

Renal Palliative Care Studies: Coming of Age

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WILLEM KOLFF, the father of the artificial kidney, built the world's first kidney dialysis machine from sausage casings and an automobile water pump component in Netherlands during World War II. He dialyzed his first patient in 1943. The procedure was originally intended to support patients with acute kidney disease for a short time while their kidneys recovered.

Patients could not tolerate Kolff's kidney machine indefinitely as their arteries and veins sustained damage over time and it was difficult to safely access the patients' vasculature to conduct dialysis. This problem was solved by Belding Scribner who invented the Teflon shunt that spared the patient's vasculature and allowed for long-term dialyses. In 1962, when Scribner started the world's first outpatient dialyses unit, he had only six dialyses machines and thus a committee was formed to decide which patients could have access to this life-saving procedure. Medicare, which was established in 1965, did not initially pay for dialyses. Thus kidney disease was a fatal condition as access to dialyses was limited. It was not until 1973 that Medicare began covering dialyses costs making dialysis the mainstay of treatment for kidney failure.

Over the past few decades, numerous patients have been on maintenance dialyses for years to decades. However, there is an increasing trend of starting dialysis on patients with greater comorbidity¹ and lower functional status.² Outpatient dialysis units are typically not equipped to manage chronically critically ill patients with decompensated cirrhosis, end-stage heart failure, or severe autonomic dysfunction, for example. When this occurs, patients are hospitalized, dialyzed in inpatient units, or sometimes discharged to subacute care facilities equipped with or associated with dialysis units. Originally, dialysis was restricted to otherwise well individuals with anticipated renal recovery or rehabilitation: Dialysis is now offered to patients irrespective of their functional status, and without exploring their goals of care giving rise to a growing cohort of "end-stage-dialysis-patients."

The adjusted all-cause mortality rate for patients on dialysis exceeds that of patients with cancer, congestive heart failure, and stroke.² The annual mortality rate of end-stage dialysis patients is likely much higher. Many patients express regret at starting dialysis and have unrealistic expectations of dialysis.³ Their symptom burden is immense including fa-

tigue, pain, cramping, and nausea, and may be worsened by treatments.⁴ The median time to recover from the dialysis treatment is more than four hours.⁵ Many patients accept this burden, particularly when little is offered as an alternative to continuing dialysis. Concurrent palliative care with maintenance dialysis is an excellent alternative that aims to mitigate symptom burden and improve quality of life in dialysis patients.

It is also vital to explore the patients' goals of care and tailor the care to be patient centered and family oriented. It is in this context that Feely et al. implemented a center-wide strategy of palliative care consultation with patients in an in-center hemodialysis unit.⁶ Their goal was to determine the impact of the specialist palliative medicine (SPM) on advance directives and patient symptoms. To do so, they measured the prevalence of completed advance directives and symptom burden before and after the consult. Advance directive completion was determined by medical record review and symptom burden was measured by the validated Modified Edmonton Symptoms Assessment scale (MESAS).

Nearly all patients participated in the intervention, which was conducted by board-certified palliative medicine physicians. Post-intervention, there were fewer patients with unknown code status, more had advance directives, and many more had goals of care discussion documented. Overall, symptoms were graded higher at follow-up, although Feely et al. note the change may not be clinically significant because of the small change in MESAS scoring. If it is significant, it may also speak of the cumulative symptom burden accrued with time on dialysis, rather than related to the intervention, which was provided to all patients. The process of inquiring about symptoms may serve to focus patients' attention on symptoms and in doing so lead to higher rating of symptoms at follow-up. Regardless, it should prompt us to design supportive care interventions that are powered to detect a clinically meaningful difference in these important symptoms.

Maintenance dialysis therapy involves benefit and burden trade-offs, which individual patients may gauge differently. There is a delicate tipping point in the illness trajectory after which the burden on dialysis may outweigh its benefits for an individual patient. Beyond this point, dialysis may not be the "best" treatment option. Thus there is a pressing need to

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incorporate concurrent palliative care into routine dialysis care. Feely et al. have effectively demonstrated that palliative care consultation can be implemented at the chairside in a large unit.⁶ This lays the groundwork for future research on how to best deliver concurrent palliative care in the dialysis unit. Kidney Disease Improving Global Outcomes (KDIGO) organized a supportive care conference in December 2013, and after extensive review of the existing literature, the workgroup outlined a research agenda.⁷ The next steps should include testing the impact of concurrent palliative care consults on outcomes relevant to patients receiving maintenance dialysis and those with advanced kidney disease.

Although the need for concurrent palliative care is vast, it cannot be met by SPM physicians alone. We need to train nephrology professionals in primary palliative care skills and we need to study the effectiveness of palliative care interventions delivered by nephrology teams. The time for renal palliative care studies is now.

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