

# Patient-Centered Care: An Opportunity to Accomplish the “Three Aims” of the National Quality Strategy in the Medicare ESRD Program

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## Abstract

In light of mounting federal government debt and levels of Medicare spending that are widely viewed as unsustainable, commentators have called for a transformation of the United States health care system to deliver better care at lower costs. This article presents the priorities of the Coalition for Supportive Care of Kidney Patients for how clinicians might achieve this transformation for patients with advanced CKD and their families. The authors suspect that much of the high-intensity, high-cost care currently delivered to patients with advanced kidney disease may be unwanted and that the “Three Aims” put forth by the National Quality Strategy of better care for the individual, better health for populations, and reduced health care costs may be within reach for patients with CKD and ESRD. This work describes the coalition’s vision for a more patient-centered approach to the care of patients with kidney disease and argues for more concerted efforts to align their treatments with their goals, values, and preferences. Key priorities to achieve this vision include using improved prognostic models and decision science to help patients, their families, and their providers better understand what to expect in the future; engaging patients and their families in shared decision-making before the initiation of dialysis and during the course of dialysis treatment; and tailoring treatment strategies throughout the continuum of their care to address what matters most to individual patients.

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## Introduction

Health care in the United States is undergoing a “delivery system transformation.” The US Centers for Medicare and Medicaid Services (CMS) is testing innovative payment and service delivery models to enhance quality care for Medicare and Medicaid beneficiaries while at the same time reducing program expenditures. In short, the goal is to deliver better care at lower cost (1). The Medicare ESRD program is among the CMS-funded programs in which value-based purchasing will be implemented (2). Increases in Medicare spending, particularly in the Medicare ESRD program, have provided the major impetus for these proposed changes (2–4). In 2010, 7.9% of all Medicare expenditures were spent on the 1.3% of Medicare beneficiaries with ESRD (5).

The CMS foresees that to achieve long-term success in health care reform, clinicians and organizations will need to make “fundamental changes in their day-to-day operations” (1). The members of the Coalition for Supportive Care of Kidney Patients (CCKP; formerly the Kidney End-of-Life Coalition), composed of renal palliative care specialists, representatives of kidney and hospice organizations, and patients with ESRD and their family members, believe that better quality care for patients with CKD and ESRD can likely be achieved at similar or lower costs. Furthermore, CCKP members agree with the CMS that reform of the care of patients with CKD and ESRD will

require fundamental changes in our approach to the care of these patients (6).

This article aims to present the CCKP’s vision for how clinicians might work together with patients with advanced CKD and their families to optimize care. Studies of dialysis patients’ preferences for end-of-life care suggest that much of the high-intensity, high-cost care currently delivered to older patients with advanced kidney disease may be unwanted, and that efforts to align treatment decisions with what matters most to individual patients may lead many patients to choose lower-intensity, lower-cost treatments (7–9). Experience in oncology reveals that efforts to align treatment plans with patient preferences and to integrate palliative care earlier in the course of illness are shown to result in better patient quality of life, less aggressive care, earlier referral to hospice, better caregiver bereavement adjustment, and lower costs (10–13). On the basis of the oncology experience, it seems likely that stronger efforts to align treatments for advanced kidney disease with patients’ informed preferences might have the added benefit of resulting in lower-cost care.

We suspect that the implementation of the CCKP’s vision will accomplish the “Three Aims” of the National Quality Strategy and the Institute for Healthcare Improvement to promote better care for the individual, better health for populations, and reduced health care costs (14). The CCKP believes that a strategy of patient-centered care based on available evidence and aligned

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with the values and goals of patients with CKD and ESRD may simultaneously enhance their care while embracing the fiscal realities of the Medicare ESRD program.

### History and Growth of the Medicare ESRD Program

The Medicare ESRD program has far exceeded initial projections in terms of the size of the population and associated costs. The social contract that is the Medicare ESRD program came into existence in 1972, when the US Congress explicitly acknowledged that withholding life-extending technology on the basis of inability to pay was ethically and morally inconsistent with our country's values (15). The program was never intended to provide RRT to all patients with advanced kidney disease. In a 1975 Report to Congress, the Department of Health, Education, and Welfare agreed with the need for guidelines to assure that whole categories of patients are not excluded from receiving treatment, but it also stated that not all patients with CKD should be dialyzed (16). The Department of Health, Education, and Welfare wrestled with defining the program, but its final policy objectives (to provide for the health care needs of patients with kidney disease, to create the infrastructure for their treatment, and to assure quality while containing costs) are still relevant (17). As the primary payer for ESRD in this country, the US Federal Government spent \$34.3 billion on the Medicare ESRD program in 2011 (18). Medicare now covers 82% of patients, with the remainder being covered by Medicaid, the US Department of Veterans Affairs, the US Department of Defense, and private insurance (18).

Since its inception, the Medicare ESRD program has implemented a number of reforms intended to reduce costs and improve the quality of care (*e.g.*, bundled payment, pay-for-performance measures) but has not generally sought to elicit patient and family preferences and priorities or to tailor care to optimize those outcomes that matter most to individual patients.

Over time, there has been a progressive liberalization of dialysis initiation practices resulting in a dramatic expansion in the size of the Medicare ESRD program. Between 1990 and 2010, the number of new patients with ESRD in the United States increased from 50,869 to 116,946, and the crude annual incidence of ESRD increased from 119.4 to 369.4 per million (19). This trend does not appear to be completely explained by trends in the prevalence of CKD (20). Furthermore, patients are not only initiating dialysis in greater numbers, but they are also doing so earlier in the course of their kidney disease. Over the last 10–15 years, there has been a pervasive trend across a wide range of different patient groups toward initiation of chronic dialysis at progressively higher levels of kidney function (21,22). Possible contributors to more liberal dialysis initiation practices over time include less stringent guideline criteria for dialysis initiation, changes in the recommended approach to measurement and classification of CKD, and active collaboration between the CMS and the Kidney Disease Outcomes Quality Initiative to eliminate regulatory barriers to dialysis initiation at higher levels of renal function (23,24).

Temporal trends in the incidence of treated ESRD have been particularly pronounced in very elderly patients, a group for whom the benefits of this treatment are least certain.

Reports of limited survival and poor outcomes after initiation of dialysis, high levels of health care intensity and low rates of hospice use at the very end of life in older dialysis patients have helped to highlight the potential burdens of dialysis treatment in this most vulnerable group (24–28). In addition, a growing number of reports from outside the United States comparing outcomes among patients who initiate dialysis versus those treated more conservatively suggest that dialysis may have little effect on life expectancy in frail older adults, and that any gains in life expectancy may be offset by more days spent in a health care setting (29,30). Collectively, this work has generated skepticism about the benefits and appropriateness of more liberal approaches to dialysis initiation in frail older adults (31,32).

Limited data are available on the benefits and harms of treatment with dialysis versus more conservative approaches in the care of frail older patients with symptomatic advanced kidney disease who are not candidates for renal transplantation (33–35). Several studies have demonstrated that some patients are willing to make tradeoffs between longer survival time and better quality of life. In one study of 578 patients with advanced CKD, only a small minority reported that they would want to live as long as possible if this would mean prolonged pain and discomfort (8). In a second study of 242 patients with CKD, 75% said they would prefer to live for a shorter period if this would mean avoiding pain and suffering (7). In a third study of 105 patients with CKD, many were willing to make substantial tradeoffs in survival (up to 15 months) in exchange for improved quality of life. Some viewed time spent on dialysis and restrictions on travel imposed by dialysis treatments as detrimental to their quality of life, and said they would be willing to accept shorter survival in order to reduce treatment time and travel restrictions (9).

In addition to the dialysis procedure itself, initiation of dialysis often means that patients are committing themselves to more intensive patterns of health care utilization overall, in many instances without full understanding of what might lie ahead. The majority of older dialysis patients in the United States initiate dialysis in the hospital and many go on to experience high rates of hospitalization after initiation (36). In a study of older Medicare beneficiaries starting dialysis, patients were classified into five levels of intensity of care around the time of dialysis initiation, ranging from outpatient initiation at one extreme to spending >2 weeks in the hospital and receiving at least one intensive procedure such as cardiopulmonary resuscitation, mechanical ventilation, or feeding tube placement at the other. For patients aged  $\geq 85$  years who received the highest level of intensity of care, median survival after dialysis initiation was <6 months, with more than one third of that time spent in the hospital (36). Many patients continue to receive very aggressive care focused on life prolongation toward the end of their lives. Almost one half (44.5%) of older United States dialysis patients die in a hospital setting compared with 35.2% of Medicare beneficiaries with other severe chronic illnesses (including congestive heart failure, advanced liver disease, dementia, and chronic obstructive pulmonary disease) (27). Rates of hospitalization (76%) and intensive care unit (ICU)

admission (49.0%) during the final month of life are also substantially higher than reported for other older Medicare beneficiaries, including those with cancer (of whom, 61.3% are hospitalized and 24.0% are admitted to an ICU) and heart failure (of whom, 64.2% are hospitalized and 19.0% are admitted to an ICU). Compared with older Medicare beneficiaries with cancer, those receiving long-term dialysis spend twice as many days in the hospital during the last month of life (9.8 versus 5.1 days) and are three times more likely to undergo an intensive procedure (29.0% versus 9%) (27). By contrast, rates of palliative care and hospice utilization among dialysis patients at the end of life are about one half of that of other chronic disease populations (28). Clinicians, patients, and families often find it difficult to say “no” to intensive interventions (including dialysis) that are intended to prolong life when these are offered. As providers, we may have to work hard to resist the “technological imperative” and “biomedicalization of aging” that currently pervade medical practice in order to support the big-picture goals of individual patients (37).

### Patient-Centered Care

In its 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century*, the Institute of Medicine (IOM) noted that the United States health care delivery system does not provide consistent, high-quality medical care to all people. The report identified six specific suggestions for improvement. Among the six was the recommendation that medical treatment should be patient centered. The IOM defined the term “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” (38). Since the publication of the IOM report, there has been growing national interest in more individualized, patient-centered models of care. These models focus on what matters most to individual patients, and less on what might matter to providers or health systems (39). Maximizing survival, which is often prioritized in conventional disease-oriented approaches to care, is often but one of several competing patient goals for patients and their families. Other possible goals that are of greater importance to some patients are to promote or maintain quality of life, preserve dignity, optimize comfort, and limit treatment time (7–9). Patients, rather than disease processes, and shared, rather than paternalistic, approaches to decision-making are usually favored in more patient-centered individualized models of care.

Shared decision-making has been described as the “pinacle of patient-centered care” (40). It is a process of communication by which physicians and patients agree on a specific course of action based on a common understanding of the patient’s preferences and treatment goals and the benefits versus harms of different treatment alternatives. Shared decision-making affords clinicians an opportunity to learn about the patient’s values, goals, and preferences, while affording patients an opportunity to learn about their prognosis, expected illness trajectory, and the consequences of available treatments (41). The recommendation that patients with CKD and their providers engage in shared decision-making before dialysis is initiated has been widely endorsed by major nephrology organizations including the

American Society of Nephrology (42) and the Renal Physicians Association (41).

There is now growing consensus that dialysis should not be viewed as a default therapy for advanced kidney disease (8,43,44). Before the initiation of dialysis, patients and their families should be informed about the benefits, burdens, and alternatives to dialysis, what dialysis treatment will involve, what the experience of being on dialysis might be like for them, and how it might affect their life and the lives of their family members (44). However, available evidence suggests that shared decision-making is currently poorly integrated into the clinical care of patients with kidney disease, that treatment decisions leading up to and including dialysis initiation may be presented to patients more as a necessity than as a choice, and that patients and their families often have little input into these decisions (45). Despite the large effect of dialysis treatment on the lives of patients and their families, available data suggest that these decisions are largely made by providers (8,45). Lack of patient choice in the dialysis decision-making process was identified as a major theme in a systematic review of 18 studies of interviews with patients with CKD and ESRD (46). In a study of 99 dialysis patients who were interviewed about their experience with dialysis decision-making, the majority felt “unprepared and ill-informed” about the decision to start dialysis and only one patient recalled being explicitly told that not starting dialysis was an option (47). Taken together, these studies indicate that treatment practices for patients with ESRD may often be out of step with the kind of care that some, if not many, patients and their families would want if they fully understood what might lie ahead. When asked after the fact, some patients report regretting their decision to initiate dialysis (8). Indeed, recent work has highlighted the presence of a large disconnect between provider and patient perceptions about prognosis and candidacy for interventions like kidney transplant that can markedly change prognosis (48). Although patients with kidney disease report being open to discussions about prognosis and future illness trajectories, a minority report never having had such conversations with their providers (8,45,49). In addition, both patients and providers cite the large degree of uncertainty about prognosis and future illness trajectory as a major barrier toward disease-related planning during the course of kidney disease (49).

The emerging experience of some centers in Europe and Australia with supportive care models for advanced kidney disease suggests that when dialysis is presented explicitly as a treatment choice and patients are offered a clear alternative, a significant percentage of patients will choose not to receive dialysis (50,51). In an Australian study, 65% of patients with stage 5 CKD were offered an option of medical management without dialysis and 14% chose this option (52). Formal supportive care pathways have been slower to emerge in the United States than in Europe and Australia, perhaps reflecting broader societal differences in the context in which treatment decisions for advanced CKD occur. Nevertheless, the Australian experience raises the possibility that efforts to frame dialysis more explicitly as a treatment choice and to develop strong positive alternatives to dialysis in this country might ultimately translate into fewer United States patients choosing

to initiate dialysis for their advanced kidney disease. An alternative to dialysis, active medical management without dialysis, has been explicitly identified as an option for United States patients with ESRD with poor prognoses in a patient-centered approach (53).

### The CSCKP's Vision for the Medicare ESRD Program

The CSCKP believes that there is ample opportunity to improve the care of patients with advanced CKD while embracing the economic realities of the Medicare ESRD program. We believe that by strengthening efforts to ensure that patients with advanced CKD participate in shared decision-making throughout the course of kidney disease, it may be possible to simultaneously improve care while reducing costs. Because patients' illness experience, preferences, health status, and treatment options often change over time, a flexible approach of reevaluation and redirection will often be needed to ensure that treatments remain aligned with patients' values and preferences. Our vision (Table 1) includes a number of priorities outlined in the CSCKP strategic plan (6).

First, efforts to better inform patients, their families, and their providers about what to expect in the future in terms of their own prognosis and illness trajectory are sorely

needed. The development of prognostic models for patients with stages 4 and 5 CKD, for life expectancy and time to and likelihood of ESRD onset, may help to provide patients with more realistic expectations. Point-of-care decision support tools that can be readily applied to real-world complex clinical cases will be helpful in supporting this goal, as would efforts to promote research that can directly inform patient-centered care (*e.g.*, inclusion of patient-important outcomes, recruitment of study populations that resemble real-world clinical populations). Advance-care planning based on realistic expectations about likely future health events may help patients and their families anticipate treatment decisions that may arise in the setting of a serious life-threatening illness, communicate their preferences regarding intensity of treatment with family members and members of the health care team, and document these preferences in a manner likely to be respected in the treatment they receive (54).

Second, engagement of patients, families, and their providers in a process of shared decision-making around the myriad treatment decisions that patients with kidney disease may encounter during the course of their illness is an important step toward helping to ensure that patient and family goals and preferences more strongly shape treatment decisions (55). These include, but are not limited to, decisions

**Table 1. Priorities of the Coalition for Supportive Care of Kidney Patients**

Priority	Goal
1. Enhance efforts to help patients, their families, and their providers to better understand the expected course of their disease	<ul style="list-style-type: none"> <li>Develop robust prognostic models to provide patients with advanced CKD with realistic expectations in terms of life expectancy, illness trajectory, and future treatment decisions</li> <li>Promote research to augment information on patient-centered outcomes associated with different treatment options that can be generalized to real-world clinical settings</li> <li>Encourage the development and implementation of point-of-care decision support tools tailored to patients with CKD</li> </ul>
2. Promote shared decision making for patients with advanced CKD	<ul style="list-style-type: none"> <li>Enhance efforts to elicit patient goals, values, and preferences</li> <li>Provide communication skills training for clinicians caring for patients with CKD</li> <li>Support reimbursement for clinician time spent in shared decision-making with patients and their families</li> <li>Promote advance care planning for patients with kidney disease, beginning early in the disease course and continuing as the illness progresses</li> </ul>
3. Tailor treatment strategies to what matters most to individual patients	<ul style="list-style-type: none"> <li>Align treatment plans and quality metrics to optimize patient-important goals and preferences to maximize patient quality of life</li> <li>Encourage regulatory and practice changes to allow for greater flexibility in the timing and prescription of dialysis and the development of strong positive treatment alternatives to dialysis</li> <li>Promote regulatory changes for greater integration of hospice and palliative care into other aspects of the care of patients with advanced kidney disease as needed to support patient goals and preferences</li> <li>Increase palliative care training, both in nephrology fellowship programs and continuing medical education</li> </ul>

about dialysis initiation, continuation, and discontinuation and may also pertain to related interventions (e.g., treatment modality for advanced kidney disease, choice and timing of vascular access placement, referral for kidney transplant) as well as broader efforts to maintain health (e.g., renoprotective and cardioprotective interventions). The emerging field of decision science and associated tools (e.g., decision aids) may be extremely helpful in supporting many of these decisions (56). Changes to reimbursement will also likely be needed to ensure that providers have adequate time to engage in shared decision-making with patients and their families.

Third, stronger efforts are needed to tailor the care of patients with advanced kidney disease to match their own goals and preferences. Development of a more individualized, patient-centered approach to the care of patients with advanced kidney disease will require changes to regulatory and care structures. Such changes would likely include greater flexibility in the approach to preparation, timing, and prescription of dialysis with the development of quality metrics to address the extent to which treatment practices support patient goals (21,57,58). Stronger efforts are also needed to ensure access to treatment modalities that best address each patient's goals at different points in their illness trajectory, such as home therapies (59) and kidney transplantation. A more patient-centered approach to the care of patients with advanced kidney disease will also benefit from the development of strong positive alternatives to dialysis with the option to integrate palliative care earlier in the course of illness. The provision of palliative care throughout the course of advanced kidney disease may require regulatory changes to allow for flexibility in the provision of dialysis to patients enrolled in hospice programs. Adaptation and testing of supportive care models developed outside the United States and provider education in the principles and practice of palliative and end-of-life care may also be helpful in supporting this goal (60–62).

In summary, stronger efforts to ensure that patients with advanced kidney disease have an opportunity to shape their own care are sorely needed. We believe that centering care on the patient by emphasizing what matters most to patients and their families and ensuring that patient values guide all clinical decisions may have the added benefit of limiting unwanted, high-intensity, high-cost care in this population.

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