

# Measuring Patient Experience with Home Dialysis in the United States

Brian M. Brady <sup>1,2</sup> and Manjula Kurella Tamura <sup>1,3</sup>

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Providing patient-centered care, one of the three pillars of health care quality, requires understanding the patient experience. Defined by the Agency for Healthcare Research and Quality as “the range of interactions that patients have with the health care system,” patient experience gauges whether an individual patient’s engagement with providers, physician practices, health care facilities, and health plans is responsive to the patient’s values, needs, and preferences (1). The national movement toward patient-centered care has paralleled federal policies linking quality measurement and reimbursement for dialysis care. Indeed, the federal government’s prominent role in financing health care for patients with kidney failure has positioned this unique disease-specific entitlement program as a bellwether for federal policy initiatives in quality measurement. Dialysis facilities were one of the first health care providers to broadly implement standardized patient experience measurement as a condition of quality reporting. The lessons learned offer valuable insights into the best means for developing, implementing, and applying patient experience measures to promote patient-centered care.

In 2002, the Centers for Medicare and Medicaid Services (CMS) partnered with the Agency for Healthcare Research and Quality to develop a survey to measure the care experience of patients undergoing in-center hemodialysis. Its explicit goals were to facilitate external facility performance monitoring by the CMS and internal performance monitoring by the dialysis facilities for quality improvement, and to allow consumers to compare patient experiences among dialysis facilities (2).

This partnership led to the development of the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) survey, the first disease-specific patient experience survey used by CMS. In 2011, CMS mandated the survey’s administration to all patients undergoing hemodialysis as part of the ESKD Quality Improvement Program (3). In 2016, CMS converted the dialysis facility performance on the survey from a reporting metric to a clinical metric (4). This move effectively linked dialysis facility payments to patient experience, marking one of the first efforts by the CMS to tie reimbursement to a patient-reported measure.

Despite its rigorous development and enthusiastic adoption by the CMS, implementation of the ICH-CAHPS

survey has spotlighted opportunities for improvement. Chief among the implementation challenges is the survey’s length (62 items) and time burden, contributing to high survey nonresponse rates. During field testing before widespread implementation, the nonresponse rate was 54% and has not improved since its implementation, despite the growth in its importance in dialysis facility reimbursement (5). In fact, high nonresponse rates preclude the majority of dialysis facilities in the United States from meeting the minimum survey response threshold (30 completed surveys per facility over two survey administration periods) for inclusion in public reporting of facility-level responses (6). The instrument’s responsiveness and interpretation present another major area of critique. What constitutes a clinically important difference in experience scores has not been defined, and there is limited study on the instrument’s responsiveness to interventions.

More recent federal policy initiatives have shifted the CMS’s focus to incentivizing the use of home dialysis modalities. The 2019 Advancing American Kidney Health Executive Order calls for an increase in the adoption of home dialysis or kidney transplantation to 80% of patients with incident ESKD by 2025, an ambitious goal from the current combined rate of 13% (7,8). In contrast to the nationally implemented ICH-CAHPS survey for patients undergoing in-center hemodialysis, there is no equivalent instrument to evaluate patient-reported experiences with home dialysis. If CMS aims to maintain its emphasis on patient-centered care, development of a validated patient-reported experience measure for home dialysis stands as a crucial component.

In this issue of *CJASN*, Rivara *et al.* (9) report a mixed-methods study to develop a patient-reported experience measurement for patients undergoing home dialysis, the Home Dialysis Care Experience (HOME-DCE) instrument. Similar to the approach used for developing the ICH-CAHPS survey, the researchers followed a rigorous, five-step process of instrument development with stakeholder engagement in each step (2,10). After a literature review of similar patient experience instruments, the investigators conducted focus groups and semistructured interviews with key stakeholders to identify care domains most important to patients. The researchers then surveyed patients and providers to rank the relative importance of candidate domains. From these rankings, the researchers drafted

<sup>1</sup>Division of Nephrology, Stanford University School of Medicine, Palo Alto, California  
<sup>2</sup>Clinical Excellence Research Center, Stanford University School of Medicine, Stanford, California  
<sup>3</sup>Geriatric Research and Education Clinical Center, Veterans Affairs Palo Alto Health Care System, Palo Alto, California

**Correspondence:**  
 Dr. Brian Brady,  
 Division of Nephrology, Stanford University School of Medicine, 777 Welch Road Suite DE, Palo Alto, CA 94304. Email: [bbrady2@stanford.edu](mailto:bbrady2@stanford.edu)

a survey instrument and conducted cognitive interviews, evaluating the completeness and comprehensibility of the instrument in focus groups, winnowing the survey items from 172 to 31. The HOME-DCE was iteratively refined until thematic saturation was reached in focus groups, culminating in the final instrument. Further validation of a Spanish-language adaptation of the instrument was undertaken, with linguists and patients representing major Spanish-speaking groups in the United States.

From this systematic process, Rivara *et al.* identified domains of care that patients undergoing home dialysis feel are the most important aspects of the patient experience: patient-staff communication and education, concern and helpfulness of staff, care coordination, and shared decision making. These domains have face validity to those who care for patients on home dialysis, given the degree to which these patients establish strong relationships and rely heavily on the home dialysis nurses and staff for education, modality training, and routine care. Although several of these domains are captured with similar items on the ICH-CAHPS, other domains, such as personalization of the treatment schedule or dialysis staff helpfulness in troubleshooting home dialysis equipment issues, are unique to the HOME-DCE. These variances highlight important ways in which patient experience on home dialysis differs from that of their in-center counterparts and reinforces the need for a patient-reported experience measure targeted to home dialysis.

The study by Rivara *et al.* has many notable strengths. The investigators followed a rigorous development process and engaged a wide range of stakeholders: patients undergoing home dialysis, caregivers, and home dialysis providers. The HOME-DCE and ICH-CAHPS share common domains: patients' perceptions of the providers' ability to listen and understand their concerns, time providers spend with patients, and the degree to which patients feel respected by their providers. Further, the investigators paralleled the wording and response format used in the ICH-CAHPS, which could facilitate future comparisons between in-center and home dialysis populations. Recognizing that the length of the ICH-CAHPS and language barriers may contribute to low response rates, the investigators made a concerted effort to reduce the number of items on the HOME-DCE and validate the instrument in Spanish speakers. These features of the study could improve implementation efforts of the HOME-DCE on a broader scale. The HOME-DCE fills an important gap in dialysis quality measurement tools, and for this accomplishment, the authors should be commended.

Field testing the HOME-DCE to understand its psychometric characteristics, such as internal consistency reliability, facility-level reliability, and construct validity in diverse populations, particularly among racial and ethnic groups underrepresented in this study, will improve its implementation. Other important steps before broad dissemination include evaluation of its measurement properties, such as floor and ceiling effects, scaling (whether scores cluster), responsiveness to change, and equivalence between administration modes. Implementation studies should assess administration burden and response rates. Further evaluation of this rigorously developed instrument can build on the trials and tribulations faced by implementation of the ICH-CAHPS survey and potentially avoid some of the important criticisms of its in-center predecessor.

As CMS works to improve the value of care delivered to patients with kidney failure and prioritize home dialysis modalities, the HOME-DCE developed by Rivara *et al.* represents the first English-language patient-reported experience measure geared specifically at evaluating patient-reported experience with home dialysis care. This laudatory work meets an important need for quality measurement tools in home dialysis, and comes at a moment when 2 decades of federal policies incentivizing patient-centered care and promoting home dialysis intersect. Further evaluation and implementation of this instrument has the potential to inform and reshape the quality of care we deliver to our patients undergoing home dialysis.

#### Disclosures

B.M. Brady reports employment with Stanford University. M. Kurella Tamura employment with Veterans Affairs Palo Alto Health Care System and Stanford University; receiving honoraria from American Federation for Aging Research; serving on the Beeson External Advisory Committee and Clin-Star Advisory Board; and serving as an Associate Editor of *CJASN*.

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See related article, “Development and Content Validity of a Patient-Reported Experience Measure for Home Dialysis,” on pages 588–598.