

Delaying and Averting Dialysis Treatment: Patient Protection or Moral Hazard?

Douglas S. Johnson and Klemens B. Meyer



In talking with patients about the prospect of kidney failure, it can be useful to frame the problem as deciding what to do “if you outlive your kidneys.” For patients and nephrologists alike, this is the dominant challenge of advanced chronic kidney disease (CKD): to anticipate the evolution of illness from declining kidney function, choose the best treatment for the individual patient, and implement it not too early, not too late, but just at the right time.

As a primary care internist (D.S.J.) and a nephrologist (K.B.M.), we are troubled by the lack of progress in meeting this challenge. In this Policy Forum Editorial, we report on the success of an End-Stage Renal Disease (ESRD) Seamless Care Organization (ESCO), established under the Affordable Care Act and operating in the context of a nondialysis CKD care coordination program, in reducing the cost and improving the quality of care for patients with CKD at high risk for kidney failure (stages G3A3, G4, and G5). We discuss the ethical challenges of accountable and fee-for-service care for advanced CKD.

Practice Lagging Knowledge

Although science has transformed CKD treatment, understanding has outstripped clinical practice. Kidney failure is a complete surprise for only a minority of patients in the United States, but many who are aware of their CKD reach it sooner than necessary, without, for example, the benefit of adequate blood pressure control.¹ Although educational programs and specialized clinics have been shown to improve outcomes and lower costs for patients beginning dialysis therapy, few patients receive these interventions.² Nephrologists think that home hemodialysis and peritoneal dialysis are the best dialysis therapies³ and that about one-third of dialysis patients would be best treated with home dialysis^{4,5}; however, only ~10% of dialyzed patients in the United States are treated by peritoneal dialysis, and only ~2.5%, by home hemodialysis.⁶ Although predialysis nephrology care treatment is associated with higher rates of

fistulas and grafts among incident patients, 34% of those who had seen a nephrologist for more than a year still begin dialysis therapy with a catheter alone.⁶ Even though the trend to earlier initiation of dialysis treatment seems to have stopped, 12% of patients still begin dialysis therapy with estimated glomerular filtration rates (eGFRs) of at least 15 mL/min/1.73 m², and an additional 27%, with eGFRs between 10 and 15 mL/min/1.73 m², with health service area variation.⁶ Mortality rates are 15% to 20% in the first year of dialysis therapy and life expectancy is far shorter for dialysis patients than for the general population, but fewer dialysis patients than nursing home patients have treatment-limiting directives and named surrogates.⁶⁻⁸ Survival and quality-of-life benefits may be marginal at best for elderly infirm patients with kidney failure; however, they are far more likely to undergo dialysis treatment in the United States than in other developed countries.⁹ Although it may be the optimal kidney replacement therapy for most patients, living donor transplantation is underused, particularly among poor, minority, and older individuals with kidney failure.¹⁰

These results reflect the design, or perhaps in this case lack of design, of the current system of care in the United States.¹¹ We propose a new model in which all patients with eGFRs < 30 mL/min/1.73 m², as well as high-risk patients with eGFRs between 30 and 60 mL/min/1.73 m² (albuminuria detectable on dipstick, albumin-creatinine ratio > 300 mg/g, or high cost of care) receive more coordinated care. As kidney function declines, the nephrologist, care coordinator, social worker, and dietitian would see the patient with increasing frequency, aiming to keep the patient well without dialysis therapy as long as possible. Every patient should understand that kidney transplantation is the best treatment, living donor transplantation is the best of the best, preemptive transplantation is the ultimate, and friends and relatives are often much more eager to donate than patients presume. Everyone, but especially those who are very

FEATURE EDITOR:
Daniel E. Weiner

ADVISORY BOARD:
L. Ebony Boulware
Kevin Erickson
Eduardo Lacson Jr
Bruce M. Robinson
Wolfgang Winkelmayr

Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients.

old and otherwise very ill, should understand that to forgo dialysis treatment is not suicide; shared decision making is the standard of care; uremia can lead to a dignified, peaceful, and comfortable death; and dialysis treatment conveys limited survival benefit.^{12,13} The spectrum of nondialytic treatment ranges from pure palliation to a very active effort to use every treatment except dialysis, including a supplemented very-low-protein diet.¹⁴ Patients should understand (and it should be true) that even if they choose nondialytic treatment, nephrologists will not abandon them, but will use knowledge of the uremic syndrome to make their lives as long and as good as possible. Patients who want dialysis should be urged and even pressured to meet with an experienced home training nurse to learn about home dialysis. Among patients who choose hemodialysis, an internal access should be created and made usable before it is needed. Declining kidney function should prompt more frequent visits, not reflexive dialysis therapy initiation. At eGFRs < 10 mL/min/1.73 m², even weekly visits may be helpful; not all need be with the primary nephrologist, but they should be with a few clinicians who know the patient well and who understand uremia.

Care Coordination: The ESCO Effect With a Booster

ESCOs are organizations participating in the Comprehensive ESRD Care model developed by the Center for Medicare and Medicaid Innovation (CMMI), established under the Affordable Care Act.¹⁵ The Palmetto Kidney Care Alliance (KCA),¹⁶ based in Spartanburg, SC, is the most advanced ESCO affiliated with Dialysis Clinic, Inc (DCI). Palmetto KCA was founded in the context of a mature nondialysis CKD care coordination program, Real Engagement Achieving Complete Health (REACH) Kidney Care of Upstate South Carolina (KCUSC),¹⁷ established in 2010, three years before CMMI announced the Comprehensive ESRD Care model and 5 years before the first ESCOs began operations. The goals of DCI's REACH programs, both in South Carolina and elsewhere, are to retard kidney function decline; promote transplantation, particularly live donor and preemptive; encourage home dialysis and early internal access creation; and make elderly and very ill patients aware of the option of advanced kidney failure treatment without either dialysis or transplantation.² Box 1 describes the REACH Program in more detail. REACH KCUSC is succeeding: since 2014, among its 116 patients initiating dialysis therapy, only 1 had an eGFR > 15 mL/min/1.73 m², and among those

Box 1. The DCI REACH Program

Patient Population: Patients with GFRs < 30 and patients with GFRs 30-59 with albuminuria detectable on dipstick, with UACRs > 300 mg/g.

Primary Goal: To treat a patient with late-stage CKD and care for that patient's current clinical needs instead of treating the patient as someone who may need dialysis.

Secondary Goal: For patients whose kidney disease has progressed to the point that GFR is <20, educate on choices of care for RRT, including transplantation, home dialysis, in-center dialysis with a permanent access, and medical management without dialysis. For a patient choosing a modality for RRT, help the patient navigate the health system to implement this choice. For a patient choosing medical management without dialysis, follow up and support the patient closely through this journey and add additional services as needed and requested, including palliative care and hospice care.

Tertiary Goal: For a patient who has chosen a modality for RRT and has not yet received a transplant, follow up the patient closely, in partnership with the patient's nephrologist, to allow a safe start of dialysis therapy later in the progression of the patient's CKD.

Frequency of Visits: Depends on the clinical needs of the patient. At a minimum, the nurse care coordinator sees the patient as frequently as the patient's nephrologist, and in the gap between visits with the nephrologist, with the net effect that the patient is seen twice as frequently. In some instances, the patient is seen by the nurse care coordinator on a weekly basis. The patient's nephrologist and other physicians receive a progress note for every visit with a nurse care coordinator.

Staff:

- **Nurse Care Coordinator:** Role described above.
- **Dietitian:** Goal is to help the patient learn what she or he can eat, instead of providing a list of foods to avoid; specific attention to the patient's culture of origin.
- **Social Worker**

In very advanced CKD, for patients who plan eventual dialysis therapy and who otherwise would have been referred to start dialysis but do not have a clinical need to start: Provide a framework for support and services for the patient so that the patient will have a safe transition to dialysis and also will have this transition later in the progression of CKD so that the patient will not be burdened by dialysis 3 days a week. Provide this consistent support so that the nephrologist feels comfortable that the patient will be followed up closely before starting dialysis. Think of very late-stage CKD as a program that provides all the services of the dialysis clinic without the dialysis and without the requirement that the patient go to the clinic 3 times a week.

Abbreviations: CKD, chronic kidney disease; DCI, Dialysis Clinic, Inc; eGFR, estimated glomerular filtration rate (mL/min/1.73 m²); REACH, Real Engagement Achieving Complete Health; RRT, renal replacement therapy; UACR, urinary albumin-creatinine ratio.

initiating in 2016, a total of 71% had eGFRs of 5 to 10 mL/min/1.73 m². More than 10% of participants have chosen medical management without dialysis therapy. Two-thirds of those beginning dialysis therapy do so as outpatients, 31% initiate with home dialysis, and 70% begin hemodialysis therapy using a permanent access.

Although the REACH KCUSC population is growing, the rate of dialysis therapy initiation among participants has declined. If we focused solely on dialysis, we should worry that this program was harming our business. However, as agents of a kidney health provider, we regard it as a success. We know that if we had CKD, we would actively seek any program that helped us avoid or delay dialysis therapy. Interestingly, claims data show that Palmetto KCA savings exceeded DCI's other ESCOs' by >\$8,000 in the first ESRD month and >\$16,000 during the first 4 months (DCI internal analysis, subject to change); we ascribe much of this benefit to REACH KCUSC.

ESCO dialysis care includes the support of a care coordinator to facilitate communication among the primary physician; nephrologist; other physicians, including both dialysis access specialists and palliative care specialists; hospital-based clinicians; home health providers; and when appropriate, hospice providers. A pharmacist performs medication therapy management following all hospitalizations. Patients and families are taught to recognize symptoms early, to distinguish urgent from emergent situations, and when possible, to call the care coordinator for help planning care.

One patient's experience illustrates the effect of ESCO interventions and shows how we can improve on the status quo. This Spanish-speaking in-center hemodialysis patient in his 60s with hypertension, type 2 diabetes, chronic pain, depression, complicated family dynamics, and other comorbid conditions was hospitalized 14 times for a total of 24 days over 10 months. Medication review at a home visit found that to simplify his medication regimen, his pharmacy had switched his medications to bubble packs; however, he was taking the pills from the bubble packs top to bottom instead of side to side. As a result, he was taking a week's worth of pain medicines one day, a week's worth of antihypertensives the next day, and so on. A Spanish-speaking health partner was introduced to the home and the patient began to take medications as prescribed. During the ensuing 9 months, his only hospitalization was for an elective surgery.

Of the 3 ESCO organizations we began in 2015, all have reduced cost during the first 15 months of operations: 2 have saved \$1,489,369 and \$1,456,648, respectively, while Palmetto KCA saved \$3,893,103 despite Palmetto's benchmark per patient-year cost being >\$3,500 and \$14,500 lower than at the other 2 sites, respectively. Palmetto lowered cost by \$9,022 per patient per year, 11.2% below benchmark.¹⁵

Does Coordinated and Accountable Care Entail Unacceptable Moral Hazard?

Usual kidney care in the United States offers few patients sufficient protection against a slide into dialysis treatment for kidney failure. Nephrologists and dialysis providers have no financial incentive to delay dialysis therapy or promote early transplantation; they have every financial incentive to initiate dialysis therapy. Notably, it is not just a matter of money: the nephrologist who allows the asymptomatic patient with an eGFR of 5 to 10 mL/min/1.73 m² to delay dialysis therapy may well worry that the patient will experience major complications or die before starting dialysis therapy. Dialysis staff are a wonderful help in watching over and taking care of very sick people. However, our ESCO experience shows that close monitoring by experienced staff protects the patient: until symptoms or absolute indications for dialysis therapy appear, it is the rest of the medical care that matters, not the blood washing. In the hospital, it is likewise much easier to dialyze a very ill patient facing imminent death than to explain to the patient and the family that treatment may no longer represent extension of life, but rather prolongation of dying. Broaching this possibility can embroil the physician in hours of sometimes difficult discussion. It is far easier to dialyze, and to bill, until the patient or family refuses.

If traditional fee-for-service reimbursement incentivizes overuse, any population-based reimbursement, capitation, payment bundling, prospective payment, or even salary payment not directly related to billing volume entails an incentive to limit services. Administrative safeguards, peer review, and quality metrics can provide protection. For example, the Centers for Medicare & Medicaid Services (CMS)-2728 (Medical Evidence) form requires justification for dialysis therapy initiation above a certain level of kidney function. We would welcome more detailed tracking of advanced CKD outcomes by the US Renal Data System better to define factors related to variability in practice patterns. Marked geographic variation, not explained by patient characteristics, is known to characterize kidney failure treatment patterns and the intensity of care for dialysis patients at the end of life.¹⁸

It is our belief that patients with advanced CKD will benefit from the approach to treatment that we describe, one that is both more intensive and more individualized than has been customary in the United States. Some patients will receive kidney transplants earlier or transplants that they might never have otherwise received. Some will choose home dialysis. Some who might otherwise have begun in-center hemodialysis treatment with a catheter will begin with an internal access. Some will choose medical management without dialysis. In this effort, it is essential that every clinician and every individual supporting the clinicians understand that the fate of the

individual patient is paramount; everything else is secondary. We are confident that in following this principle, we cannot go astray.

Article Information

Authors' Full Names and Academic Degrees: Douglas S. Johnson, MD, and Klemens B. Meyer, MD.

Authors' Affiliations: Dialysis Clinic, Inc, Nashville, TN (DSJ); and Division of Nephrology, Tufts Medical Center, Boston, MA (KBM).

Address for Correspondence: Klemens B. Meyer, MD, Tufts Medical Center Box 391, 800 Washington St, Boston MA, 02111. E-mail: kmeyer@tuftsmedicalcenter.org

Support: None.

Financial Disclosure: Dr Meyer's employer, the Tufts Medical Center Physicians Organization, receives funds from DCI that are used to support his salary. Dr Johnson is a full-time employee of DCI and serves as Vice-Chairman of its Board of Directors. DCI is a national not-for-profit provider of dialysis services, organ procurement services, and CKD care coordination services that has ownership interest in 6 ESCOs.

Disclaimer: The statements contained in this document are solely those of the authors and do not necessarily reflect the views or policies of CMS. The authors assume responsibility for the accuracy and completeness of the information contained in this document.

Peer Review: Received July 14, 2017, in response to an invitation from the journal. Evaluated by 2 external peer reviewers and a member of the Feature Advisory Board, with direct editorial input from the Feature Editor, who served as Acting Editor-in-Chief. Accepted in revised form January 27, 2018. The involvement of an Acting Editor-in-Chief was to comply with AJKD's procedures for potential conflicts of interest for editors, described in the Information for Authors & Journal Policies.

Publication Information: © 2018 by the National Kidney Foundation, Inc. Published online March 14, 2018. doi: [10.1053/j.ajkd.2018.01.042](https://doi.org/10.1053/j.ajkd.2018.01.042)

References

- Sumida K, Molnar MZ, Potukuchi PK, et al. Blood pressure before initiation of maintenance dialysis and subsequent mortality. *Am J Kidney Dis.* 2017;70(2):207-217.
- Johnson DS, Kapoian T, Taylor R, Meyer KB. Going upstream: coordination to improve CKD care. *Semin Dial.* 2016;29(2):125-134.
- Fluck RJ, Fouque D, Lockridge RS. Nephrologists' perspectives on dialysis treatment: results of an international survey. *BMC Nephrol.* 2014;15:16.
- Mendelssohn DC, Mullaney SR, Jung B, Blake PG, Mehta RL. What do American nephrologists think about dialysis modality selection? *Am J Kidney Dis.* 2001;37(1):22-29.
- Thamer M, Hwang W, Fink NE, et al. US nephrologists' recommendation of dialysis modality: results of a national survey. *Am J Kidney Dis.* 2000;36(6):1155-1165.
- Saran R, Robinson B, Abbott KC, et al. US Renal Data System 2016 annual data report: epidemiology of kidney disease in the United States. *Am J Kidney Dis.* 2017;69(3)(suppl 1):S1-S688.
- Kurella Tamura M, Montez-Rath ME, Hall YN, Katz R, O'Hare AM. Advance directives and end-of-life care among nursing home residents receiving maintenance dialysis. *Clin J Am Soc Nephrol.* 2017;12(3):435-442.
- US Social Security Administration. Period Life Table, 2013. <https://www.ssa.gov/oact/STATS/table4c6.html>. Accessed May 21, 2017.
- Wong SPY, Kreuter W, O'Hare AM. Healthcare intensity at initiation of chronic dialysis among older adults. *J Am Soc Nephrol.* 2014;25(1):143-149.
- Rodrigue JR, Kazley AS, Mandelbrot DA, et al. Living donor kidney transplantation: overcoming disparities in live kidney donation in the US—recommendations from a consensus conference. *Clin J Am Soc Nephrol.* 2015;10(9):1687-1695.
- IHI Multimedia Team. Like Magic? ("Every system is perfectly designed..."). <http://www.ihio.org/communities/blogs/origin-of-every-system-is-perfectly-designed-quote>. Accessed February 28, 2018.
- Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int.* 2015;88(3):447-459.
- Rosansky SJ, Schell J, Shega J, et al. Treatment decisions for older adults with advanced chronic kidney disease. *BMC Nephrol.* 2017;18(1):200.
- Brunori G, Viola BF, Parrinello G, et al. Efficacy and safety of a very-low-protein diet when postponing dialysis in the elderly: a prospective randomized multicenter controlled study. *Am J Kidney Dis.* 2007;49(5):569-580.
- Center for Medicare & Medicaid Innovation. Comprehensive ESRD care model. <https://innovation.cms.gov/initiatives/comprehensive-esrd-care/>. Accessed November 19, 2017.
- Palmetto Kidney Care Alliance. <http://www.palmettokidneycare.com/>. Accessed October 15, 2017.
- Reach Kidney Care. Upstate South Carolina. <http://www.reachkidneycare.org/upstate-south-carolina/>. Accessed October 15, 2017.
- O'Hare AM, Rodriguez RA, Hailpern SM, Larson EB, Kurella Tamura M. Regional variation in health care intensity and treatment practices for end-stage renal disease in older adults. *JAMA.* 2010;304(2):180-186.