Shared Decision Making and Ethical Issues in Dialysis

By Alvin H. Moss

Based on cases I hear about from all over the country, I also get the sense that disruptive and difficult patients are more violent and threatening to dialysis staff than they used to be 10 to 20 years ago. Sadly, every year or two we hear of a dialysis nurse who was murdered by a patient.

**KN:** Please give us a summary of your work on Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis.

**Dr. Moss:** This clinical practice guideline was developed by use of the approach recommended by the Institute of Medicine, is evidence based, and makes 10 recommendations about the treatment of adult patients with acute kidney injury, chronic kidney disease (CKD), and ESRD. The Institute of Medicine defines clinical practice guidelines as “statements that include recommendations, intended to optimize patient care, that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.” With each recommendation in the Shared Decision Making guideline, there is a rationale with a literature review and also suggested strategies or resources that the nephrologist can use to implement the recommendation. There is a tool kit section in the guideline with helpful resources to calculate a comorbidity score, assess pain and symptoms, rate malnutrition, communicate with patients and families about their goals for treatment, and respond with a systematic process to a decision about whether to withhold or withdraw dialysis. This guideline has been recognized as the international gold standard for dialysis decision making. Unfortunately, in surveys of dialysis personnel in the United States, only about 15 percent are aware of and use the guideline. Ironically, when dialysis personnel are asked what would most help them in providing palliative care in their dialysis unit, they identify as their number one most helpful thing a clinical practice guideline just like the Shared Decision Making guideline. The guideline is now available for free for download from the Renal Physicians Association website at [http://www.renalmd.org/catalogue-item.aspx?id=682](http://www.renalmd.org/catalogue-item.aspx?id=682).

**KN:** As you know, we live in the age of technology, the age of social media, the age of the Internet. How has this influenced the minds of present-day clinicians in dealing with ethical issues?

**Dr. Moss:** I am afraid that the technological imperatives “if you can dialyze a patient, you must dialyze the patient” and the influence of social media have led nephrologists to think they are ethically obligated to dialyze everyone. Nephrologists are still under the Hippocratic maxim “to be of benefit and do no harm.” There is accumulating evidence that dialysis is not likely to benefit certain patients, particularly those over the age of 75 with significant comorbidities. Clinicians need to be more aware of the recent literature and the Shared Decision Making guideline, and know how to apply the ethical principles in the guideline to decisions with patients and families when dialysis is not medically indicated.

**KN:** Please briefly describe one or two unforgettable patients you have been involved with, and share with us your knowledge and experience in handling their cases.

**Dr. Moss:** I alluded to the first patient above. He was a 54-year-old gentleman with membranous glomerulonephritis but no other significant medical problems. He had a great arteriovenous fistula, and his dialysis treatments were smooth. He had the best set of laboratory results in the unit. When he asked to stop dialysis, I could not believe it. I did not know much then about ethical issues in dialysis. I punished and said to him, “I understand if we have been helpful to you for a month, and then if you still feel that way we can talk about it some more.” Fortunately, at the end of the month he did not bring it up, and I did not either. The following spring he said to me, “Doc, I’m really glad that you didn’t listen to me last fall, I just really enjoyed putting in my garden, and I’m looking forward to a great crop this summer.” I thought nothing more about it until November of that year, when he made the same request to me about stopping dialysis. It was only at that point that I realized that he had seasonal affective disorder. With appropriate treatment, he continued with dialysis for many more years! He did not want a transplant because he was doing so well with dialysis.

The second patient was a 75-year-old woman who had severe chronic lung disease from berylliosis. It was occupational acquired from working in a lighting plant in a nearby West Virginia town. She wore oxygen 24 hours a day and had recurrent problems with bronchitis and pneumonia. When she experienced advanced CKD, I recommended against dialysis because I was afraid that between the dialysis and the lung disease her quality of life would be very poor. She told me that she still had things to live for and that she wanted to give dialysis a try. Against my better judgment at the time, I had an arteriovenous fistula placed, and when ESRD developed she started dialysis. Fortunately I had a long discussion with her about the circumstances under which she would want to stop dialysis. Three years later she had a massive stroke, which left her in a coma, and I discussed with her family that she would no longer want to continue dialysis in her present state. The family agreed, and the decision to stop dialysis was made without conflict.

These cases taught me the importance of learning the patient’s perspective and identifying patients’ goals for treatment. Advance care planning is very important to conduct with patients to learn their wishes for treatment now and in the future. Once I had talked to that first patient, he had many reasons for wanting to live. Both cases highlight the importance of having a systematic process for addressing the decision to stop dialysis.

**KN:** What is your perspective on hospice in the dialysis population?

**Dr. Moss:** Hospice is for patients who have 6 months or less to live if their disease process takes its normal course. In my experience, many dialysis patients want to continue dialysis, but they also want better pain and symptom management to improve their quality of life. It would be ideal if patients did not need terminal diagnoses unrelated to their kidney disease to qualify for hospice and yet still continue dialysis. Concurrent dialysis and hospice would both meet the needs of these patients for meticulous pain and symptom management, comprehensive advance care planning, and psychological and social support for the patient and the family. I hope in my lifetime I will see a change in Medicare coverage to allow concurrent hospice and dialysis when the terminal diagnosis is related to kidney disease. I suspect that patients and families will report greater satisfaction and the cost of care will decrease because patients will have fewer hospitalizations.
Dr. Moss: You are right to state that the approach must be individualized. The most important factor in determining the survival of a patient on dialysis is not age but the severity of the patient’s comorbidities. Evidence over the past decade points to the following four factors as being statistically significant independent predictors of poor prognosis for dialysis patients: multiple significant comorbidities, particularly dementia and peripheral arterial disease; poor nutritional status; poor functional status; and age over 75. If the patient has two or more of these factors, the likelihood that dialysis will benefit the patient is questionable. Research findings now allow us to use a highly accurate validated integrated prognostic model that can be used for free online to predict 6-month and 12-month survival for hemodialysis patients (http://touchcalc.com/calculators/sq).

To use the website, nephrologists enter the patient’s age, serum albumin, the nephrologist’s response to the surprise question “Would I be surprised if this patient died in the next 6 months?” and whether or not the patient has dementia or peripheral arterial disease. The website then estimates the likely 6-month, 12-month, and 18-month survival times. This online calculator is based on research involving a thousand patients, with 500 patients in a derivation sample for the model and 500 patients in a validation sample. The C-statistic for accuracy of this integrated prognostic model was 0.8. This is as good a C-statistic for a prognostic model as is available for any other chronic disease. I would recommend that nephrologists use the integrated prognostic model and the recommendations in the Shared Decision Making clinical practice guideline to conduct individualized, patient-centered decision making about dialysis with patients and their families (see sidebar for Shared Decision Making guideline recommendations).

Dr. Moss: Palliative dialysis involves a transition from a conventional disease-oriented focus on dialysis as rehabilitative treatment to an approach to dialysis patient care in which the treatment the patient receives is aligned with the patient’s preferences for comfort and dignity over prolonged survival.

The goal of palliative dialysis is to improve the patient’s quality of life, to reduce the burden of symptoms, and to enable the patient to live as long as and as well as possible (the way the patient defines it) and to die gently. Patients receiving palliative dialysis likely will want limitations on other treatments. For example, likely they would not want intubation and mechanical intervention in an intensive care unit, they would not want CPR, and they would not want vasopressors used in the event of shock.

KN: Do you think that most clinicians today are more cognizant of this concept? Why or why not?

Dr. Moss: I believe only a minority of nephrology clinicians are aware of this concept. This concept is presented in the Shared Decision Making clinical practice guideline, which has not been well received. Several articles published on palliative dialysis have been published since that time, and I think palliative dialysis is still largely misunderstood.

KN: Do you think many of our colleagues opt not to discuss advance care planning with our future potential dialysis patients? Why or why not?

Dr. Moss: Most nephrologists have not been trained in how to conduct advance care planning conversations and therefore do not feel comfortable doing so. More and more it has been realized that nephrologists can team with a nurse practitioner, a nurse, or a social worker in the dialysis unit to facilitate advance care planning. The nephrologist does not need to conduct the whole discussion but needs to provide information to the patient, family, and other dialysis personnel about the patient’s present medical condition, prognosis, and likely future medical complications. In surveys, dialysis patients report that they want to participate in advance care planning discussions. These discussions are important because they are the only way nephrologists and other nephrology clinicians will be able to identify and respect patients’ future treatment wishes.

KN: Do you have any final practice advice to our colleagues, young and old, on this issue?

Dr. Moss: I recommend that everyone reading this article and download, save, read, and refer to the Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis, 2nd edition, clinical practice guideline as needed when clinical situations arise. The guideline contains strategies for implementing each recommendation in patient care. In addition, I would refer colleagues to the Coalition for Supportive Care of Kidney Patients website, www.kidneysupportivecare.org. This website has many resources that can aid nephrology clinicians in learning about pain and symptom management, advance care planning, and other aspects of supportive care for the kidney patient. It includes an up-to-date bibliography of articles published about palliative dialysis. Third, I would recommend to my colleagues that they download the free iTunes app made possible by the Renal Physicians Association with a grant from DaVita. The app contains workflow for renal palliative care for patients before dialysis, during dialysis, and as dialysis is stopped. It contains links to the above websites and to many helpful palliative care resources for kidney patients. Finally, I would recommend to my colleagues that they identify a palliative care physician in the community with whom they can collaborate in the care of more complex patients. It is unreasonable to expect that nephrology clinicians have the time and the skills needed to treat all the issues raised by a dialysis center full of patients. Palliative care clinicians can assist nephrologists even before the patient is thought to be terminally ill. There are strong collaborations between nephrologists and palliative care clinicians throughout the country, and the patients and the clinicians benefit from this teamwork.

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