

Research Priorities for Palliative Care for Older Adults with Advanced Chronic Kidney Disease

Ann M. O'Hare, MD, MA,¹ Mi-Kyung Song, PhD, RN, FAAN,²
Manjula Kurella Tamura, MD, MPH,³ and Alvin H. Moss, MD⁴

Abstract

Older adults with advanced chronic kidney disease (CKD) often have multiple comorbid conditions, a high symptom burden, and limited life expectancy. There is mounting concern that the intensive patterns of care that many of these patients receive at the end of life are discordant with their values and preferences. The nephrology community has recognized that there are significant unmet palliative care needs in this population.

In this article, we identify three broad areas of knowledge deficit where more evidence is needed to support the “best care possible” for this population: (1) what matters most to older adults with advanced CKD and their caregivers near the end of life; (2) how the nephrology community can best support older adults with advanced CKD to navigate complex treatment decisions throughout their illness; and (3) how the healthcare system should be reconfigured to promote patient- and family-centered care for older adults with advanced CKD.

Research priorities include identifying opportunities for improving the end-of-life experience of older adults with CKD and their caregivers; developing and testing communication interventions before and during dialysis to ensure that treatment decisions reflect patients' preferences; and assessing the effectiveness of palliative care in improving quality of life for patients and caregivers, satisfaction with care, and aligning treatment decisions with patient goals and preferences.

Keywords: chronic kidney disease; geriatric chronic illness; geriatric palliative care; nephrology; palliative care research

Outline of the Scope of the Problem

OLDER ADULTS with advanced chronic kidney disease (CKD) often have multiple other comorbid conditions and a limited life expectancy, and report a high symptom burden comparable to that of patients with terminal cancer.^{1–3} As their illness progresses, many face complex treatment decisions about whether and when to accept treatments that might extend life, and there is growing concern that the intensive patterns of care (e.g., intensive care unit admission) that many of these patients go on to receive at the end of life might not reflect their values and preferences.⁴

Despite ongoing efforts to improve quality of care for patients with advanced CKD, these patients continue to experience substantial physical, emotional, and spiritual suffering.¹ Contemporary approaches to care tend to focus on

optimizing disease management, and most providers are not trained to address the broad range of palliative care needs of these patients and their caregivers.^{5,6} Patients with complex comorbidity and functional limitations often face competing health priorities and may not be optimally served by care models that focus on managing a single health condition.^{7–9} Evidence is needed to improve current clinical practice to ensure that care is aligned with what matters most to older adults with advanced CKD and their caregivers, so that they can receive the “best care possible.”^{10,11}

Summary of the Current Evidence

In this article, we identify three broad priority areas for which we summarize currently available evidence, describe knowledge gaps, and propose research priorities. Priority

¹Department of Medicine, University of Washington and Veterans Affairs Puget Sound Healthcare System, Seattle, Washington.

²Center for Nursing Excellence in Palliative Care, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia.

³VA Palo Alto Geriatric Research and Education Clinical Center, Palo Alto, California.

⁴Sections of Nephrology and Supportive Care, West Virginia University School of Medicine, Morgantown, West Virginia.

Accepted December 6, 2016.

areas include the following: (1) what matters most to older adults with advanced CKD near the end of life and their caregivers; (2) how the nephrology community can best help the patients navigate complex treatment decisions during the course of illness; and (3) how the healthcare system should be reconfigured to promote patient- and family-centered care for this population.

What matters most to older adults with advanced CKD and those who care for them near the end of life?

During the final months of life, many older patients treated with dialysis receive intensive patterns of care intended to lengthen life and address disease complications (e.g., mechanical ventilation and vasopressors).^{4,12,13} The extent to which these intensive patterns of end-of-life care support the goals and reflect the values and preferences of individual older adults with advanced CKD is uncertain.

Little is known about what matters most to those who care for older adults with advanced CKD. In this article, we use the term caregiver broadly to describe those individuals who have a range of relationships and roles, including paid or formal caregivers, but also family members, friends, colleagues, neighbors, and others who may provide support for an older adult with advanced CKD. In the general population, it is often these individuals rather than the patients themselves, who, as surrogate decision makers, are responsible for most of the critical treatment decisions that arise toward the end of life.^{14,15} Few studies to date have described the experiences and perspectives of caregivers for patients with advanced CKD. Survey data suggest that despite sizeable differences in end-of-life care practices for patients with end-stage renal disease (ESRD), the quality of care as judged by bereaved family members was remarkably similar to that for patients with other forms of organ failure and frailty, although somewhat worse than for patients with cancer and dementia. Similarities in the quality of end-of-life care between patients with ESRD and those with other forms of organ failure perhaps suggest that the challenges of caring for patients with serious illness as they approach the end of life transcend boundaries between disease processes and care models,⁴ or perhaps, current instruments for assessing quality of end-of-life care fail to fully capture differences in the end-of-life experience of patients with different conditions and those who care for them. More detailed qualitative work will be needed to better understand the end-of-life experience of older adults with advanced CKD and their caregivers. To date, few qualitative studies have addressed this area broadly.¹⁶ Most prior qualitative work among caregivers has been limited to specific treatments or situations where they tend to be most heavily involved such as home dialysis; conservative, nondialytic care; and dialysis discontinuation.^{4,16–26}

To better align the evidence base with the priorities of patients, there is growing interest in engaging patients and their caregivers in all aspects of the research enterprise. A few groups have engaged patients with CKD and their caregivers in setting research goals^{19,27–29} and designing research protocols.^{30–33} Several key elements of palliative care have been identified as priority areas for research (communication with providers, management of symptoms, and psychosocial impact of kidney failure) in these efforts (Table 1).^{19,27–29} The recent international KDIGO (Kidney

Disease Improving Global Outcomes) Controversies Conference on Supportive Care in CKD has identified knowledge gaps and set research priorities for palliative care for patients with kidney disease.³⁴ However, this effort did not explicitly involve patients with advanced CKD and their family members, nor did it focus specifically on older adults with advanced CKD. To date, we know relatively little about what elements of palliative care older adults with advanced CKD and their caregivers see as most worthy of study and how research might be most responsive to their concerns and promote better patient-centered outcomes.

How can the nephrology community best help older adults with advanced CKD and their caregivers navigate complex treatment decisions throughout their illness trajectories?

Choosing dialysis or comprehensive conservative care (hereinafter means medical management of symptoms and signs of advanced kidney disease without dialysis) can be a challenging decision for patients with advanced CKD and those who care for them. While clinical guidelines have been developed to help guide decision making about kidney transplantation or dialysis initiation or withdrawal,^{35,36} most are intended to support clinicians rather than patients. Few studies have focused on interventions intended to help patients with advanced CKD make decisions about whether and when to initiate dialysis.^{37–40} The lack of decision aids or other types of interventions to guide decisions about dialysis is problematic because dialysis initiation has become increasingly common among older adults over the past decades, despite concerns that dialysis may not restore health or prolong life in older adults with a high burden of comorbidity and functional limitation.^{41,42} Although shared decision making has been promoted as an ideal framework for providers to involve patients with CKD and their caregivers in treatment decision making,³⁵ evidence suggests that shared decision making is poorly integrated into the clinical care of patients with CKD, dialysis initiation may be presented to patients more as a necessity than as a choice, and patients and their family members may have little input into these decisions.^{10,43} This appears to be especially true for older adults.^{44,45}

Although more than one in four patients ultimately discontinue dialysis treatments before death,⁴⁶ this possibility is very rarely (<6%) discussed with patients and their families at the time of dialysis initiation or in enough time to consider alternatives such as hospice or dying at home.^{47–50} In a study of over 530 patients receiving maintenance dialysis, only 19% indicated that they would want to continue dialysis if they were to become severely cognitively or functionally impaired, and 65% stated that they would prefer to die at home or in hospice rather than in a hospital.⁵¹ Yet a substantial number of dialysis patients die in the hospital.^{41,42,46} Although advance care planning (ACP) is a central tenet of caring for patients with a serious illness,³⁵ most dialysis patients report never engaging in ACP discussions with their care providers.^{52,53} A recent systematic review of ACP for adults with CKD⁵⁴ indicates that very few studies have tested interventions to enhance ACP or have evaluated the effect of ACP on downstream patient and caregiver outcomes. Despite interest from funding agencies in testing the effectiveness and efficacy of interventions to promote ACP,⁵⁵ there is a

TABLE 1. RECOMMENDATIONS FOR RESEARCH PRIORITIES FOR PALLIATIVE CARE FOR OLDER PATIENTS WITH ADVANCED CHRONIC KIDNEY DISEASE

<i>Research priority</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Study design</i>
What matters most to older adults with CKD and caregivers at the end of life?	To describe the end-of-life experience of older adults with advanced CKD and identify opportunities for improvement	Real-world settings, dialysis centers and outpatient CKD clinics	Older adults with advanced CKD; their bereaved caregivers	Longitudinal descriptive studies, either qualitative or quantitative (survey); case-control cohort studies
	To describe the experiences of caregivers of older adults with advanced CKD in engagement in directing care?	Real-world clinical settings, dialysis centers and outpatient CKD clinics	Informal caregivers (e.g., family members, friends) of older adults with advanced CKD	Longitudinal descriptive studies, either qualitative or quantitative (survey); case-control cohort studies
	To understand the research priorities of older adults with advanced kidney disease and their caregivers	Real-world clinical settings, dialysis centers and outpatient CKD clinics	Older adults with advanced kidney disease and their caregivers	Qualitative; quantitative (surveys)
Identifying effective approaches to support older adults and their caregivers during RRT decision making	Develop and test interventions to support patients and caregivers during RRT decision making	Outpatient centers, including the dialysis centers and the primary doctor's office Inpatient care settings	Older adults with advanced CKD with multiple chronic conditions and their caregivers; Older adults with multiple chronic conditions who develop renal failure as a complication	Traditional randomized controlled trials; center-level or provider-level cluster randomized trials; pragmatic trials
Develop effective ACP interventions to improve end-of-life care for older adults and their caregivers	Examine the effects of ACP interventions in outcomes of patients and their caregivers, including care concordant with the patient's preferences and post-bereavement outcomes Examine approaches to implementing efficacious ACP interventions in clinical practice	Outpatient centers, including dialysis centers and the primary doctor's office	Older adults with advanced CKD with multiple chronic conditions and their caregivers	Traditional randomized controlled trials; center-level or provider-level cluster randomized trials; pragmatic trials; effectiveness implementation hybrid designs
Reconfiguring the healthcare system	Symptom management strategies	Outpatient clinic and dialysis center	Older adults with advanced CKD and high symptom burden	Traditional RCT of specific pharmacologic or nonpharmacologic interventions Cluster RCT at center or provider level of comparing symptom management strategies

(continued)

TABLE 1. (CONTINUED)

<i>Research priority</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Study design</i>
	Effectiveness of different strategies for delivering palliative care	Outpatient and inpatient	Older adults with advanced CKD and high symptom burden and/or poor predicted prognosis	RCT of palliative care as add on to usual care or comparing different approaches to delivering palliative care
	Effectiveness of different payment models or pay-for-performance incentives on uptake of palliative care	Outpatient dialysis center	Patients receiving dialysis	Cluster RCT or matched case-control study
	Effectiveness of concurrent hospice and dialysis	Outpatient dialysis center	Patients receiving dialysis with poor predicted prognosis	Cluster RCT or matched case-control study
	Outcomes of comprehensive conservative care	Outpatient	Patients with advanced CKD and poor predicted prognosis	Observational cohort

CKD, chronic kidney disease; RRT, renal replacement therapy; ACP, advance care planning; RCT, randomized controlled trial.

very limited repertoire of ACP interventions proven to be efficacious in patients with CKD.^{56,57} Available data indicate that ACP can be conducted in the dialysis center setting by trained staff or peer mentors and can improve a range of psychosocial outcomes for dialysis patients and their surrogates, including family bereavement outcomes.

Clinical guidelines recommend that providers incorporate prognostic information into the care of older adults with advanced CKD, including shared decision making around the initiation and withdrawal of dialysis. Several studies have validated prognostic scores for predicting mortality in patients receiving dialysis.^{58–60} Others have validated prognostic scores for predicting progression to treated ESRD among adults with CKD.^{61,62} Three studies utilized prognostic information to identify patients receiving dialysis for an ACP intervention.^{57,63,64} To our knowledge, there are no prognostic instruments that have been validated among patients with advanced CKD not yet on dialysis. While the availability of prognostic information is important in supporting shared decision making, there will likely always be some element of uncertainty around estimates from prognostic models when applied to individual patients. More work is therefore needed to understand how to incorporate information uncertainty into prognostic estimates, communicate this information to patients and their families, and integrate this information into the shared decision-making process.⁶⁵

How should the healthcare system be reconfigured to promote patient- and family-centered care for older adults with advanced CKD?

Symptom management is a key priority identified by patients with CKD,²⁷ yet there is limited information about the efficacy of pharmacologic treatments for common symptoms in patients with CKD as most studies have been underpowered and/or did not address global symptom burden. Nonpharmacologic in-

terventions (e.g., mind-body interventions) may be especially appealing for older adults with advanced CKD as polypharmacy is common in this population, but these approaches have been understudied. In addition to limited evidence regarding the efficacy of pharmacologic and nonpharmacologic interventions to treat specific symptoms, it is also unclear how the information provided by symptom assessment tools should be optimally incorporated into clinical practice.

Because patients who receive dialysis spend a large portion of their time at the dialysis center, it is possible that the delivery of palliative care services during dialysis visits could address their unmet needs without adding to patients' travel burden. This approach has been taken for delivering specific elements of palliative care such as ACP or symptom management, although, to our knowledge, there are no reports of a more comprehensive coordinated approach to the delivery of palliative care services within the dialysis center. To integrate palliative care services into the provision of dialysis care, several barriers would need to be addressed. Due to a shortage of palliative care specialists and their uneven geographic distribution,⁶⁶ dialysis professionals (e.g., physicians, nurses, social workers, dietitians, and technicians), would require additional education and resources to be able to deliver high-quality primary palliative care ("primary palliative care"). To facilitate the delivery of primary palliative care in dialysis centers, "best practice" approaches for identifying patients most likely to benefit, engaging patients in ACP in a timely manner, and addressing care needs at end of life need to be defined.⁶ Alternative models for delivering palliative care to patients with ESRD, such as outpatient consultative palliative care and inpatient palliative care, have not been well studied.

Comprehensive conservative care is a viable treatment option for older adults with symptomatic advanced CKD who prefer not to initiate dialysis.³⁴ However, conservative care is rarely offered in the United States unlike other countries, such

as United Kingdom and Canada, where conservative care pathways are firmly established.^{67,68} Limited data suggest that symptom experiences and quality of life among patients receiving comprehensive conservative care are no worse than those of patients on dialysis. However, these data come exclusively from studies conducted outside where healthcare systems and the cultural context may differ substantially from the United States, and most of these studies had no comparison groups to provide high-quality evidence.⁶⁹

CMS has partnered with dialysis providers to test the effectiveness of a new payment and service delivery model, the Comprehensive ESRD Care (CEC) Model, intended to provide more patient-centered care.⁷⁰ In the current model of care, the ESRD prospective payment system, dialysis centers receive a per-treatment payment, which “bundles” dialysis services, including laboratories, drugs, and equipment related to dialysis care.⁷¹ The CEC Model seeks to create incentives to enhance care coordination and create a person-centered, coordinated care experience, intended to ultimately improve health outcomes.^{70,72} The model encourages dialysis centers, nephrologists, and other providers to join together in an ESRD Seamless Care Organization (ESCO), akin to an Accountable Care Organization, eligible to receive shared savings payments and liable for shared losses. An earlier iteration of this model found that rates of advance directive completion could be increased, although the effect on care near the end of life was not examined.⁷³

The ESRD quality incentive program (QIP) is a pay-for-performance initiative in which dialysis centers are incentivized to meet or exceed performance standards established by CMS. Current QIP measures have been criticized because they are disease oriented and often laboratory based.⁷⁴ Two types of metrics are eligible for inclusion in the QIP—reporting measures, which are process measures such as the percent of patients who were referred for transplant evaluation, and clinical measures, which are outcome measures, such as 30-day re-

hospitalization rates. Proposed patient-centric reporting metrics include the documentation of patient quality of life, patient satisfaction, regular symptom assessments, ACP, medication reconciliation, and measures of care coordination.⁷⁴ At present, no patient-centered clinical outcome measures have been suggested for inclusion in the QIP, in large part, because there is limited evidence to support the effect of interventions on patient-centered outcomes.

While a large number of patients receiving dialysis have limited life expectancy, for Medicare beneficiaries who are receiving dialysis, access to hospice care is largely limited to patients who have a second life-limiting diagnosis (e.g., cancer). For those for whom ESRD is the life-limiting diagnosis, hospice care is usually only accessed after discontinuing dialysis (because the cost of paying for dialysis is prohibitive for most hospices). Consequently, for most patients with ESRD, hospice care is limited to the final few days of life, a time frame generally considered insufficient to optimize end-of-life care.⁷⁵

Outline of Knowledge Gaps

Future research should focus on understanding the values, preferences, and goals of older adults with advanced CKD and the extent to which these are addressed by current practices (Table 2). Specifically, detailed data on the end-of-life experience of older adults with advanced CKD are needed to provide a deeper understanding of observed population-level trends and ultimately identify opportunities to enhance end-of-life care for this population. More information is also needed on the roles, experiences, and perspectives of caregivers for older adults with advanced CKD over the course of illness and on the effectiveness of different approaches to engaging and supporting these caregivers. It is also not known what elements of palliative care older adults

TABLE 2. KNOWLEDGE GAPS FOR PALLIATIVE CARE FOR OLDER PATIENTS WITH ADVANCED KIDNEY DISEASE

<i>Area</i>	<i>Knowledge gap</i>
What matters most to older adults with advanced CKD and those who care for them near the end of life?	<ol style="list-style-type: none"> 1. End-of-life experience of older adults with advanced kidney disease 2. Roles, experiences, and perspectives of those who care for older adults with advanced kidney disease 3. Research priorities of older adults with advanced kidney disease and their caregivers
What are the most effective approaches to supporting older adults and their caregivers to navigate complex treatment decisions?	<ol style="list-style-type: none"> 1. Interventions to support older adults and caregivers facing decisions surrounding dialysis initiation. 2. Tailored shared decision-making approaches to meet the needs of older adults and their caregivers. 3. The optimal use of prognostic information in the decision-making process. 4. Advance care planning interventions that facilitate provision of end-of-life care consistent with patients' goals and preferences.
How do we reconfigure the health system to ensure that older adults with advanced CKD receive care that supports their goals and is consistent with their values and preferences?	<ol style="list-style-type: none"> 1. Optimal use of symptom assessment tools 2. The effect of different payment models and/or pay-for-performance incentives on uptake of palliative care, and effectiveness of different models for delivering palliative care 3. Measure outcomes of conservative, nondialytic care. 4. The effectiveness of concurrent dialysis and hospice care in dying patients

with advanced CKD and their caregivers see as most worthy of study and how research might be most responsive to their concerns.

With regard to navigating complex treatment decisions, future research should focus on developing and testing interventions to support older adults and their caregivers as they face decisions about whether and when to initiate dialysis, including identifying best approaches to tailoring shared decision making to meet the needs of older adults and their caregivers. The optimal use of prognostic information in the decision-making process, including upstream of dialysis on patient quality of life among patients with less advanced CKD also needs to be determined. In addition, future research is needed to develop and test ACP interventions that align patterns of end-of-life care with patients' goals and preferences, and to determine the best approach to implementing these interventions in clinical practice.

To reconfigure the healthcare system to be more patient and family centered, future research will need to examine how symptom assessment tools should be optimally incorporated into clinical practice. Another research priority is to compare the effectiveness of different models for the delivery of palliative care in dialysis centers and determine the effect of different payment models and/or pay-for-performance incentives on uptake of palliative care. Pragmatic trials are well suited for building the evidence base for these research questions in a timely manner as they can expedite the process of knowledge translation into clinical practice.⁷⁶ Because dialysis may not always benefit older patients with significant comorbidities, there is an urgent need to develop and measure outcomes of conservative, nondialytic care models in the U.S. healthcare system. For older adults on dialysis, a clinical trial or CMS demonstration project evaluating the effectiveness of concurrent dialysis and hospice care would fill a large knowledge gap regarding the optimal management of dying patients receiving dialysis.⁷⁷

Summary of Research Priorities

What matters most to older adults with advanced CKD and their caregivers near the end of life?

Future research should seek to understand the following: (1) the end-of-life experience of older adults with advanced kidney disease and identify opportunities for improvement; (2) the experience of their caregivers and identify opportunities to engage and support them; and (3) research priorities of older adults with advanced kidney disease and their caregivers.

How can the nephrology community best help older adults with advanced CKD and their caregivers navigate complex treatment decisions throughout their illness trajectories?

Future research should also focus on the following: (1) developing and testing interventions to support older adults and their caregivers as they face decisions about whether and when to initiate dialysis, including conservative care for those with symptomatic advanced kidney disease who prefer not to receive dialysis; (2) determining the optimal use of prognostic information in treatment decision making; (3) developing and testing ACP interventions that result in end-

of-life care, which is concordant with patients' preferences and improved bereavement outcomes for caregivers; and (4) identifying approaches to facilitate implementation of these interventions in clinical practice.

How should the healthcare system be reconfigured to promote patient- and family-centered care for older adults with advanced CKD?

Future research should focus on the following: (1) how to incorporate symptom assessment tools into the real-world practice of advanced CKD and ESRD patient care, (2) defining expected survival and quality of life for patients who receive comprehensive conservative care, (3) comparing the effectiveness of palliative care integrated with standard care versus standard care alone on quality of life, patient and caregiver satisfaction with care, and healthcare utilization, including different methods for delivering palliative care, and (4) determining the effect of alternative payment models for dialysis care on uptake of palliative care.

Author Disclosure Statement

No competing financial interests exist.

References

1. Davison SN, Moss AH: Kidney supportive care: Meeting the needs of patients with advanced chronic kidney disease. *Clin J Am Soc Nephrol* 2016;11:1879–1880.
2. Weisbord SD, Fried LF, Arnold RM, et al.: Prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *J Am Soc Nephrol* 2005;16:2487–2494.
3. United States Renal Data System: 2015 USRDS Annual Data Report. Bethesda, MD 2015.
4. Wachterman MW, Pilver C, Smith D, et al.: Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med* 2016;176:1095–1102.
5. Combs SA, Culp S, Matlock DD, et al.: Update on end-of-life care training during nephrology fellowship: A cross-sectional national survey of fellows. *Am J Kidney Dis* 2015; 65:333–339.
6. Culp S, Lupu D, Arenella C, et al.: Unmet supportive care Needs in U.S. dialysis centers and lack of knowledge of available resources to address them. *J Pain Symptom Manage* 2016;51:756–761 e752.
7. Tinetti ME, Fried T: The end of the disease era. *Am J Med* 2004;116:179–185.
8. Tinetti ME, Fried TR, Boyd CM: Designing health care for the most common chronic condition—multimorbidity. *JAMA* 2012;307:2493–2494.
9. Boyd CM, Darer J, Boult C, et al.: Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: Implications for pay for performance. *JAMA* 2005;294:716–724.
10. O'Hare AM, Armistead N, Schrag WL, et al.: Patient-centered care: An opportunity to accomplish the "Three Aims" of the National Quality Strategy in the Medicare ESRD program. *Clin J Am Soc Nephrol* 2014;9:2189–2194.
11. Byock I: *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life*. New York: Avery Books-Penguin Group USA, 2012.

12. Saran R, Li Y, Robinson B, et al.: US Renal Data System 2015 Annual Data Report: Epidemiology of kidney disease in the United States. *Am J Kidney Dis* 2016;67(3 Suppl 1): Svi, S1–S305.
13. 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;172:661–663; discussion 663–664.
14. Silveira MJ, Kim SY, Langa KM: Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211–1218.
15. Vig EK, Starks H, Taylor JS, et al.: Surviving surrogate decision-making: What helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 2007;22:1274–1279.
16. Tong A, Cheung KL, Nair SS, et al.: Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in CKD. *Am J Kidney Dis* 2014;63:913–927.
17. Gayomali C, Sutherland S, Finkelstein FO: The challenge for the caregiver of the patient with chronic kidney disease. *Nephrol Dial Transplant* 2008;23:3749–3751.
18. Miller HM, Tong A, Tunnicliffe DJ, et al.: Identifying and integrating patient and caregiver perspectives for clinical practice guidelines on the screening and management of infectious microorganisms in hemodialysis units. *Hemodial Int* 2016. [Epub ahead of print; DOI: 10.1111/hdi.12457].
19. Urquhart-Secord R, Craig JC, Hemmelgarn B, et al.: Patient and caregiver priorities for outcomes in hemodialysis: An International Nominal Group Technique Study. *Am J Kidney Dis* 2016;68:444–454.
20. Walker RC, Howard K, Morton RL, et al.: Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: A semi-structured interview study. *Nephrol Dial Transplant* 2016;31:133–141.
21. Walker RC, Morton RL, Tong A, et al.: Patient and caregiver preferences for home dialysis—the home first study: A protocol for qualitative interviews and discrete choice experiments. *BMJ Open* 2015;5:e007405.
22. Walker RC, Hanson CS, Palmer SC, et al.: Patient and caregiver perspectives on home hemodialysis: A systematic review. *Am J Kidney Dis* 2015;65:451–463.
23. Low J, Myers J, Smith G, et al.: The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: Contested discourses of ageing. *Health (London)* 2014;18:613–630.
24. Aasen EM, Kvangarsnes M, Heggen K: Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scand J Caring Sci* 2012;26:61–69.
25. Cohen LM, McCue JD, Germain M, et al.: Dialysis discontinuation. A “good” death? *Arch Intern Med* 1995;155: 42–47.
26. Cohen LM, Germain MJ, Poppel DM, et al.: Dying well after discontinuing the life-support treatment of dialysis. *Arch Intern Med* 2000;160:2513–2518.
27. Hemmelgarn BR, Pannu N, Ahmed SB, et al.: Determining the research priorities for patients with chronic kidney disease not on dialysis. *Nephrol Dial Transplant* 2016; [Epub ahead of print; DOI: 10.1093/ndt/gfw065].
28. Tong A, Chando S, Crowe S, et al.: Research priority setting in kidney disease: A systematic review. *Am J Kidney Dis* 2015;65:674–683.
29. Tong A, Crowe S, Chando S, et al.: Research Priorities in CKD: Report of a National Workshop Conducted in Australia. *Am J Kidney Dis* 2015;66:212–222.
30. Cukor D, Cohen LM, Cope EL, et al.: Patient and other stakeholder engagement in patient-centered outcomes research institute funded studies of patients with kidney diseases. *Clin J Am Soc Nephrol* 2016;11:1703–1712.
31. van der Veer SN, Haller MC, Pittens CA, et al.: Setting priorities for optimizing vascular access decision making—an International survey of patients and clinicians. *PLoS One* 2015;10:e0128228.
32. Howell M, Wong G, Rose J, et al.: Eliciting patient preferences, priorities and trade-offs for outcomes following kidney transplantation: A pilot best-worst scaling survey. *BMJ Open* 2016;6:e008163.
33. Dahlerus C, Quinn M, Messersmith E, et al.: Patient perspectives on the choice of dialysis modality: Results from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) Study. *Am J Kidney Dis* 2016;68:901–910.
34. Davison SN, Levin A, Moss AH, et al.: Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney Int* 2015;88:447–459.
35. Renal Physicians Association: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis: Clinical Practice Guideline, 2nd ed.* Rockville, MD: Renal Physicians Association, 2010.
36. Kasiske BL, Cangro CB, Hariharan S, et al.: The evaluation of renal transplantation candidates: Clinical practice guidelines. *Am J Transplant* 2001;1 Suppl 2:3–95.
37. Loiselle MC, O'Connor AM, Michaud C: Developing a decision support intervention regarding choice of dialysis modality. *CANNT J* 2011;21:13–18.
38. Winterbottom AE, Gavaruzzi T, Mooney A, et al.: Patient acceptability of the Yorkshire Dialysis Decision Aid (Yodda) Booklet: A prospective non-randomized comparison study across 6 Predialysis Services. *Perit Dial Int* 2015;36:374–381.
39. Patzer RE, Basu M, Larsen CP, et al.: iChoose kidney: A clinical decision aid for kidney transplantation versus dialysis treatment. *Transplantation* 2016;100:630–639.
40. Fortnum D, Grennan K, Smolonogov T: End-stage kidney disease patient evaluation of the Australian “My Kidneys, My Choice” decision aid. *Clin Kidney J* 2015;8:469–475.
41. Wong SP, Kreuter W, O'Hare AM: Healthcare intensity at initiation of chronic dialysis among older adults. *J Am Soc Nephrol* 2014;25:143–149.
42. Jassal SV, Watson D: Dialysis in late life: Benefit or burden. *Clin J Am Soc Nephrol* 2009;4:2008–2012.
43. Song MK, Lin F-C, Gilet CA, et al.: Patients' perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant* 2013;28:2815–2823.
44. Schell JO, Patel UD, Steinhauer KE, et al.: Discussions of the kidney disease trajectory by elderly patients and nephrologists: A qualitative study. *Am J Kidney Dis* 2012;59: 495–503.
45. Song MK, Ward SE: The extent of informed decision-making about starting dialysis: Does patients' age matter? *J Nephrol* 2014;27:571–576.
46. United States Renal Data System: *2015 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2015.
47. Holley JL, Hines SC, Glover JJ, et al.: Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *Am J Kidney Dis* 1999;33:688–693.

48. Calvin AO: Haemodialysis patients and end-of-life decisions: A theory of personal preservation. *J Adv Nurs* 2004; 46:558–566.
49. Cohen LM, Germain MJ, Poppel DM: Practical considerations in dialysis withdrawal: “to have that option is a blessing.” *JAMA* 2003;289:2113–2119.
50. Weisbord SD, Carmody SS, Bruns FJ, et al.: Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients. *Nephrol Dial Transplant* 2003;18:1345–1352.
51. Davison SN: End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 2010;5:195–204.
52. Davison SN: Facilitating advance care planning for patients with end-stage renal disease: The patient perspectives. *Clin J Am Soc Nephrol* 2006;1:1023–1028.
53. Goff SL, Eneanya ND, Feinberg R, et al.: Advance care planning: A qualitative study of dialysis patients and families. *Clin J Am Soc Nephrol* 2015;10:390–400.
54. Luckett T, Sellars M, Tieman J, et al.: Advance care planning for adults with CKD: A systematic integrative review. *Am J Kidney Dis* 2014;63:761–770.
55. Patient-Centered Outcomes Research Institute: Community-based palliative care delivery for adult patients with advanced illnesses and their caregivers. 2016; www.pcori.org/funding-opportunities/announcement/community-based-palliative-care-delivery-adult-patients-advanced (Last accessed June 25, 2016).
56. Perry E, Swartz J, Brown S, et al.: Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients. *Am J Kidney Dis* 2005;46:111–119.
57. Song MK, Ward SE, Fine JP, et al.: Advance care planning and end-of-life decision making in dialysis: A randomized controlled trial targeting patients and their surrogates. *Am J Kidney Dis* 2015;66:813–822.
58. Cohen LM, Ruthazer R, Moss AH, et al.: Predicting six-month mortality for patients who are on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2010;5:72–79.
59. Thamer M, Kaufman JS, Zhang Y, et al.: Predicting early death among elderly dialysis patients: Development and validation of a risk score to assist shared decision making for dialysis initiation. *Am J Kidney Dis* 2015;66:1024–1032.
60. Couchoud C, Labeeuw M, Moranne O, et al.: A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease. *Nephrol Dial Transplant* 2009;24:1553–1561.
61. Tangri N, Grams ME, Levey AS, et al.: Multinational assessment of accuracy of equations for predicting risk of kidney failure: A meta-analysis. *JAMA* 2016;315:164–174.
62. Drawz PE, Goswami P, Azem R, et al.: A simple tool to predict end-stage renal disease within 1 year in elderly adults with advanced chronic kidney disease. *J Am Geriatr Soc* 2013;61:762–768.
63. Amro OW, Ramasamy M, Strom JA, et al.: Nephrologist-facilitated advance care planning for hemodialysis patients: A quality improvement project. *Am J Kidney Dis* 2016; 68:103–109.
64. Kirchhoff KT, Hammes BJ, Kehl KA, et al.: Effect of a disease-specific advance care planning intervention on end-of-life care. *J Am Geriatr Soc* 2012;60:946–950.
65. Smith AK, White DB, Arnold RM: Uncertainty—the other side of prognosis. *N Engl J Med* 2013;368:2448–2550.
66. Lupu D: Estimate of current hospice and palliative medicine physician workforce shortage. *J Pain Symptom Manage* 2010;40:899–911.
67. Carson RC, Juszczak M, Davenport A, et al.: Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol* 2009;4:1611–1619.
68. Murtagh FE, Burns A, Moranne O, et al.: Supportive care: Comprehensive conservative care in end-stage kidney disease. *Clin J Am Soc Nephrol* 2016; [Epub ahead of print; DOI: 10.2215/CJN.04840516].
69. Brown MA, Collett GK, Josland EA, et al.: CKD in elderly patients managed without dialysis: Survival, symptoms, and quality of life. *Clin J Am Soc Nephrol* 2015;10:260–268.
70. Medicaid CfMa: Comprehensive ESRD Care Model. <https://innovation.cms.gov/initiatives/comprehensive-esrd-care> (Last accessed July 11, 2016).
71. Swaminathan S, Mor V, Mehrotra R, et al.: Medicare's payment strategy for end-stage renal disease now embraces bundled payment and pay-for-performance to cut costs. *Health Aff (Millwood)* 2012;31:2051–2058.
72. Wish D, Johnson D, Wish J: Rebasement of the medicare payment for dialysis: Rationale, challenges, and opportunities. *Clin J Am Soc Nephrol* 2014;9:2195–2202.
73. Arbor Research Collaborative for Health. End-Stage Renal Disease (ESRD) Disease Management Demonstration Evaluation Report: Findings from 2006–2008, the First Three Years of a Five-Year Demonstration 2010.
74. Moss AH, Davison SN: How the ESRD quality incentive program could potentially improve quality of life for patients on dialysis. *Clin J Am Soc Nephrol* 2015;10:888–893.
75. Teno JM, Gozalo PL, Bynum JP, et al.: Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309:470–477.
76. Dember LM, Archdeacon P, Krishnan M, et al.: Pragmatic trials in maintenance dialysis: Perspectives from the kidney health initiative. *J Am Soc Nephrol* 2016;27:2955–2963.
77. Grubbs V, Moss AH, Cohen LM, et al.: A palliative approach to dialysis care: A patient-centered transition to the end of life. *Clin J Am Soc Nephrol* 2014;9:2203–2209.

Address correspondence to:
 Alvin H. Moss, MD
 Center for Health Ethics and Law
 West Virginia University
 PO Box 9022
 Morgantown, WV 26506-9022
 E-mail: amoss@hsc.wvu.edu