



Recommendations for Public Policy Changes to Improve Supportive Care for Seriously Ill Patients With Kidney Disease

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National and international nephrology organizations have identified substantial unmet supportive care needs of patients with kidney disease and issued recommendations. In the United States, the most recent comprehensive effort to change kidney care, the Advancing American Kidney Health Initiative, does not explicitly address supportive care needs, although it attempts to implement more patient-centered care. This Perspective from the leaders of the Coalition for Supportive Care of Kidney Patients advocates for urgent policy changes to improve patient-centered care and the quality of life of seriously ill patients with kidney disease. It argues for the provision of supportive care by an interdisciplinary team led by nephrology clinicians to improve shared decision-making, advance care planning, pain and symptom management, the explicit offering of active medical management without dialysis as an option for patients who may not benefit from dialysis, and the removal by the Centers for Medicare & Medicaid Services and all other payors of financial and regulatory disincentives to quality supportive care, including hospice, for patients with or approaching kidney failure. It also emphasizes that all educational and accreditation programs for nephrology clinicians include kidney supportive care and its essential role in the care of patients with kidney disease.

Complete author and article information (including a list of the members of the Steering Committee of the Coalition for Supportive Care of Kidney Patients) provided before references.

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Introduction

The KDIGO (Kidney Disease: Improving Global Outcomes) Controversies Conference on supportive care recognized a great need for supportive care* for patients with kidney disease because of their high burden of physical and psychosocial symptoms, shortened life expectancy, and high burden of comorbidities, but noted that supportive care is underused.¹ This Perspective from the Coalition for Supportive Care of Kidney Patients Steering Committee reviews proposed national and international recommendations to improve supportive care for seriously ill patients with or approaching kidney failure and advocates for urgent policy changes. It argues for the provision of supportive care by an interdisciplinary team led by nephrology clinicians to improve shared decision-making, advance care planning, and pain and symptom management and the explicit offering of active medical management without dialysis as an option for patients who choose not to begin dialysis. The target change agents for the policies discussed are payors, physician and nurse clinician specialty societies, dialysis organizations, physician practices, nephrology social workers, hospice and palliative care programs, nephrology fellowship programs, the Accreditation Council for Graduate Medical Education, and patient advocacy groups.

The Centers for Medicare & Medicaid Services (CMS) is the major payor covering 80%

of patients undergoing maintenance dialysis, so this Perspective focuses heavily on the policy issues controlled by CMS. Despite constituting approximately 1% of total Medicare beneficiaries, patients with kidney failure treated by kidney replacement therapy account for approximately 7% of Medicare funds,² providing quite an incentive for Medicare to seek better value for this population. Patients are also covered by Medicaid, private insurance, and the US Department of Veterans Affairs, and these payors are sometimes able to introduce innovations more rapidly than Medicare is.

Countries with strong kidney supportive care programs include Canada, the United Kingdom, Australia, New Zealand, and Hong Kong. In contrast to the United States, these countries have overcome misperceptions of palliative medicine, inadequate training, lack of access to experts, and financial systems that

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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.

*Supportive care is often used as a synonym for palliative care. Palliative care is the name of the specialty and the field. In this article, we use the term “supportive care” because patients and health care professionals prefer it.¹ At times, we distinguish supportive care from palliative care. Supportive care generally refers to the care the nephrology team provides, whereas palliative care refers to the care provided by palliative care specialists. Supportive care (also called “primary palliative care”) encompasses skills that, ideally, all clinicians should have, including management of uncomplicated pain and symptoms and essential discussions about prognosis, goals of treatment, code status, QoL, and suffering.

disincentivize palliative care.^{3,4} They have also succeeded in gaining widespread acceptance in their nephrology communities (“buy-in”) that palliative medicine is appropriate care for some older patients with chronic kidney disease (CKD) with multiple risk factors for marginal benefit from dialysis because it respects informed patients’ wishes. [Box 1](#) summarizes 6 major national and international efforts to develop a comprehensive set of recommendations for implementing kidney supportive care, and [Table 1](#) summarizes major national and international recommendations for research priorities to improve kidney supportive care. The recommendations from KDIGO¹ and the International Society of Nephrology’s second Global Kidney Health Summit⁵ encompass high- and low-health resource areas. Taken as a whole, they show that substantial work is needed to change financing mechanisms, professional education, quality, and care delivery for patients with kidney disease.

The most recent comprehensive effort to change kidney care in the United States does not explicitly address supportive care needs, although it attempts to implement more patient-centered care. The 2019 Advancing American Kidney Health (AAKH) initiative, announced by the US Department of Health and Human Services in July 2019, correctly notes that the US kidney care and treatment system has been shaped by policy that paid “for sickness and procedures” rather than “paying for health and outcomes.”⁶ With its overarching goal of enhancing patient choices through new programs and changes in financial incentives, the initiative seeks to improve access to and quality of person-centered treatment options. However, despite the admirable language of patient choice and person-centered options, the initiative ignores the needs of the approximately 20% of patients with kidney disease who are seriously ill,⁷ that is, those who have a high risk of death over the course of 1 year and an impaired quality of life (QoL) with decreased function.⁸ In particular, the initiative omits realistic options (ie, active medical management without dialysis) that are likely to be desired by many in the subpopulation of seriously ill patients.⁹

This Perspective discusses key public policy issues and related clinical concerns and makes explicit practical recommendations for improving the quality of supportive care for seriously ill patients with kidney disease by instituting changes in public policy in the United States ([Table 2](#)).

Shared Decision-Making

Supportive care is patient-centered. The National Consensus Project for Quality Palliative Care, the National Quality Forum, and other organizations have defined palliative care as “patient- and family-centered care that optimizes QoL by anticipating, preventing, and treating suffering.”¹⁰ Shared decision-making is a fundamental component of patient-centered care, is an ongoing process

rather than a single event, and has been called the “pinnacle” of patient-centered care.¹¹ Shared decision-making begins with eliciting patient values and priorities for current care, sharing medical information about the patient’s condition and likely future contingencies, and assisting the patient in making treatment choices. As a result, an older patient in frail condition with stage 5 CKD might choose active medical management without dialysis as the preferred treatment. Advance care planning is a process for identifying the patient’s treatment preferences for a time in the future when the patient no longer has decision-making capacity. Decisions reached during advance care planning form the basis for documenting the patient’s wishes in writing in advance directives and, as appropriate, in medical orders such as the physician orders for life-sustaining treatment. The National Quality Partners promoted shared decision-making for patients with kidney disease,¹² and nephrology professional organizations have issued clinical practice guideline recommendations¹³ and advised that shared decision-making should occur before the initiation of dialysis.¹⁴ Despite the consensus that nephrology clinicians should implement shared decision-making in their treatment of patients, the practice is not well integrated into care.^{9,15–17} Fostering better integration of shared decision-making could follow the model CMS uses for implantable cardioverter defibrillators, which requires shared decision-making before defibrillator implantation and other cardiac procedures.¹⁸ Because CMS requires advance care planning in the end-stage renal disease (ESRD) Conditions for Coverage, this model could be applied to the seriously ill kidney patient. Clinicians can bill for those services by using Medicare-reimbursable Current Procedural Terminology codes 99497 and 99498.

Active Medical Management Without Dialysis

The International Society of Nephrology’s 2nd Global Kidney Health Summit called supportive care services, including active medical management without dialysis, an “essential element” of comprehensive kidney care,⁵ yet it is largely unavailable in the United States. Dialysis may not benefit all seriously ill patients, especially those who are older with comorbidities, frailty, or dementia or who consider time spent undergoing dialysis to be inordinately burdensome. However, in the absence of an organized pathway for active medical management without dialysis, physicians, patients, and family members may perceive medical management as “doing nothing” and may feel pressure to initiate dialysis to provide some care.^{19,20}

A model for active medical management without dialysis was recommended by KDIGO,¹ but financial incentives have inhibited its adoption in the United States. Adequate reimbursement for time-intensive processes such as shared decision-making and advance care planning in which the option of active medical management without dialysis could be offered, and for interdisciplinary team skills such as psychologic management of depression and

Box 1. National and International Comprehensive Policy Proposals to Foster Access to Kidney Supportive Care**Moss et al⁴³ (Robert Wood Johnson Foundation ESRD Workgroup)**

Recommendations about QoL, quality of dying, and professional education addressed to CMS, NIH, researchers, educators, certifying boards, dialysis corporations, dialysis units, ESRD networks, patient advocacy organizations, health care providers, and public and private research funders. The recommendations to CMS were:

- Update “Conditions of Participation” for dialysis units to include requirements for ACP and the provision of palliative care.
- Collect data on hospice use on the ESRD Death Notification form (“2746 form”).
- Allow the Medicare hospice benefit to be applied to patients with kidney failure who are certified by their physicians as terminally ill but who choose to continue dialysis until they die.
- Work in conjunction with hospice and the ESRD networks to develop manuals and training for clinicians regarding coordination of dialysis and hospice care for patients with kidney failure.
- Require dialysis-unit staffing to provide reasonable time for social workers to counsel patients on psychosocial issues that surround EOL care.

Kurella Tamura & Meier²¹

1. Universal screening for palliative care needs.
2. Incorporate palliative care measures in the ESRD QIP.
3. Train the nephrology workforce to deliver palliative care.
4. Payment reforms for palliative care services.
5. Fund palliative care research.

Davison et al¹ (Executive Summary of KDIGO Controversies Conference on Supportive Care)

1. Primary supportive care should be available to all patients with advanced CKD and their families throughout the entire course of their illness. Provision of supportive care should be based on need rather than an estimation of survival. Kidney care teams should:
 - Identify patients most likely to benefit from supportive care interventions.
 - Assess and manage symptoms effectively.
 - Estimate and communicate prognosis.
 - Develop appropriate goals of care that address individual patients’ preferences, goals, and values.
 - Possess knowledge of, and experience with, available local supportive care services.
 - Assist with care coordination, including referral to specialist supportive care and hospice service as available and appropriate.
2. Education: supportive care should be recognized as a core competency and constitutes an essential component of CME and the nephrology curriculum for trainees.
3. The nephrology community should support and participate in kidney supportive care research.
4. “Comprehensive conservative care” should include:
 - Interventions to delay progression of kidney disease and minimize risk of adverse events or complications.
 - Shared decision-making.
 - Active symptom management.
 - Communication including ACP.
 - Psychologic support.
 - Social and family support.
 - Cultural and spiritual domains of care.

O’Hare et al⁴⁵(p. 455-457)

Reviews current evidence, then proposes a research agenda for palliative care for patients with advanced CKD to address 3 main knowledge gaps:

What matters most to older adults with advanced CKD and those who care for them near EOL? Knowledge gaps:

1. EOL experience of older adults with advanced kidney disease.
2. Roles, experiences, and perspectives of those who care for older adults with advanced kidney disease.
3. Research priorities of older adults with advanced kidney disease and their caregivers.

What are the most effective approaches to supporting older adults and their caregivers to navigate complex treatment decisions?

Knowledge gaps:

1. Interventions to support older adults and caregivers facing decisions surrounding dialysis initiation.
2. Tailored shared decision-making approaches to meet the needs of older adults and their caregivers.
3. The optimal use of prognostic information in the decision-making process.
4. ACP interventions that facilitate provision of EOL care consistent with patients’ goals and preferences.

How do we reconfigure the health system to ensure that older adults with advanced CKD receive care that supports their goals and is consistent with their values and preferences? Knowledge gaps:

1. Optimal use of symptom assessment tools.
2. The effect of different payment models and/or pay-for-performance incentives on uptake of palliative care and effectiveness of different models for delivering palliative care.

(Continued)

Box 1 (Cont'd). National and International Comprehensive Policy Proposals to Foster Access to Kidney Supportive Care

3. Measure outcomes of conservative, nondialytic care.
4. The effectiveness of concurrent dialysis and hospice care in dying patients.

Kurella Tamura et al⁴⁹

1. Expand access to palliative care (for patients with CKD).
2. Develop a new model of serious illness care for patients with advanced CKD (redesigned around “early goals of care conversation” rather than using the current narrowly disease-oriented focus on “early dialysis preparation”).
3. Test new payment models for delivering palliative care (in patients with kidney failure).

Lam et al⁵⁰ (p. 640)

Use alternative payment models and payer-provider partnerships to pilot kidney palliative care interventions. Examples:

- Reform the kidney palliative care payment model to include CKD stage 5 not receiving KRT.
- Update hospice reimbursement to allow concurrent hospice and dialysis for patients with kidney failure for a defined time period.

Harris et al⁵

“Supportive care and comprehensive conservative care programs should be established in parallel with preventive care programs.”⁵(p. S25) Key “considerations” are:

- Improve information on prognosis and support.
- Make available evidence-based guidance on supportive care that is context-sensitive.
- Establish transparent, spiritually and culturally sensitive processes and metrics for monitoring equity and quality of care in advanced CKD.
- Communicate clearly and effectively on the role of supportive and comprehensive conservative care in advanced CKD.
- Integrate and align supportive and comprehensive care with existing renal and chronic disease supply chains and infrastructure.

ACP, advance care planning; EOL, end of life; CKD, chronic kidney disease; CME, continuing medical education; ESRD, end-stage renal disease; KDIGO, Kidney Disease: Improving Global Outcomes; KRT, kidney replacement therapy; QoL, quality of life; CMS, Centers for Medicare & Medicaid Services; QIP, Quality Incentive Program.

spiritual distress in approaching end of life, should be incorporated into the new payment models.²¹

Quality Measures

Since inception, the CMS ESRD program has been at the forefront of efforts to contain cost and improve quality of care. In 2012, CMS introduced the ESRD Quality Incentive Program designed to promote high-quality services in outpatient dialysis facilities.²² The Quality Incentive Program is a “pay-for-performance” or “value-based purchasing” program that penalizes providers who fail to achieve specific quality measures by reducing payment by as much as 2%. Current measures apply to all patients receiving dialysis, including those who are seriously ill. Recognizing that the “Surprise Question” is a useful tool for identifying patients undergoing hemodialysis who are seriously ill and that it has been incorporated into an integrated prognostic model to improve accuracy of identification of this subpopulation of dialysis patients,^{7,23} it is appropriate to develop new measures for these patients so that dialysis centers are not penalized for honoring patient wishes and aligning treatment to their preferences.^{17,24,25} The creation of Current Procedural Terminology codes to recognize the interdisciplinary nature of, and full complement of medical, psychosocial, and spiritual issues associated with, identification and management of supportive care needs of the seriously ill patient should be explored.²⁶

The National Committee on Quality Assurance has undertaken a review of current measures of quality of care and has launched a project to develop a suite of performance measures suitable for use in serious illness care

accountability programs.²⁷ Efforts to inform the research and development of measures for quality improvement, accountability, and payment are being undertaken by multiple national organizations. The National Quality Forum focuses on measures in 7 care domains to support internal quality improvement, to inform payment policy, and to support accountability and public reporting, and the American Academy of Hospice and Palliative Medicine focuses on comprehensive assessment screening for physical, emotional, psychologic, and religious domains and solicitation of treatment preferences.

The National Quality Forum has endorsed 23 measures for quality palliative care, some of which are applicable to seriously ill patients with CKD, including pain screening and pain assessment, care preferences documented for patients admitted to the intensive care unit, and percentage of patients who have chart documentation of life-sustaining treatment preferences.²⁸ The National Committee on Quality Assurance identified as a high priority the need to develop measures to evaluate the quality of goal-concordant care for patients with serious illness, including patients with advanced kidney disease. This care aligns patients’ values, preferences, and goals with the treatment they receive.

Reimbursement Models

The legislation enabling the ESRD program designated a special population for Medicare entitlement. However, the Medicare program provides no specific benefit to patients with CKD not requiring KRT despite the return-on-investment advantages represented by prevention of kidney failure.

Table 1. National and international recommendations for research priorities for kidney supportive care

Priority	Moss et al ⁴³	Kurella Tamura & Meier ²¹	Davison et al ¹	O'Hare, et al ⁴⁵	Kurella Tamura et al ⁴⁹	Harris et al ⁵
Symptom assessment and management	X	X		X	X	X
QoL: patient assessment, quality measures, strategies to support	X					X
Quality measurement of outcomes related to supportive care			X		X	
Prognostic tools, prognostic studies that incorporate QoL, impact of treatment courses on prognosis		X		X		X
Health services research on implementation of supportive care models ^a		X	X	X	X	X
EOL experience, including hospice use, bereavement	X			X		
Shared decision-making, decision aids, ACP, communication	X			X		X
Other						
Interventions to improve patient satisfaction with dialysis; peer mentoring impact on psychosocial measures of QoL	X					
Initiate a multiinstitution ESRD palliative care research collaborative to address the lack of evidence		X				
Determine education and skill needs across settings and disciplines to address the shortages worldwide of CKD providers trained in supportive care skills; effective curricula leading to measurable provider behavior change and improved care			X			
Research priorities of older adults with advanced kidney disease and their caregivers; experience of their caregivers and opportunities to engage and support them				X		

Note: Table S1 provides explicit description of proposed research topics in each publication.

Abbreviations: ACP, advance care planning; EOL, end of life; QoL, quality of life.

^aIncluding medical management without dialysis and covering their impact, costs, and policy options and payment models.

In 2015, the Center for Medicare & Medicaid Innovation introduced the Comprehensive End-Stage Renal Disease Care Initiative with its ESRD Comprehensive Care Organization (ESCO) model of reimbursement based on Medicare's Accountable Care Organizations model.²⁹ This model encourages dialysis providers to think beyond their traditional roles in care delivery and to support patient-centered care, improved communication, and coordination of care that addresses beneficiaries' health needs in and outside of the dialysis clinic. There is little evidence that any of the ESCOs are addressing the provision of supportive care services, including active medical management without dialysis.

Johnson and Meyer discuss the fragmented care delivered to patients with advanced CKD and those undergoing dialysis, saying "It misses many opportunities to improve patient experience of care and population health as well as to reduce cost."³⁰ They note that the current ESCO model does not address efforts to slow CKD progression, an important component of the AAKH Initiative. The reason ESCOs should cover patients with CKD is to enable early shared decision-making and advance care planning that include all the options for patients with advanced

progressive CKD: kidney transplantation, peritoneal dialysis, home hemodialysis, in-center hemodialysis, and active medical management without dialysis. ESCOs could then provide a "home" for patients who choose active medical management without dialysis; these are patients who are unlikely to benefit from dialysis or who find that dialysis does not meet their QoL goals. ESCOs can further mitigate the financial incentives that drive patients to undergo dialysis regardless of their medical circumstances.

The AAKH Initiative may address some of these reimbursement issues. It proposes 4 new voluntary payment models that offer hope for addressing barriers to patient-centered care, but do not speak specifically to the multiple supportive care needs of the seriously ill stage 4/5 CKD population.

Hospice

It is clear from hospice use statistics that current policies result in underuse for patients with kidney disease and hinder them from receiving hospice services.³¹ A decade ago, fewer than 14% of patients reported to have died with kidney failure received hospice care, compared with more

Table 2. Policy Recommendations from the Coalition for Supportive Care of Kidney Patients

Recommendation	Target Change Agents	Rationale
Provide patient-centered, individualized care for seriously ill patients with kidney disease: eliminate one-size-fits-all approach; screen for seriously ill with surprise question	Payors, nephrology and palliative care clinicians and social workers, dialysis organizations, fellowship programs	Seriously ill patients constitute 20% of kidney disease population, with different prognosis and needs than those who are not seriously ill. They need focused supportive care aligned with their values, preferences, and goals to improve their QoL.
Make integration of shared decision-making and advance care planning a priority: tie reimbursement to comprehensive process; create registries so that advance directives and medical orders are accessible in times of need	Payors, nephrology and palliative care clinicians and social workers, dialysis organizations, fellowship programs	Research highlights the diversity of values of patients with CKD and lack of preparedness of nephrology clinicians to elicit patients' values, preferences, and goals. To provide patient-centered care, patients' values need to be systematically elicited, documented, and accessible across health care settings so patients' wishes can be known and respected.
Explicitly offer active medical management without dialysis to seriously ill older patients with CKD who may not live longer with dialysis than without it	Payors, nephrology and palliative care clinicians and social workers, fellowship programs, patient advocacy groups	Accumulating evidence indicates that patients with CKD with ≥ 2 of the following may not live longer with dialysis than without it: age ≥ 75 y, multiple comorbidities, frailty, functional impairment, cognitive impairment, "no" response to Surprise Question.
Implement systematic pain and symptom assessment and management	Payors, nephrology and palliative care clinicians, fellowship programs, patient advocacy groups	Multiple studies show that attention to CKD symptoms improves patient QoL, but nephrology clinicians are largely unaware of patients' troublesome symptoms. Systematic pain and symptom assessment needs to be implemented with validated tools such as ESAS-R and iPOS-R. Algorithms for treating symptoms need to be widely available.
Emphasize importance of kidney supportive care and its essential role in care of patients with CKD in all educational and accreditation programs for nephrology clinicians	Nephrology and palliative care specialty societies, social worker organizations, ACGME, nephrology fellowship programs, academic medical centers, certifying examination boards	Patients with CKD have significant unmet supportive care needs, and failure to address their needs negatively impacts their QoL and that of their families.
CMS and all other payors need to remove financial and regulatory disincentives to quality supportive care for patients with CKD: enable and reimburse concurrent hospice and dialysis services for terminally ill patients; develop and accept alternative ESRD QIP quality metrics for seriously ill patients; create incentives for dialysis organizations to move upstream and collaborate in shared decision-making with nephrology clinicians so not all patients with advanced CKD begin dialysis	Payors, ESRD QIP, hospices	The CKD population is heterogeneous. Reimbursement strategies and regulations need to take account of patient diversity. Research shows that terminally ill patients enrolled in hospice receive the best end-of-life care. Seriously ill patients undergoing dialysis prioritize and evaluate quality care differently than what the ESRD QIP measures. Current financial incentives promote disease-oriented care for patients with stage 5 CKD, such that most begin dialysis without realizing they had a choice.

Abbreviations: ACGME, Accreditation Council for Graduate Medical Education; CKD, chronic kidney disease; ESAS-R, Edmonton Symptom Assessment Scale-Renal; ESRD, end-stage renal disease; iPOS-R, integrated Palliative Care Outcome Scale-Renal; QIP, Quality Incentive Program; QoL, quality of life.

than 50% of persons with cancer, and only 3% received concurrent hospice and dialysis care.³² The situation has improved, with 27% of Medicare ESRD decedents using hospice in 2015.³³ This is still just half of the 50.4% rate for all regular Medicare beneficiary decedents in 2015.³³ Rates of end-of-life hospitalization and hospice use vary widely by state, suggesting that it is not just patient preference driving use, but factors amenable to policy influence such as capacity and practice patterns.³⁴ In 2015, hospice use was much greater for those who discontinued dialysis versus for those who did not (62% vs 16%),^{35(p12)} showing the limited access to concurrent dialysis and hospice.

Current hospice coverage for patients undergoing dialysis is inconsistently applied. Many hospices refuse to accept a dialysis recipient under the Medicare hospice benefit for a terminal diagnosis other than ESRD even though the patient could continue to use the ESRD Medicare benefit for continuing dialysis.³⁶ If hospice benefits are based on ESRD as the terminal diagnosis, the hospice must provide the coverage for dialysis, and the Medicare ESRD benefit ceases. For many reasons (financial and philosophical), a hospice may be unwilling to accept a patient in this situation.

There are patient-centered arguments to support the option of palliative dialysis^{37,38} and concurrent hospice

and palliative dialysis.^{39,40} They represent an approach to support those dying patients who, for example, want to be alive for a particular life event (wedding of a family member or birth of a grandchild). Policies that flexibly help achieve patient-centered goals that enhance QoL should be the ultimate aim of any public policy for supportive care of patients with kidney failure.

Education

Dissemination and adoption of guidelines and best practices is, in part, an educational issue. Providers, specifically nephrologists, receive little, if any, formal education in the delivery of palliative care.⁴¹ Having serious illness conversations can be difficult and emotionally draining, and it is an area that, to be done well, usually requires communication-skills training most nephrology practitioners have not received.⁴² These skills lend themselves to an interdisciplinary team approach and can promote holistic patient care.

End-of-life care and pain management are part of the Accreditation Council for Graduate Medical Education program requirement for nephrology training, but this training is variable and often limited.⁴¹ Specialty societies such as the Renal Physicians Association and the American Society of Nephrology address supportive care in their policies and programming, but it constitutes a small segment of their overall attention.

As supportive care services are integrated with routine care, specific educational efforts should be undertaken for those in dialysis-facility and nephrology-practice settings to provide them with kidney supportive care training and resources.

Research

The evidence base for kidney supportive care has improved since the 2002 ESRD Workgroup of the Promoting Excellence in End-of-Life Care project laid out an agenda of high-priority questions for the kidney research community and research funders⁴³ (Table 1; Table S1). There is now ample documentation of the need for kidney supportive care, the lack of access to those services, and the concerning high-intensity/high-cost use pattern at the end of life for patients undergoing dialysis.^{1,33(p12),44–46}

Yet, despite the fact that the average number of articles published per year on PubMed found with the search terms “kidney” and “palliative care” has more than doubled in the past decade compared to the decade before (92.6 vs 34.7), research in this field is still lacking. There are no outcomes studies on dialysis patients who receive palliative dialysis or concurrent hospice and dialysis. Neither are there prospective studies of mortality and QoL comparing patients who receive medical management without dialysis versus those who start dialysis. Finally, development of tools and quality measures that can assess and track concepts such as patient-centered care, shared decision-making, and goal-concordant care is needed.

Table 1 displays the research priorities advanced by several groups to fill these evidence gaps (Table S1 includes the explicit research recommendations of the groups). There is commonality in the call for much expanded clinical, quality, and health-services studies to expand the evidence base to enable effective delivery of kidney supportive care. For example, O’Hare et al articulated a palliative care research agenda for patients with kidney disease that encompasses 3 broad areas: (1) what matters most to older adults with advanced CKD and their caregivers near the end of life, (2) how the nephrology community can best support older adults with advanced CKD to navigate complex treatment decisions throughout their illness, and (3) how the health care system should be reconfigured to promote patient- and family-centered care for older adults with advanced CKD.⁴⁵ This evidence is needed to improve current clinical practice and to inform changes in policy so that patients with kidney disease can receive goal-concordant care.

Summary

This Perspective focuses on current policy and changes needed to improve supportive care for seriously ill patients with kidney disease. Given the dominant role of CMS, without a change in their policy and reimbursement practices, the majority of these changes will not occur. Some of the financial incentives that CMS can operationalize include payment for concurrent hospice and dialysis, funding for demonstration efforts that explore medical management without dialysis as a treatment option, and a separate set of ESRD Quality Incentive Program metrics for seriously ill patients undergoing dialysis who can be predicted based on the evidence^{15,23,47,48} to be at high risk for mortality in the next year. These metrics could include documented shared decision-making and advance care planning discussions, completion of advance directives and medical orders (do-not-resuscitate and physician orders for life-sustaining treatment) to ensure patients’ wishes are known and respected, rate of referral to hospice, and out-of-hospital death. Certainly, the nephrology workforce can be trained to provide kidney supportive care. However, the financial incentives to provide dialysis with a one-size-fits-all approach and the disincentives to offer active medical management without dialysis will need to be addressed by CMS. Further, quality measurement that influences payment, such as the ESRD Quality Incentive Program, needs to accommodate patient-centered care and palliative dialysis for patients near the end of life. These provisions must also be added to the policies being developed under the AAKH Initiative. At the end of life, dialysis patients’ access to hospice is severely limited. CMS and Congress should look for further ways to remove the legislative and regulatory barriers to access to concurrent hospice and dialysis. There is much to be done. The first step is to identify the challenges and

propose practical solutions that will improve QoL for seriously ill patients with or approaching kidney failure.

Supplementary Material

Supplementary File (PDF)

Table S1: National and international recommendations for research priorities for kidney supportive care.

Article Information

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