



Honoring Patient Preferences: The 2016 National Kidney Foundation Presidential Address

This is a summary of the presidential address delivered at the 2016 Spring Clinical Meetings held in Boston, MA. The 2017 Spring Clinical Meetings will take place April 18 to 22, 2017, in Orlando, FL.

Initiation of dialysis therapy with a home-based modality has grown steadily since 2007, but even so only accounts for approximately 10% of incident dialysis patients.¹ Recent trends show increasing use of home dialysis, particularly peritoneal dialysis (PD),¹ suggesting that home dialysis therapies may have been substantially underused in the past. However, it is not possible to know the “right” fraction for home dialysis uptake because this would require knowing—both before and after the start of dialysis therapy—what fully informed and educated patients would choose, free from misinformed or biased opinions of others and from forces imposed by economic factors on their health care providers.

In considering the modalities used by patients at the start of dialysis therapy, it is interesting to consider what nephrologists would choose. In a survey of 629 nephrologists, if transplantation was not an immediate option, only 6% reported that they would choose conventional in-center thrice-weekly hemodialysis (HD), whereas 45% would choose PD and 46% would choose some form of home HD.² The difference between what nephrologists would choose for themselves and what patients actually choose is striking.

Even when patients with chronic kidney failure elect to start with PD therapy, barriers often emerge. In one study, fewer than half the patients who wanted to initiate kidney replacement therapy with PD did so, and very few of these patients later switched to PD therapy.³ Thus, to a large extent, “once an HD patient, always an HD patient,” and almost always an in-center HD patient, something most of us would not choose for ourselves.

Although there are many barriers to initiating home dialysis therapy (Box 1),⁴ there has been a remarkable upturn in its use (particularly in the case of PD) in the United States in recent years, even though most of these barriers have remained unchanged.^{1,5} The recent move toward home dialysis therapy is likely explained at least in part by a Medicare payment structure introduced in 2011 that favors the use of PD by providing financial incentives that benefit the dialysis facility owners and nephrologists with a financial stake in the facility (such as with a joint venture arrangement).⁵⁻⁷ In recent years, many corporate dialysis providers have had double-digit growth in the percentage of their patients using PD. A goal of the Centers for Medicare & Medicaid Services was to increase the use of at-home therapy,

and this is happening. This trend speaks loudly to a serious flaw in the structure of our health care delivery system for patients with kidney failure if the dialysis modality they use hinges on the financial rewards to dialysis providers. Careful selection of patients for PD therapy is essential because there are substantial rates of hospitalization, peritonitis, and switching to HD therapy within the first year of renal replacement therapy among incident PD patients.⁸ There is also a high dropout rate for home HD therapy.⁹ I hope someone is minding this store.

Decisions about the initial dialysis modality are influenced by the patient’s circumstances and individuals who may have contact with the patient. Education is key to optimal modality selection. A Kidney Disease Education benefit for Medicare recipients with stage 4 chronic kidney disease (CKD) has been relatively poorly used (unfortunately, this benefit is not offered to patients with stage 5 CKD).^{10,11} That this benefit requires a 20% patient copay and that the Medicare Part B deductible applies to this service likely impede its widespread use. Other impediments likely include limitations on who can charge for education (eg, nurse practitioners and physician assistants are eligible, but registered nurses are not). CKD patient education about kidney replacement therapy options has traditionally been the responsibility of the patient’s nephrologist, but this is gradually being taken over by corporate dialysis providers as they move “upstream” and provide care for patients with later stages of CKD.^{12,13} Whether this shift is good for patients remains undetermined. A payment model that covers education for CKD and kidney replacement modality, including conservative care, in the nephrologist’s office rather than a dialysis facility would be welcome.

The fraction of patients starting dialysis therapy with higher estimated glomerular filtration rates (eGFRs) has increased markedly during the last 15 to 20 years.¹ In 1996, there were 19% of patients with

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Box 1. Barriers to Home Dialysis**Educational Barriers**

Patients and family/caregivers
Physicians and other health care providers
Dialysis facility staff

Regulatory and Governmental Barriers

Monthly visit requirements
Funding mechanism for home care support
Accreditation and certification of new home units
Equipment, supplies, and dialysate inadequacies

Dialysis Provider Barriers

Availability of solutions and equipment
Delivery and storage of supplies
Pharmacy and laboratory limitations
Need for improved quality improvement data and focus
Staffing depth and expertise

Based on Golper et al.⁴

eGFRs > 10 mL/min/1.73 m² and only 4% had eGFRs > 15 mL/min/1.73 m² at dialysis therapy initiation. In 2011, those values were 54% and 20%, respectively. This trend has reversed a bit in the last few years, with 13% of patients initiating dialysis therapy at eGFRs > 15 mL/min/1.73 m² in 2013. In part, these trends may reflect factors affecting serum creatinine level, rather than “true” GFR, such as standardization of creatinine assays, and initiating dialysis therapy in older sicker patients with lower muscle mass. It is likely that it also reflects initiating dialysis therapy at higher “true” GFRs. Nonetheless, neither randomized controlled trial data nor retrospective observational cohort study data demonstrate a meaningful benefit of an earlier dialysis therapy start,¹⁴⁻¹⁷ with observational data suggesting possible harms.

To explore which factors prompt the start of dialysis therapy, a recent study by Wong et al¹⁸ used a qualitative analysis of electronic health records of 1,691 Department of Veterans Affairs patients who had initiated dialysis therapy. As expected, study participants were mostly men, but otherwise, they were similar to the patient population seen in US nephrology practices: mean age of 62.7 years, racially diverse, and high prevalences of diabetes mellitus, hypertension, coronary artery disease, heart failure, and chronic obstructive lung disease. Of the 95% of patients who started kidney replacement therapy with HD, 76% initiated with a catheter. The authors noted that the “timing of initiation of dialysis reflected the complex interplay of at least 3 interrelated and dynamic processes.”^{18(p228)} These included physician practices, such as preparing patients for dialysis, as well as efforts to manage their CKD medically and postpone the start of dialysis therapy; sources of momentum, such as acute illness or a perceived need to optimize a patient’s clinical status prior to surgery

or other procedures; and patient-physician dynamics, including what often appeared to be a “push-pull” relationship, with the patient’s resistance to starting dialysis therapy overcome by physician or family pressures, and paternalism. Wong et al¹⁸ noted that interactions between patients and their physicians were at times adversarial, leading to the initiation of dialysis therapy when doing so was thought to conflict with the patient’s priorities. The authors further observed that patients’ goals and values were rarely documented in the medical record, leading them to conclude that “there may be opportunities to make these processes more patient-centered.”^{18(p232)}

Providing patient-centered care around the initiation of dialysis therapy requires that patients know what they want and that we, as their providers, understand what is important to and desired by our patients. This is particularly important for our increasingly aging population of patients with advanced CKD, for whom we need to consider conservative care as a viable and potentially preferred option to dialysis. The patient perspective in this regard was examined in a survey of 584 patients with CKD stages 4 and 5, including in-center HD, home HD, and PD patients, in Alberta, Canada.¹⁹ Among those receiving dialysis, 61% regretted their decision to start and 66% reported initiating dialysis therapy rather than choosing conservative care because of the wishes of their doctors or family over their own wishes. Less than 10% of patients reported having a discussion about end-of-life care in the previous 12 months.

Knowing what is important to dialysis patients may help inform decision making around dialysis therapy initiation. A recent study conducted in 11 HD units in Australia and Canada surveyed patients and 24 caregivers.²⁰ Among 33 listed outcomes, mortality was 14th most important to patients, but 3rd most important to caregivers. Outcomes most important to patients included, in order, fatigue/energy, resilience/coping, ability to travel, dialysis-free time, impact on family, ability to work, and sleep. In contrast, outcomes that constitute dialysis facility quality measures, including hospitalization and laboratory results such as hemoglobin, calcium, and parathyroid hormone levels, were among the outcomes lowest ranked by patients in terms of importance.

We live in an era in which providing high-value care is increasingly emphasized. One might define high-value care as the best possible care that is patient centered and reduces unnecessary health care costs. Dialysis is, of course, a very expensive therapy that, as mentioned in the preceding, increasingly has been initiated earlier in the course of CKD. More than 100,000 dialysis patients in the United States are 75

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