Palliative Care and Nephrology: Moving Upstream Together

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Patients with ESRD experience a high degree of symptom burden—physical symptom burden akin to patients with advanced cancer, along with emotional and spiritual suffering. In addition, ESRD patients on maintenance dialysis have the highest levels of medicalization at the end of life, surpassing what is experienced by their counterparts with other advanced chronic illnesses (1). Although high-intensity health care at the end of life may be goal concordant for a minority of patients, it is not on a population level. A large Veterans Affairs study evaluated family-reported quality of end-of-life care among 57,753 decedents and noted that quality of end-of-life care was significantly better for patients with cancer and dementia than for patients with ESRD, cardiopulmonary failure, or frailty (2). This quality advantage was mediated by palliative care consultation among other variables and is evidence for what many clinicians already know; there is a need to better integrate palliative care principles in ESRD care.

Palliative care is specialized interprofessional care for anyone with serious illness focused on relieving the symptoms and stress of that illness. The goal is to improve quality of life not only for the patient, but also for their friends and family. Within the field of nephrology, provision of palliative care for patients with advanced kidney disease is also known as kidney supportive care. The care is interprofessional precisely because patients suffer in multiple domains, including decision support for renal replacement therapy and assessment and treatment for emotional, physical, or spiritual and existential needs. This means that palliative care can and should be provided in conjunction with life-prolonging measures (Figure 1).

Much of the literature on kidney supportive care focuses on conservative (nondialysis) management of ESRD. However, there are existing models in the United Kingdom and Australia of kidney supportive care programs that also provide concurrent palliative care for maintenance ESRD patients. For instance, Brown et al. (3) in Australia have established a Renal Supportive Care Clinic that sees not only patients on a nondialytic maximal conservative management pathway but also patients on maintenance dialysis in order to assist with advance care planning (ACP), goals of care, and complex symptom management (4). Clinician education programs have also been developed to better equip interprofessional staff to address these issues.

Murtagh and coworkers (5) in the United Kingdom developed the Renal Specific Advanced Communication Training Program to improve communication skills for hemodialysis nurses and nephrologists. Currently, a multicenter study at Baystate Medical Center and the University of New Mexico is implementing a multimedial shared decision-making intervention for dialysis social workers and nephrologists who work with high-risk patients (6). The intervention will use the surprise question (Would I be surprised if this person died in 6 months?), which has been shown to be predictive of survival, to screen for the highest-risk patients. Dialysis social workers will be the primary facilitators of this intervention for improved end-of-life communication.

In reimagining how we can continue to improve the experience of dialysis patients and their friends, families, and caregivers, we can also learn from the oncology experience. In 2017, the American Society of Clinical Oncology published evidence-based recommendations regarding the integration of palliative care into standard oncology care. On the basis of the existing evidence, a recommendation was made that patients with advanced cancer should receive dedicated palliative care services early in the disease course concurrent with active treatment (7). One of the landmark trials of early palliative care supporting this guideline occurred in a population of patients with metastatic non–small cell lung cancer. Patients randomized to the early palliative care group had not only significant improvements in anxiety and depression but also a 2.7-month survival benefit—akin to the benefit of adjunctive chemotherapeutic agents in this population (8). The study used a palliative care intervention embedded within the oncology clinic—a model of care that could be adapted to the ESRD space.

In addition, ESRD Seamless Care Organization programs established through the Comprehensive ESRD Care Model present a unique opportunity to re-envision care delivery for dialysis patients, including better integration of palliative care. Innovative interventions have included nephrologist and dialysis social worker training to improve advance care planning (ACP) and end-of-life communication among staff, patients, and families. At Northwest Kidney Centers in Seattle, Washington, a novel Mobile Renal Supportive Care Team is being created to provide specialty-level palliative care in the dialysis facility and the home. Ultimately, the most successful strategies will leverage education to elevate interprofessional ability to provide primary palliative care—the palliative skills that every clinician should have—as well as improve access to specialty-level palliative care.

Because all ESRD patients have a serious illness and could stand to benefit from palliative care, how might we think of this heterogeneous group of patients? One could group patients in the following way: the older stable patient on dialysis, the patient with severe symptoms despite optimized dialysis, the patient considering dialysis withdrawal, and the patient with a poor prognosis. The strategy to meet their needs will be necessarily different: normalizing ACP and establishing long-term goals of care for future care planning in the first patient, ameliorating symptoms in the second patient, uncovering and addressing potential unmet palliative needs that may be driving a request for dialysis withdrawal and guiding through the process of withdrawal if goal concordant in the third patient, and expediting ACP in anticipation of approaching future decline in the fourth patient.

In summary, there are existing and emerging models of integrating palliative care principles into existing care delivery to meet the needs of the dialysis population. These include normalizing ACP earlier in the trajectory of disease and leveraging interprofessional training to improve meaningful ACP as well as formalized kidney supportive care teams to provide specialty-level palliative care for patients with the highest needs. In lieu of dedicated kidney supportive care staff, nephrologists can partner with local outpatient palliative care providers to address the needs of the patients they serve.

References