Opportunities to Improve End-of-Life Care in ESRD

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With their 1986 publication, Neu and Kjellstrand acknowledged that some dialysis patients choose to stop dialysis (1). At the time, their report was provocative because the topic had not been acknowledged. Since then, stopping dialysis is recognized as a common practice that is a leading cause of death in this population. At the time of this landmark article, palliative medicine was not yet a known subspecialty and although some had heard of hospice care, it was nascent and rarely considered in diseases other than cancer. Since 1986, however, hospice and palliative medicine have experienced tremendous growth in oncologic patients. Presently, more patients with noncancer illnesses are in hospice than those with cancer. In nephrology, we now appreciate that some patients do poorly on dialysis and that this treatment may impart more harm than benefit. Recognizing the potential harm of dialysis, we have clinical practice guidelines to assist nephrologists in withholding and withdrawing dialysis as a guide to assist decision making (2).

However, these guidelines have not translated into improved hospice care for patients with ESRD. Although they experience an annual mortality rate >20%, dialysis patients are half as likely to receive hospice services compared with other hospice diagnoses (3). Hospice underutilization in ESRD can partly be explained by a lack of education in palliative care aspects of clinical nephrology (4) and training in how to engage in timely discussions of advance care planning and end-of-life counseling (5).

Another barrier is how hospice is currently financed for ESRD patients. Administrative and financial issues dictate that two Medicare benefits (e.g., hospice and dialysis) can accrue only if each is covered under distinct diagnoses. If a patient enrolls in hospice under an ESRD diagnosis, dialysis is typically stopped and Medicare pays for hospice services. If dialysis continues, the hospice program would likely be responsible for the Medicare dialysis costs if a secondary insurance is not available to pay for dialysis. Hospices can rarely afford to pay for dialysis. This is quite different from other hospice diagnoses that will pay for treatments such as palliative chemotherapy or noninvasive ventilation. In addition, compared with these diseases, stopping dialysis has a worse prognosis (e.g., patients typically live only 1–2 weeks after dialysis is stopped). Therefore, patients typically are offered and choose hospice late in their illness, after an acute preterminal illness.

The ability to deliver high-quality hospice care is limited by a patient’s short survival time. In this issue of CJASN, O’Connor et al. present a description of patients who stop dialysis and are admitted to hospice. The authors verify Neu and Kjellstrand’s finding that dialysis patients who stop dialysis and enroll in hospice live an average of approximately a week after hospice enrollment, a significantly shorter survival than non-ESRD patients admitted to hospice. Even patients who continued dialysis while enrolled in hospice lived a median of only 17 days (6). Given the symptom burden of patients living on dialysis, earlier hospice services may positively affect symptom management, end-of-life outcomes, and family bereavement (7).

The authors provide descriptive information regarding location of care before hospice admission. Within this cohort of 1947 patients, 52.8% of patients enrolled in hospice from either the hospital or an inpatient hospice unit compared with 27% of other hospice patients (6). It is likely that many of their patients were stopping dialysis in the setting of an acute event, rather than as a result of a chronic, progressive course leading to incremental loss of function and quality of life. From our experience, it seems that there are two general kinds of patients who stop dialysis: those with an acute, intervening illness and those who do not have an acute event but tire of the burden of dialysis and so choose to stop, although they are chronically ill. This latter subset represents a unique population who may benefit from earlier introduction of palliative care services, such as symptom management, advance care planning, and spiritual and bereavement care. This study limits our ability to distinguish between these two groups of patients. Hospital as the location of care before hospice admission is not surprising and commonly occurs in dialysis patients compared with patients with other illnesses (8).

This study does not include information on health status before the decision to stop dialysis and initiate hospice. However, there are suggestions that the dialysis patients were more functionally limited compared with other hospice patients. Over 60% of dialysis patients had a Palliative Performance Score ≥20, indicating a health state characterized as bed bound with minimal intake and profound mental status impairment. We do not know the symptom burden in these patients; however, there was no difference in intravenous opioid use between patients who stopped dialysis and other hospice patients. Dialysis patients have a high
symptom burden and, although information is limited, also seem to have significant symptoms at the end of life (9). The suggestion that patients in the study by O’Connor et al. had similar intravenous opioid needs compared with other hospice patients calls for better information about symptom management in CKD and ESRD patients at the end of life.

The authors identified predictors of survival in dialysis patients after stopping dialysis to guide survival estimates after the decision is made. Discussing what to expect after dialysis is stopped can help patients and families prepare for end of life; however, we need improved preparation and care upstream to the decision to stop dialysis. Patients experience multiple transitions throughout the kidney disease course such as progression of kidney disease, dialysis initiation, and consideration for dialysis withdrawal (10). These transitions illustrate the need to regularly readdress symptom needs and initiate end-of-life planning with patients and families. Patients living on dialysis would benefit from these palliative care domains throughout the disease course.

The question remains whether the full benefits of hospice can be realized if one is enrolled only a week or two before dying. We believe this time is insufficient to meet the symptom and end-of-life needs in ESRD. It seems reasonable that early palliative care would provide a mechanism for improved hospice delivery to patients and their families. However, even with early palliative care introduction, the current Medicare benefit serves as a disincentive for patients to receive hospice and continue dialysis. Ideally, concurrent dialysis and hospice services would encourage early assessment and management of symptoms and end-of-life planning in a way that improves patient experience and preparation for end of life. For timely palliative care integration into nephrology, early access to hospice services is needed.

Better integration of palliative care and hospice into nephrology also may lead to earlier discussion of advance care planning. In the study by O’Connor et al., only 25.7% of the dialysis patients who discontinued dialysis and enrolled in hospice had advance directives (6). This finding suggests a lack of preparation for end of life and the potential for caregivers to have to make the difficult decision to stop dialysis without the patient’s input. Advance care planning is a dynamic process that involves more than completing written advance directives. This process involves determining care preferences depending on health state, designation of a proxy or surrogate decision maker, and invoking physician orders for life-sustaining treatment where available (11). Advance care planning ideally occurs over time and typically requires that quality of life and goals of care be readdressed at intervals depending on life and health circumstances (12,13). Patients have told us they want physicians to raise these issues (14), that they desire information on prognosis early in the course of CKD (15), and that they rarely consider stopping dialysis among end-of-life treatment decisions (16,17). Early and repeated efforts to assist patients and families in identifying goals of care are a palliative care intervention worthy of our time and effort. Advance care planning would reasonably then lead to earlier hospice referral and improved symptom management.

Many dialysis patients choose to stop dialysis. It is a leading cause of death in dialysis patients and serves as an accelerated transition to end of life. As palliative medicine becomes standard of care for patients living with chronic illness, we are tasked with how best to provide these services. Currently, hospice access is not uniform and may occur too late to have a large effect. As important, we worry that the care before hospice does not sufficiently treat their symptoms or prepare them for when they may decide to end dialysis. With improved education and care models, nephrologists and/or other dialysis unit personnel (nurses, advance practice providers, social workers) may embrace their role as providers of palliative care so that earlier, more effective care could be delivered to our patients independent of dialysis status. By eliminating dialysis as a barrier to these services, timely investigation of goals of care can be incorporated into the overall dialysis care plan for each patient and promote patient-centered consideration of care options, including stopping dialysis. We can better serve and treat our patients by earlier incorporation of palliative care into our care plans to maximize our end-of-life treatments.

Disclosures
None.

References
voluntarily divulge survival data to potential dialysis patients: A

Failure of advance care planning to elicit patients’ preferences
for withdrawal from dialysis. *Am J Kidney Dis* 33: 688–693,
1999

17. Janssen DJ, Spruit MA, Schols JM, van der Sande FM, Frenken
LA, Wouters EF: Insight into advance care planning for
patients on dialysis. *J Pain Symptom Manage* 45: 104–113,
2013

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See related article, “Survival after Dialysis Discontinuation and
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