

Palliative Care for Patients With Advanced CKD: Moving Beyond the Status Quo

Emily Lu and Craig D. Blinderman



Recognition of the need for integrating palliative care in nephrology has increased dramatically during the past decade. We have noticed a progressive conceptual awareness among our colleagues in both fields—influenced no doubt by studies revealing disparities in the quality of end-of-life care for patients with chronic kidney disease (CKD)—that integrating palliative care principles and practices can address key areas of unmet need in advanced CKD and end-stage kidney disease care: high symptom burden, insufficient advance care planning, poor utilization of hospice care, and limited communication skills training for nephrology providers.^{1,2}

What is necessary now is the development of sustainable renal palliative care models for patients with advanced kidney disease. The recent Executive Order on Advancing American Kidney Health echoes this need for macro-level change to address high mortality, limited communication, and poor quality of life in CKD and end-stage kidney disease, emphasizing the prioritization of patient and provider education, expansion of treatment options beyond dialysis alone, and introduction of new payment models.³ Unfortunately, for now, due to complex financial, policy, educational, and cultural barriers outside the scope of this editorial,⁴ we face a paucity of comprehensive renal supportive care programs in the United States.⁵

Building the “right” conceptual model of renal supportive care that fits each institution or health care system will likely require significant system-level alterations over time.⁵ However, in the interim, we can concurrently start to move the field forward as clinicians by asking: How can we, as individual providers, begin to address the palliative care “deficiency” in kidney disease management and help change the culture of nephrology practice?

By drawing on existing concepts developed outside of nephrology, including primary palliative care or other specialties, and adapting them for the care of patients with kidney disease, we propose several unique strategies that can be used by nephrology and palliative care providers in their daily practice. While we recognize that these discrete strategies alone are unlikely to shift the paradigm of CKD management, affect accompanying financial disincentives, or upend current cultural views regarding dialysis, we believe that they can allow us to rethink our status quo and broaden our view of possible solutions to advancing CKD care.

Integrate Palliative Care and Communication Skills Training Into Nephrology Fellowship Training—and Beyond

Despite our best intentions, advanced care planning discussions only occur for a minority of patients with advanced

CKD.⁶ Nephrology providers strive to achieve “shared decision making,” but underlying uncertainty about disease trajectory continues to challenge good communication.⁷ Without access to structured training in communication and palliative care approaches, clinicians may skip essential questions necessary to understand patients’ hopes, fears, priorities, and tradeoffs. Instead, they may appeal to patient autonomy, hoping that by simply explaining the risks, benefits, and complexities of each treatment option, the patient will make “the right decision”—despite our realization that even maximizing prognostic knowledge alone may not affect treatment choices if underlying emotions are not adequately addressed.⁸ Likewise, nephrology trainees have long reported insufficient palliative care education, but unlike in hematology and oncology, there are no renal fellowship Accreditation Council for Graduate Medical Education requirements or curriculum standards for palliative care training,⁹ despite our knowledge that patients with advanced CKD and end-stage kidney disease have a magnitude of symptom burden and prognosis comparable to that of patients with cancer.¹⁰

Advanced care planning discussions and shared decision making may hold the key to navigating the discrepancy between patient and provider values on perceived quality of care.^{11,12} However, major fellowship curriculum changes are lagging and the use of structured educational programs, such as NephroTalk,¹³ may be limited at some institutions by the inherent time and resource investment required. We suggest looking beyond our existing teaching tools⁵ and engaging our learners by presenting “bite-sized” palliative care concepts and communication teaching that can be embedded more readily into our daily workflow and practice of kidney disease management.

As a first step, we advocate using a model of shared decision making that conceptualizes the clinician as a guide in serious illness conversations and devotes particular attention to the pathway to attaining a goal-concordant recommendation.¹⁴ Although there are other established communication techniques available,¹⁵ this concise framework can help nephrology trainees learn not only to evaluate prognoses and available treatment options, but also to prioritize patients’ range of priorities in this context.¹⁴ Nephrology training programs may also consider adapting innovative communication tools from other patient populations undergoing a major intervention to dialysis decision making in advanced CKD. For example, by re-formulating a semi-structured script originally developed for heart failure PreVAD evaluation (before left ventricular assist device [LVAD] implantation) and applying it to dialysis decision making, we may be better

Box 1. Semi-structured Script for Predialysis Evaluation

1. Patient comfort
2. Patient and family understanding of dialysis
 - a. When did you hear about dialysis?
 - b. How did you feel about dialysis as your treatment option?
 - c. Is that in-center hemodialysis, home dialysis, or peritoneal dialysis?
 - d. Have you heard about nondialysis care (conservative management, medical management)?
3. Patient goals and expectations
 - a. What makes your life meaningful? What is your quality of life?
 - b. What are you hoping to achieve by being on dialysis? What are things you look forward to doing after starting dialysis?
4. Spiritual needs (FICA tool)
 - a. Are you a spiritual person? Are you religious?
 - b. How important is it?
 - c. What role do your beliefs play in regaining your health? Are you part of a spiritual or religious community?
 - d. How would you like your health care provider to address these issues in your health care?
5. Possible complications and exploration of unacceptable conditions
 - a. Being on dialysis can cause its own problems, such as stroke or infection. What if things do not go well?
 - b. These complications can cause significant disability and keep you from achieving your goals.
 - c. What is the condition you would find unacceptable?
 - d. Debilitative comorbid conditions (not associated with dialysis; rather, caused because dialysis can prolong survival)
 - e. Being on dialysis means that you are going to live with a catheter, fistula, or graft the rest of your life. The better you do on dialysis, the greater the possibility you are going to have problems, such as cancer or dementia. They can become greater issues than kidney failure.
 - f. Are you aware that you can discontinue dialysis at any future point if it no longer meets your goals of care?
6. Discussion making and information sharing preferences
 - a. Who is your health care agent? Have you discussed the above with that person?

Abbreviation: FICA, Federal Insurance Contributions Act.
Adapted from Nakagawa et al.¹⁶

equipped to reflect on patient values and “unacceptable condition(s)” affecting treatment choices throughout the disease course (Box 1).¹⁶ Using these strategies in conjunction with interdisciplinary palliative care rotations, both nephrology trainees and mid- or late-career clinicians can begin to help patients more effectively navigate their treatment options and goals of care.¹⁷

Integrate Both Routine Symptom Assessment and Symptom-Based Treatment Networks Into Advanced CKD Care

Patients with advanced kidney disease view symptom management as a priority, but it is frequently hindered by

incomplete identification and fragmented treatment of their symptom burden.¹ Like others, we strongly advocate using validated symptom assessment tools at regular intervals.^{1,2}

However, what do we then do with the symptom information attained? As demonstrated in oncology patients with solid tumors, we suggest using standardized criteria to implement systematic referrals to palliative care and other specialists (eg, mental health clinicians) based on the measured severity and impact of patients’ symptom distress to help reduce the downstream costs of care and avoid delays in appropriate symptom management.¹⁸ Recognizing the limited number of palliative care specialists, we view creating symptom-based treatment networks, either interinstitutionally, intrainstitutionally, or regionally, as the next step in allowing for adequate referral options and access to multidisciplinary treatment approaches to complex symptoms. For example, by partnering not only with palliative care specialists but also with local integrative medicine, mental health, social work, and chaplaincy experts, dialysis providers may better address frequently multidimensional symptoms such as pain or fatigue.

Revise the Default in Dialysis Decision Making From “Offer Dialysis” to “Consider Dialysis”

When patients either chronically or acutely lose kidney function, they often travel down an inexorable pathway toward dialysis initiation. Patients and families have been primed by their providers, hospital systems, and society to, often resignedly, accept dialysis as the next step in their care despite our knowledge that survival and quality of life may be comparable with or without dialysis in high-risk patients.¹⁹ Choosing medical management requires them in a sense to actually opt out of routine practice. Even when patients with advanced CKD express wishes to pursue medical management, they may find resistance from their providers or difficulty accessing alternatives to dialysis.²⁰

Borrowing from decision-making frameworks for considering other forms of life-sustaining treatment such as cardiopulmonary resuscitation,²¹ we can begin to shift our default approach in dialysis decision-making conversations from “offer dialysis” to “consider dialysis” or even “recommend against dialysis.” In this way, we base our discussion of dialysis initiation on the likelihood and plausibility of providing benefit versus harm in the context of the patient’s unique goals, rather than assuming that dialysis must always be offered. Moreover, as new policies regarding home treatment modalities and transplantation emerge following the recent executive order on kidney disease in the United States, our conversations may allow space for the development of new defaults. By re-examining our choice architecture and underlying assumptions, we can encourage more goal-concordant care at the end of life.

Conclusion

These strategies are only a starting point for actionable approaches to developing renal supportive care on the level of the individual provider. Future studies should evaluate the feasibility and effectiveness of specialist- and generalist-level palliative care interventions. Physician leaders and educators in nephrology and palliative medicine should take the lead in bringing our 2 disciplines in closer proximity, both conceptually and in practice.

Changing the status quo at a minimum requires that we have a shared common goal, a willingness to challenge, and reinvent, existing approaches, and leaders who make change their priority.

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REFERENCES

1. Davison SN, Levin A, Moss AH, et al; Kidney Disease: Improving Global Outcomes. 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.
2. Kane PM, Vinen K, Murtagh FE. Palliative care for advanced renal disease: a summary of the evidence and future direction. *Palliat Med.* 2013;27(9):817-821.
3. "Advancing American Kidney Health." Executive Order 13879. July 10, 2019. <https://www.whitehouse.gov/presidential-actions/executive-order-advancing-american-kidney-health/>. Accessed August 8, 2019.
4. Grubbs V, Tuot DS, Powe NR, O'Donoghue D, Chesla CA. System-level barriers and facilitators for foregoing or withdrawing dialysis: a qualitative study of nephrologists in the United States and England. *Am J Kidney Dis.* 2017;70(5):602-610.
5. 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.
6. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol.* 2010;5(2):195-204.
7. Selman LE, Bristowe K, Higginson IJ, Murtagh FEM. The views and experiences of older people with conservatively managed renal failure: a qualitative study of communication, information and decision-making. *BMC Nephrol.* 2019;20(1):38.
8. Cox CE, White DB, Hough CL, et al. Effects of a personalized web-based decision aid for surrogate decision makers of patients with prolonged mechanical ventilation: a randomized clinical trial. *Ann Intern Med.* January 29, 2019.
9. 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.
10. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage.* 2006;31(1):58-69.
11. Harrison TG, Tan-Tham H, Hemmelgarn BR, James MT, Sinnarajah A, Thomas CM. Identification and prioritization of quality indicators for conservative kidney management. *Am J Kidney Dis.* 2019;73(2):174-183.
12. Saeed F, Lupu D, Moss AH. The donut or the hole? Prioritizing patient and caregiver values in the delivery of high-quality medical management without dialysis. *Am J Kidney Dis.* 2019;73(2):153-155.
13. Schell JO, Green JA, Tulsy JA, Arnold RM. Communication skills training for dialysis decision-making and end-of-life care in nephrology. *Clin J Am Soc Nephrol.* 2013;8(4):675-680.
14. Jacobsen J, Blinderman C, Alexander Cole C, Jackson V. "I'd Recommend..." How to incorporate your recommendation into shared decision making for patients with serious illness. *J Pain Symptom Manage.* 2018;55(4):1224-1230.
15. 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.
16. Nakagawa S, Yuzefpolskaya M, Colombo PC, Naka Y, Blinderman CD. Palliative care interventions before left ventricular assist device implantation in both bridge to transplant and destination therapy. *J Palliat Med.* 2017;20(9):977-983.
17. Kamal AH, Maguire JM, Meier DE. Evolving the palliative care workforce to provide responsive, serious illness care. *Ann Intern Med.* 2015;163(8):637-638.
18. Adelson K, Paris J, Horton JR, et al. Standardized criteria for palliative care consultation on a solid tumor oncology service reduces downstream health care use. *J Oncol Pract.* 2017;13(5):e431-e440.
19. 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.
20. Wong SPY, McFarland LV, Liu CF, Laundry RJ, Hebert PL, O'Hare AM. Care practices for patients with advanced kidney disease who forgo maintenance dialysis. *JAMA Intern Med.* January 22, 2019.
21. Blinderman CD, Krakauer EL, Solomon MZ. Time to revise the approach to determining cardiopulmonary resuscitation status. *JAMA.* 2012;307(9):917-918.