The Role of Dialysis Organizations in Promoting and Facilitating Access to Nondialytic Treatment Options

Catherine R. Butler and Suzanne Watnick

Patients’ experience with progressive kidney failure and its associated treatments, including dialysis, transplantation, and conservative kidney management, are clinically and psychosocially complex, and the optimal treatment modality depends on individual values and life goals. Person-centered care requires that patients be supported in decision making about a range of treatment options and that the approach to care is actively re-evaluated over time as goals evolve. However, the majority of Americans with kidney failure are treated with a single modality—in-center hemodialysis—and tend to receive intensive patterns of end-of-life care, which may not align with their preferences. For many people with kidney failure receiving maintenance dialysis, a majority of interactions with the health care system occur via their dialysis centers. This sustained engagement provides an opportunity for dialysis organizations to educate, promote, and facilitate access to multiple treatment options throughout the course of illness.

In this issue of Kidney Medicine, Allen and Saeed report their findings from a quantitative content analysis using natural language processing to mine website educational content of 2 large for-profit dialysis organizations from November 2020 through March 2021. The authors identified and quantified references to dialysis, transplantation, and conservative kidney management in this online educational material and also described the affective quality of this content. They report that dialysis was featured more frequently than transplantation or conservative kidney management. Specifically, transplantation was mentioned 26% and 17% as often as dialysis in educational material on each organization’s website. Conservative kidney management was referenced 3% as often as dialysis in educational material on one organization’s website while there were no references identified on the other organization’s website. Prognosis of people with kidney failure was infrequently mentioned, and, when it was, tended toward optimistic estimates of longevity. The authors also evaluated how the educational material framed trade-offs involved in choosing to pursue dialysis. Materials from one dialysis organization’s website were explicit about possible symptoms attributable to dialysis including nausea and muscle cramping. The other organization’s website listed symptoms attributable to kidney failure but did not specify possible burdens of dialysis itself. Both websites offered encouraging descriptions of patients’ ability to maintain important components of psychosocial wellbeing including physical intimacy, employment, and travel.

This work represents a novel approach to investigating one element of support for shared decision making about treatment modalities for kidney failure, which can be contextualized in the broader landscape of complex factors affecting access to treatment options. The findings raise questions about whether dialysis organization websites offer an adequate amount of information on nondialytic modalities to inform decision making and about what proportion of a dialysis organization’s educational efforts (and website content) would be appropriately dedicated to nondialytic modalities. A more comprehensive depiction of educational efforts within dialysis organizations will require additional investigation, such as assessment of in-person classes, printed materials, and unstructured communication between staff and patients. Further, this empirical approach is not designed to capture educational material from external organizational partners that may focus on other treatment modalities. Investigation into smaller for-profit or not-for-profit dialysis groups would also contribute to an understanding of how organizational scale and mission may shape the ability of dialysis organizations to offer resources and support for nondialytic options. Beyond these methodologic considerations, this work also prompts broader ethical, clinical, and political questions about the role of dialysis organizations in promoting and facilitating access to transplantation and conservative kidney management as well as the effectiveness of US policy in supporting these practices.

Role of Dialysis Organizations in Promoting and Facilitating Access to Nondialytic Treatment Options

Corporate models are increasingly prevalent in US health care, and for-profit health care companies, including dialysis organizations, encounter overlapping obligations to provide care for individual patients and to manage commercial interests. Unlike many other private sector enterprises, medical services are necessarily overseen not only by business leaders but also by governmental agencies with obligations to residents and beneficiaries and by health professionals with medical licenses and obligations to patients. An American College of Physicians position statement underscores a duty that “physicians in any practice setting should challenge prioritization of business over patient interests.” This perspective is codified in national policy including...
Centers for Medicare & Medicaid Services (CMS) regulation requiring dialysis organizations to provide education on treatment modalities for kidney failure as a condition of coverage, even if the organization itself does not provide these services.\textsuperscript{4-6}

Dialysis providers represent a critical node in a complex network of stakeholders and health care system processes supporting treatment for the growing population of people with kidney failure. The substantial amount of time that a patient may spend receiving in-center dialysis treatments presents a unique opportunity to offer longitudinal education, frequently re-evaluate needs, and facilitate transitions in care. However, care pathways for different treatment modalities have been historically siloed, and the resulting fragmented care is inefficient at best and harmful for patients at worst.\textsuperscript{10} A model of integrated care necessitates communication and collaboration between dialysis centers, nephrologists, transplant centers, hospice agencies, and other care providers. Formal and informal networks of care providers are emerging, including interorganizational relationships intended to address the diverse needs of people with kidney disease throughout their lives.\textsuperscript{4-6}

**Incentives (and Disincentives) for Dialysis Organizations to Promote and Facilitate Access to Nondialytic Treatment Options**

Active and sustained engagement of dialysis organizations in supporting access to nondialytic treatment modalities requires the alignment of national regulations and reimbursement with person-centered goals. CMS covers treatment costs for >80\% of Americans with kidney failure,\textsuperscript{11} and, for this reason, dialysis and transplantation providers have been subject to an evolving set of wide-ranging and complex national regulations including public reporting, quality metric ratings, and payment incentives.\textsuperscript{12} The landscape of care processes for people with kidney failure is also rapidly changing, necessitating new models of care, incentive structures, and regulation. A series of national initiatives, exemplified most recently by the Advancing American Kidney Health initiative and the Center for Medicare and Medicaid Innovation’s kidney care models, seek to redesign the kidney health care system with a goal to improve access to a range of treatment options.\textsuperscript{13,14}

In an effort to improve access to kidney transplantation, CMS has long required dialysis organizations to document education, appropriate referrals, and plans for pursuing transplantation,\textsuperscript{9} but the interpretation and approach to fulfilling these requirements varies substantially among centers. Several recent publications have raised concern that the for-profit status of dialysis organizations may be associated with lower rates of referral and waitlisting for kidney transplantation,\textsuperscript{15} signaling possible financial disincentives to support this valuable treatment option. New payment structures shift the focus of performance evaluation downstream in the kidney transplantation process by offering incentives to dialysis organizations to increase the proportion of patients who are waitlisted and/or receive a kidney transplant.\textsuperscript{14} These downstream outcome metrics also encourage dialysis organizations to partner with transplantation organizations to coordinate efforts around education and support throughout the transplant evaluation process.\textsuperscript{6} Lingering concerns that specific rules defining reimbursement may result in incentives for patients to be merely waitlisted, rather than actually receive a transplant, reinforce the need to continue to monitor the real-world effect of new policies.

End-of-life planning and palliative treatments are indispensable components of care for people with kidney failure, especially for the growing population of older adults with complex comorbid conditions who may have particularly limited prognoses. However, provision of palliative care can be resource intensive. While some CMS value-based measures are intended to capture patient experience,\textsuperscript{16} there remains relatively little financial incentive for dialysis organizations to invest in palliative services. Dialysis centers are judged by their adherence to specified metrics, such as the proportion of patients meeting dialysis adequacy, catheter use, and mineral metabolism targets,\textsuperscript{16} which may be associated with long-term survival but are often not relevant for patients who prefer a focus on palliation. Further, Medicare benefits support either dialysis or hospice but not both concurrently (unless patients have a clear second life-limiting diagnosis). These policy structures reflect an outdated view that life-extending and comfort-oriented treatment options are mutually exclusive, rather than reflecting what patients report to be overlapping and dynamic values around optimizing longevity and/or quality of life.\textsuperscript{17,18} Promising pilot programs have centered on local partnerships between dialysis organizations and hospice agencies to provide concurrent care as well as in-house palliative care programs.\textsuperscript{19,20} These innovative approaches to provide multiple types of kidney care show promise in supporting patient goals and avoiding excess costs, but broader dissemination will require revised CMS policies.

Person-centered care for people with kidney failure requires a conceptual shift from siloed care pathways focused on specific treatment modalities, to a more flexible and integrated approach to treatment options. Efforts to describe how dialysis organizations support patients’ access to multiple treatment modalities will require additional work using creative empirical approaches—as suggested by the work of Allen and Saeed—as well as future investigation into efforts across partnering organizations and the kidney community.

**ARTICLE INFORMATION**

**Authors’ Full Names and Academic Degrees:** Catherine R. Butler, MD, MA and Suzanne Watnick, MD

**Authors’ Affiliations:** Division of Nephrology, Department of Medicine, University of Washington, Seattle, Washington (CRB, SW); Veterans Affairs Puget Sound Healthcare System, Seattle,
REFERENCES

1. Kalantar-Zadeh K, Wightman A, Liao S. Ensuring choice for people with kidney failure - dialysis, supportive care, and hope. *N Engl J Med.* 2020;383(2):99. doi:10.1056/NEJMp2001794

2. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol.* 2010;5(2):195-204. doi:10.2215/cjn.05960809

3. Allen RJ, Saeed F. Dialysis organization online information on kidney failure treatments: a content analysis using corpus linguistics. *Kidney Med.* Published online April 4, 2022. doi:10.1016/j.xkme.2022.100462

4. Davita Inc. DaVita acquires MedSleuth, dedilphabet efforts to improve transplant experience: transplant software company helps DaVita bolster its presence among the kidney care journey. January 18, 2022. Accessed April 11, 2022. [https://newsroom.davita.com/2022-01-18-DaVita-Acquires-MedSleuth-Deepens-Endors-To-Improve-Transplant-Experience](https://newsroom.davita.com/2022-01-18-DaVita-Acquires-MedSleuth-Deepens-Endors-To-Improve-Transplant-Experience)

5. CISION PR Newswire. Three-way merger combines focus on physician and patient engagement with industry-leading technology platform to create the nation's premier value based kidney care provider. March 21, 2022. Accessed April 23, 2022. [https://www.prnewswire.com/news-releases/three-way-merger-combines-focus-on-physician-and-patient-engagement-with-industry-leading-technology-platform-to-create-the-nations-premier-value-based-kidney-care-provider-301506315.html](https://www.prnewswire.com/news-releases/three-way-merger-combines-focus-on-physician-and-patient-engagement-with-industry-leading-technology-platform-to-create-the-nations-premier-value-based-kidney-care-provider-301506315.html)

6. National Kidney Foundation. DaVita and the NKF join forces to improve health equity in kidney transplantation. June 10, 2021. Accessed April 11, 2022. [https://www.kidney.org/news/davita-and-nkf-join-forces-to-improve-health-equity-kidney-transplantation](https://www.kidney.org/news/davita-and-nkf-join-forces-to-improve-health-equity-kidney-transplantation)

7. Crowley R, Atiq O, Hilden D. Health and Public Policy Committee of the American College of Physicians. Financial profit in medicine: a position paper from the American College of Physicians. *Ann Intern Med.* 2021;174(10):1447-1449. doi:10.7326/m21-1178

8. DeCamp M, Snyder Sulmasy L; American College of Physicians Ethics, Professionalism and Human Rights Committee. Ethical and professionalism implications of physician employment and health care business practices: a policy paper from the American College of Physicians. *Ann Intern Med.* 2021;174(6):844-851. doi:10.7326/m20-7093

9. Centers for Medicare & Medicaid Services. Conditions for Coverage of End-Stage renal Disease Facilities; Final Rule. 42 C.F.R. 494.90(d) (2008).

10. Sloan CE, Zhong J, Mohottige D, et al. Fragmentation of care as a barrier to optimal ESKD management. *Semin Dial.* 2020;33(6):440-448. doi:10.1111/sdi.12929

11. Johansen KL, Chertow GM, Foley RN, et al. US Renal Data System 2020 Annual Data Report: epidemiology of kidney disease in the United States. *Am J Kidney Dis.* 2021;77(4)(suppl 1):A7-A8. doi:10.1053/j.ajkd.2021.01.002

12. Mendu ML, Weiner DE. Health policy and kidney care in the United States: core curriculum 2020. *Am J Kidney Dis.* 2020;76(5):720-730. doi:10.1053/j.ajkd.2020.03.028

13. United States, Executive Order of the President [Donald Trump]. Executive order 13879: Advancing American Kidney Health. July 10, 2019.

14. Centers for Medicare & Medicaid Services. ESRD treatment choices (ETC) model. October 29, 2021. Accessed April 21, 2022. [https://innovation.cms.gov/innovation-models/esrd-treatment-choices-model](https://innovation.cms.gov/innovation-models/esrd-treatment-choices-model)

15. Gander JC, Zhang X, Ross K, et al. Association between dialysis facility ownership and access to kidney transplantation. *JAMA.* 2019;322(10):957-973. doi:10.1001/jama.2019.12803

16. Weiner D, Watnick S. The ESRD quality incentive program-can we bridge the chasm? *J Am Soc Nephrol.* 2017;28(6):1697-1706. doi:10.1681/asn.2016101079

17. O’Hare AM, Butler CR, Taylor JS, et al. Thematic analysis of hospice mentions in the health records of veterans with advanced kidney disease. *J Am Soc Nephrol.* 2020;31(11):2667-2677. doi:10.1681/asn.2020040473

18. Oestreich T, Sayre G, O’Hare AM, Curtis JR, Wong SPY. Perspectives on conservative care in advanced kidney disease: a qualitative study of US patients and family members. *Am J Kidney Dis.* 2021;77(3):355-364.e1. doi:10.1053/j.ajkd.2020.07.026

19. Schell JO, Johnson DS. Challenges with providing hospice care for patients undergoing long-term dialysis. *Clin J Am Soc Nephrol.* 2021;16(3):473-475. doi:10.2215/cjn.10710720

20. Lam DY, Scherer JS, Brown M, Grubbs V, Schell JO. A conceptual framework of palliative care across the continuum of advanced kidney disease. *Clin J Am Soc Nephrol.* 2019;14(4):635-641. doi:10.2215/cjn.09330818