Palliative Care in the Advancing American Kidney Health Initiative: A Call for Inclusion in Kidney Care Delivery Models

Samantha L. Gelfand, Ernest I. Mandel, Mallika L. Mendu, and Joshua R. Lakin

The Advancing American Kidney Health (AAKH) Initiative aims to promote high-value patient-centered care by improving access to and quality of treatment options for kidney failure. The 3 explicit goals of the initiative are to reduce the incidence of kidney failure, increase the number of available kidneys for transplantation, and increase transplantation and home dialysis. To ensure a patient-centered movement toward home dialysis modalities, actionable principles of palliative care, including systematic communication and customized treatment plans, should be incorporated into this policy. In this perspective, we describe 2 opportunities to strengthen the patience-centeredness of the AAKH Initiative through palliative care: (1) serious illness conversations should be required for all dialysis initiations in the End-Stage Renal Disease Treatment Choices model, and (2) conservative kidney management should be counted as a home modality alongside peritoneal dialysis and home hemodialysis. A serious illness conversation can help clinicians discern whether a patient’s goals and values are best respected by a home dialysis modality or whether a nondialytic strategy such as conservative kidney management should be considered. An intensive and careful patient- and family-centered selection process will be necessary to ensure that no patient is pressured to forego conventional dialysis.

Regarding the AAKH Initiative’s goal of increasing home treatment modalities for kidney failure, we propose 2 palliative additions that could help ensure patient-centered success. (1) A “serious illness conversation” should be a required part of every dialysis initiation in the End-Stage Renal Disease Treatment Choices (ETC) mandatory model. (2) Conservative kidney management (CKM) should be counted as a “home modality” in the ETC model.

These suggestions are conceptualized in the context of the ETC model as originally described in July 2019; significant changes to the ETC model may necessitate different methods for incorporating palliative care.

Proposals 1: Serious Illness Conversation in Every Dialysis Initiation in the ETC Model

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**What Is a Serious Illness Conversation?**

Within palliative care, a serious illness conversation is a systematic exploration of a patient’s goals, values, and priorities in the context of their illness and its anticipated trajectory. It can be used to bring prognosis-informed patient perspectives into decisions about medical care (Box 1). Depending on the patient’s informational preferences, a serious illness conversation may include a prognostic disclosure, as well as discussion of a patient’s hopes, worries, and priorities for the future in the context of their illness. The prognostic contextualization is key...
because what matters most is usually influenced by the individual’s sense of what their remaining life is likely to be like and approximately how long it is expected to be.8

A serious illness conversation does not necessarily involve a medical decision. Instead, within a shared decision-making model, a serious illness conversation is the process by which the clinician becomes acquainted with the individual patient’s outlook, priorities, and prognostic awareness while the patient becomes familiar with the medical context of their illness in a gentle and guided way.9 It ideally occurs separately from information sharing and decision making about treatment options.10

**Box 1. Serious Illness Conversation Guide: Patient-Tested Language**

**Set Up**

“I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want—is this okay?”

**Assess**

“What is your understanding now of where you are with your illness?”

“How much information about what is likely to be ahead with your illness would you like from me?”

**Share**

“I want to share with you my understanding of where things are with your illness…”

*Uncertain:* “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”

*Time:* “I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, eg, days to weeks, weeks to months, months to a year).”

*Function:* “I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult.”

**Explore**

“What are your most important goals if your health situation worsens?”

“What are your biggest fears and worries about the future with your health?”

“What gives you strength as you think about the future with your illness?”

“What abilities are so critical to your life that you can’t imagine living without them?”

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

“How much does your family know about your priorities and wishes?”

**Close**

“I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”

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Why Should Serious Illness Conversations Be a Part of Dialysis Initiation?

In oncology, there is evidence that serious illness conversations are associated with enhanced goal-concordant care, positive family outcomes, and less unwanted medical care near death, which is associated with reduced cost.7 Serious illness conversations are also now being studied in the fields of heart failure and coronavirus disease 2019 (COVID-19) care.11,12 The AAKH Initiative presents an important opportunity to incorporate and study serious illness conversations in the care of patients with incident kidney failure.

Additionally, survey data show that this kind of communication is highly valued by patients with kidney disease, most of whom are unaware of their prognosis but have increased morbidity and mortality compared with their age-matched controls.13-15 This is particularly important for patients who develop kidney failure later in life, whose mortality receiving dialysis is high (at age >75 years, 1- and 3-year mortality rates are 37% and 67%, respectively). Making serious illness conversations an obligatory part of kidney failure care may deepen patients’ and families’ prognostic awareness, which in turn can lead to increased patient activation and engagement with care, which is a quality measure within the AAKH Initiative.
Who Should Conduct Serious Illness Conversations and How and When Should They Occur?

Palliative care specialists are trained in communication techniques that facilitate serious illness conversations. There is a precedent in the field of cardiology for obligatory specialty palliative care consultation. In 2013 The Joint Commission and the Centers for Medicare & Medicaid Services (CMS) made specialty palliative consultation a requirement for all patients pursuing ventricular assist device placement, which, like dialysis, constitutes a burdensome yet life-saving therapy for a life-threatening chronic illness. However, more than 120,000 people start dialysis each year, 50% of whom will be enrolled in the ETC mandatory model, compared with just more than 2,500 yearly ventricular assist device implantations. Additionally, ventricular assist device programs tend to be in tertiary medical centers that have access to inpatient palliative care teams, whereas dialysis infrastructure extends across urban, suburban, and rural areas. Although the growth of telehealth and the specialty palliative care workforce in coming years may allow for greater reach, limited and variable access to palliative care specialists is currently a major consideration in allocating the task of conducting serious illness conversations with patients with new kidney failure.

We believe that most of these conversations should be conducted by interprofessional kidney care teams (including nephrologists, nurses, and social workers).

Proposal 2: CKM Should Count as a Home Modality

What Is CKM?

Among the population of people who develop kidney failure, there is a small and as yet undefined percentage who would prefer a conservative nondialytic approach over dialysis of any modality. Current kidney care delivery systems do not optimally account for the complex and evolving needs of these patients, and incorporating CKM into the new payment models could be a major catalyst for innovation in this area. Also called “medical management without dialysis,” CKM is intensive medical management of kidney failure by clinicians trained in nephrology, sometimes aided by palliative care specialists. CKM includes pharmacologic and behavioral interventions aimed at reducing symptoms of uremia, anemia, and mineral and bone derangements, as well as psychological distress related to living with serious illness. Existing CKM programs have used multidisciplinary teams that often include physicians, advanced practice nurses, social workers, dieticians, and chaplains. Collectively, they have generated data about the symptom burden, functional status, and holistic care needs for patients who elect this approach. This has led to a global
consensus that CKM is a valid treatment option for kidney failure\textsuperscript{28} that, like dialysis and transplantation, should be discussed with patients who are weighing treatment options.

Contrary to its therapeutic intention, dialysis may not prolong life or improve quality in patients with advanced age or certain comorbid illnesses.\textsuperscript{29,30} International experience shows that usual survival with CKM is in the range of months to years, which is similar to the survival of the elderly who initiate dialysis in the United States (as mentioned, aged > 75 years, 1- and 3-year adjusted survival is 63% and 33%, respectively).\textsuperscript{11} Months to years longevity with CKM has been consistently demonstrated in 18 patient cohorts in 10 different countries during the last 2 decades.\textsuperscript{11} These studies have heterogeneity in what constitutes “time zero” for CKM initiation, with some using a glomerular filtration rate cutoff and others using an “upstream” decision made before any specific glomerular filtration rate or conventional indication to initiate kidney replacement therapy. For the purposes of including CKM as a home dialysis equivalent in the ETC, CKM should be formally initiated at the juncture when kidney replacement therapy would otherwise be commenced.

**Why Should CKM Be Considered a Home Modality?**

The AAKH Initiative has emphasized home dialysis for its potential positive impact on patients’ quality of life. Most of the putative benefits of home dialysis also apply to CKM: more time at home, reduced dietary restrictions, increased schedule flexibility, avoidance of major volume shifts, and less postdialysis fatigue. It can also be acknowledged, without equating lowest cost care with best care, that CKM is less costly than any form of dialysis, even after accounting for the financial investment needed to create interprofessional clinical teams and quality metrics focused on quality of life.\textsuperscript{52} CKM should therefore be considered a home dialysis equivalent.

Despite its potential benefits, it is currently rare for patients with advancing chronic kidney disease to choose CKM in the United States. Those who do must navigate a system that is not designed to meet their medical and psychosocial needs. A recent survey of US nephrologists who have provided CKM illustrates the deficits in our current clinical infrastructure.\textsuperscript{57} Kidney care teams relied on “cobbling together” resources from other domains such as primary care, telemedicine, and home care agencies. Many also advised patients to avoid urgent care and emergency departments due to concern that they would be started on dialysis by clinicians who were unfamiliar or uncomfortable with CKM.

Housing CKM and its payment within existing dialysis payment infrastructure could lead to neutralization of some of the potential infrastructural biases that result in default dialysis initiation. For example, consider the elderly widower with slowly progressive advanced chronic kidney disease, social isolation, low appetite, and low energy. Initiation of in-center hemodialysis creates an immediate medical and social community for him; enrolling in a CKM program could involve the same, with nephrologists, social workers, dieticians, chaplains, and access to clinic- and home-based specialty palliative care services.

Consider the risks of both including and not including CKM within the initiative to expand home treatment (Box 3). The main risk of including CKM is the potential for psychosocially complex, “noncompliant,” elderly, or medically frail patients to be pressured into CKM to improve a facility’s reimbursement. This is ethically indefensible: although those with advanced debility may be most likely to prefer a nondialytic strategy, these vulnerable patients must be protected against pressure to forego dialysis. There should never be a comorbidity score, mortality predictor, or age cutoff that determines who receives CKM, especially because these are likely to potentiate systemic racism, ageism, and prejudice toward those with disabilities.\textsuperscript{33-35} One protective safeguard would be required iterative serious illness conversations that document patient and caregiver preferences for CKM over dialysis. The risk of not counting CKM as a home modality is also significant: in the absence of incorporating it into dialysis care and payment models, CKM in the United States may remain sparse and variable in quality.

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**Box 3. Potential Benefits, Risks, and Ways to Mitigate Risks of Including CKM in the ETC Payment Model**

**Benefits**
- Enhanced goal-concordant care for patients whose goals and priorities are unlikely to be met by dialysis initiation
- More time at home, less time hospitalized, reduced morbidity from access complications
- Reduced risk for abandonment and loss of support services for patients who do not want dialysis
- Reduced cost

**Risks**
- Patients with medical or psychosocial complexity may be pressured to forego dialysis
- CKM may be underresourced or misunderstood as hospice
- Providers may not feel adequately trained to discuss or provide CKM

**Ways to Mitigate Risk**
- Require documentation of patient’s values, reasoning, and priorities that led to selection of CKM over dialysis
- Require CKM programs to be run by an interprofessional team including physicians, nurses, social workers, dieticians, and chaplains
- Increase training in communication and nondialytic therapy among nephrology trainees, attendings, and nurses
- Bolster specialty palliative care resources available to nephrology teams

Abbreviations: CKM, conservative kidney management; ETC, End-Stage Renal Disease Treatment Choices.
Conclusion

The AAKH Initiative presents a special opportunity to incorporate palliative practices into kidney health systems in the United States. With this opportunity also comes major vulnerability. If not implemented correctly, CKM could be misjudged as poor care or misapplied in the name of cost savings. To develop CKM as a home modality in a safe and effective way, the AAKH Initiative should incentivize high-quality communication in the form of serious illness conversations, as well as training for kidney care clinicians in these necessary palliative skills. Ultimately, these actions will ensure that innovations in care delivery and payment align with this diverse patient population’s broad range of needs.

Article Information

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References

1. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010;363(8):733-742.
2. Rogers JG, Patel CB, Metnz RJ, et al. Palliative care in heart failure: the PAL-HF randomized controlled clinical trial. J Am Coll Cardiol. 2017;70(3):331-341.
3. Center to Advance Palliative Care. Palliative care ensures value. Accessed February 25, 2019, https://www.capc.org/documents/245/.
4. Gelfand SL, Scherer JS, Koncicki HM. Kidney supportive care: core curriculum 2020. Am J Kidney Dis. 2020;75(5):793-806.
5. Gelfand SL, Schell JO, Eneanya ND. Palliative care in nephrology: the work and the workforce. Adv Chronic Kidney Dis. 2020;27(4):350-355.e1.
6. Mandel EI, Bernacki RE, Block SD. Serious illness conversations in ESRD. Clin J Am Soc Nephrol. 2017;12(5):854-863.
7. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014;174(12):1994-2003.
8. Paladino J, Lakin JR, Sanders JJ. Communication strategies for sharing prognostic information with patients: beyond survival statistics. JAMA. 2019;322(14):1345-1346.
9. Lakin JR, Jacobsen J. Softening our approach to discussing prognosis. JAMA Intern Med. 2019;179(1):5-6.
10. Koncicki HM, Schell JO. Communication skills and decision making for elderly patients with advanced kidney disease: a guide for nephrologists. Am J Kidney Dis. 2016;76(4):688-695.
11. Manning KA, Lakdawala NK, Theodat HG, Tulsky JA, Schaefer KG. Serious illness communication training for heart failure and cardiology fellows. J Card Fail. 2019;25(8)(suppl):S145.
12. Thomas JM, Leiter RE, Abraham JL, et al. Development of a palliative care toolkit for the COVID-19 pandemic. J Pain Symptom Manage. 2020;60(2):e22-e25.
13. Davison S. End of life care preferences and needs: perceptions of patients with chronic kidney disease. Clin J Am Soc Nephrol. 2010;5(2):195-204.
14. Wachterman MW, Marcantonio ER, Davis RB, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. JAMA Intern Med. 2013;173(13):1206-1214.
15. Saran R, Robinson B, Abbott KC, et al. US Renal Data System 2017 Annual Data Report: epidemiology of kidney disease in the United States. Am J Kidney Dis. 2018;71(3)(suppl 1):S1-S676.
16. Yancy CW, Jessup M, Bozkurt B, et al. 2013 ACCF/AHA guideline for the management of heart failure: executive summary: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. Circulation. 2013;128(16):1810-1852.
17. Saran R, Robinson B, Abbott KC, et al. US Renal Data System 2018 Annual Data Report: epidemiology of kidney disease in the United States. Am J Kidney Dis. 2019;73(3)(suppl 1):A7-A8.
18. Han JJ, Acker MA, Atulri P. Left ventricular assist devices: synergistic model between technology and medicine. Circulation. 2018;138(24):2841-2851.
19. Kamal AH, Wolf SP, Troy J, et al. Policy changes key to promoting sustainability and growth of the specialty palliative care workforce. Health Aff (Millwood). 2019;38(6):910-918.
20. Combs SA, Culp S, Matlock DD, Kutner JS, Holley JL, Moss AH. Update on end-of-life care training during nephrology fellowship: a cross-sectional national survey of fellows. Am J Kidney Dis. 2015;65(2):233-239.
21. Holley JL, Carmody SS, Moss AH, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. Am J Kidney Dis. 2003;42(4):813-820.
22. Bernacki R, Hutchings M, Vick J, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. BMJ Open. 2015;5(10):e009032.
23. Auriemma CL, Nguyen CA, Bronheiro R, et al. Stability of end-of-life preferences: a systematic review of the evidence. JAMA Intern Med. 2014;174(7):1085-1092.
24. Davison SN, Tupala B, Wasylnuk BA, Sui V, Sinnarajah A, Triscott J. Recommendations for the care of patients receiving conservative kidney management: focus on management of CKD and symptoms. Clin J Am Soc Nephrol. 2019;14(4):626-634.
25. Lam DY, Scherer JS, Brown M, Grubbs V, Schell JO. A conceptual framework of palliative care across the continuum of advanced kidney disease. *Clin J Am Soc Nephrol*. 2019;14(4):635-641.

26. Murtagh FEM, Addington-Hall JM, Higginson IJ. End-stage renal disease: a new trajectory of functional decline in the last year of life. *J Am Geriatr Soc*. 2011;59(2):304-308.

27. 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.

28. 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(3):447-459.

29. Murtagh FEM, 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.

30. Verberne WR, Geers ABMT, Jellemma WT, Vincent HH, van Delden JJM, Bos WJJ. Comparative survival among older adults with advanced kidney disease managed conservatively versus with dialysis. *Clin J Am Soc Nephrol*. 2016;11(4):633-640.

31. 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.

32. Davison SN, Jassal SV. Supportive care: integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clin J Am Soc Nephrol*. 2016;11(10):1882-1891.

33. Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. National Academies Press (US); 2003.

34. Thomas BA, Rodriguez RA, Boyko EJ, et al. Geographic variation in black-white differences in end-of-life care for patients with ESRD. *Clin J Am Soc Nephrol*. 2013;8(7):1171-1178.

35. Eneanya AD, Yang W, Reese PP. Reconsidering the consequences of using race to estimate kidney function. *JAMA*. 2019;322(2):113-114.