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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 patient-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.

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The Advancing American Kidney Health (AAKH) Initiative, launched in July 2019, aims to promote patient-centered care by improving access to and quality of treatment options for kidney failure. The AAKH Initiative states that the current state of kidney care is “unacceptable” and “treatment options are expensive and do not produce an acceptable quality of life.” Palliative care, a field dedicated to maximizing patients’ quality of life during any serious illness, is not explicitly included in the AAKH Initiative. This is a missed opportunity given that palliative care has also been shown to result in cost savings for health systems through better alignment of care with patient wishes.¹⁻³

Palliative care is distinct from hospice; it is patient-centered specialized medical care that aims to optimize quality of life by anticipating, preventing, and treating suffering across the continuum of illness and helping patients and their families navigate complex treatment decisions. Much of this is accomplished through deliberate communication practices that can be used by practitioners in any field of medicine (ie, primary palliative care skills) or by palliative care clinicians (specialty palliative care skills). The relevance of both primary and specialty palliative care for patients living with advanced kidney disease has been described in detail elsewhere.^{4,5} We believe that all patients living with the serious illness of kidney failure would benefit from palliative care.

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.

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

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.^{6,7} The prognostic contextualization is key

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Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients.

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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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

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.¹⁶ 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.^{17,18} 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,¹⁹ 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).

Box 2. Educational Tools for Increasing Serious Illness Communication Skills Among Non-Palliative Care Clinicians

Online Curricula

NephroTalk Conservative Care Curriculum (nephro-talk.com)
Stanford Palliative Training Portal (palliative.stanford.edu)
Coalition for Supportive Care of Kidney Patient Webinar Series (kidneysupportivecare.org/for-patients-families/additional-resources/webinars/)

In-Person Training Programs

NephroTalk (community.asn-online.org/events/calendar)
VitalTalk (vitaltalk.org/courses)
Palliative Care Education and Practice (pallcare.hms.harvard.edu/courses/pcep)

Bedside Tools

Best Case/Worst Case Scenarios ([youtube.com/watch?v=FnS3K44sbu0](https://www.youtube.com/watch?v=FnS3K44sbu0))
Serious Illness Conversation Guide, Ariadne Labs^{22,a} (ariadnelabs.org/wp-content/uploads/sites/2/2017/05/SI-CG-2017-04-21_FINAL.pdf)
VitalTalk Tips App: Mobile app that includes communication tips by communication topic

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^aOne of several Ariadne Labs resources available for clinicians related to serious illness communication.

Some of these clinicians may need additional training in serious illness communication because survey data suggest that the necessary primary palliative communication skills are rarely taught during nephrology fellowship training.^{20,21} With the increase of renal supportive care programs in the United States and internationally, there are now multiple tools and programs aimed at increasing primary palliative care skills among non-palliative care clinicians (Box 2). Eventually, this skill set should become a core competency in the Accreditation Council for General Medical Education requirements for nephrology trainees.

The information derived from serious illness conversations should be documented, tracked, and defined clearly as a quality metric within the ETC model and the Kidney Disease Education benefit. There are multiple potential ways to accomplish this. Akin to the Form CMS-2728-U3 (which confirms medical need for dialysis), standardized documentation of a serious illness conversation could be a required part of Medicare certification. Additionally, treatment reimbursement could also be contingent on repeat serious illness conversation documentation at set intervals (biannually or yearly at minimum) because evidence shows that the preferences of seriously ill patients evolve over time.²³ Of note, oncology studies show that conversations themselves, rather than completion of forms, drive improved quality of care and lower cost.⁷ Therefore, policy should focus on incentivizing clinicians to master and use communication skills while requiring minimally burdensome documentation.

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.²⁴ Existing CKM programs have used multidisciplinary teams that often include physicians, advanced practice nurses, social workers, dietitians, and chaplains.²⁵ Collectively, they have generated data about the symptom burden, functional status, and holistic care needs for patients who elect this approach.^{26,27} This has led to a global

consensus that CKM is a valid treatment option for kidney failure²⁸ 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.^{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).⁵ Months to years longevity with CKM has been consistently demonstrated in 18 patient cohorts in 10 different countries during the last 2 decades.³¹ 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.³² 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.¹⁷ 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

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, dietitians, 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.

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, dietitians, 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 systematic racism, ageism, and prejudice toward those with disabilities.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.

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

Authors' Full Names and Academic Degrees: Samantha L. Gelfand, MD, Ernest I. Mandel, MD, Mallika L. Mendu, MD, MBA, and Joshua R. Lakin, MD.

Authors' Affiliations: Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute (SLG, JRL); Harvard Medical School (SLG, EIM, MLM, JRL); and Renal Division, Department of Medicine, Brigham and Women's Hospital, Boston, MA (SLG, EIM, MLM).

Address for Correspondence: Samantha L. Gelfand, MD, 450 Brookline Ave, Boston, MA 02215. E-mail: samantha_gelfand@dfci.harvard.edu

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