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Using Patient-Reported Measures in Dialysis Clinics

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Introduction

Patient-reported measures (PRMs), including patient-reported outcomes (PROs), are one of two primary sources of data about patients on dialysis (1); the other is biologically based patient data. The Food and Drug Administration definition of a PRO is “any report coming from patients about a health condition and its treatment, without interpretation of the patient’s response by a clinician or anyone else” (2). We argue that this definition fits PRMs more generally and that PROs are a subset of that. Like other fields of medicine, in dialysis, PRMs are used as quality assessment and performance measures. Incorporating PRMs into clinical practice across medicine improves outcomes, such as patients’ survival (3). In a meta-analysis, 65% of studies provided evidence that PRMs improved processes of care (*e.g.*, patient education and diagnoses), 47% of studies provided evidence that PRMs improved the outcomes of care (*e.g.*, functional status), and 42% of studies provided evidence that PRMs improved satisfaction with care (4).

Because the Centers for Medicare and Medicaid Services (CMS) pays for the cost of dialysis for the vast majority of patients with ESRD, they have a significant stake in understanding the quality of that care and its outcomes. The CMS is particularly interested in patient experience with care and health-related quality of life (HRQOL) and has codified recommendations or requirements that these PRMs be collected on all patients on dialysis.

This paper outlines the major methodologic recommendations around use of PRMs in dialysis that we generated in a white paper commissioned by the Kidney Care Quality Alliance (KCQA). These recommendations were generated through a systematic review of the PRM literature and include (1) continue the use of the Kidney Disease Quality of Life 36-item version (KDQOL-36) for dialysis centers’ internal quality improvement activities and the In-Center Hemodialysis Consumer Assessment of Health Care Providers and Systems (ICH-CAHPS) measures for public dialysis center performance monitoring but promote efforts to modify these instruments by incorporating Patient Reported Outcomes Measurement Information System (PROMIS) general health items (KDQOL-36) and reducing the length of the ICH-CAHPS, (2) adopt a PRM of whether patients on dialysis have been informed about their option

for transplant and all dialysis options, (3) evaluate equivalence between electronic and paper versions of PRMs before widespread use of electronic administration, (4) explore reimbursement of costs of PRM administration and training, and (5) continue development of provider trainings in PRM administration and interpretation (Table 1). These recommendations were made to the KCQA on the basis of our review and research into methodologic challenges around the use of PRMs in dialysis.

Recommendation 1

Two of the most commonly used PRM instruments in dialysis facilities are the KDQOL-36 (5) and the ICH-CAHPS (6). The KDQOL-36 is the measure of choice for the CMS’s requirement of annual HRQOL assessment among all patients on dialysis. The ICH-CAHPS is mandated to be assessed twice annually by all patients on dialysis and is included as a clinical measure in the payment year 2019 Quality Improvement Program (QIP). Both of these instruments were developed with extensive patient and expert input, helping ensure that they represent the views and experiences of patients on dialysis and providers (5,6). In addition, support for the reliability (*e.g.*, internal consistency reliability ≥ 0.80) and validity of the KDQOL-36 has been evidenced (7). Support for the reliability and validity of the ICH-CAHPS has also been presented (6). Finally, both of these measures have been administered to thousands of patients on dialysis, making possible clinically meaningful comparisons of individual patients with national and state norms and key clinical subgroups. As noted above, the ICH-CAHPS is administered as part of the CMS’s QIP. The KDQOL-36 is often administered to help meet the CMS’s requirement for annual quality of life assessment by vendors, like the Medical Education Institute, which administer the KDQOL-36 to thousands of patients on dialysis yearly. Considering these advantages, we recommend the continued use of the KDQOL-36 instrument with patients on dialysis for the purposes of dialysis centers’ internal quality improvement and the continued use of the ICH-CAHPS for the CMS’s dialysis center performance monitoring.

There are opportunities to improve both of these measures. The KDQOL-36 incorporates the Medical Outcomes Study 12 Item Short Form Health Survey

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Table 1. Recommendations for use of patient-reported measures in dialysis centers

Category	Recommendations
Selection of PRMs	Continue the use of the KDQOL-36 for dialysis centers' internal quality improvement activities and the ICH-CAHPS for public dialysis center performance monitoring but promote efforts to modify these instruments by incorporating PROMIS general health items (KDQOL-36) and reducing the length of the ICH-CAHPS Adopt a PRM of whether patients have been informed about their option for transplant and all dialysis options
Mode of administration	Evaluate equivalence between electronic and paper versions of PRMs before widespread use of electronic administration
Support for PRM use	Explore reimbursement of costs and support for training for PRM administration from the CMS, the ESRD Networks, or professional societies Continue development of provider trainings in PRM administration and interpretation

PRM, patient-reported measure; KDQOL-36, Kidney Disease Quality of Life 36-item version; ICH-CAHPS, In-Center Hemodialysis Consumer Assessment of Health Care Providers and Systems; PROMIS, Patient Reported Outcomes Measurement Information System; CMS, Centers for Medicare and Medicaid Services.

(SF-12) as its generic HRQOL core. However, the National Institutes of Health PROMIS measures are the state of the science in generic HRQOL measurement (8) and suitable as a replacement for the SF-12. In head to head comparisons, the PROMIS measures have shown better reliability than legacy measures, like the SF-12. The ICH-CAHPS composites could be made more parsimonious by using an approach similar to that used for the Consumer Assessment of Health Care Providers and Systems clinician and group survey, resulting in shorter surveys (9).

Recommendation 2

In addition to HRQOL and patient experience, there are many other PRMs that provide relevant information about patients on dialysis. The decision making of patients with ESRD about their treatment is one domain where the use of PRMs in dialysis centers should be expanded. Patients with ESRD have multiple types of dialysis from which they may choose. In addition to dialysis, they may choose to pursue a living or deceased donor kidney transplant. All of these treatment options vary in the length and quality of additional life-years that they offer to patients (10).

The importance of providing information about transplants to patients is evidenced by the fact that it increases the likelihood that they will pursue and receive transplants (11). For this reason, the CMS's 2008 Conditions for Coverage for dialysis facilities require that information about the option for kidney transplant be provided to each patient on dialysis. However, patients on dialysis report having received information about transplant less than their providers report giving transplant information, indicating that provider reports may not be as accurate for this purpose (12). Additionally, there is evidence that alternative dialysis options may improve patients' survival and HRQOL (10). It has been argued recently that, when patients on dialysis are not given access to information about the risks and benefits of all their treatment options, they cannot make informed consent for their dialysis treatment (13). We contend that patient reports of receiving information about their treatment options may be better

indicators of whether informed decision making and consent around treatment choices actually occur among patients on dialysis compared with provider reports. Therefore, we recommend that the CMS adopt a PRM of whether patients on dialysis have been informed about their option for transplant and all of their dialysis options.

Recommendation 3

A major methodologic challenge faced by dialysis facilities is implementing the best mode of survey administration. The International Society of Quality of Life Research reviewed the resources needed and tradeoffs associated with different modes of administration of PRMs (14), including self-, interviewer-, and computer-administered surveys given in the clinic, by mail, over the telephone, and electronically *via* the web. All of these options involve a balance of advantages, disadvantages, and resource inputs, each of which is detailed in our full manuscript (J.D. Peipert, R.D. Hays, unpublished manuscript).

However, one mode of administration with expanding potential, electronically based PRM surveys, deserves special attention. Electronic administration, either on a computer or portable technologies like tablets, may offer attractive efficiencies over the other modes. One particularly attractive benefit of web-based surveys is the ability to input data into a database directly, avoiding potential problems with data entry. Many PRM instruments were originally developed to be administered in a paper/pencil format. Although these instruments likely do not need to be redeveloped for electronic administration, additional testing for equivalence should be conducted to determine if smaller modifications are required (*e.g.*, updates to instructions and formatting or minor wording changes). Therefore, we recommend that new studies evaluate equivalence between electronic and paper versions of PRMs before widespread use of electronic administration. Additionally, inquiries into the challenges of this mode of administration for older adults, the frail, and those without high levels of technology literacy should be made before large-scale rollout.

Recommendation 4

Another major challenge facing dialysis facilities around administering PRMs regards their financial and human resource costs. Administering PRMs requires significant staff time and expertise as well as material costs. Many dialysis staff, who are primarily responsible for administering PRMs to patients, already have a high workload. Along with data entry, interpretation of PRMs' results and incorporation of these results into clinical intervention are expensive and difficult to accomplish without significant discretionary spending and resource investment (1). Therefore, we recommend that efforts be undertaken to explore reimbursement of costs and support for training for PRM administration from the CMS, the ESRD Networks, or professional societies.

Recommendation 5

Related to recommendation 4, an important practical challenge faced in administering standardized PRM instruments in dialysis clinics regards the expertise required to properly administer them. The dialysis providers and staff administering PRMs in face to face or telephonic interviews require a special skill set, including the abilities to gather accurate responses, help patients with their questions and concerns without biasing their responses, execute complex skip patterns, and detect when patients may be giving untruthful responses. PRMs implemented through self-administered surveys (e.g., mailed to the patients) also require expertise, including the ability to execute standardized data entry protocols. These skills are not likely part of the training of many dialysis providers and staff, and therefore, additional training is often required. We recommend the continued development of provider trainings in PRM administration and interpretation to help dialysis providers build these skills. These trainings should target dialysis organizations to help their dialysis providers (e.g., nephrologists) and staff members (e.g., nurses and social workers) sharpen their ability to administer PRMs in clinic.

In conclusion, dialysis payers, administrators, providers, and staff deserve recognition for their considerable efforts and successes in incorporating PRMs into routine care. However, there are still many challenges facing dialysis facilities around administering PRMs to their patients. We have identified multiple practical specific recommendations to assist in facing these challenges. These recommendations are intended to help dialysis care decision makers, clinicians, and applied researchers continue to improve the excellent track record of PRM use.

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around using patient-reported measures in dialysis. The recommendations presented in this manuscript represent the results of the authors' research but do not necessarily represent the views of the KCQA. R.D.H. was among the team of investigators who originally developed Kidney Disease Quality of Life 36-item version and the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems. Neither investigator benefits financially from the use of these measures.

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