

“I Realized It Was Kind of Too Late” Integrating Advance Care Planning into the Care of Patients with Kidney Disease

By Dale Lupu, MPH, PhD; Alvin H. Moss, MD; Nancy Armistead, MPA; and Brandy Vinson

“There’s no doubt that my wife and I waited too long to have that discussion, and part of that is—my wife is very quiet ... we’ve been married for 55 years. So we never really had that discussion. And before I realized, it was kind of too late.” (interview 6, man, health care proxy for patient with cognitive impairment) (1).

“I think that discussion should come before you get to the critical point. At the jump of a dime things could turn, so I think the more prepared you are, the better you could handle things when situations get tough.” (interview 1, family, woman) (1).

Patient and caregiver perspectives on advance care planning

In numerous studies, patients with chronic kidney disease (CKD) and ESRD have indicated that they want to talk about advance care planning (ACP) with their nephrologist and care teams (1, 2). ACP discussions are associated with improved goal-consistent care, including increased likelihood of dying in the patient’s preferred setting, reduced hospitalization, and less aggressive care at the end of life (3, 4). Yet only 6% to 38% of dialysis patients have an advance care plan (5). Even when ACP is documented in the dialysis patient’s medical record, it rarely documents specific patient preferences regarding dialysis. A study of Mayo Clinic dialysis patients found that only one half (49%) of the patients had a documented advance directive in their chart. Of these, only 10.6% of documents specifically mentioned patient preferences regarding dialysis, and less than one half (44.2%) addressed preferences for cardiopulmonary resuscitation (CPR) (6).

If this were merely a matter of getting more people to file paperwork, it might not be alarming. However, the low rates of ACP go hand in hand with evidence that patient preferences are not routinely elicited and followed. Davison (7) found that only 10% of patients reported an end-of-life care conversation with their nephrologist, despite the fact that such conversations were patients’ highest priority in end-of-life planning (8).

Barriers to ACP for CKD and ESRD patients

Leaders in nephrology have advocated for more widespread integration of ACP into care (9), but many barriers have slowed progress. Providers often do not feel this is their job, many do not adequately understand ACP, and there is a lack of integration of multidisciplinary resources that could help (10, 11). Furthermore, many implementation details—such as the best timing, setting, and team—have not been well researched, leaving providers to experiment on their own.

A 2015 editorial on ACP for nephrology patients explicitly called for studies of earlier ACP before choosing dialysis, with particular attention to the concerns of patients choosing supportive care (2). The editorial also called for studies that illuminate implementation, stating “[t]he nephrology community would benefit greatly from well conducted clinical studies of the implementation and effectiveness of advance care planning programs. It is time to stop discussing the need for such clinical processes and to start exploring ways to make it work” (2).

Recent systematic reviews have synthesized current knowledge about ACP (12). Through two decades of research, we have learned that multimodal interventions that treat ACP as an ongoing process involving two-way communication are usually more effective than a narrow focus on forms to be completed. We have also learned that family members often do not know what patients prefer, even when they are the designated decision-maker; that patients and family members prefer earlier communication; that ACP does not have a detrimental effect on distress or anxiety; that certain interventions are effective in improving the match between patient preferences and care received; and that certain interventions are associated with cost-savings, although true cost-effectiveness has not been studied.

ACP resources from the Coalition for Supportive Care of Kidney Patients

To help address the need for ACP tools specific to nephrology settings, the Coalition for Supportive Care of Kidney Patients (CCKP) has developed two patient brochures: one for patients before a dialysis decision and one for patients already on dialysis. A guide for staff to use in conducting an ACP discussion using motivational interviewing techniques complements the patient brochures.

The CCKP approach to ACP is to normalize the process by decoupling it from worsening prognosis. The CCKP suggests that everyone—especially those with a chronic disease—should have an advance care plan that specifies who should be called on to make medical decisions if the patient is unable to make them for herself and gives some guidance as to the principles to follow in making those decisions. The CCKP advises patients to follow five steps:

- 1) Choose someone to make health care decisions for you if you get sick and cannot speak for yourself.
- 2) Think about what kind of health care you would want if you were unlikely to get better. Discuss your wishes with your family and friends.
- 3) Write your wishes down in a legal form known as an advance directive (sometimes called a living will or a medical power of attorney).
- 4) Give a copy of your advance directive to your health care agent and your kidney care team. Continue talking to your family about your wishes.
- 5) Work with your kidney care team to complete a medical order form (usually called POLST, MOLST, or POST; polst.org) to record your wishes.

Ideally, ACP is one part of ongoing discussions that the nephrology team initiates about the issues that arise in serious illness and is integrated into the workflow for the nephrology clinic or dialysis center (13). Table 1 shows

common barriers to routine ACP and suggests resources or steps that a practice can take to improve its processes.

The nephrology community recognizes that successfully implementing ACP for CKD and ESRD patients is necessary to provide individualized patient-centered care. Multiple studies are underway to develop best practices for ACP for this patient population. ●

Dale Lupu, MPH, is affiliated with the Center for Aging, Health and Humanities, George Washington University, Washington DC. Alvin H. Moss, MD, is affiliated with West Virginia University School of Medicine Sections of Nephrology and Supportive Care, Morgantown, WV. Nancy Armistead, MPA, and Brandy Vinson are affiliated with Quality Insights Mid-Atlantic Renal Coalition, Richmond, VA.

References

1. Goff SL, et al. Advance care planning: A qualitative study of dialysis patients and families. *Clin J Am Soc Nephrol* 2015; 10:390–400.
2. Holley JL, Davison SN. Advance care planning for patients with advanced CKD: A need to move forward. *Clin J Am Soc Nephrol* 2015; 10:344–346.
3. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliat Med* 2014; 28:1000–1025.
4. Lockett T, et al. Advance care planning for adults with CKD: A systematic integrative review. *Am J Kidney Dis* 2014; 63:761–770.
5. Kurella Tamura M, Goldstein MK, Pérez-Stable EJ. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transplant* 2010; 25:237–242.
6. Feely MA, et al. Prevalence and contents of advance directives of patients with ESRD receiving dialysis. *Clin J Am Soc Nephrol* 2016; 11:2204–2209.
7. 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.
8. Weiner S. End-of-life care discussions: A survey of dialysis patients and professionals. *J Nephrol Soc Work* 2008; 28:52–60.
9. Combs SA. Working toward more effective advance care planning in patients with ESRD. *Clin J Am Soc Nephrol* 2016; 11:2107–2109.
10. O’Hare AM, et al. Provider perspectives on advance care planning for patients with kidney disease: Whose job is it anyway? *Clin J Am Soc Nephrol* 2016; 11:855–866.
11. Culp S, 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.
12. Bernacki RE, Block SD. Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Intern Med* 2014; 174:1994–2003.
13. Mandel EI, Bernacki RE, Block SD. Serious illness conversations in ESRD. *Clin J Am Soc Nephrol* 2016, in press.

Table 1

Barrier	Solution	Resources
Providers uncertain about how to discuss ACP	Use a conversation guide; enhance provider communication skills.	CSCKP ACP curriculum (kidneysupportivecare.org); VitalTalk training online (www.vitaltalk.org); Serious Illness Conversation Guide (https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&Tools)
Uncertainty over who should initiate ACP—nephrologist? Primary care provider? Patient?	Commit to taking the lead.	See CSCKP resources for professionals (http://www.kidneysupportivecare.org/For-Professionals/Advance-Care-Planning.aspx)
Uncertainty over which patients are appropriate and when	Use an opt-out standard—assume that all patients should be offered ACP unless there is a specific contraindication.	
Need educational materials and forms for patients	Multiple resources now available; review and select the one that best suits your practice and patients.	Prepare for your care (https://www.prepareforyourcare.org/page); recognized forms in all states (www.caringinfo.org/i4a/pages/index.cfm?pageid=328); additional resources (www.kidneysupportivecare.org/For-Patients-Families/Advance-Care-Planning.aspx)
Time crunch for nephrologist	Involve other team members, such as nurse practitioners, social workers, or other trained coaches.	American Nephrology Nurses Association's "Techniques to Facilitate Discussions for Advance Care Planning (ACP)" module is the first in a series of educational modules on EOL decision-making, and the Nephrology Nurse is an in-depth national program to promote education for nurses and improve end-of-life care
Not part of regular workflow of clinic	Develop a standard process; make it a standing agenda item at QAPI meetings.	The CSCKP has a model Advance Care Planning Policy template to assist dialysis facility staff in developing ACP policies and procedures (http://www.kidneysupportivecare.org/For-Professionals/Advance-Care-Planning.aspx)
Not integrated within EMR	Use a template within the EMR that captures key data, including proxy contact information and content of discussions about patient values and preferences; train all staff so that ACP discussions are consistently documented in the same location.	Most EMRs have a place where advance directives can be stored; use the EMR capacity and improve on it with custom fields; however, make sure everyone knows how to use it, what information needs to be documented, and where to find the information when needed
ACP documents information not shared across settings	Participate in the POLST registry if your state has one; participate in other registries as available; if no local registry, make sure that ACP information is conveyed routinely to other providers along with information, such as laboratory values; help patients recognize the importance of keeping documents accessible.	POLST programs by state (http://polst.org/programs-in-your-state/)
This all takes time, which is costly	Appropriately code ACP sessions to receive Medicare reimbursement for ACP.	https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf
Do not know whether ACP is making improvements	Adopt quality measures and conduct performance improvement projects for ACP.	Measuring What Matters—measures 7 to 9 (http://aahpm.org/quality/measuring-what-matters); additional suggestions in the work by Mandel et al. (13)

Abbreviations: ACP = advance care planning; CSCKP = Coalition for Supportive Care of Kidney Patients; EMR = electronic medical record; EOL = end of life; POLST = Physician's Orders for Life-Sustaining Treatment; QAPI = Quality Assurance & Performance Improvement.

Integrating Geriatrics into Nephrology: A Report on the 2017 American Geriatric Society Annual Scientific Meeting

By Rasheeda Hall, MD

The US dialysis population is growing faster than the number of new nephrologists. At the same time, our population is aging, and there is a shortage of geriatricians. Beyond efforts to expand the nephrology and geriatrics workforces, it is also extremely important to pursue interdisciplinary collaboration. How can we ensure that older adults receiving dialysis receive quality care for their geriatric conditions? How can geriatricians be great partners in managing older adults with chronic kidney disease? Communication between nephrologists and geriatricians will add value for patient care and generate ideas for research.

As the liaison between the American Society of Nephrology (ASN) and the American Geriatric Society (AGS), I attended the AGS annual meeting in May 2017. The meeting focused on current issues in aging and was geared toward all health care professionals who care for older adults, including nephrologists. The value of individualized care for older adults on the basis of life expectancy prediction was the focus of a compelling talk by Sei Lee of the University of California, San Francisco Department of Medicine, Division of Geriatrics. Patients predicted to have limited life expectancy are not likely to benefit from preventive interventions, such as colon cancer screening, Lee noted. This theme overlapped with my own presentation showing that the cost-effectiveness of

arteriovenous fistula is reduced in older adults with limited life expectancy.

Beyond life expectancy, another key theme at the meeting was co-management. A poster from Laura Fernandez and Julie Paik at the Boston Veterans Affairs Medical Center highlighted a Geriatric-Nephrology Collaborative Clinic, in which a geriatrician performed comprehensive geriatric assessments in older veterans with chronic kidney disease. The geriatrician then identified geriatric syndromes and provided treatment recommendations to the nephrology team. Although functional impairment was the most common geriatric syndrome, the most common treatment recommendations were medication changes followed by referrals to nonphysician services, such as rehabilitation or audiology.

Laura Plantinga and her colleagues at Emory University presented a study about the association of serious fall injuries in dialysis patients who received a kidney transplant. They found that patients who experienced a serious fall injury were nearly 80% less likely to be waitlisted. Among the waitlisted patients, those who had a serious fall injury were 53% less likely to subsequently receive a transplant. Prior studies show that falls increase mortality risk in dialysis patients, so these findings bring attention to yet another complication of injurious falls in this population.

Another highlight from the AGS annual meeting is

its annual morning meeting for medical subspecialists. As ASN liaison, I highlighted the ASN's Supportive Care online community and the Coalition for the Supportive Care of Kidney Patients Luncheon held at Kidney Week 2016. I also described current National Institute on Aging-funded research involving frailty, disability, and shared decision-making in older adults with ESRD. From other subspecialists' presentations, I learned about integrated working groups, such as the Cancer and Aging Research Group that pursues research collaborations across multiple institutions. This model of collaboration among various specialists at multiple institutions is an intriguing example for growing the field of geriatric nephrology.

Want to learn more and/or get involved in geriatric nephrology? Through the ASN's website, you can access the Online Curriculum on Geriatric Nephrology and the Supportive Care online community. At ASN Kidney Week 2017, you may network with members of the Supportive Care online community who will be present for a Supportive Care Meetup at the ASN Communities Lounge. Last, consider attending the next AGS annual meeting May 3 to 5, 2018, in Orlando, FL. ●

Rasheeda Hall, MD, is a medical instructor in the Division of Nephrology, Department of Medicine, at Duke University School of Medicine, in Durham, NC.