Better Informing Older Patients With Kidney Failure in an Era of Patient-Centered Care

Since 2000, the adjusted prevalence of end-stage renal disease in the United States has increased 31% for patients aged 65-74 years and 48% for those aged 75 and older, a growth rate 2 to 3 times higher than that seen among younger adults. With increasing rates of diabetes, obesity, and chronic kidney disease (CKD), the growing number of older adults confronting kidney failure in the United States and worldwide constitutes a significant public health concern. For many, treatment with maintenance dialysis can prolong life and relieve some symptoms, but for others, it may be painful or burdensome, and could worsen quality of life. This may be especially true for older incident dialysis patients; among those 75 years and older, for whom 1- and 3-year adjusted survival is 63% and 33%, respectively, dialysis initiation may result in a less favorable tradeoff and perhaps even harm. Older patients suffer disproportionately from cognitive decline and loss of functional status, potentially further reducing the benefits of dialysis compared with conservative management.

While over half of patients with terminal cancer and nearly 40% of those with heart failure choose hospice care, only 20% of dialysis patients elect hospice, with this often occurring only in the last days of life. One small study suggests that patients with kidney failure who elect conservative management often experience higher quality of life, have more frequent access to palliative care services, and are less likely to be admitted to or die in a hospital than patients electing to begin dialysis. Despite the potential benefits of conservative management and the marginal longevity gains from dialysis for some older adults, most American patients pursue aggressive care focused on prolonging life. This has resulted in disproportionately high rates of hospitalization (76%) and intensive care unit admission (49%) during the final month of life compared to older Medicare beneficiaries, along with hospitalizations twice as long as those occurring in Medicare recipients with cancer during the last month of life.

Little is known about how older adults with chronic kidney failure approach treatment decisions, or even how many elect to forgo dialysis, with most data reflecting international contexts. Additionally, few multicenter studies to date have examined decision making or decisional stability related to initiating dialysis treatment. Though qualitative studies have identified some factors underlying patient preferences for one treatment modality over another, they also have largely overlooked the effect of local center policies on patient perceptions and choices. In this context, Tonkin-Crine and colleagues report in this issue of AJKD a qualitative study based on semi-structured interviews with 42 adults aged 75 years or older from 9 nephrology departments in England, exploring their reasons for selecting dialysis or conservative management for kidney failure. Using thematic analysis to analyze interviews of 14 patients with stage 5 CKD who planned to initiate dialysis, 14 patients who had recently initiated dialysis, and 14 patients who had elected conservative management of kidney failure, the authors concluded that patients hold divergent views regarding the benefits of dialysis, often reflecting established practice patterns and provider recommendations common to their treatment center. Patients opting for different treatments appear to hold contrasting beliefs about the potential advantages of dialysis, with some understanding that the longevity difference could be several years, while others (often at centers with established conservative management pathways) reporting that dialysis would not confer any survival benefit. Patients also had conflicting perceptions of their disease severity, often associating a lack of CKD symptoms with less-severe disease. An additional and important conclusion was that treatment decisions appear conditional and unstable, and are subject to revision, particularly when patients experience more severe symptoms. The authors attribute this to a poor understanding of the illness trajectory and lack of discussion of death and dying. This study has several limitations, most notably limited generalizability beyond the UK context, lack of information about actual clinician practices, and the presence of well-established conservative management programs at some but not all of the nephrology departments. Additionally, by virtue of their ability to participate in the study, many patients may be healthier and more literate than the average older adult with stage 5 CKD.

The decision to initiate dialysis is complex and incorporates significant tradeoffs. Many patients facing kidney failure do not fully understand the risks
and benefits of initiating treatment and have unaddressed concerns related to their daily lives. The study by Tonkin-Crine and colleagues raises important questions about how to optimally care for older adults with kidney failure, and, in particular, whether uniformly referring patients to dialysis reflects best practices in patient-centered care. Notably, low utilization of palliative care seems discordant with the expressed preferences of most Americans to die at home. In a study of maintenance dialysis patients in the United States, only 18% preferred longevity at the cost of suffering, and studies of Canadian patients mirror this preference, with a majority of patients favoring decreasing pain and suffering over life-extending dialysis.

The changing demographics of the dialysis patient population increasingly necessitate that nephrologists be involved in end-of-life care decisions for older adults. Yet studies reveal that nephrologists feel unprepared to discuss palliative care, prognosis, and treatment options for older patients, with a recent survey of American and Canadian physicians finding that only 11.1% of nephrologists felt very well prepared to make end-of-life decisions. Importantly, Tonkin-Crine and colleagues find that, at centers with well-established conservative management protocols and conservative management experience, more patients select conservative management, indicating that experience and competence in providing appropriate renal palliative care may result in more patients choosing conservative management. In 2010, the Renal Physicians Association published evidence-based guidelines describing best practices related to withholding and withdrawing from dialysis. These practices include establishing a physician-patient relationship for shared decision making, fully informing patients about all treatment options, providing all patients with a realistic prognosis estimate, facilitating advanced directives, forgoing dialysis when appropriate, resolving conflicts when disagreements arise about dialysis treatment, and providing effective palliative care.

In light of these guidelines and new evidence from Tonkin-Crine and colleagues, we highlight potential applications of this research and next steps to promote both future research and patient-centered care for older dialysis.

1. Promoting shared decision making. Shared decision making is a model of medical decision making thought to support high-quality patient-centered care, largely because it encourages patient autonomy by ensuring that patients’ values and preferences play a prominent role, and facilitates informed consent by discussing the risks and benefits of treatment. Due to the complexity and timing of decision making as well as low levels of health literacy among dialysis patients, further efforts are needed to assist clinicians in providing clear and comprehensible information about the tradeoffs associated with treatment options, including quality-of-life considerations.

2. Supporting caregivers in both decision making and care provision. Deciding between initiating kidney replacement therapy and conservative management often involves patients’ friends and family. Each step of the process requires social support, including reaching an optimal decision, adhering to a complex treatment regimen, and in many cases, proxy decision making (where friends or family often assume the role of medical proxy) due to the high burden of cognitive impairment and comorbid medical illness. Although integral to both decision making and caregiving, caregivers (often legal proxies) are inconsistently educated about treatment options and are seldom integrated into the patient care experience. Educating caregivers early in the process, involving them in conversations about decision making, and providing supportive services may help improve patient-centered care.

3. Culturally sensitive, tailored approaches to renal palliative care. Better understanding of what is important to patients seeking treatment, and how treatment preferences relate to life goals is central to providing quality care. Race, ethnicity, gender, religion, and social status may also play an important role informing preferences. More research is needed to understand the role of medical distrust, inconsistent access to care prior to kidney failure, and differing cultural norms in alleviating treatment disparities for older CKD patients.

4. Promoting end-of-life planning. Incentivizing conversations about end-of-life wishes and hospice by improving reimbursement, support, and formal training for physicians could enhance quality of care and reduce unnecessary health care costs. With recent studies demonstrating that some patients live longer and have superior quality of life while receiving hospice care, integrating palliative care and multidisciplinary care teams offers a promising approach to improving patient-centered outcomes.

In sum, lack of patient-centered decision making for older adults with chronic kidney failure can result in low patient satisfaction, caregiver distress over treatment burdens and decision-making role, poor adherence and outcomes, and feelings of regret. The new findings from Tonkin-Crine et al raise vital questions about what should be considered “ordinary.”
versus “extraordinary” care. Future research should help delineate the factors involved in decision making, the outcomes patients value most, and the role of supports. These could inform the development of decision aids and clinical guidelines inclusive of patient preferences, autonomy, and needs.

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REFERENCES


