

When Enough Is Enough: Guiding End Stage Renal Disease Patients through Cessation of Dialysis

Nina O'Connor, MD

Dr. O'Connor (nina.oconnor@uphs.upenn.edu) is an associate professor of clinical medicine at the Perelman School of Medicine and the director of hospice and palliative care for the University of Pennsylvania Health System.

M*K is a 62-year-old male with diabetes and hypertension who has been on hemodialysis for almost 10 years. He underwent a right below-the-knee amputation last year for a nonhealing wound and osteomyelitis. More recently, he has had two hospitalizations for sepsis from presumed line infections. Imaging for back pain now leads to a new diagnosis of Stage IV prostate cancer with widespread bone metastases.*

In 2013, more than 117,000 new cases of end-stage renal disease (ESRD) were diagnosed in the United States.¹ The total number of patients with ESRD continues to rise by about 21,000 cases per year, and more than 80% of ESRD patients receive hemodialysis.¹ Dialysis patients have substantially higher mortality than patients with other chronic illnesses, including diabetes and cardiovascular disease.¹ The elderly on dialysis have especially poor prognosis. Dialysis patients over age 75 have a one-year survival of 53% and spend 20% of their time in a hospital.²

Patients may contemplate stopping dialysis for many reasons. Some patients for example suffer a catastrophic event, such as a stroke or heart attack. Other patients develop a second life-limiting illness, such as cancer. For some patients, declining functional status and quality-of-life prompt questions about whether dialysis should be continued. One large study of nursing home residents reported substantial and sustained decline in functional status in the year after dialysis initiation.³

Unfortunately, very few ESRD patients have talked to their physi-

Table 1: Renal Physicians Association Guideline for Shared Decision Making about Stopping Dialysis⁴

Clinical Situations in which Cessation of Dialysis Should Be Considered
• Request to stop dialysis by a patient with decision-making capacity
• Request to stop dialysis by the legal surrogate of a patient who lacks decision-making capacity
• Irreversible, profound neurological impairment
• Inability to cooperate with the technical process of dialysis (e.g., advanced dementia patient who pulls out dialysis needles)
• Unstable condition that makes dialysis difficult (e.g., hypotension)
• Development of a non-renal terminal illness

cians about end-of-life preferences. Most advance directives fail to capture circumstances in which an ESRD patient would no longer want dialysis. Despite perceived barriers to raising this difficult topic, data suggests that ESRD patients want more conversation about end-of-life options including stopping dialysis. The Renal Physicians Association has affirmed a patient's right to stop dialysis and encourages physicians to use a shared decision-making model when discussing this option with patients and families (see Table 1).⁴

If patients share thoughts about wanting to stop dialysis, physicians should respond with open, nonjudgmental attention. A request to discontinue dialysis may reflect either a long-standing desire or short-lived expression of frustration. Physicians should explore motivating factors using open ended questions and an invitation to "tell me more." Importantly, requests to discontinue life-sustaining treatments are not equivalent to suicidality. A time-limited trial of treatment for co-existing

depression is reasonable, but even patients with a positive depression screen can make end-of-life treatment decisions if they have decision-making capacity.

Unlike patients who decide not to start dialysis (and can live for months or longer), patients who discontinue dialysis have a very short prognosis. One study of 1,947 patients who enrolled in hospice after dialysis discontinuation reported a mean survival of 7.4 days (range 0-40 days).⁵ Two older studies both reported a mean survival of 8 days (range 1-46 days).^{6,7} The wide range in survival in these studies likely reflects residual renal function which is difficult to assess while patients are still receiving dialysis. Among patients who do stop dialysis, certain clinical factors can be used to predict survival when counseling patients and families (see Table 2).⁵

Patients who discontinue dialysis often experience pruritus, anorexia, and progressive somnolence due to uremia. They are also prone to volume overload, resulting in pulmonary

continued on page 2

MORNING REPORT

continued from page 1

edema, peripheral edema, and secretions. Diuretics are unlikely to be effective, so dyspnea should be treated with opioids instead. Respiratory secretions can be treated with anticholinergic medications, such as glycopyrrolate, scopolamine, or hyoscyamine. Myoclonus sometimes develops due to electrolyte abnormalities or accumulation of medications including opioids. If myoclonus causes distress, it can be treated with benzodiazepines. Aggressive electrolyte management is inappropriate at the end of life.

Opioid selection requires special consideration in patients who have discontinued dialysis. Fentanyl is considered the safest opioid in ESRD because of its hepatic metabolism and lack of active metabolites, but other opioids can be used safely at end-of-life. Morphine is the opioid of choice in ESRD patients with a prognosis of hours or days given its low cost, widespread availability, and multiple routes of administration including sublingual formulations for patients who cannot swallow. If morphine is used, clinicians should monitor for myoclonus and rotate to another opioid if myoclonus develops. Prolonged administration of morphine in renal failure can lead to delirium and seizures.

All patients who discontinue dialysis are eligible for hospice, so hospice should be recommended concurrent with cessation of dialysis. ESRD patients who receive hospice services are three times less likely to die in the hospital than patients who do not receive hospice.⁸ End-of-life care costs are also significantly lower for ESRD patients who

Table 2: Predictors of Survival after Dialysis Discontinuation⁵

Clinical Characteristic	Adjusted Median Survival in Days (Interquartile Range)
Palliative performance score of 10-20	3 (1-4)
Palliative performance score > 20	7 (3-9)
Initial site of care at home	9 (6-12)
Initial site of care in a hospital or inpatient hospice	4 (2-7)
White race	8 (5-12)
Nonwhite race	5 (2-8)
Male gender	6 (3-10)
Female gender	7 (4-9)
Oxygen use	6 (3-9)
No oxygen use	7 (4-9)
Peripheral edema	4 (2-5)
No peripheral edema	8 (5-11)

receive hospice.⁸ Despite these benefits, only 25% of Medicare beneficiaries who died with ESRD in 2012 were enrolled in hospice.¹

Several studies have examined dialysis discontinuation from the perspective of bereaved family members. One prospective cohort study followed 131 family members longitudinally after dialysis discontinuation of a loved one.⁹ In post-death interviews, these family members rated 38% of deaths as “very good” and 47% of deaths as “good.” Another study found low levels of family distress five years after dialysis withdrawal and death of a loved one.¹⁰ These studies suggest that families successfully adapt to the loss of a loved one after discontinuation of dialysis.

MK undergoes radiation and hormonal therapy for his prostate cancer, but his cancer progresses. He is

dependent in all activities of daily living, and his bone pain requires increasing doses of opioids. Dialysis becomes difficult, and MK begins to express interest in comfort-focuses care. After multiple conversations with his internist and his oncologist, MK decides to stop dialysis and enroll in hospice. His family is supportive. MK dies peacefully at home 9 days later.

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MORNING REPORT

continued from page 2

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