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HHS Public Access
Author manuscript
Am J Kidney Dis. Author manuscript; available in PMC 2019 June 01.

Published in final edited form as:
Am J Kidney Dis. 2018 June ; 71(6): 866–873. doi:10.1053/j.ajkd.2017.12.017.

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

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Abstract

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, under-developed 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 healthcare 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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Financial Disclosure: MKT, AO, LH, EM and AHM have received grant support and/or consultant fees from the Gordon and Betty Moore Foundation.

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Keywords

chronic kidney disease (CKD); end-stage renal disease (ESRD); palliative care; dialysis; health policy; quality of life; advance care planning; goals of care; patient-centered care

Introduction

The Medicare End-Stage Renal Disease (ESRD) Program has long been at the forefront of innovations in healthcare payment and delivery models. While 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 where the value of care is perceived to be low is among seriously ill patients -- including those with multi-morbidity, those with a high symptom burden, and those near the end of life.

The dominant healthcare 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. 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.[45]

Better integration of palliative care into advanced CKD and dialysis care has been proposed to address the needs of these patients with multi-morbidity, high symptom burden, and limited life expectancy. [67] 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 from 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 four 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 healthcare policies that shape delivery of care for patients with advanced CKD and ESRD, and suggest how healthcare delivery might be reformed to support a more patient-centered palliative approach to care for these seriously ill patients.

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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 extending Medicare eligibility to persons with ESRD in order to provide a much-needed funding mechanism for maintenance dialysis treatments. Unanticipated growth in the number of patients starting dialysis and increasing use of expensive injectable medications created cost pressures. In response, Medicare policies evolved over time with two 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 ESRD patients and was a key facilitator of decisions to forego or withdraw from dialysis.[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 (Figure 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 three factors. First, specialty palliative care services are regionalized in a limited number of geographic areas and within tertiary medical centers. In seven states, fewer than 40% of hospitals with more than 50 beds have a palliative care team.[16] Consequently, the majority of U.S. 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 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 care needs and limited training in palliative care among nephrology providers.[12,17–19]

Under-developed models of care for seriously ill patients with advanced CKD and ESRD

Palliative care is appropriate at any stage of an illness and can be delivered along with curative therapy. Perhaps the best-known model of palliative care in the U.S. is hospice care, a type of palliative care for patients with terminal illness who are forgoing curative or life-extending treatments. Hospice care covers all medical care related to the terminal illness,

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and can be delivered at home, in a nursing home, or in an inpatient facility. However, the hospice model alone is insufficient to meet the needs of seriously ill patients with advanced CKD and ESRD. Medicare hospice eligibility criteria require that patients have a life expectancy of six months or less if the disease takes its normal course and that patients forgo treatments related to their primary hospice diagnosis. This means Medicare beneficiaries can receive hospice care only if (1) they have advanced CKD, are expected to die within 6 months, and agree to forgo dialysis; (2) their terminal illness is ESRD and they withdraw from dialysis; (3) their terminal illness is ESRD and a hospice program agrees to pay the costs of dialysis care; or (4) they have a terminal illness unrelated to ESRD which allows them to receive concurrent hospice and dialysis care. Because the cost of dialysis is prohibitive for most hospice programs, access to hospice care is largely limited to ESRD patients who have an unrelated terminal diagnosis such as cancer or to the final few days of life after withdrawal from dialysis, a time frame generally considered insufficient to optimize end-of-life care.[20] Because it is designed to care for patients with a terminal illness who experience a predictable progressive decline towards death, the hospice model is also not a good fit for patients with advanced CKD who elect to forgo dialysis, as their end-of-life illness trajectories may be unpredictable.[21] Finally, lack of parity in reimbursement for outpatient palliative care programs compared to dialysis care disincentivizes outpatient palliative care; specifically, it is easier and more profitable to start a patient on dialysis than to manage the same patient with advanced CKD in an interdisciplinary palliative care program.[13]

The lack of a patient-centric model of care for seriously ill patients with advanced CKD and ESRD is exemplified by the absence of coordinated and meaningful advance care planning. Few patients engage in advance care planning, and the vast majority lack a written advance directive or surrogate decision maker, leaving them unprepared to make medical decisions in a crisis.[22] For patients with multi-morbidity, maintenance dialysis is one of many complex treatment decisions they face, and limited data suggest dialysis may not meaningfully extend life for such patients.[23,24] The current narrow focus on dialysis preparation misses an opportunity to explore patient goals as part of the advance care planning process. Separation between dialysis decision-making and advance care planning may result in care that is not aligned with patient preferences and leave patients feeling that they either lacked choice about dialysis or were uninformed about what to expect.[25] Similarly, advance care planning is not routinely offered to patients receiving maintenance dialysis, contributing to high utilization of intensive procedures near the end of life.[4,22]

Misaligned incentives

The ESRD QIP is intended to incentivize high value care, but applying uniform standards of care to all patients irrespective of their treatment goals may be counter to patient-centered care.[26,27] Patients with primarily palliative goals who wish to continue receiving dialysis are often held to the same quality standards in the ESRD QIP as patients who are candidates for kidney transplantation (Table 2). For example, incentives to increase use of arteriovenous fistulas could have the unintended effect of subjecting patients with limited life expectancy to procedures from which they are unlikely to benefit and may be harmed.[28] Dialysis facility mortality rates do not distinguish between patients for whom death is an expected or even

desired outcome, such as those who die after discontinuing dialysis, and those for whom death is unexpected. In response to criticism that the ESRD QIP is overly reliant on aspects of care that are easily measured rather than aspects of care that are meaningful to patients, two patient-reported outcomes, pain and depression, have been incorporated in the 2018 version of the QIP as reporting metrics. How best to utilize the information from these metrics to improve care remains the subject of considerable debate.[262729]

The goal of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) is to increase value in Medicare fee-for-service programs.[3031] Under this Act, providers must participate in either the Merit-Based Incentive Payment System (MIPS) or an advanced alternative payment model (advanced APM).[32] Both arms are intended to incentivize the provision of cost-effective, high-quality care through appropriate metrics. However, of the 17 nephrologist-specific quality measures, only two relate to palliative care: advance care planning and hospice referral after dialysis withdrawal.[33] Since providers only report on 6 metrics of their choosing (out of over 270 total metrics), many nephrologists will opt for quality measures that are easier to fulfill.

Under the advanced APM track, dialysis organizations are encouraged to join with nephrologists and other providers to form ESRD Seamless Care Organizations (ESCOs). ESCOs are incentivized to create a person-centered, coordinated care experience.[3435] By financially aligning nephrologists, dialysis facilities, hospitals, nursing homes, and other providers involved in the care of patients with ESRD, the model intends to reduce incentives for volume and fragmentation of care. Because ESCOs are subject to many of the same quality metrics as the ESRD QIP and, in fact, have a more extensive pay-for-performance program than traditional dialysis facilities, concerns about misaligned incentives also apply to ESCOs (Table 2). Of note, a metric for presence of an advance care plan is applicable to ESCOs but is not in the ESRD QIP.[3637]

Overall, the limited set of existing quality measures for palliative care means that the Quality Payment Program (QPP) that emerged from MACRA does not currently incentivize provision of palliative care for patients with advanced CKD and ESRD, though this may change once the Centers for Medicare and Medicaid Services develops and implements cost measures. A recent stakeholder panel identified gaps in quality measurement that are relevant to the care of seriously ill patients with ESRD (Table 3),[38] and recommended the implementation or development of quality measures to address these gaps.

Reforms to address barriers to palliative care for patients with CKD?

1. Expand access to palliative care

For communities with mature specialty palliative care programs, several strategies could increase access to this care. These include universal screening for palliative care needs, with palliative care referral as appropriate. Specific strategies for screening and suggested tools have been described.[626] Partnerships with local palliative care and hospice programs are needed to facilitate timely palliative care and hospice referrals, protocols for co-management of patients, and best practices for dialysis withdrawal.

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Provision of primary palliative care services by nephrology team members trained in palliative care, and/or delivery of specialty palliative care services at dialysis facilities are additional strategies that could expand access to palliative care. Delivery of specific elements of palliative care in dialysis facilities (such as symptom management and advance care planning) has been previously tested with mixed results, and one recent report has described feasibility of embedded palliative care in the dialysis facility.[39–42] In addition, expanded training for fellows, practicing nephrologists, and interdisciplinary team members could alleviate the palliative care workforce shortage.[43]

2. Develop a new model of serious illness care for patients with advanced CKD

We propose that serious illness care for patients with advanced CKD should be redesigned around "early goals of care conversation" rather than using the current narrow disease-oriented focus on "early dialysis preparation". In this proposed model, patients could receive multi-disciplinary team care for symptom management and decision support, commensurate to the level of care provided to home dialysis patients, across the care continuum from advanced CKD and ESRD. The model would be flexible enough to support populations with differing and/or evolving treatment goals, including patients who desire conservative care without dialysis, those preparing for dialysis, those who wish to delay dialysis for as long as possible, those who are not sure whether they want to receive dialysis, those who wish to receive palliative dialysis, and those receiving standard dialysis treatment.

There are several models and examples which may offer useful lessons for redesigning CKD care. These include organized programs of conservative non-dialysis management in Australia, the United Kingdom, and Canada;[4445] and U.S. community-based serious illness programs such as the Veterans Affairs Home Based Primary Care service and Program of All Inclusive Care for the Elderly.[46] Common features of these models include team-based care, caregiver training, symptom management, and care transition management. The integration of palliative care into management of advanced heart failure also serves as a useful example, given the unpredictable disease trajectory shared by CKD and heart failure, and guidelines recommending palliative care consultation prior to implantation of left ventricular assist devices.[47] Patients receiving care under such a model could have their own set of broad-based quality measures distinct from those of the ESRD QIP.

3. Test new payment models for delivering palliative care

Several new payment models show promise as potential means of delivering palliative care to seriously ill patients with ESRD, and should be high priorities for comparative effectiveness research.

The ESCOs may be the best developed payment model that is poised to improve delivery of palliative care to patients with ESRD under Medicare. An earlier iteration of the ESCO model found that rates of advance directive completion could be increased (though the effect on care near the end of life was not examined).[48]

The QPP is another opportunity to promote palliative care. Within the MIPS, the Centers for Medicare and Medicaid Services has yet to implement cost measures mandated by the legislation.[33] These cost measures will use episodes of care, which encompass the treatment,

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aftercare, and complications associated with a specific condition, such as CKD.[49] If constructed effectively, they will reward providers who are effective at coordinating care, reducing preventable complications, and curtailing unnecessary healthcare---goals that align with patients opting for less aggressive healthcare. Similarly, an advanced CKD care model analogous to the ESCOs could also promote palliative care. Such a model would likely qualify as an advanced APM and could incentivize patient-centered approaches to preparing for ESRD, including conservative care. The National Kidney Foundation and Renal Physicians Association have already started developing such a model and have introduced provisions to include palliative care.[50] Efforts like these will require close input from the nephrology community to ensure that providers are neither dissuaded from nor incentivized to offer conservative care options when these do not align with patients' goals and values.[51]

In 2017 Medicare launched the Care Choices Model, a new payment and delivery demonstration that allows beneficiaries to receive hospice-like support services from hospice providers while concurrently receiving curative or life-extending care.[52] In this demonstration, Medicare will determine whether this new model increases access to supportive care services, improves quality of life and patient/family satisfaction, and changes use of life-extending treatments. While participation is currently limited to Medicare beneficiaries with advanced cancer, lung disease, heart disease, and AIDS, there may be an opportunity to extend this payment model to patients with ESRD with support from the nephrology community. The approach is conceptually similar to proposed models of "palliative dialysis" and "dialysis as destination treatment" that have been described for patients with ESRD who desire dialysis but whose goals are primarily palliative.[53,54]

Finally, recently passed and pending legislation addressing reimbursement for advance care planning, telemedicine for home-based primary care, and palliative care training (Table 3), serve as examples of additional policy measures that could support the provision of palliative care.

Potential pitfalls

Value-based models of care carry risks for undertreatment, cherry picking, poor quality of care, and cost-shifting to informal caregivers.[16, 55] These risks might be mitigated by surveillance and transparent reporting of care processes, outcomes and patient experience of care. As for all care models, it will be important to guard against situations in which providers are incentivized to provide treatments that do not align with patient goals and values. Some have recommended disclosure of financial arrangements and better integration of shared decision-making to manage the potential ethical conflicts arising from cost containment incentives,[55,56] such as the partnership between dialysis providers, hospitals and hospice organizations in ESCOs.

The diffusion of palliative care delivery innovations into practice could also be impeded by physician attitudes and perceptions about the benefits of palliative care. Effecting culture change to address these barriers is also crucial for disseminating and sustaining innovations.[57,58]

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Summary

New models of care and associated policies that makes the provision of interdisciplinary palliative care with or without dialysis financially possible are needed to counterbalance significant financial incentives to start all patients on dialysis, regardless of expected benefits and harms. Redesigning health care for patients with advanced CKD and ESRD will require coordinated efforts from key stakeholders, including patients, caregivers, professional societies, dialysis providers, ESRD networks, and Medicare and other payors, starting with local demonstrations of feasibility in receptive communities. Reforming healthcare delivery in ways that remove policy disincentives to palliative care, coupled with efforts to strengthen support for palliative care in the nephrology community, could transform the approach to caring for seriously ill patients with advanced CKD and ESRD.

Acknowledgments

Support: This work is supported by grants U01DK102150 and F32DK107123 from the National Institutes of Diabetes and Digestive and Kidney Diseases.

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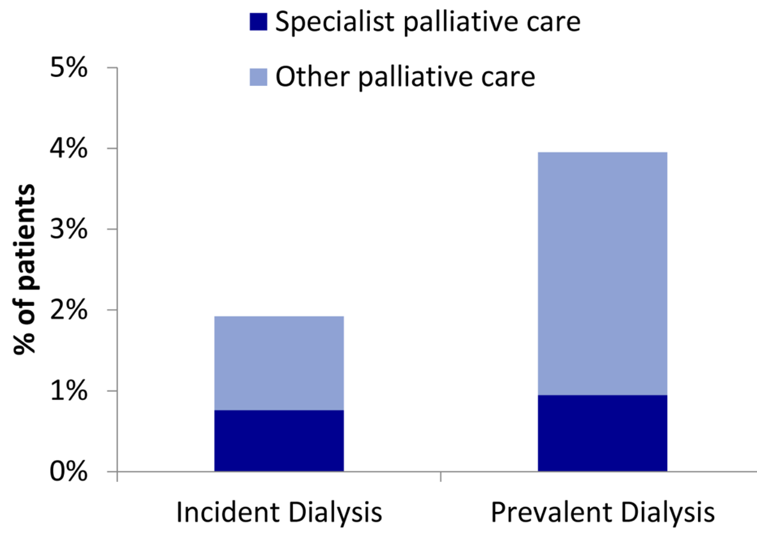

Figure 1.

Prevalence of palliative care among incident and period prevalent Medicare beneficiaries with ESRD receiving maintenance dialysis in 2013. Specialist palliative care refers to care delivered by physician with specialty training in palliative care.

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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-level 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 six 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 healthcare providers to provide high-quality, cost-efficient care.
Comprehensive ESRD Care Model	2015	Dialysis clinics, nephrologists and other providers join together 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 non-physician 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: CHIP – Children's Health Insurance Program; ESRD, end-stage renal disease program; ESCO, ESRD Seamless Care Organization; COPD, chronic obstructive pulmonary disease; CHF, congestive heart failure

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Table 2

Quality measures included in the 2018 ESRD QIP and the ESCO QIP, and their applicability for palliative care.

ESRD Quality Measures	ESRD QIP	ESCO QIP	Applicable to palliative care
Clinical measures			
Standardized mortality ratio			
Blood stream infections			
Standardized hospitalization ratio			
Standardized readmission ratio			
Dialysis adequacy (Kt/V)			
Vascular access type			
Hypercalcemia			
Blood transfusions			
Patient experience with care			
Quality of life			
Reporting measures			
Mineral metabolism			
Anemia management			
Pain assessment and follow-up			
Depression screening and follow up			
Healthcare personnel influenza vaccination			
Documentation of current medications			
Medication reconciliation post discharge			
Falls screening and plan of care			
Advance care plan			
Diabetes eye exam			
Diabetes foot exam			
Influenza vaccination (patient)			
Pneumonia vaccination (patient)			
Tobacco use screening and cessation plan			

Abbreviations: ESRD, end-stage renal disease program; ESCO, ESRD Seamless Care Organization; QIP, Quality Incentive Program. Adapted from CMS’s comprehensive ESRD care model.

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Table 3

Recommendations to address gaps in quality measurement in serious illness care

Recommendation	Issues relevant to ESRD
1. Implement existing quality measures applicable to the seriously ill in Medicare quality programs	Advance Care Planning measure present in ESCO QIP
2. Improve collection of patient and caregiver feedback	No existing quality measures in ESRD capture experience of patients who have died or cannot speak for themselves, or experience of bereaved family members
3. Standardize data collection to help identify vulnerable individuals	Standardized functional and cognitive data is currently not captured by dialysis providers
4. Create new tools to ensure patients are in control of their care	No measures exist to capture whether patients' goals, preferences, and values are honored
5. Develop and implement measures that align with new payment models	A separate set of incentives exists for the ESCO QIP (*see* Table 2)

Abbreviations: ESRD – end-stage renal disease, ESCO – ESRD Seamless Care Organization, QIP - Quality Incentive Program

Recommendations are based on "Building Additional Serious Illness Measures into Medicare Programs".[38]