in data interpretation; S.J.R. and K.A.-K. drafted the manuscript; S.J.R., C.R.-C., E.D.S., A.B., T.G.S., M.H.E.-S., L.L., T.A.I., and K.A.-K. revised the manuscript; all authors approved the final version of the manuscript.

DISCLOSURES

None.

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SUPPLEMENTAL MATERIAL

Health outcome prioritization tool script.

Supplemental Table 1. Demographic and clinical characteristics of the patients by first-choice health outcome priority.

Supplemental Table 2. All choices for health outcome priorities.

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SUPPLEMENTAL MATERIAL

Contents:

- 1) Health outcome prioritization tool script
- 2) Supplemental Table 1. Demographic and clinical characteristics of the patients by 1st-choice health outcome priority
- 3) Supplemental Table 2. All choices for health outcome priorities

HEALTH OUTCOME PRIORITIZATION TOOL SCRIPT

There are times when we can't get everything we want. A trade-off is when you have to give up one thing to get another. When a doctor is trying to treat you they have four goals:

- 1) **Keeping you alive**
- 2) **Maintaining independence (i.e., able to do your daily activities without help)**
- 3) **Reducing or getting rid of pain**
- 4) **Reducing or getting rid of symptoms (can fill in our symptoms)**

I'd like you to think about the importance of each of these goals. Think of a situation when your doctor can't give you all of those goals at the same time. You will have to choose the most important.

I'd like you to tell me where you would put each box on the scale of 0 to 100. The higher you put the box, the more important that goal is to you. The only rule is that you can't put two boxes on the same number (i.e., on top of each other). For the goals of reducing or getting rid of pain and other symptoms, I want you to think about what would be most important to you **if you were having pain or feeling symptoms** now.

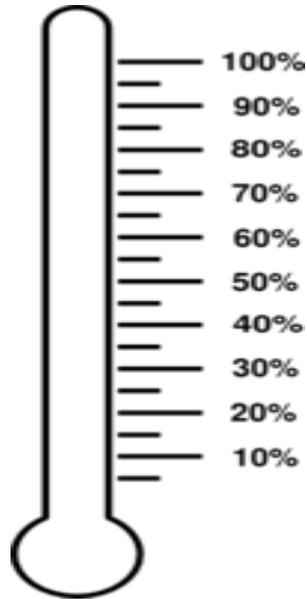
By picking one of the goals as most important, it means you would be ok giving up some of the others. For example, if you choose, **"Keeping you alive" as most important, it means you can accept not being able to do some of your everyday activities by yourself and having more symptoms and pain in order to live longer.**

If you choose **"Maintaining independence," it means you can accept a shorter life and more symptoms in order to keep your ability to do your everyday activities by yourself.**

If you choose **"Reducing / getting rid of symptoms" or "pain" as most important, it means you can accept not being able to do some of your everyday activities by yourself and a shorter life to be free of symptoms or pain.**

How far up or down you put the box shows how much you would give up (i.e., trade-off) one thing to have more of another. Take your time with this. You can move the boxes after you have placed them. Do you have any questions? Let's begin.

Health Outcome Prioritization VAS (minature sample)



Laminated boxes with each health priority were placed onto an enlarged VAS thermometer by the patient.

Supplemental Table 1. Demographic and clinical characteristics of the patients by 1st-choice health outcome priority

	Maintaining independence (n=133)	Staying alive (n=96)	Reducing pain (n=25)	Reducing other symptoms (n=17)	P*
Age, years	73 (67, 78)	70 (66, 76)	69 (65, 77)	67 (65, 75)	0.19
Women	58 (43.6)	45 (46.9)	13 (52.0)	7 (41.2)	0.85
Race					0.98
Black	23 (17.3)	19 (19.8)	5 (20.0)	3 (17.6)	
Non-black**	110 (82.7)	77 (80.2)	20 (80.0)	14 (82.4)	
Marital status					0.87
Married	82 (61.7)	66 (68.8)	16 (64.0)	11 (64.7)	
Divorced	17 (12.8)	9 (9.4)	3 (12.0)	2 (11.8)	
Widowed	28 (21.1)	12 (12.5)	5 (20.0)	3 (17.6)	
Single / other	6 (4.5)	9 (9.4)	1 (4.0)	1 (5.9)	
Highest education level					0.52
Less than high school diploma	12 (9.0)	14 (14.6)	1 (4.0)	2 (11.8)	
High school diploma or equivalent	33 (24.8)	23 (24.0)	7 (28.0)	5 (29.4)	
Some college	25 (18.8)	22 (22.9)	8 (32.0)	4 (23.5)	
College degree or higher	63 (47.4)	37 (38.5)	9 (36.0)	6 (35.3)	
Yearly household income***					0.17
Less than \$20,000	17 (13.0)	18 (18.8)	3 (12.0)	4 (23.5)	
\$20,000-39,999	37 (27.8)	20 (20.8)	3 (12.0)	7 (41.2)	
\$40,000-59,999	25 (18.8)	21 (21.9)	8 (32.0)	0 (0.0)	
\$60,000-79,999	19 (14.3)	12 (12.5)	9 (36.0)	3 (17.6)	
\$80,000-99,999	8 (6.0)	8 (8.3)	0 (0.0)	0 (0.0)	
\$100,000 and above	25 (18.8)	16 (16.7)	2 (8.0)	3 (17.6)	
Insurance type					0.12
Private	35 (26.3)	28 (29.2)	9 (36.0)	3 (17.6)	
Medicaid / medical assistance	2 (1.5)	8 (8.3)	0 (0.0)	1 (5.9)	
Medicare	96 (72.2)	60 (62.5)	16 (64.0)	13 (76.5)	
ADL score	5 (5, 5)	5 (5, 5)	5 (5, 5)	5 (5, 5)	0.08
iADL score	8 (8, 8)	8 (7, 8)	8 (5, 8)	8 (7, 8)	0.05
POS-S Renal score	9.5 (5, 15)	8 (4, 14)	8 (4, 17)	9 (6, 21)	0.52
eGFR, mL/min/1.73 m ² ****	22.3 (16.9, 27.9)	23.5 (17.7, 28.2)	24.1 (17.3, 29.0)	19.7 (12.6, 25.0)	0.33
BMI, kg/m ²	29.4 (25.4, 35.2)	30.2 (26.9, 34.9)	31.0 (26.6, 36.1)	29.1 (27.8, 34.5)	0.69
Charlson Comorbidity Index	4 (3, 6)	5 (3, 6)	5 (4, 6)	5 (4, 6)	0.58
Specific comorbidities					
Hypertension	131 (98.5)	95 (99.0)	23 (92.0)	16 (94.1)	0.12
Diabetes mellitus	65 (48.9)	47 (49.0)	12 (48.0)	10 (58.8)	0.89
Coronary artery disease	44 (33.1)	28 (29.2)	7 (28.0)	7 (41.2)	0.74
Cerebrovascular disease	29 (21.8)	13 (13.5)	5 (20.0)	3 (17.6)	0.46
Peripheral vascular disease	19 (14.3)	8 (8.3)	2 (8.0)	2 (11.8)	0.52
All cardiovascular disease	64 (48.1)	35 (36.5)	8 (32.0)	10 (58.8)	0.11
Heart failure	33 (24.8)	22 (22.9)	7 (28.0)	4 (23.5)	0.96
Cancer	34 (25.6)	22 (22.9)	9 (36.0)	2 (11.8)	0.33
Chronic lung disease	14 (10.5)	18 (18.8)	3 (12.0)	3 (17.6)	0.33

Continuous variables expressed as median (interquartile range); categorical variables expressed as *n* (%). ADL, activities of daily living. iADL, instrumental activities of daily living. POS-S Renal, Palliative Care Outcome Scale-Symptoms Renal. eGFR, estimated glomerular filtration rate. BMI, body mass index.

Total percentages may not add up to 100 because of rounding.

**P*-value calculated using ANOVA for continuous variables and chi-square test for categorical variables.

**218 white, 3 other.

***268 responses, as 2 patients who ranked maintaining independence first and 1 patient who ranked staying alive first declined to answer.

****As calculated using the Modification of Diet in Renal Disease Study equation.²⁹

Supplemental Table 2. All choices for health outcome priorities

1 st choice	2 nd choice	3 rd choice	4 th choice	n (%)
Maintaining independence (n=133)	Reducing pain	Reducing other symptoms	Staying alive	30 (11.1)
		Staying alive	Reducing other symptoms	23 (8.5)
	Reducing other symptoms	Reducing pain	Staying alive	33 (12.2)
		Staying alive	Reducing pain	13 (4.8)
	Staying alive	Reducing other symptoms	Reducing pain	19 (7.0)
		Reducing pain	Reducing other symptoms	15 (5.5)
Staying alive (n=96)	Maintaining independence	Reducing other symptoms	Reducing pain	27 (10.0)
		Reducing pain	Reducing other symptoms	26 (9.6)
	Reducing pain	Reducing other symptoms	Maintaining independence	17 (6.3)
		Maintaining independence	Reducing other symptoms	11 (4.1)
	Reducing other symptoms	Maintaining independence	Reducing pain	8 (3.0)
		Reducing pain	Maintaining independence	7 (2.6)
Reducing pain (n=25)	Maintaining independence	Reducing other symptoms	Staying alive	9 (3.3)
		Staying alive	Reducing other symptoms	1 (0.4)
	Reducing other symptoms	Maintaining independence	Staying alive	6 (2.2)
		Staying alive	Maintaining independence	4 (1.5)
	Staying alive	Reducing other symptoms	Maintaining independence	3 (1.1)
		Maintaining independence	Reducing other symptoms	2 (0.7)
Reducing other symptoms (n=17)	Maintaining independence	Reducing pain	Staying alive	6 (2.2)
		Staying alive	Reducing pain	0 (0.0)
	Reducing pain	Maintaining independence	Staying alive	6 (2.2)
		Staying alive	Maintaining independence	1 (0.4)
	Staying alive	Maintaining independence	Reducing pain	4 (1.5)
		Reducing pain	Maintaining independence	0 (0.0)

All percentages are of sample total, n=271. Total percentage does not add up to 100 because of rounding.

SIGNIFICANCE STATEMENT

Although older adults with advanced CKD carry a substantial burden from symptoms and disability and often have to accept trade-offs in their treatment, little is known about these patients' health outcome priorities or their nephrology providers' perceptions of these priorities. This study found that more of these patients prioritize maintaining independence than staying alive. Furthermore, these priorities are associated with what patients would find acceptable toward the end of life. Nephrology providers, however, tend to show limited awareness of which health outcomes their individual patients value most. This discordance raises questions regarding nephrology providers' readiness to participate in patient-centered decision-making about initiation of maintenance dialysis and other medical interventions.