How the ESRD Quality Incentive Program Could Potentially Improve Quality of Life for Patients on Dialysis

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Abstract
For over 20 years, the quality of medical care of the Medicare ESRD Program has been a concern. The Centers for Medicare and Medicaid Services have implemented the ESRD Quality Incentive Program, which uses the principles of value-based purchasing; dialysis providers are paid for performance on predefined quality measures, with a goal of improving patient outcomes and the quality of patient care. The ESRD Quality Incentive Program measures have been criticized, because they are largely disease oriented and use easy-to-obtain laboratory-based indicators, such as Kt/V and hemoglobin, that do not reflect outcomes that are most important to patients and have had a minimal effect on survival or quality of life. A key goal of improving quality of care is to enhance quality of life, a patient-important quality measure that matters more to many patients than even survival. None of the ESRD Quality Incentive Program measures assess patient-reported quality of life. As outlined in the National Quality Strategy, the Centers for Medicare and Medicaid Services are holding providers accountable in six priority domains, in which quality measures have been and are being developed for value-based purchasing. Three measures—patient experience and engagement, clinical care, and care coordination—are particularly relevant to quality care in the ESRD Program; the 2014 ESRD Quality Incentive Program includes six measures, none of which provide data from a patient-centered perspective. Value-based purchasing is a well intentioned step to improve care on patients of dialysis. However, the Centers for Medicare and Medicaid Services need to implement significant change in what is measured for the ESRD Quality Incentive Program to be patient centered and aligned with patients’ values, preferences, and needs. This paper provides examples of potential quality measures for patient experience and engagement, clinical care, and care coordination, which if implemented, would be much more likely to enhance quality of life for patients with ESRD than present ESRD Quality Incentive Program measures.


Concerns about Quality Care and Patient Quality of Life in the ESRD Program
For over 20 years, nephrologists and other researchers studying the Medicare ESRD Program have been concerned about the quality of medical care and the quality of life of patients on dialysis (1–4). The Centers for Medicare and Medicaid Services (CMS) have implemented value-based purchasing to improve quality in patient care (5). The CMS calls the ESRD Quality Incentive Program (QIP) their most recent step in fostering improved patient outcomes by establishing incentives for dialysis facilities to meet or exceed performance standards that the CMS has established (6). The ESRD QIP measures have been criticized, because they are disease oriented (7) and use easy-to-obtain laboratory-based indicators, such as Kt/V and hemoglobin, that do not reflect outcomes that are important to patients and that have had a minimal effect on survival or quality of life (3,8). For example, the CMS has been criticized for the continuing inclusion in the ESRD QIP of dialysis adequacy, when 98% of dialysis facilities are already meeting the target adequacy measure (3). In fact, the CMS has recognized that quality measures need to increasingly transition from setting-specific, narrow snapshots to meaningful, broad-based, patient-centered assessments of care along the continuum of treatment (5). They acknowledge that the primary purpose of quality measurement is the delivery of patient-centered, outcome-oriented, quality health care.

A key goal for nephrology clinicians is to provide optimal patient care to maximize patient quality of life (9). However, patient perception of quality of life is multifactorial and composed of objective and subjective physical, emotional, and social aspects (10). Sadly, numerous studies suggest that the quality of life of patients with ESRD is below that of general age-, race-, and sex-matched populations (4,9,10). Disease-oriented approaches to improve patient quality of life, such as more intense and frequent hemodialysis, which have had disease-related benefits like reducing left ventricular mass and hypertension, have not had a major effect on the quality of life of patients on dialysis (11,12). Palliative care is patient centered. Use of palliative care quality metrics is feasible, and palliative care can improve patient quality of life and quality of care (13). The purpose of this paper is to explain how incorporation of palliative care quality metrics into the ESRD QIP can improve its patient centeredness and likely lead to outcomes that
patients on dialysis have reported are most important to them.

**Problems with Current and Proposed ESRD QIP Measures**

Quality of life is a patient-important quality measure of care that often matters more to patients on dialysis than survival (3,9,14–16). Researchers have found that patient-reported quality of life is inversely proportional to the number of troublesome symptoms that patients report, such as pain (17,18), and treatment of symptoms improves patient quality of life (19,20). Although there are limited numbers of studies examining treatment of depression and targeted intervention for psychosocial stressors on the quality of life of patients on dialysis, researchers believe that it is reasonable to speculate that treatment of these problems holds the promise for improving patient quality of life (10,20,21). Because quality of life is a uniquely personal perception, it is not a one size fits all concept, and the best assessments of patient quality of life are self-reports (22). None of the ESRD QIP measures assess patient-reported quality of life.

The CMS have recognized the need to develop more patient-centered quality metrics in the ESRD QIP. In 2013, the CMS convened a Technical Expert Panel (TEP) to recommend metrics for the Comprehensive ESRD Care initiative. In addition to their disease-oriented measures, this TEP recommended the inclusion of several patient-centered measures: the Kidney Disease Quality of Life, which includes a patient self-report of health; an advance care plan; and an assessment of patient functional status. The nephrology community has raised numerous concerns regarding the TEP-recommended measures (23–25), and the CMS is conducting additional research on the feasibility, usability, and technical considerations of the TEP-proposed measures. Dialysis facility-specific scoring on quality measures will also need to be adjusted for the population served by the facility, because patients who are ethnic minorities and those from impoverished areas vary in their self-reported health ratings and care satisfaction (26).

In addition, the CMS reported in the July 11, 2014, Federal Register that they propose in Payment Year 2018 to implement the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) as a clinical measure as well as depression screening, follow-up for depression, pain assessment, and pain follow-up as reporting measures (6). The ICH CAHPS measures patient attitudes toward the quality of care that they receive from nephrologists, other dialysis staff, and the treatment center. In this regard, it is patient centered, but the ICH CAHPS has 58 questions, and it is not clear how the CMS plans to analyze it to further patient-centered care. Because treating pain and depression is known to improve quality of life (27), these measures are potentially among the most promising of the ones proposed for the ESRD QIP if transitioned to clinical measures.

Reporting measures are process measures, and clinical measures are outcome measures. As currently proposed, the pain and depression measures are process measures and not outcome measures. The weakness in this approach is that, although it provides incentives for compliance with the process of screening, it does not do so for ensuring optimal patient outcomes, such as effective management of pain and depression. Process measures may also increase overall costs, discourage innovation in health care delivery, and not add value for patients (28). For example, for the reporting measure of infection-related dialysis events, dialysis personnel need to enroll, complete training, and report data on events, such as central line-associated blood infections, to the National Healthcare Safety Network (8). They also need to contract with a vendor for the administration of the ICH CAHPS. Unless additional detail is provided to fulfill the Payment Year 2018 ESRD QIP measures, dialysis facilities will be free to use a number of different tools. For example, the proposed measure to assess pain does not require use of validated measures in ESRD, such as the numeric 10-point pain scale, which is used in the Edmonton Symptom Assessment System--revised: Renal and World Health Organization Analgesic Ladder algorithm (29–31). The proposal to measure depression also does not require one of the well validated depression scales for patients with ESRD: the Beck Depression Inventory, the Hospital Anxiety and Depression Scale, or Patient Health Questionnaire-9 (32,33). Because pain and depression are major contributors to poor quality of life for patients on dialysis (10), it is important that these symptoms be managed effectively.

However, the use of process measures will allow the various tools to be evaluated for feasibility and ease-of-use in the clinical setting. Starting with process measures will also allow time for a consensus to be reached on which tools adequately guide clinicians to provide quality care, the frequency with which screening should be performed, and potential action measures to be used for positive screens. The CMS, Kidney Care Partners, the American Nephrology Nurses Association, and the Renal Physicians Association all agree that quality measures for patients on dialysis should be reliable, feasible, specific, and actionable. We recognize that there is a relative lack of data on interventions that dialysis providers can undertake to improve quality of life for patients with ESRD and measures to document benefit from the interventions. In addition to the experience that will be gained with the use of process measures to aid the development of outcome measures, federal funding for additional research in this area is urgently needed.

Compounding the problems with the ESRD QIP one size fits all approach is that patients on dialysis are a heterogeneous population (34). Three groups of patients with ESRD have been described in an article on a vision for patient-centered care: (1) dialysis as a bridging or long-term maintenance treatment, (2) dialysis as a final treatment destination for patients with a poor prognosis, whose treatment goals are focused on maximizing quality of life with continuation of dialysis as long as physical and psychosocial symptoms are controlled adequately, and (3) active medical management without dialysis (conservative care). Optimal treatment, especially for groups 2 and 3, requires a patient-centered rather than a disease-oriented approach focusing on patients' values, preferences, and goals in light of their prognosis and encouraging informed choices about treatment as a result of shared decision making. Shared decision-making discussions, including advance care planning that focuses on end of life care, have been recommended by the American Society of Nephrology (35) and the Renal Physicians Association (36) as a priority before the initiation of chronic dialysis and continuing through the illness trajectory,
but, thus far, they have not been incorporated into the ESRD QIP and are not in the planning for the next 3 payment-years. Advance care planning could begin as a process measure with attestation, which has been proposed by the National Quality Forum in Endorsed Measure 0326 (37). With study, it could transition to an outcome measure with documentation of one of several outcomes: patient declined to participate in advance care planning, patient completed an advance directive, patient agreed to a do not resuscitate order, and/or patient agreed to and participated in the completion of a physician orders for life-sustaining treatment or similar form depending on the state.

The clinical practice guideline Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis (36) also recognized that patients with advanced kidney disease represent a heterogeneous population. The guideline noted three groups of patients whose treatment goals are distinctly different: (1) patients who choose aggressive therapy with dialysis without limitations on other treatments; (2) patients with a poor prognosis who choose dialysis but with limitations on other treatments, such as cardiopulmonary resuscitation, intubation, and mechanical ventilation, because they want to balance life prolongation and comfort; and (3) patients who decline dialysis and prefer that the primary goal of care be their comfort (36). These groups correspond well with those mentioned in the article on a vision for patient-centered care for patients on dialysis described above (34). The consistent recognition of distinct groups of patients with advanced kidney disease who have different goals of care underscores the need for advance care planning as a quality metric in this population.

Domains of Quality Measurement Particularly Relevant to the ESRD Program
As outlined in the National Quality Strategy, the CMS is holding providers accountable in six priority domains, in which quality measures have been and are being developed for value-based purchasing (5). Three domains—patient experience and engagement, clinical care, and care coordination—are particularly relevant to quality care in the ESRD QIP (5). The ICH CAHPS measures patient experience and engagement, but it does not assess patient quality of life or the most important concerns that patients report about living on dialysis. Particularly relevant to the experience and engagement of patients on dialysis is a recent thematic synthesis of 26 papers on perceptions of care of patients with CKD or ESRD and caregivers, which found that patients suffered from bodily deterioration, unyielding fatigue and pain, and loss of freedom and independence. They felt personally vulnerable and were negotiating existential tensions feeling that they were living on borrowed time. Patients on dialysis reported being ambivalent about continuing it (38). Another recent paper identifying priorities for research of patients on dialysis and caregivers found that one of their top 10 research questions was “What is the psychological and social impact of kidney failure on patients, their family, and other caregivers, and can this be reduced?” (16). None of the present or proposed ESRD QIP measures tap into patient and caregiver psychosocial and existential experiences of illness or measure the success of interventions to improve them. Furthermore, Tong et al. (38), who wrote the thematic synthesis, recommended palliative care strategies to improve patient quality of life and experience of care. Others have similarly noted the top priority of palliative care for improving patient quality of life and reducing suffering (14,34,39). Again, none of the present or proposed ESRD QIP measures assess the provision of palliative care to patients with ESRD, although most patients on dialysis have multiple comorbidities, a high symptom burden, and a shortened life expectancy. Much like the advance care plan measure, the surprise question could begin as a reporting measure and transition to a clinical measure with one of several outcomes required for a “No, I would not be surprised if the patient died in 6 months” response: advance care planning as described above, palliative care consultation, patient declined palliative care consultation, and referral for hospice evaluation (40).

Clinical care is another of the six domains of quality measurement for value-based purchasing relevant to the ESRD QIP in which the CMS hope to align measures around patient-centered outcomes across the continuum of care (5). In its 2001 report Crossing the Quality Chasm: A New Health System for the 21st Century (41), the Institute of Medicine (IOM) proposed patient-centered care as one of six specific aims for improvement of United States health care delivery system quality. The IOM defined patient centered as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (41). Since the publication of the IOM report, there has been growing national interest in more individualized, patient-centered models of care (7,42). Patient-centered care seeks to tailor treatment strategies to what matters most to individual patients and align treatment plans and quality metrics to optimize patient-important goals and preferences to maximize patient quality of life (43). If care is to be patient-centered care, it follows that patients and their caregivers should be included when priorities for clinical care and research are being established. It is only recently that studies have elicited systematically the priorities of patients receiving dialysis (16). They named among their top 10 priorities communication with patients and families about dialysis modality (this would include conservative care), optimal management of patient-relevant symptoms (itching, depression, poor energy, nausea, cramping, and restless legs), and how to address the psychologic and social needs of patients. These priorities seem to focus more on improving symptoms and optimizing communication and less on determining how to extend life. Standard dialysis delivery, therefore, which achieves the ESRD QIP dialysis adequacy measure, seems not to be aligned with the goals of care of many patients with ESRD (44).

For the three groups of patients with advanced kidney disease described in the vision for patient-centered care article and the clinical practice guideline, the clinical care goal is to align treatment with the patients’ preferences as a result of an advance care planning discussion, in which the patient’s goals for treatment are identified (34). For those in group 1, the goal will be a focus on rehabilitation and extending life. For groups 2 and 3, the focus will be on palliative care, prioritizing comfort, maximizing quality of life, and reducing symptom burden (44). Care coordination is another domain of quality measurement for value-based purchasing relevant to the ESRD QIP. It
Proposed Patient–Centered Quality Metrics for the ESRD QIP

Implementation of patient-centered, value-based purchasing in the Medicare ESRD QIP, which the CMS has proposed to do with all quality measurement (5), will require considerable transformation of the ESRD QIP measures, the vast majority of which are disease oriented. Table 1 provides examples of potential metrics that would fulfill the recommendations for quality measures that are patient centered and outcome oriented in patient experience and engagement, clinical care, and care coordination. For example, referral to hospice as appropriate is listed in Table 1 as a quality metric under clinical care. About two thirds of patients on dialysis would like to die at home or in an inpatient hospice (13), but yet, only about 20% do (47). Because death while receiving hospice care is recorded on the CMS 2746 Death Notification form for patients on dialysis, this measure should be feasible and reliable. It is promising that the CMS has accepted “adult kidney disease: referral to hospice” as a measure under consideration in the 2014 Physician Quality Reporting System and that this measure is to be evaluated by the Measure Application Partnership (48). Studies of patients’ perceptions of life in patients with CKD and ESRD and their top 10 priorities for research questions support the proposed quality metrics in Table 1 (16,38). Implementation of such measures will likely enhance the quality of care and quality of life for patients with ESRD.

Value-based purchasing is a well intentioned step in the right direction. The CMS need to implement significant changes in how they develop measures for the ESRD QIP for it to be patient centered and assess what matters most to patients on dialysis (3,43).

Acknowledgments

This research was supported, in part, by the Mei-Ying Huang Research Fund of the West Virginia University Center for Health Ethics and Law.

Disclosures

None.

References


Table 1. Proposed quality measures for a patient-centered ESRD Quality Incentive Program

<table>
<thead>
<tr>
<th>Quality Domain</th>
<th>Proposed Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient experience and engagement</td>
<td>Measurement of patient quality of life (17,49)</td>
</tr>
<tr>
<td>Patient experience and engagement</td>
<td>Assessment of psychologic and social effects of kidney failure and their families and means to reduce it (8,16,21,50); patient satisfaction with life; satisfaction with care</td>
</tr>
<tr>
<td>Clinical care</td>
<td>Global symptom assessments quarterly using validated tools measuring pain, depression, anxiety, itching, patient satisfaction with care, and psychosocial stressors (19,21,36,51,52)</td>
</tr>
<tr>
<td>Clinical care</td>
<td>Advance care planning at initiation of dialysis and yearly thereafter or when the patient’s condition changes (36)</td>
</tr>
<tr>
<td>Clinical care</td>
<td>Documentation of preferred surrogate decision maker in the event of incapacity (14,36)</td>
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<tr>
<td>Clinical care</td>
<td>Universal screening for patients whom palliative care would be appropriate with the surprise question (34,39,40)</td>
</tr>
<tr>
<td>Clinical care</td>
<td>Process for shared decision making for all patients, including those with a poor prognosis (35,36)</td>
</tr>
<tr>
<td>Clinical care</td>
<td>Referral to hospice when appropriate (36,39)</td>
</tr>
<tr>
<td>Care coordination</td>
<td>Assessment of “high risk domains [for rehospitalization]” on first dialysis visit after hospitalization (46)</td>
</tr>
<tr>
<td>Care coordination</td>
<td>Medication reconciliation as a continual process, including on first dialysis visit after hospitalization, to improve care and reduce likelihood of readmission (46)</td>
</tr>
<tr>
<td>Care coordination</td>
<td>Completion of the physician orders for life-sustaining treatment (53) form for patients with a poor prognosis</td>
</tr>
</tbody>
</table>


33. Preljevic VT, Østhus TBH, Sandvik L, Opjordsmoen S, Nordhus IH, Øs I, Dammen T: Screening for anxiety and depression in dialysis patients: Comparison of the Hospital Anxiety and Depression Scale and the Beck Depression Inventory. J Psychosom Res 73: 139–144, 2012


Published online ahead of print. Publication date available at www.cjasn.org.