

# Five Policies to Promote Palliative Care for Patients with ESRD

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## Summary

Patients with ESRD experience complex and costly care that does not always meet their needs. Palliative care, which focuses on improving quality of life and relieving suffering for patients with serious illnesses, could address a large unmet need among patients with ESRD. Strengthening palliative care is a top policy priority for health reform efforts based on strong evidence that palliative care improves value. This commentary outlines palliative care policies for patients with ESRD and is directed at policymakers, dialysis providers, nephrology professional societies, accreditation organizations, and funding agencies who play a key role in the delivery and determination of quality of ESRD care. Herein we suggest policies to promote palliative care for patients with ESRD by addressing key barriers, including the lack of access to palliative care, lack of capacity to deliver palliative care, and a limited evidence base. We also provide examples of how these policies could be implemented within the existing ESRD care infrastructure.

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## Introduction

The care of patients with chronic illness in the last several years of life is characterized by high symptom distress for patients, functional limitations, tremendous burden on family caregivers, and patient and family experience of a fragmented, confusing, and unresponsive healthcare system. In most parts of the United States, a patient with a symptom crisis or an exhausted family caregiver has no alternative but to call 911 and go to the emergency department. Because of the poor alignment of patient and family needs for expert and responsive care in the home and community with what is actually paid for (*i.e.*, the acute care and procedurally focused delivery structure of our fee-for-service healthcare system), care of this group of patients relies on the high cost acute care system, accounts for one-third of total Medicare spending, but yields care that is too often of low quality (1). Improving the value of healthcare for patients with chronic illness (*i.e.*, delivering the highest quality care at the lowest possible cost) is a major focus for policymakers.

In many ways, the value crisis confronting Medicare today is encapsulated in the Medicare End-Stage Renal Disease program. Half of the patients who start dialysis in the United States are aged >65 years and the majority have multiple chronic conditions in addition to ESRD. Although dialysis therapy extends life for most patients with ESRD, it often fails to restore health, and despite frequent contact with the healthcare system, many patients suffer from unrecognized and untreated distressing symptoms, functional and cognitive disability, and high caregiver burden before death (2–7).

The current model of ESRD care is poorly equipped to deal with the complexity of family, social, behavioral

health, and medical conditions typically affecting patients with ESRD. In most cases, ESRD care is delivered in free-standing dialysis clinics that are disconnected geographically and administratively with local hospitals, primary care providers, and non-nephrology subspecialists. This silo effect leads to fragmented care in which ESRD management is disconnected from other aspects of the patient's health care. In the absence of coordinated care, treatment decisions may be more likely to reflect local practice patterns rather than the patient's goals and prognosis. For example, although patients with ESRD have higher mortality rates than age-matched persons in the general population, less than half of patients with ESRD complete advance directives, compared with approximately 70% of adult decedents (8–10). Accordingly, patients with ESRD are more likely to receive intensive care at the end of life compared with patients dying of cancer or heart failure (11). Reflecting the high complexity of care and poor coordination, Medicare expenditures for ESRD approached \$30 billion in 2010, with approximately one-third attributable to hospitalizations (12).

The Center to Advance Palliative Care defines *palliative care* as follows (13):

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care

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is appropriate at any age and at any stage in a serious illness, and can be provided together with curative and life-prolonging treatment.

Hospice care, in contrast, is a type of palliative care delivered only to patients with a predictably short prognosis (weeks to months) who agree to forego life-prolonging/curative treatment.

Recently, the National Priorities Partnership identified palliative care as one of six national priorities “with the potential to result in substantial improvements in health and healthcare” if addressed in health reform efforts (14). The American Board of Internal Medicine’s Choosing Wisely Campaign also reflects recognition by the American Society of Nephrology that the current model of dialysis care does not provide high-value care for all patients with ESRD (15). Translating these recommendations into practice requires a concrete set of policies aimed at increasing palliative care for patients with ESRD.

This commentary outlines palliative care policies for patients with ESRD and is directed at policymakers and other stakeholders—dialysis providers, nephrology professional societies, accreditation organizations, and funding agencies—that play a key role in the delivery and determination of quality of ESRD care. Herein we identify barriers to palliative care and suggest five policies supported by the evidence base that would promote palliative care for patients with ESRD. We also provide examples of how these policies could be implemented within the existing ESRD care infrastructure.

### How Does Palliative Care Improve Value?

Palliative care and hospice programs improve value by targeting several drivers of low-value care, including financial incentives for quantity and fragmentation, financial and structural disconnects between acute and postacute care settings, and lack of training in managing patients with multiple chronic conditions with functional limitations (16). Specialist-level palliative care is often delivered through multidisciplinary care teams that focus on treating pain and other distressing symptoms, supporting decision making, aligning treatment plans with patient goals, integrating psychosocial and spiritual needs with medical care, coordinating medical and social services, and supporting loved-ones in their caregiving roles. There is a large body of research supporting the assertion that palliative care improves the quality of care. Specifically, palliative care improves physical and psychosocial symptoms, patient and family satisfaction, level of practical supports in the community, and bereavement outcomes (17). Finally, several studies suggest that palliative care may be associated with improved survival (18–20). In one clinical trial of patients newly diagnosed with stage 3 or 4 lung cancer, palliative care provided in conjunction with disease-focused treatment extended survival by 2.7 months compared with usual cancer care alone (19). In other observational studies, survival was similar or longer for Medicare decedents diagnosed with a life-limiting illness who received hospice care compared with similar decedents who received usual care (18,20). Whether these findings might be generalizable to ESRD is not yet known.

As an epiphenomenon of improving care, palliative care in turn results in less reliance on the most expensive settings for care: the emergency department and the acute care hospital (21–23). For example, one study examined health care costs among hospitalized patients who received a palliative care consultation compared with matched patients who received usual care (21). Among patients who died during their hospitalization, palliative care consultation was associated with net savings of \$4900 per admission, whereas palliative care consultation was associated with a net savings of almost \$1700 per admission among those discharged alive. Among ESRD patients who decide to stop dialysis, spending is \$3000 lower in the last week of life among those who use hospice care compared with those who do not (24).

### What Are the Barriers to Palliative Care for Patients with ESRD?

Several aspects of the organization of ESRD care in the United States could facilitate delivery of high-quality palliative care. For example, because Medicare is the primary payer for >80% of patients with ESRD, changes to Medicare policy that strengthen palliative care will have a large influence on the care received by patients with ESRD. A value-based purchasing program, the Medicare ESRD Quality Incentive Program (QIP), was initiated in 2012 and could serve as the framework for promoting high-value care services because providers are incented to meet certain quality targets or face financial penalties. In addition, robust quality measurement systems are in place to monitor the quality of care at the patient and facility levels. With relatively modest effort, these systems could be modified to promote and monitor the delivery of palliative care. Finally, the elements of a multidisciplinary care team already exist in many dialysis centers. By enhancing the palliative care skills of existing teams, palliative care could be integrated into routine standard of ESRD care rather than solely relying on specialty-level palliative care teams for comanagement or consultation.

However, several barriers must be addressed in order to fully realize the potential of the existing ESRD care infrastructure. To strengthen palliative care for patients with ESRD, policies must address ways to improve access to palliative care, build capacity to deliver quality palliative care, and strengthen the evidence base upon which ESRD palliative care is practiced (Table 1).

### Policy 1: Universal Screening for Palliative Care Needs

Access to palliative care services for patients with ESRD is uneven across the United States. For example, there is >2-fold variation in rates of decisions to stop dialysis and hospice use across states (24). Importantly, states with the most hospice facilities per capita or the highest rates of stopping dialysis are not necessarily states with the highest rates of hospice use (24). Utilization of palliative care also varies across hospital referral regions with available palliative care services, independent of illness severity (25). The incidence of dialysis initiation also exhibits geographic variation, with regions that have a higher density of nephrologists also having higher incidence rates of dialysis initiation (25). Many of

**Table 1. Policies to promote palliative care for patients with ESRD**

Policy	Barrier Addressed	Stakeholders	Examples of Implementation
Universal screening for palliative care needs	Access	Nephrologists, dialysis providers, insurers, clinical organizations	Screen patients with the surprise question at dialysis initiation and at hospital admissions Standardized symptom assessments and treatment algorithms for pain, depression, and sleep disorders
Incorporate palliative care measures in the ESRD QIP	Access	Nephrologists, dialysis providers, CMMS	Documentation of the advance care plan or surrogate decision maker in the medical record
Train the nephrology workforce to deliver palliative care	Capacity	Fellowship programs, accreditation organizations, professional societies	Enhance palliative care content and assess competencies in nephrology fellowship curriculum Emphasize palliative care training for dialysis nurses, social workers, and pharmacists
Payment reforms for palliative care services	Capacity	CMMS	Shared-savings model ( <i>i.e.</i> , including non-ESRD services in the “bundle”) Concurrent dialysis and hospice care Reimbursement for time-intensive services such as advance care planning
Fund palliative care research	Evidence base	Funding agencies, professional societies	Joint NIH/CMMS/VA funding of high-priority palliative care trials Dedicated funding streams for junior and midcareer palliative care researchers Multi-institution ESRD palliative care research collaboratives

QIP, Quality Incentive Program; CMMS, Centers for Medicare and Medicaid Services; NIH, National Institutes of Health; VA, Veterans Affairs.

these patients die in hospital and intensive care settings and withdraw from dialysis when actively dying. They often do not receive hospice or palliative care.

To address uneven access, we propose universal screening for palliative care needs. The goal of screening is to identify patients with a high burden of symptoms, family distress, or poor life expectancy who might benefit from the addition of palliative care. The method of screening need not be complex. For example, the “surprise” question (“Would I be surprised if this patient died in the next year?”) has been validated in a variety of populations including patients with ESRD (26,27). An ESRD prognostic tool that uses the surprise question in conjunction with four other clinical variables accurately predicts 6-month mortality (27). In a randomized clinical trial, Gade *et al.* screened hospitalized patients with the surprise question (2% had ESRD) and then randomly assigned those who screened positive to palliative care consultation versus usual care. Patients randomized to palliative care consultation had significant improvements in satisfaction with care and completion of advance directives, longer hospice stays, and lower costs of care, with no significant differences in survival (28).

Standardized symptom assessments that are associated with treatment algorithms could reduce variability for care

focused on quality of life (29). For example, Weisbord *et al.* used the McGill Pain Questionnaire and Patient Health Questionnaire-9 to screen dialysis patients for pain and depression, respectively (30). Among 179 patients, 81% reported pain and 30% had depression. Informing providers of their patients’ symptoms and a nurse-implemented treatment algorithm were equally effective strategies for improving patient symptoms in this study (30). The modified Edmonton Symptom Assessment System, the Palliative Care Outcomes Scale, and the Dialysis Symptom Index are alternative screening tools for measuring distress from physical and emotional symptoms (3,29,31). A logical first step would be to implement universal screening during care transitions, such as at the initiation of dialysis and at admission to the hospital or nursing home.

**Policy 2: Incorporate Palliative Care Measures in the ESRD QIP**

An efficient framework for promoting access to palliative care services is the ESRD QIP. The current QIP is based on attainment of two quality targets, one for anemia and one for dialysis dose. Beginning in 2014, additional quality targets and reporting measures will be incorporated, and more are under consideration. To be included in the QIP, a

measure must first be endorsed by the National Quality Forum (NQF), which uses four criteria to evaluate a quality measure: measurement of a high-priority area, scientific acceptability, usability and relevance, and feasibility of collection. The NQF has endorsed several measures relevant to palliative care that could be adapted to the ESRD QIP (Table 2) (32–34).

For example, one quality measure endorsed by the NQF is documentation of an advance care plan or surrogate decision maker in the medical record for patients aged  $\geq 65$  years, or documentation that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan. The rationale for this measure is that approximately 30% of deaths among older adults are preceded by a need for surrogate decision making, and patients who have prepared an advance directive are very likely to receive preference-concordant care (35). A preliminary report of the Medicare ESRD Disease Management Demonstration Project indicated that rates of advance care planning can be increased through targeted efforts (36). Surveys of patients with ESRD suggest that initiatives to improve advance care planning would address a high-priority unmet need (37). Once sufficient data are

accumulated on national performance, the measure could be converted from a reporting measure to a clinical target.

Inclusion of standardized hospitalization ratios, the number of observed versus expected hospital admissions for patients under the care of a specific dialysis facility based on each facility's patient characteristics, is reportedly under consideration for future years in the QIP (38). Given the evidence that palliative care reduces the utilization of acute care (39–41), this measure, or related measures such as readmission rates would indirectly support the goal of promoting palliative care. It is also important to consider the unintended consequences that future QIP measures might have on the provision of palliative care. For example, it would seem appropriate to exclude patients who receive concurrent hospice care when assessing attainment of dialysis specific performance measures.

### Policy 3: Train the Nephrology Workforce to Deliver Palliative Care

There currently exists a mismatch between the need for palliative care among patients with ESRD versus the capacity of the current health delivery system to address those needs. This mismatch is related to both an insufficient

**Table 2. Selected palliative care quality metrics**

Domain	Process Measure	Outcome Measure	Example Data Collection Tools
Symptom assessment at initial encounter	Frequency of documentation	Symptom scores	Modified Edmonton Symptom Assessment Scale
Daily reassessment for moderate to severe symptoms	Frequency of documentation	Change in symptom scores over time	Palliative Care Outcome Scale Dialysis Symptom Index McGill Pain Questionnaire
Reassessment of all symptoms every 3 days	Frequency of documentation	Change in symptom scores over time	Patient Health Questionnaire-9
Goals of care/goals of treatment	Documentation frequency or documentation that the patient did not want to discuss		Physician Orders for Life Sustaining Treatment (POLST) Medical Orders for Life Sustaining Treatment (MOLST) Appointment of health care agent Documentation of goals of care conversations Documentation of advance care planning
Support to patient and caregivers	Frequency of documentation	Patient/family satisfaction surveys	Consumer Assessments and Reports of End of Life (CARE) Bereaved Family Survey (PROMISE) Family Evaluation of Hospice Care Family Assessment of Treatment at End-of-Life (FATE-S-VA)
Transition management	Frequency of documentation, advance directives follow patient across care settings		Care Transitions Measure

Adapted from Weissman *et al.* (34).

number of providers who are trained to deliver palliative care and the location of these providers in settings separated from the usual delivery of dialysis care.

Although palliative care as a specialty is expanding, palliative medicine physicians by themselves will not be sufficient to meet America's growing demand for palliative care. A recent study estimated a shortfall of between 6000 and 18,000 palliative care specialists to meet the existing demand from hospices and hospital palliative care programs without considering additional demand from patients with ESRD (42). These estimates, when considered in light of the projected nephrology workforce shortfall, are certainly daunting (43). Moreover, although palliative medicine is expanding into outpatient settings, most access to palliative medicine specialists will occur in the inpatient setting and in larger medical centers in the immediate future; thus, in-person access to palliative medicine specialists at dialysis centers is likely to be limited.

Addressing these shortages will require a multipronged approach. First, it is clear from the above projections that both nephrologists and the interdisciplinary team in dialysis centers will need to be trained to deliver palliative care in the short to intermediate term. Although end-of-life care and pain management are part of Accreditation Council for Graduate Medical Education program requirements for nephrology training, empirical data suggest that this training is variable and often limited (44,45). A coordinated approach from nephrology training program directors is needed in order to enhance curriculum content and share best practices. Training should consist not only of lectures (which have been shown not to change clinician behavior), but also direct observation of trainees conducting goals of care conversations and symptom management in patient-simulations and clinical settings in order to ensure competency (46,47).

The reasons for declining interest in nephrology as a subspecialty are probably diverse (43). Anecdotally low interest and burnout might be in part related to frustration from lack of training in the core skills needed to address the most important and meaningful concerns of ESRD patients in modern nephrology practice ("What are my options if I decide to delay or stop dialysis?" "What will it be like if I stop dialysis?" "Who will help me and my family?" "Can I get hospice at the same time as my dialysis?" "Can you help me with fatigue/pain/itching/trouble sleeping?") and the associated devaluing of these activities expressed by poor reimbursement.

Second, training in palliative care should be emphasized not only for physicians, but for other ESRD interprofessional teams including advance practice nurses, physician-assistants, dialysis nurses, pharmacists, dieticians, and social workers. For example, universal screening for palliative care or pain management could be implemented largely through nurse-driven or pharmacist-driven protocols (30). Dialysis facility social workers could take a larger role in overseeing initiation and completion of the advance care planning process. A number of resources are available to provide palliative care education specifically applicable to patients with ESRD (Table 3).

#### Policy 4: Payment Reforms for Palliative Care Services

To support capacity building, broader reforms of the payment structure for hospice and palliative care services

are needed. In 2010, Medicare began allowing coverage of kidney disease patient education as part of Medicare Part B services for patients with stage 4 CKD. In theory, this provision could support some of the activities required for shared decision making, advance care planning, and assessment of family and social needs at time of consideration of dialysis. To date, however, utilization of this benefit appears low (48). The Center for Medicare and Medicaid Innovation, established by the Affordable Care Act (ACA), recently announced funding to test the effectiveness of coordinated care delivery in which dialysis providers may be eligible for shared savings (or losses) in exchange for accepting greater responsibility and risk for comprehensive patient care. The Comprehensive ESRD Care Initiative, which would incorporate hospitalizations and other services beyond dialysis care into the ESRD Prospective Payment System ("bundle"), could also promote the use of palliative care because the nephrologist or dialysis center is now financially disincented to rely on the acute care hospital and instead is now financially incented to focus on preventing crises and helping support patients safely at home.

Currently, patients with ESRD can receive Medicare-covered hospice benefits under two scenarios. The first requires patients to decline dialysis or stop dialysis in order to enroll in hospice. However, if patients have a terminal condition that is not related to ESRD, they may also enroll in hospice care while continuing to receive dialysis treatment. Many have questioned whether this approach unnecessarily restricts hospice services for patients with noncancer serious illnesses for whom prognosis is often uncertain, such as ESRD (49). Illustrative of this point, <14% of ESRD decedents receive hospice care (compared with >50% of persons with cancer), and only 3% receive concurrent hospice and dialysis care (24).

The ACA includes provisions that allow concurrent hospice and life-prolonging care for children with serious illness as well as funding for a Medicare demonstration project to evaluate this model in adults (16); however, funds have not yet been appropriated for this purpose. Other payment reforms to support palliative care are under consideration. Among these reforms are proposals to provide compensation for time-intensive cognitive services such as advance care planning, a provision that was removed from the ACA but could be revisited, and a requirement to provide access to palliative care services as a condition of receiving designation as an Accountable Care Organization.

#### Policy 5: Fund Palliative Care Research

The delivery of high-quality palliative care for patients with ESRD is hampered by a limited evidence base. For example, the published world-wide experience with non-dialytic care for ESRD (*i.e.*, palliative care without dialysis treatment) appears to be limited to case series totaling <650 patients, with no representation of US patients (50,51).

Improved funding for palliative care research, and in particular health services research assessing models and outcomes of palliative care comanagement, is needed to test strategies for managing symptoms, communicating

Initiative	Description	Link
ASN Geriatric Nephrology Curriculum	An online curriculum addressing the most significant aspects of caring for aging patients with kidney disease	<a href="http://www.asn-online.org/education/distancelearning/curricula/geriatrics/">www.asn-online.org/education/distancelearning/curricula/geriatrics/</a>
ASN Advances in Geriatric Nephrology Course	A 2-day precourse to the annual ASN meeting	<a href="http://www.asn-online.org/education/kidneyweek/2012/program-early.aspx">www.asn-online.org/education/kidneyweek/2012/program-early.aspx</a>
ASN Improving Dialysis Rounds for Geriatric Patients	A series of videos conveying skills in geriatric nephrology	<a href="http://www.asn-online.org/kidneydisease/geriatrics/rounds">www.asn-online.org/kidneydisease/geriatrics/rounds</a>
ASN End-of-Life Care Visiting Professor Program and Geriatric Nephrology Travel Grants	A visiting professor program whose aim is to foster interest in palliative care among nephrology fellows. ASN also provides travel support to the Advances in Geriatric Nephrology Course	<a href="http://www.asn-online.org/grants/additional.aspx">www.asn-online.org/grants/additional.aspx</a> and <a href="http://www.asn-online.org/grants/travel/">www.asn-online.org/grants/travel/</a>
RPA Clinical Practice Guidelines on Shared Decision-Making in Dialysis & Toolkit	Recommendations for initiation, withholding and withdrawing dialysis and toolkit for estimating prognosis and assessing symptoms	<a href="http://www.renalmd.org/catalogue-item.aspx?id=682">www.renalmd.org/catalogue-item.aspx?id=682</a>
Coalition for Supportive Care of Kidney Patients	Formed by ESRD Network 5, this website includes a variety of resources to support palliative and end-of-life care in ESRD	<a href="http://www.kidneysupportivecare.org">www.kidneysupportivecare.org</a>
NephroTalk	A communication skills workshop for nephrology fellows	See Schell <i>et al.</i> (46)
Supportive Care for the Renal Patient	A textbook reviewing palliative care management for patients with ESRD	See Chambers <i>et al.</i> (47)

ASN, American Society of Nephrology; RPA, Renal Physicians Association.

prognosis, and delivering palliative care to the diverse population of patients with ESRD. A search of ClinicalTrials.gov using the terms *cancer* and *palliative or hospice* yielded 505 unique studies. The same search substituting *ESRD* for *cancer* yielded only nine studies. Unfortunately, <\$0.01 of every \$1000 of the total National Institutes of Health (NIH) extramural funding has gone to palliative care-related research in recent years (16,52). Although an increase in federally funded research in palliative care has been observed in the last 5 years, funding for palliative care remains low in the National Institute of Diabetes and Digestive and Kidney Diseases, the main NIH institute funding ESRD research (53). The newly formed Patient-Centered Outcomes Research Institute, the Veterans Health Administration, the Agency for Healthcare Research and Quality, as well as the National Palliative Care Research Center and private foundations interested in health and aging are alternate sources of research support for ESRD palliative care research outside of the NIH.

Several strategies are necessary to address the funding gap for palliative care research in ESRD. First, joint funding of high-priority clinical trials between the NIH and both the Centers for Medicare and Medicaid Services and/or the Veterans Health Administration has been successfully implemented in the past. Second, ensuring that NIH study sections include members with expertise in palliative care

could help to facilitate a rigorous scientific review process while keeping in mind the special ethical and design considerations unique to palliative care research. Third, dedicated funding for junior and midcareer scientists conducting palliative care and aging research in ESRD is important to ensure a pipeline of qualified investigators. Finally, coordination with other subspecialty societies to form palliative care research collaboratives for patients with chronic disease given the similarities in chronic debilitating disease trajectories (*i.e.*, heart failure, chronic obstructive pulmonary disease, dementia, frailty) could also be a productive strategy. These collaboratives could focus on developing research capacity at participating sites, standardizing methodology, and advancing strategies for rapid implementation into practice (54).

Strengthening palliative care is a top policy priority for health reform efforts based on strong evidence that palliative care improves value. The Medicare ESRD program could serve as a model for how to successfully implement and scale palliative care into existing care delivery systems for patients with complex chronic noncancer illness. To sustain the momentum generated by individual efforts in this area, policymakers must take actions that incent providers and researchers to make long-term investments in the resources and infrastructure necessary to build high-quality palliative care programs for patients with ESRD.

## Disclosures

None.

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