

Time to Talk About End-of-Life Care

By Alvin H. Moss, MD

It is not uncommon for physicians to poke fun at oncologists. Many have heard the joke, "Why do they put nails in coffins? To keep the oncologists from giving more chemo." Nephrologists might shake their heads when they read studies reporting that only one-third of oncologists have discussed end-of-life treatment preferences with patients who have metastatic cancer that did not respond to first-line chemotherapy.

While it is easy to laugh at our oncologist colleagues, it is sobering to learn that the five-year survival rate of incident dialysis patients—39%—is only slightly better than half that of incident oncology patients—70%. Furthermore, dialysis patients only live one-fifth as long as age-matched patients who do not have kidney disease, as documented by the United

States Renal Data System (USRDS). The average dialysis patient lives only three to four years.

Dialysis is a life-sustaining treatment, and more than three-quarters of patients on dialysis report that they would want to stop it in certain health states, such as permanent coma or severe dementia. Hence, there is a real need for not only oncologists, but also nephrologists, to talk to their patients about what treatments they would and would not want at the end of life.

What Patients Want

The vast majority of dialysis patients want to talk about end-of-life care, and most would like to have that discussion with their nephrologist.

In one study of 100 Canadian dialysis patients, 93% of respondents expressed

their desire to have these types of conversations with their physicians and learn as much information as possible about life expectancy and quality of life on dialysis.

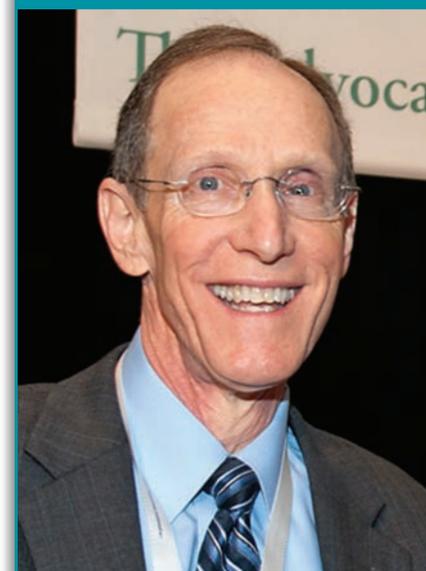
In a 2007 survey of dialysis patients and professionals conducted by the National Kidney Foundation, 76% of patients said they wanted to talk to a renal care team member about end-of-life care, and only 5% indicated that they would not want to discuss this topic if directly asked by a team member. Most patients—54%—had not had a conversation about end-of-life care with a member of the care team, and, in the professional survey, there was confusion on the part of the team about who was responsible for such discussions. The professionals also were not in agreement on when was the right time to have an end-of-life care conversation.

Nephrology journal articles and the recently published second edition of the Renal Physicians Association clinical practice guideline, *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis*, recommend that nephrologists conduct end-of-life

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The purpose of advance care planning with the dialysis patient is to help the patient understand his or her condition, identify his or her goals for care, and prepare for the decisions that may have to be made as the condition progresses.

VIEWPOINT



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conversations with their patients as part of the process of advance care planning.

The “surprise” question, “Would I be surprised if this patient died in the next year?” has been identified as a useful tool for nephrologists to identify dialysis patients who have a much greater risk of dying within the next year and are appropriate candidates for a discussion about advance care planning.

In the general medical literature, advance care planning conversations are associated with statistically significant benefits. The following are the most notable: better patient quality of life, less patient depression, lower costs of medical care, less aggressive medical care, earlier referral to hospice for dying patients, and better bereavement adjustment by the family.

Four Essential Elements

There are four essential elements to advance care conversations:

1. Determine the patient’s understanding of his or her current health condition and prognosis. (“As you understand it, what is your major medical problem? How serious is it?”)

2. Ask the patient what his or her goals for care are. (“What is most important to you in receiving treatment for your illness? Are there treatments you would want to avoid? Which is more important to you, living as long as possible regardless of pain, suffering, and being kept alive on machines, or living a shorter period of time to avoid pain and suffering and machines?”)

3. Identify the patient’s preferred decision maker in the event the patient loses decision-making capacity. (“Who would you want to make decisions for you if you become too sick to make them for yourself?”) Patients should

More Information Is Just a Click Away

Visit the *Nephrology Times* website to read more about caring for patients at the end of life:

- Withholding or Withdrawing Dialysis in the ICU: What’s Your Policy? http://bit.ly/ICU_Dialysis
- Dialysis and the Elderly Patient: Decision, Not Default http://bit.ly/Elderly_Dialysis
- In La Crosse, WI, End-of-Life Planning Begins Early <http://bit.ly/LaCrosseWI>



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Rather than taking away their hope, advance care planning leaves patients feeling empowered and armed with information that can help them plan and cope.

be encouraged to talk to this person to ensure their wishes are known and will be followed.

4. Complete a Physician Orders for Life-Sustaining Treatment (POLST)

form (or similar form depending on the state—see www.polst.org) to convert the patient’s treatment wishes into medical orders that will be followed throughout all health care settings.

The nephrologist, as part of the interdisciplinary renal care team, should encourage patient-family discussions about the patient’s values, preferences, and treatment goals, and include advance care planning in the overall plan of care for each individual patient.

The box contains a comprehensive list of steps for performing advance care planning with dialysis patients.

It relieves families of anxiety and guilt over whether they have made the right decision.

All Sides Benefit

Patients appreciate it when their physicians talk to them in a process of advance care planning. Rather than taking away their hope, patients report, such a process leaves them feeling empowered and armed with information that can help them plan and cope.

Families are also grateful for such discussions. They indicate that it is much easier to make end-of-life decisions if they have talked with their loved one about his or her wishes and can make the choices that they know their loved one would want. It relieves families of anxiety and guilt over whether they have made the right decision.

In other words, all sides benefit when nephrologists talk to their patients about their end-of-life treatment wishes. It is time for more of these conversations to occur. •

Advance Care Planning, Step by Step

- Assess decision-making capacity.
- Include advance care planning in the Comprehensive Assessment and Plan of Care for each patient.
- Inform dialysis patient of his or her right to complete an advance directive and of the dialysis facility’s policy with regard to these directives, as required by the 2008 End-Stage Renal Disease Conditions for Coverage.
- Encourage patient-centered advance care planning among patients and families, and raise the issue of advance care planning with each patient at the initiation of dialysis (earlier is preferred) and at least yearly after that. Hospitalizations or significant changes in medical, physical, or functional status should prompt reconsideration of advance care planning.
- Use the “surprise” question and be sure to initiate advance care planning when the physician would not be surprised if the patient died in the next year.
- Discuss advance care planning by asking:
 - If you become unable to make decisions for yourself, whom do you want to make decisions for you?
 - If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering, which would you choose?
 - Under what circumstances, if any, would you want to stop dialysis?
 - If your heart stops beating or you stop breathing, would you want to allow a natural death?
- Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
 - Where do you prefer to die, and who do you wish to be with you when you die?
- Determine whether the patient has an appointed legal agent through a written advance directive. If the patient lacks decision-making capacity and has not completed an advance directive, arrange for or initiate the process for appointing a surrogate according to state law.
- Encourage patients to be specific about their preferences with their legal agent, family, friends, and providers.
- Document provider’s discussion and understanding of patient’s preferences, show the patient the documentation, and offer to assist the patient in documenting the patient’s agreement or modification of the documentation. Where available, complete a Physician Orders for Life-Sustaining Treatment (POLST) or similar form to translate the patient’s wishes into medical orders (see www.polst.org).
 - Place a copy of advance directives, do-not-resuscitate (DNR) order card, and/or POLST form in multiple medical records as appropriate, including those of the dialysis facility, commonly attended clinics, hospital, home, and nursing home.
 - Encourage the patient, family, and/or legal agent to carry a current copy of the patient’s advance directive, DNR order card, and/or POLST form whenever traveling or being admitted for overnight medical care.