When Dr. Belding Scribner founded the world’s first outpatient dialysis facility in 1962, he likely never imagined that half a century later there would be >450,000 people on dialysis in the United States. Dialysis is now a common life-sustaining treatment that is provided as a Medicare benefit to all United States citizens who require and choose it. With advancements in all aspects of medicine people are living longer, and older patients are now the fastest growing incident dialysis group in the United States (1). These patients have a high disease burden; people ≥65 years with ESRD have a mortality rate exceeding other age-matched Medicare patients with cardiovascular disease, cerebrovascular disease, cancer, or heart failure (1).

ESRD patients are faced with many decisions, including whether to initiate dialysis, preferences for cardiopulmonary resuscitation (CPR), and when to cease dialysis if it no longer allows them to meet their goals. As the dialysis population becomes older and sicker, the particular decision of whether to initiate or stop dialysis is often much more complex than asking the patient whether they want to live or die. There is increasing evidence that many older patients with multiple comorbidities may not live longer on dialysis (2–4), and that dialysis is unlikely to improve the functional status of frail older patients with progressive CKD (5). Decisions of this complexity require a collaborative decision-making process that takes into account the best medical evidence while eliciting the patient’s goals and values. The importance of effective shared decision-making in the initiation and cessation of dialysis is nationally and internationally recognized by nephrology providers and patient groups (6–8).

Advance care planning (ACP) is the practice of a patient learning about decisions that she or he may need to make throughout their lifetime on the basis of their medical condition(s), discussing preferences regarding these decisions ahead of time with surrogate decision-makers, and then communicating these preferences to others verbally and in writing in the form of an advance directive (AD) or living will. An AD often also legally designates a medical power of attorney—someone to act as a surrogate medical decision-maker in the event that the patient cannot make their own medical decisions. When surveyed, patients with progressive CKD expressed the desire to engage in ACP with their nephrology providers, but few patients report having done so (9).

Until recently, studies have relied on patient surveys or interviews to assess completion rate or content of ADs in patients on dialysis. In this issue of the Clinical Journal of the American Society of Nephrology, Feely et al. (10) present a retrospective chart review of prevalent in-center patients on maintenance hemodialysis at dialysis units associated with the Mayo Clinic from 2007 to 2012, to quantify the number of ADs completed, to assess the content of the ADs, and to test for clinical associations with AD completion. They reviewed the charts of a total of 808 patients receiving hemodialysis with a mean age of 68.6 years. Half (49%) of the patients had a documented AD in their chart. Of those patients with a documented AD, 69.2% had both living will and power of attorney components, 7.8% had only a living will, 8.1% had only a power of attorney, and 14.9% had other forms of ADs, such as physician orders for life-sustaining treatments or forms that documented preferences for CPR. Only 10.6% of AD documents specifically mentioned patient preferences regarding dialysis, whereas less than half (44.2%) of ADs addressed preferences for CPR. Patients with ADs were older (74.5 versus 65.4 years old). Those patients who died during the study period were more likely to have an AD (64.4% versus 46.6%). Patients who received a consultation by palliative medicine were more likely to have an AD (59.3% versus 47.0% of those without a consult), but overall only 16.7% of patients received a palliative care consult.

As the majority of patients with ESRD in the United States receive their dialysis in units run by large, for-profit companies rather than in not-for-profit centers affiliated with academic institutions, this study may not be representative of the United States ESRD population as a whole. As the authors point out, their results come from a single institution (the Mayo Clinic), the study population is homogenous (86.5% white), and ADs completed by patients but not provided to the health care institution for inclusion in the chart are not accounted for in this study. In addition, its observational design is by no means complex, and its findings are unlikely to be surprising.
to most practicing nephrologists. Indeed, it provides minimal data on the association between ACP and clinically relevant outcomes.

However, while it only scratches the surface of the topic of ADs in patients with ESRD, as the first study of its size to utilize chart review rather than relying on patient report to characterize ADs in a dialysis cohort, it nonetheless represents an important data point in the field. Further, the fact that it may not be representative of the majority of ESRD patients in the United States only serves to further highlight this study as an important piece of the growing body of evidence that the nephrology community in the United States has a lot of work to do to improve ACP for patients with ESRD. Most who are involved in direct care of in-center patients on hemodialysis would likely speculate that this particular patient group obtaining dialysis from the Mayo Clinic represents a “best case scenario” of AD completion in real-life dialysis units. Despite this, only half of patients in this study had an AD. While disease-specific ADs have been studied in other medical conditions, such as heart failure and HIV/AIDS (11,12), there are limited data on effectiveness and feasibility of kidney disease-specific ADs. Only 10% of the ADs in this study even mentioned dialysis itself, the life-sustaining treatment keeping these patients alive. Finally, despite sudden cardiac death being the number one cause of death in patients with ESRD (1), only half of ADs addressed patient preferences for CPR.

Further highlighting the need for improved ACP and shared decision-making in the care of patients with ESRD, a recent study by Wong et al. (13) demonstrated that most patients (85.5%) in the United States start on dialysis or prepare for its initiation despite advanced age or significant comorbidity. Additionally, Wachterman et al. (14) recently compared end-of-life care received by patients with ESRD, dementia, cancer, or other organ failure, demonstrating that patients with ESRD die more often in the intensive care unit and receive fewer palliative care consults compared with those patients with cancer and dementia.

We know from other fields of medicine that ACP and documentation of patient preferences leads to less aggressive care at the end of life (15). A recent study of dialysis patients comparing an ACP intervention with usual care demonstrated that ACP improved surrogate decision-maker confidence, improved decision concordance between patients and their surrogates, and decreased depression, anxiety, and post-traumatic stress disorder among surrogates after patient death (16).

How to best provide ACP to patients with ESRD remains unclear, but ongoing studies aimed at addressing the issue will be essential for effective ACP delivery to our patients. As of January 1, 2016, ACP has been designated a billable service by Medicare. Regardless, an essential component of improving ACP is to change the nephrology community’s culture. O’Hare et al. (17) published an examination of provider perspectives of ACP that revealed that many dialysis providers do not feel this is their job, that many do not adequately understand ACP, and that we often fail to utilize the multidisciplinary resources available to assist in providing ACP to our patients.

Unlike many other countries in the world, the United States has the financial resources to be able to provide dialysis to virtually all citizens who need it, regardless of their individual financial situation. The ability to provide this life-sustaining treatment comes with great responsibility. These responsibilities include the need to inform patients whether dialysis is likely to benefit them or help them meet their goals, and to explain that not pursuing dialysis at all or stopping dialysis are viable choices that are available and will be supported. As routinely as we adhere to anemia protocols and strive for achieving bone mineral disease targets in our patients on dialysis, we should be routinely addressing ACP in all patients with ESRD, ideally using CKD-specific ADs. It is time we step up to the plate and provide the care that is best for our growing ESRD population, recognizing that for many patients with ESRD, provision of dialysis may not be part of that care.

Disclosures
None.

References


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See related article, “Prevalence and Contents of Advance Directives of Patients with ESRD Receiving Dialysis,” on pages 2204–2209.