Kidney Medicine

A Blueprint for Planning Person-Centered Dialysis Care

Philip Kemp and Robert A. Cohen

The quality of dialysis care is currently measured by such variables as adequacy, fluid and blood pressure, access type, anemia, and mineral and bone disease. Focusing primarily on such objective measures and their associated

Related article, p. 193

incentives reinforces a disease-centered approach to care that often diverts attention from the experience and priorities of dialysis patients.¹ Beyond providing clinically appropriate dialysis, delivering person-centered care should be emphasized.² This holistic paradigm seeks to individualize treatment by bearing in mind that each patient is unique, with their own cultural identity, role in a community and family, and distinct set of strengths and challenges. Within this paradigm, the quality of dialysis care therefore should also be measured by how well patients achieve quality of life as manifested by optimal physical function, psychosocial well-being, and personal fulfillment.

Support has grown in recent years for adopting personcentered care. A recent Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference recommended incorporation of patient input into individualized dialysis regimens,³ expanding on Centers for Medicare & Medicaid Services regulations that currently mandate that patients be included as part of the interdisciplinary team that creates a care plan.⁴ Despite the articulated benefits of providing person-centered care, barriers interfere with achieving this goal, often resulting in reduced patient satisfaction and potentially worse outcomes.^{5,6} Frequently cited impediments are time and resource constraints, competing demands in a complex care setting, poor communication skills by providers, and low health literacy of patients.^{7,8} Given such obstacles, nephrologists need guidance on how to establish programs to deliver effective person-centered dialysis care.

In this issue of Kidney Medicine, Dorough et al⁹ describe the implementation of one such program, named "My Dialysis Plan," at a single dialysis center in North Carolina associated with an academic medical center. To operationalize My Dialysis Plan, the Consolidated Framework for Implementation Research, a set of tools for identifying factors or conditions that facilitate successful implementation of a quality improvement initiative, was used. Input from patients and clinic stakeholders was elicited through semi-structured interviews conducted before, during, and after the program to collect qualitative data and optimize program enactment, and stakeholders were part of the research team at all phases of the program.¹⁰ Analysis and reporting of the project followed the commonly-used SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines, which provides a framework for publishing the aims, actions, findings, and implications of health care quality improvement interventions.¹¹

Forty-nine dialysis patients agreed to participate in the study, which involved meeting with the interdisciplinary care team at the dialysis unit and resulted in 54 care plans. Team members facilitated a partially scripted conversation designed to elicit patient priorities and goals, as well as barriers or difficulties relevant to their dialysis experience. Individual team members were then assigned specific tasks to help enact the patients' self-determined plans of care. After the meetings, dialysis center staff continued to collaborate with the patients and document the progress toward completion of the action items identified at the meetings. To measure the impact of the program, twothirds of the dialysis patients were also enrolled in a substudy in which they responded to 2 sets of surveys completed before and after project implementation. These were designed to measure change in patient-reported autonomy support, patient-centeredness of care, and dialysis care individualization.

The most frequent treatment goal among patients was relief from physical symptoms such as fatigue, pain, or shortness of breath, consistent with findings from other descriptive studies.¹² Action items to address these symptoms often fell within the traditional medical model, such as referral to a specialist or adjustment of the dialysis prescription. Patients also highly prioritized their ability to maintain social interactions with friends, family, and their community. Mitigating the psychosocial challenges associated with dialysis and its impact on patient well-being required more creative approaches and highlighted ways in which the existing resources and expertise in the dialysis center could be redirected to address patient-specific needs. Even if patients' goals could not be completely fulfilled, care plan meeting participation resulted in participants being heard and respected and in providers being better able to understand patients' behaviors and motivations in a manner that fostered shared decision making.

Several challenges to implementing My Dialysis Plan were identified. Although the average duration of the care plan meetings was less than 30 minutes, scheduling a large number of these encounters proved burdensome. Care team members initially found it difficult to discuss goals and priorities with patients, but this became easier with experience and the adoption of an interview script. Despite





Kidney Medicine -

this improved conversation fluency, no increase in the documentation of advanced care planning occurred, perhaps indicative of the sensitive nature of end-of-life discussions. The authors also describe inconsistency in documenting or communicating follow-up of the care plan action items, in part due to the lack of procedures or infrastructure for doing so.

The authors identified several limitations to their study. Because this program was implemented at a single dialysis center, the results might be different if done at other centers due to variability in a number of factors such as patient demographics or program size. Although interviews with patients and staff painted a positive picture of the care plan meetings, no significant change in the patient-reported autonomy support, patientcenteredness of care, or dialysis care individualization was identified in the surveys completed by dialysis patients after compared with before implementation. Possible reasons for this discrepancy included a susceptibility to several types of survey bias and a lack of statistical power to capture true differences in pre- and postproject responses. These findings also raise a separate fundamental issue of how to optimally measure personcentered care.

Despite these challenges and limitations, this study provides valuable information about the facilitators and barriers associated with adopting a program to promote person-centered dialysis care. The study bears the hallmarks of methodologically sound quality improvement and implementation research by using stakeholder analysis, a deliberate implementation scheme, and iterative adaptations. Conforming to the SQUIRE guidelines for reporting quality improvement work ensured scholarly rigor, transparency, and completeness.

The goal of dialysis, as with any medical or surgical intervention, should be to maximize the quality of life for a given patient. Nephrologists must listen carefully to patients with the purpose of learning what gives their lives meaning and what burdens they encounter. By conducting conversations designed to elicit patient priorities and concerns, care plans that incorporate these values are more likely to occur. This was the lofty objective delineated by the research team, who are to be commended for their comprehensive approach to designing, implementing, and studying a program that addresses such conversations that lead to a greater likelihood of person-centered care. In summary, this article should serve as a valuable blueprint for other dialysis centers interested in implementing either My Dialysis Plan or a similar program with the goal of enhancing person-centered care and shared decision making in dialysis.

ARTICLE INFORMATION

Authors' Full Names and Academic Degrees: Philip Kemp, MD, and Robert A. Cohen, MD.

Authors' Affiliation: Division of Nephrology, Department of Medicine, Beth Israel Deaconess Medical Center, Boston, MA.

Address for Correspondence: Philip Kemp, MD, Beth Israel Deaconess Medical Center, Libby 2, 171 Pilgrim Rd, Boston, MA 02215. E-mail: pkemp@bidmc.harvard.edu

Financial Disclosure: The authors declare that they have no relevant financial interests.

Peer Review: Received February 12, 2021, in response to an invitation from the journal. Direct editorial input by the Editor-in-Chief. Accepted in revised form February 19, 2021.

Publication Information: © 2021 The Authors. Published by Elsevier Inc. on behalf of the National Kidney Foundation, Inc. This is an open access article under the CC BY-NC-ND license (http:// creativecommons.org/licenses/by-nc-nd/4.0/). Published online March 6, 2021 with doi 10.1016/j.xkme.2021.03.002

REFERENCES

- 1. Kliger A. Quality measures for dialysis: time for a balanced scorecard. *Clin J Am Soc Nephrol.* 2016;11:363-368.
- Morton R, Sellars M. From patient-centered to person-centered care for kidney diseases. *Clin J Am Soc Nephrol.* 2019;14: 623-625.
- Chan CT, Blankestijn PJ, Dember LM, et al. Dialysis initiation, modality choice, access, and prescription: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. *Kidney Int.* 2019;96(1):37-47.
- Department of Health and Human Services. 42 CFR Parts 405, 410, 413, et al. Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule. April 15, 2008. https://www.cms.gov/Regulationsand-Guidance/Legislation/CFCsAndCoPs/Downloads/ ESRDfinalrule0415.pdf. Accessed February 5, 2021.
- Lewis RA, Benzies K, Macrae J, Thomas C, Tonelli M. An exploratory study of person-centered care in a large urban hemodialysis program in Canada using a qualitative case-study methodology. *Can J Kidney Health Dis.* 2019;6:1-15.
- Bear R, Stockie S. Patient engagement and patient-centred care in the management of advanced chronic kidney disease and chronic kidney failure. *Can J Kidney Health Dis.* 2014;1: 24.
- 7. Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. *Health Aff* (*Millwood*). 2010;29:1310-1318.
- Green JA, Mor MK, Schields AM, et al. Prevalence and demographic and clinical associations of health literacy in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol.* 2011;6: 1354-1360.
- 9. Dorough A, Forfang D, Mold JW, et al. A person-centered interdisciplinary plan-of-care program for dialysis: implementation and preliminary testing. *Kidney Med.* 2021;3(2): 193-205.
- Damschroder LJ, Aron DC, Keith RE, et al. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009;4:50.
- Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (Standards for QUality Improvement Reporting Excellence): revised publication guidelines from a detailed consensus process. *BMJ Qual Saf.* 2016;25(12): 986-992.
- 12. Weisbord S. Patient-centered dialysis care: depression, pain and quality of life. *Semin Dial.* 2016;29(2):158-164.