Four Plus Forty-Four: Hours to Modify, Theirs to Enjoy

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The evolution of dialysis care over the last 60 years is noteworthy. From the earliest days, when Kolff used the drum dialyzer, through many iterative changes, discoveries, and developments, dialysis can now be used in multiple settings under numerous adverse circumstances for prolonged periods of time. However, with these innovations and successes come new and perhaps, more challenging questions around appropriateness, futility, and how we as clinicians can measure benefit. Many clinicians will recall times when, in hindsight, it was unclear whether the patient benefitted from dialysis treatments, whereas some may recall situations where, perhaps, the initiation of dialysis played a role in what resulted in a difficult or prolonged dying process.

As the evidence against dialysis treatment is growing, so are the questions around appropriateness in certain subgroups (1–5). Increasingly, studies are showing, particularly in older individuals with a high burden of comorbidity, that patients can do equally well with or without dialysis treatments (6–11). In several centers, nondialysis (or conservative care) pathways are being incorporated into clinics, and patients are being educated about their right to choose to not include dialysis in their renal care plan. In this issue of CJASN, Brown et al. (12) further add to the data supporting nondialytic pathways. Brown et al. (12) present data that show that symptoms can be effectively controlled and that patients experience similar quality of life with or without dialysis. In their program, patients who opt for a nondialytic care plan are seen by both the nephrologist and a palliative care team (12). The palliative care team members actively elicit and manage physical symptoms and existential issues and help with advance care planning, whereas the nephrology team continues to work at preserving residual renal function, anemia management, and fluid balance. At the 6- and 12-month marks, 42% and 57% of patients, respectively, in the collaborative program reported reduced symptom burden, which one assumes is despite progression of their renal disease.

The option to forgo dialysis as part of the renal care plan is increasingly being offered to patients and families, and similar clinics are slowly being established worldwide. Studies from the United Kingdom, Australia, and Canada suggest that around 15%–20% of those advised to consider a conservative or nondialytic route would actually opt out of dialysis care (6,7,9–11). A few will change their mind over time, but most do not, and families report a satisfactory or good dying process. Although the proportion of patients opting out of dialysis care varies with patient demographics, geographic location, and cultural environment, one would expect these numbers to continue to stabilize over time as we improve prognostication and more and more clinicians receive formal training in shared decision-making. Prognostic calculators are helpful; however, they are best used to initiate frank and open discussions about the expectations that patients and families have rather than guide modality choices (13,14). Not all patients starting dialysis with a high score do poorly. Around 25% will survive past the first year, and of those, many will report quality of life scores marginally higher than their younger counterparts. It is with these people in mind that the study by Brown et al. (12) becomes important. Their data should remind us that both those patients opting for dialysis and those patients opting for a nondialytic care pathway have a high symptom burden (12). Our patients look to us for their medical care during not only the 4-hour dialysis treatments but also, the intervening 44 hours! Symptoms, such as difficulty sleeping; dry or itchy skin; anxiety, sadness, or depression; and pain and restless legs, are common (15–17), and yet, they are often overlooked and undertreated. Brown et al. (12) show that palliative care teams can reduce the symptom burden. So why not shift our thinking? Rather than restricting symptom management to those who elect to forgo dialysis, should we not be developing policies that help us extend symptom care to all patients with renal disease? Should we not more actively seek to help those for whom dialysis is the final destination (18,19)?

Neither the concept of a collaborative program nor the concept of introducing palliative care early in a disease course is novel. In 2010, Temel et al. (20) randomized patients newly diagnosed with metastatic nonsmall cell cancer to either collaborative care with an oncologist and a palliative care team or the more traditional oncologist-led care. The data from the study by Temel et al. (20) suggest that addressing the physical and psychological symptoms of patients can help patients manage what are otherwise unpleasant and burdensome treatment interventions. Although from a small single-centered study open to biases because of its nonblinded design, their data suggested that the use of collaborative care from an early stage resulted in improved patient-reported outcomes, reduced use of inappropriate medical interventions, and possibly, extended survival. Many now advocate for earlier use of palliative services in oncology (21).
There is also a subtle shift in the world of nephrology. Several recent publications advocate for a patient-focused approach to care (18,22–24), and there have been a number of events or changes that have occurred in the past 18 months (a few are listed below).

In December of 2013, Kidney Disease Improving Global Outcomes held a Controversies Conference on Supportive Care in Mexico. As a result of this conference, several attendees from across the world have been working together to synthesize the current knowledge about which treatments are most effective for the most common symptoms experienced by patients with renal disease. At present, these findings are close to publication. Additional knowledge translation strategies are also being reviewed.

Policies that hinder the provision of quality care are being slowly identified and modified across the world. For example, patients established on dialysis who have a non-ESRD terminal illness are often not accepted into hospice care unless they agree to discontinue dialysis therapy. In July of 2014, the American Society of Nephrology (ASN) successfully petitioned the Centers for Medicare and Medicaid Services to fund concurrent dialysis and hospice care, setting the stage for other jurisdictions to re-evaluate their policies. Policies are also changing in other countries. In British Columbia, Canada, drugs used commonly for symptom management were, until recently, not being funded unless the patient had started dialysis. Advocacy groups at the Provincial British Columbia Renal Agency have now established funding structures to allow for coverage to flow to those opting for a conservative care pathway.

Two special interest groups, the ASN Dialysis Advisory Group and the Geriatric Nephrology Advisory Group, have taken steps toward implementing symptom-focused dialysis care through a recent collaborative position paper (23). These advisory groups identified knowledge gaps in how dialysis care is currently provided and have proposed modified treatment protocols that may benefit those with limited life expectancy. Ongoing work to address if funding policies may hinder symptom-focused dialysis care is underway.

The US Renal Data System has undertaken a special study, led by Drs. Ann O’Hare and Manjula Kurella-Tamura, that will collect information on symptom burden, palliative care needs, and patient and caregiver engagement in advance care planning as well as study patient knowledge and understanding of their prognosis and treatment options (25).

There is an increase in cross-training activities between palliative care and nephrology. Several academic training programs now offer cross-training, an increasing number of members of the renal community are actively involved with the Supportive Care Coalition, and there is a growing number of continuing education opportunities for practicing nephrologists.

These are exciting times. It will take time and much effort; like in the oncology world, there will be many hurdles along the way, but in the words of the Irish poet W.B. Yeats, “Do not wait to strike till the iron is hot; but make it hot by striking.”

Disclosures

None.

References


25. O’Hare AM, Kurella Tamura M: USRDS Special Study Center on Palliative and End-of-Life Care, US Renal Data System

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