Nephrologists’ Interactions and Attitudes toward Palliative Care, End of Life

By Areeba Jawed

“Can I stop dialysis?” asked my 88-year-old wheelchair-bound patient on a late fall afternoon. I squinted my eyes to block not only the streaming sunlight but my reaction: one of bewilderment.

In a 2015 study of nephrology fellows, 99% of respondents agreed that physicians have a responsibility to help patients at the end of life (EOL) and in preparing for death; however, in their fellowship training, less than one-half were taught how to respond to a patient’s request to discontinue dialysis therapy, conduct a family meeting about dialysis options, or determine when to refer patients to hospice or palliative care (1). As per the US Renal Data System, patients older than 75 years are the fastest growing dialysis population (2), and among the elderly with acute kidney injury who need dialysis, studies show that 50% or more die within the hospitalization (3). Now, more than ever, nephrologists face the question of EOL care in patients with chronic kidney disease and encounter the need for shared decision-making in the intensive care unit (ICU) when offering acute dialysis to the elderly with poor prognosis.

Patients on dialysis have a remarkably low rate of documented EOL preferences, despite known high mortality rates and evidence supporting that advance care planning (ACP) improves EOL care (4). Compared with cancer or congestive heart failure patients, ESRD patients are far more likely to be admitted to the ICU and much less likely to be enrolled in hospice in the last month of life, demonstrating the need for increased use of palliative resources by the nephrology community (5). It is particularly disappointing to see patients with ESRD do so poorly compared with others with chronic illnesses in this regard while there exists an environment conducive to eliciting patients’ preferences giving the frequent interaction with dialysis providers three times per week and continuity of care that may last for years.

Many reasons may account for the current attitude of nephrologists toward ACP and the suboptimal utilization of palliative care resources for dialysis patients. In a qualitative study undertaken to evaluate provider perspectives regarding ACP and to identify system-level barriers for its provision, four overlapping themes emerged that focused on the complex and fragmented nature of ESRD care, the lack of understanding of ACP by providers, the unclear locus of responsibility for ACP, and a dearth of active collaboration among different providers of the same patients (6).

Most dialysis patients welcome discussions regarding prognosis and EOL preferences; however, they report a lack of initiation of such conversations by providers (4). These attitudes may be explained by multiple reasons: lack of time, discomfort experienced by clinicians when approaching EOL issues, clinicians not viewing it as their responsibility, and the uncertainty associated with communicating prognosis owing to a lack of reliable prognosticaton tools to help guide clinical decision-making. There is little emphasis during clinical training on providing learners with a skill set for effective conversations about serious illnesses (1); however, more recently, communication skills models for learning have been developed, such as NephroTalk, and various prognostication tools are available (7, 8).

Lack of knowledge among providers and patients regarding palliative care and hospice options further limits their use. In a survey study from Europe representing 45 countries, the majority of nephrologists stated that their core curricula did not include palliative care. Additionally, they had not attended continuous medical education sessions on this topic (9).

Current metrics to assess delivery of standard of care in dialysis patients focus on disease-specific parameters and leave little room to recognize the need and reward of the provision of palliative care to reduce symptom burden in patients. In fact, nephrologists in the United States identified financial incentives for dialysis as a potential barrier to withdrawal of dialysis therapy when warranted; this was compounded by lack of compensation for lengthy EOL care discussions with patients and families (10). Electronic health records can also facilitate or hinder the job of the nephrologist in ACP depending on how well the interface interacts with multiple providers; instances have been described where patients reportedly had conversations with primary care providers (PCPs) regarding EOL care that were not communicated to nephrologists by the patient or the PCP (11).

Patients on dialysis have multiple comorbidities, high symptom burden, and mortality approaching those for certain malignancies. There is a well recognized need for subspecialist palliative care skills in the nephrology world. Efforts need to be made to incorporate palliative care education within the nephrology curriculum for trainees, and system-level barriers should be addressed to facilitate provision of appropriate EOL care to dialysis patients. Nephrologists must advocate for the rights of their patients to live the life they desire, because “…in stories, endings matter” (12).

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References