Palliative Care Disincentives in CKD: Changing Policy to Improve CKD Care

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The dominant health delivery model for advanced chronic kidney disease (CKD) and end-stage renal disease (ESRD) in the United States, which focuses on provision of dialysis, is ill-equipped to address many of the needs of seriously ill patients. Although palliative care may address some of these gaps in care, its integration into advanced CKD care has been suboptimal due to several health system barriers. These barriers include uneven access to specialty palliative care services, underdeveloped models of care for seriously ill patients with advanced CKD, and misaligned policy incentives. This article reviews policies that affect the delivery of palliative care for this population, discusses reforms that could address disincentives to palliative care, identifies quality measurement issues for palliative care for individuals with advanced CKD and ESRD, and considers potential pitfalls in the implementation of new models of integrated palliative care. Reforming health care delivery in ways that remove policy disincentives to palliative care for patients with advanced CKD and ESRD will fill a critical gap in care.

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Introduction

The Medicare End-Stage Renal Disease (ESRD) Program has long been at the forefront of innovations in health care payment and delivery models. Although the program has achieved notable successes,[1] the high cost of care and the perception that care is not patient centered make the program a high-profile target for additional reforms. Foremost among the areas in which the value of care is perceived to be low is among seriously ill patients, including those with multimorbidity, those with a high symptom burden, and those near the end of life.

The dominant health care delivery model for patients with advanced chronic kidney disease (CKD) and ESRD focuses almost exclusively on optimizing provision of dialysis care, to the extent that patient needs beyond dialysis treatment have been largely neglected. This current dominant model is poorly equipped to help patients and families address the emotional and existential challenges of advanced illness and navigate complex treatment decisions, such as starting or stopping dialysis therapy. More than a decade ago, the Institute of Medicine documented the consequences of failing to deliver "the right care to the right patient at the right time" in its landmark report "Crossing the Quality Chasm."[2] Many patients with advanced CKD and ESRD have wide-ranging unmet care needs, including a high burden of distressing symptoms and functional limitations.[3] Although they receive high-cost high-intensity care near the end of life, family members rate the quality of care that patients with ESRD receive at this time as poor.[4,5]

Better integration of palliative care into advanced CKD and dialysis care has been proposed to address the needs of these patients with multimorbidity, high symptom burden, and limited life expectancy.[6,7] Palliative care refers to holistic medical, psychosocial, and spiritual care for people with serious illness and was originally developed to address the needs of patients dying of cancer. With a focus on relief of symptoms and improving quality of life, palliative care is appropriate at any stage in a serious illness, including in conjunction with curative or life-extending treatment.[3] Nephrology, along with other medical specialties, has lagged behind oncology in the adoption of palliative care.

In 2016, the National Institute on Aging and the National Palliative Care Research Center convened a workshop to identify palliative care research priorities in 4 subspecialty fields: CKD, heart disease, critical care, and surgery.[8] In the context of the palliative care research agenda for CKD recently published in the *Journal of Palliative Medicine*,[9] in this article we outline health care policies that shape delivery of care for patients with advanced CKD and ESRD and suggest how health care delivery might be reformed to support a more patient-centered palliative approach to care for these seriously ill patients.

Policies That Affect the Care of Patients With Advanced CKD and ESRD

The policies that shape delivery of care for patients with ESRD originated from legislation

Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients.

extending Medicare eligibility to persons with ESRD to provide a much-needed funding mechanism for maintenance dialysis treatments. Unanticipated growth in the number of patients starting dialysis therapy and increasing use of expensive injectable medications created cost pressures. In response, Medicare policies evolved over time with 2 overarching goals: restraining spending growth in the ESRD Program while simultaneously ensuring that patients receive outpatient dialysis care that meets quality standards (Table 1). To accomplish these goals, Medicare now uses a value-based purchasing model consisting of: (1) bundled payments to dialysis facilities for outpatient dialysis services, (2) a set of pay-for-performance initiatives known as the ESRD Quality Incentive Program (QIP),[10] and (3) a tiered fee-for-service physician reimbursement schedule based on the number of visits per month.[11]

Current Barriers to Palliative Care for Seriously Ill Patients With CKD and ESRD

Uneven Access to Specialty Palliative Care Services

Most patients with ESRD who receive maintenance dialysis lack access to specialty palliative care services. In a survey of dialysis providers, access to specialty palliative care was identified as the second highest priority to improve palliative care for patients with ESRD and was a key facilitator of decisions to forego or withdraw from dialysis therapy.[12,13] Medicare data indicate that 2% of incident dialysis patients and 4% of prevalent patients received palliative care services in 2013; of these, half received care from a palliative care specialist (Fig 1). These utilization rates are similar to those found in advanced heart failure, but far lower than rates observed in advanced cancer.[14,15]

Lack of access to palliative care services is attributable to at least 3 factors. First, specialty palliative care services are regionalized in a limited number of geographic areas and within tertiary medical centers. In 7 states, <40% of hospitals with more than 50 beds have a palliative care team.[16] Consequently, most US patients who are seriously ill but are neither hospitalized nor imminently dying are unable to access specialist palliative care. Second, access challenges due to regionalization of palliative care are compounded by the time-intensive requirements for dialysis therapy and associated travel. Third, there is a workforce shortage of specialty trained palliative care physicians (an estimated 10,000 more are needed to meet existing demand), while concurrently there is limited awareness of patients' unmet

Table 1. Major Policy Changes in ESRD and Palliative Care in the Past 15 Years

Policy	Year of Introduction	Description
Tiered fee-for-service physician reimbursement for dialysis services ("G-codes")	2004	Changed physician reimbursement for outpatient dialysis services from capitated payment to tiered fee-for-service payments.
ESRD Prospective Payment System (PPS; "the bundle")	2010	A patient- and facility-level–adjusted per-treatment (dialysis) payment for renal dialysis services that includes drugs, laboratory services, supplies, and capital-related costs related to furnishing maintenance dialysis.
ESRD Quality Incentive Program (QIP)	2010	A value-based purchasing program in which payments to ESRD facilities are reduced for facilities that do not meet certain performance standards.
Pre-ESRD Education in the Medicare Improvements for Patients and Providers Act (MIPPA)	2010	Entitles Medicare beneficiaries with stage 4 CKD to receive 6 educational sessions about management of comorbid conditions, preventing complications, and kidney replacement therapy options.
Medicare Access and CHIP Reauthorization Act (MACRA)	2015	A Medicare value-based purchasing program that financially incentivizes health care providers to provide high-quality cost-efficient care.
Comprehensive ESRD Care Model	2015	Dialysis clinics, nephrologists, and other providers join in ESCOs to coordinate care for beneficiaries with ESRD receiving dialysis. Providers are eligible for shared savings payments based on Medicare Part A and Part B costs and may be liable for shared losses.
Medicare Care Choices Model	2015	Allows Medicare beneficiaries to receive hospice-like support services while concurrently receiving curative care. Participation is limited to beneficiaries with advanced cancers, COPD, CHF, and AIDS.
Hospice Wage Index and Payment Rate Update	2015	Re-affirmed eligibility of dialysis patients with non-ESRD terminal diagnoses to receive both dialysis services and hospice.
Advance Care Planning Reimbursement	2016	Voluntary advance care planning services may be billed by physicians and nonphysician practitioners as a separate Medicare Part B service or an optional element of Annual Wellness Visit.
CHRONIC Care Act (proposed)	2017	Expands telemedicine coverage under Medicare Advantage Plans, including telemedicine in home dialysis facilities and home-based primary care services for people with multiple chronic conditions.
Palliative Care and Hospice Education and Training Act	Pending	Establishes palliative care workforce training, supports national palliative care education and awareness campaign, and enhances research in palliative care.

Abbreviations: CHF, congestive heart failure; CHIP, Children's Health Insurance Program; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease program; ESCO, ESRD Seamless Care Organization.