A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life

Vanessa Grubbs,*† Alvin H. Moss,‡ Lewis M. Cohen,§ Michael J. Fischer,§ Michael J. Germain,§ S. Vanita Jassal,** Jeffrey Perl,†† Daniel E. Weiner,‡‡ and Rajnish Mehrotra§§ on behalf of the Dialysis Advisory Group of the American Society of Nephrology

Abstract
As the importance of providing patient-centered palliative care for patients with advanced illnesses gains attention, standard dialysis delivery may be inconsistent with the goals of care for many patients with ESRD. Many dialysis patients with life expectancy of <1 year may desire a palliative approach to dialysis care, which focuses on aligning patient treatment with patients’ informed preferences. This commentary elucidates what comprises a palliative approach to dialysis care and describes its potential and appropriate use. It also reviews the barriers to integrating such an approach into the current clinical paradigm of care and existing infrastructure and outlines system-level changes needed to accommodate such an approach.


Introduction
In response to the high burden of physical and psychological symptoms among individuals with ESRD, recent commentary has called for policies to promote palliative care (1). However, among the ESRD population undergoing maintenance dialysis, much of the symptom burden may be attributable to dialysis therapy itself, particularly for those nearing the end of life. Also needed, then, is a palliative approach to how dialysis care itself is provided, but the current system of dialysis delivery and regulatory oversight in the United States is not well suited to accommodate such an approach.

Defining a Palliative Approach to Dialysis Care
We define a palliative approach to dialysis care as a transition from a conventional disease-oriented focus on dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden for maintenance dialysis patients in their final year of life. This transition aligns with palliative care in general as well as with the current demographic of the United States dialysis population.

The Centers for Medicare & Medicaid Services (CMS) recognize palliative care as “patient- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering” (2). Provision of palliative care is appropriate at any age and at any stage in serious illness and it is not exclusively reserved for patients who have exhausted or decided to forgo life-prolonging therapies (3). CMS further states that “as age or illness progress, and cure or rehabilitation are no longer realistic expectations, care focuses increasingly on palliation” (2).

ESRD is a unique illness in that while there is no cure and it portends a higher mortality rate than do some cancers, some patients with ESRD survive decades while receiving dialysis or following transplantation (4). Therefore, a one-size-fits-all approach to dialysis care cannot be expected to meet the needs of such a heterogeneous demographic. This heterogeneity reflects a dramatic change in the ESRD patient population over the past 4 decades. A similar shift in how we approach dialysis care should follow suit.

At the inception of the ESRD Medicare Entitlement Program in 1972, the ESRD population was predominately young and not experiencing progressive comorbid disorders, such as diabetes. Accordingly, the primary goal of care beyond merely extending life was rehabilitation—to enable patients disabled by ESRD to return to work or normal activities. Currently, however, more than half of patients initiating dialysis are >60 years of age and have multiple chronic illnesses in addition to ESRD, so the predominant goal is often restricted to prolongation of life. Patients have a wide spectrum of prognoses, including many with a life expectancy of <1 year (4,5). For this group, the burdens of dialysis care may outweigh its benefits, thus making desirable a palliative approach to dialysis care in which the emphasis is shifted toward minimizing physical and psychologic burdens of standard maintenance dialysis schedules (such as fatigue and travel to and from dialysis), and away from achieving standard performance metrics (such as creation of an arteriovenous fistula or intensification of the dialysis prescription to achieve a target Kt/V) (Figure 1) (6).

Several domains of care apply within a palliative approach to dialysis care. While the rigorous quality measurement framework outlined by National Quality Forum (NQF) is directly applicable to developing standards of care for conventional dialysis, the current

Correspondence: Dr. Vanessa Grubbs, Division of Nephrology, University of California, San Francisco/San Francisco General Hospital Renal Center, Box 1341, 1001 Potrero Avenue, Building 100, Room 342, San Francisco, CA 94110. Email: grubbsv@medschl.ucsf.edu
specific measures endorsed by the organization have less relevance to a palliative approach to dialysis (7). Patient-centered metrics, such as those focused on quality of life, psychosocial health, and satisfaction with care, are not currently established by CMS or NQF for patients with CKD or ESRD. However, broad palliative care metrics endorsed by NQF and reported by the Center to Advance Palliative Care could be adapted to a palliative approach to dialysis care (1,8). Potential key domains include eliciting patient goals of care; physical, psychological, and spiritual symptom management; patient and caregiver satisfaction; and caregiver support (8).

Within this framework, dialysis care providers must assume responsibility for initiating discussion of goals and prognosis and encouraging patient-family communication, with the broad understanding that the goals of a palliative approach to dialysis care are to ameliorate symptoms and minimize suffering (9). Once identified, patient preferences for care should routinely be written as medical orders to ensure that patients receive the treatment they want throughout the health care system. The Physician Orders for Life-Sustaining Treatment (POLST) program has been validated and recommended as a best practice for patients whose physicians would not be surprised if they died in the next year (10,11). The POLST is intended to serve as a living documentation of patient preferences for current care among the seriously ill, in addition to medical orders for future end-of-life care (12). Because goals of care may change over time, this should be an iterative process, revisited over time (13). Similarly, it is imperative that symptoms, quality of life, and clinical status be regularly assessed and evaluated within a palliative approach to dialysis care.

Patient and caregiver satisfaction with care is also an important patient-centered domain for maintenance dialysis but has only recently been evaluated. Studies suggest patient satisfaction with care correlates with perceived quality of life and disease burden, thus supporting its relevance to a palliative approach to dialysis care (14,15).

Finally, social support for caregivers is linked to improvements in psychological health, adherence with treatment, and survival among dialysis patients (16). Whether the patient is undergoing in-center or home dialysis, the quality of life for the caregiver correlates strongly with the patients’ level of dependency (16,17). Patients choosing a palliative approach to dialysis care may be in the midst of substantial functional decline, and as this process unfolds, there will likely be more demands and stress on their caregivers (18).

Why a Palliative Approach to Dialysis Care Is Needed

In justifying the need for a palliative approach to dialysis care, it is important to underscore the substantial morbidity and mortality among maintenance dialysis patients. The mean age for prevalent dialysis patients in the United States is now 62.7 years, and the prevalence of maintenance dialysis among patients ≥75 years of age has doubled during the last 2 decades (4). The dialysis population has an adjusted 76% 1-year survival rate and only a 36% 5-year survival rate (4). The adjusted mortality rate of maintenance dialysis patients is nearly twice that of adults with cancer and more than twice that of adults with congestive heart failure or stroke (4).

Patients treated with maintenance dialysis have a high prevalence of debilitating symptoms, which are multifactorial in origin and include uremia, other complications of ESRD, demands of routine dialysis, or comorbid conditions (19). Physical and emotional symptoms are highly prevalent, are often severe and undertreated, and correlate directly with impaired quality of life among maintenance dialysis patients (19–21). Using the Edmonton Symptom Assessment System, Davison et al. (22) found a mean of 7.5 symptoms per maintenance dialysis patient, 4.5 of which were characterized as moderate or severe (23). Only 6%–35% of dialysis patients complete advance directives planning; the default then becomes intensive care patterns, including multiple admissions, surgical procedures, and resuscitation attempts at the end of life (13).
Most older dialysis patients in the United States initiate dialysis in the hospital, and many experience high rates of subsequent hospitalization (23). In a study of older Medicare patients starting dialysis, patients were classified into five levels of intensity of care, with the highest level being those who had longer than a 2-week hospital stay and received at least one intensive procedure, such as cardiopulmonary resuscitation, mechanical ventilation, or a feeding tube. In patients ≥85 years who received the highest intensity of care, the median duration of survival after dialysis initiation was <6 months, with more than a third of that time spent in the hospital (23).

Many older adults treated with maintenance dialysis in the United States continue to receive aggressive care focused on life prolongation toward the end of their lives. Almost half (45%) of older United States dialysis patients die in a hospital setting as compared with 35% of Medicare beneficiaries with other severe chronic illness (including congestive heart failure, advanced liver disease, dementia, and chronic obstructive pulmonary disease) (24). Rates of hospitalization (76%) and intensive care unit (ICU) admission (49%) during the final month of life are also substantially higher than reported for other older Medicare beneficiaries, including those with cancer (of whom 61% are hospitalized and 24% are admitted to an ICU) and heart failure (of whom 64% are hospitalized and 19% are admitted to an ICU). Additionally, older dialysis patients spend twice as many days in the hospital during the last month of life as do Medicare recipients with cancer (9.8 versus 5.1 days) and are three times more likely to undergo an intensive procedure (29% versus 9%). In contrast, rates of palliative care and hospice utilization among dialysis patients at the end of life are extremely low (24). Compared with hospice use in patients with terminal cancer (55%) and heart failure (39%), hospice is used in only 20% among dialysis patients and is often only initiated within the last days of life (24–26).

These current patterns of death and treatment intensity do not appear congruent with patient wishes when actively elicited. In a study of United States maintenance dialysis patients, only 18% preferred to live as long as possible even if suffering (27). Similarly, in a study of patients with advanced CKD in Canada, a majority preferred their care to focus on decreasing pain and suffering, while only 18% favored dialysis to extend their lives (28). More patients wished to die at home (36%) or in an inpatient hospice (29%) than in a hospital (27%) (28).

### Appropriate Use of a Palliative Approach to Dialysis Care

Given the high prevalence of advanced age, severe comorbid conditions, and high mortality rate among the ESRD population, a substantial proportion of patients undergoing maintenance dialysis may be nearing the end of life and could be candidates for a palliative approach to dialysis care (4,5,19). Such patients may have difficulty tolerating conventional dialysis regimens, and conversations with patients about preferences and goals of care are warranted. While a discussion of dialysis withdrawal may be considered, many patients and family members may not feel ready to discontinue dialysis completely because of concerns about suffering from ESRD-related symptoms or death within the mean 8-day time frame following dialysis cessation in patients with no residual kidney function (26,29–31). A palliative approach would not inevitably lead to withdrawal but could provide a transition to this option.

Specific clinical scenarios of maintenance dialysis patients with limited life expectancy in which a palliative approach to dialysis care may be considered include (1) the maintenance dialysis patient who develops a severe illness that causes an abrupt decline in life expectancy, (2) the patient started on dialysis in the setting of AKI with unclear life expectancy and goals of care, and (3) the maintenance dialysis patient with progressive functional or cognitive decline. In a palliative approach to dialysis care, the transition of care for each of these scenarios would begin with a conversation about the goals of care.

### Barriers to a Palliative Approach to Dialysis

#### Provider Barriers

Several factors pose barriers to a palliative approach to dialysis care for appropriate patients. For example, while patients with ESRD prefer to be given information about their prognosis by their physicians and those who participate in end-of-life discussions tend to prefer less aggressive care, few dialysis patients report having had even limited discussions about their wishes (28,32–34). The dearth of discussions is likely fueled by provider uncertainty about prognosis and a lack of attention during training (35–37). However, reliable instruments have been developed to identify dialysis patients at highest risk of death, and fellowship training programs have been encouraged to attend more to building this skill (36,38,39).

A lack of understanding of palliative care and/or negative perceptions among patients, caregivers, and providers alike may also function as a barrier to a palliative approach to dialysis care (40,41). While current guidelines and practice standards have resulted in most dialysis staff being highly trained to recognize signs of underdialysis and fluid overload, few if any are trained to identify or manage symptoms that may be addressed with palliative care. Even small changes in protocols, such as relaxation of biochemical targets (e.g., for serum phosphorus) or flexibility around dialysis time/prescription, may be viewed as improper or inadequate care, thus leading to conflict among providers who strictly adhere to standard dialysis quality metrics versus those advocating for treatment aligned with the patient’s goals.

#### Fiscal Barriers

Economic and regulatory factors also pose barriers. As the payer of 90% of prevalent dialysis patients, CMS establishes the targets for dialysis care through its performance standards and frequently includes incentives to ensure an acceptable level of care (4,42). Within the ESRD Prospective Payment System, these incentives exist in the Quality Incentive Program, which is composed of performance metrics that include measures of dialysis dose, avoidance of high hemoglobin levels, and maximizing arteriovenous fistula use while minimizing central venous catheter use (43,44). End-of-life goals seldom conform to disease-focused
incentivized metrics (Table 1), but the failure of a facility to achieve adequate performance on the Quality Incentive Program measures can result in up to a 2% loss of reimbursement for all Medicare beneficiaries in the facility (45). Therefore, the juxtaposition of incentivized metrics and individualized, patient-centered care may create conflict among the facility management (who bear the financial penalty for unmet metrics), physicians and other dialysis staff (who have an interest in seeing the facility succeed financially but are also charged with advocating for the best interests of the individual patient), and the patient (for whom goals may not align with quantifiable metrics).

Care Delivery Barriers
The lack of wide-scale infrastructure or universal reimbursement for providing staff-assisted home hemodialysis or peritoneal dialysis (PD) contributes to the underuse of a palliative approach to dialysis. Staff-assisted home dialysis, which involves the delivery of hemodialysis or PD with the aid of visiting nurses who assist to varying degrees in the tasks needed for the patient and/or caregiver to safely and effectively perform maintenance dialysis at home, is well established and supported by governments in Canada, France, Belgium, and Denmark, but not in the United States (46–49). Staff-assisted home dialysis may be particularly attractive over facility-based hemodialysis for elderly, frail patients who would need varying degrees of assistance to perform dialysis at home, thus serving as a palliative approach to dialysis care by avoiding potentially lengthy transportation to and from the dialysis facility and potentially allowing the dose of dialysis to be better tailored to the needs of patients with variable uremic symptoms.

Finally, CMS policy regarding provision of hospice benefits for patients in whom ESRD is the primary terminal condition contributes to the underuse of a palliative approach to dialysis care by requiring that hospice agencies pay for the costs of continuing dialysis care in such cases (50). Such a proposition is not financially tenable for hospice providers, thus potentially depriving such patients who have a life expectancy consistent with hospice requirements (<6 months) an important aspect of supportive care services.

Recommendations for Implementing a Palliative Approach to Dialysis Care
Achieving the most effective use of a palliative approach to dialysis care requires several system-wide changes. We suggest the following recommendations to accommodate this approach (Table 2):

Recommendation #1: Nephrologists and Nephrology Fellows Should Develop Expertise in Discussing Prognosis and Goals of Care
Reliable instruments have been developed to help identify dialysis patients at highest risk of death within a 6- and 12-month time frame and should be used widely (38,39). Nephrology organizations have long advocated shared decision-making and discussion of prognosis for patients with AKI, advanced CKD, and ESRD (51). Palliative care physicians have recommended that nephrologists and other physicians providing primary care to specific disease populations develop generalist palliative care skill sets (37). These skill sets include basic management of symptoms and comfort with discussions about patients’ preferences for goals of treatment.

It is commonly assumed by clinicians that they do not have the time to discuss end-of-life issues with their patients and families and that sufficient space and privacy are not possible in the open dialysis unit. However, improved expertise would allow clinicians to facilitate such discussions with greater ease and efficiency. Further, patient and family members could be invited to have such discussions as part of care plan conferences that are already required by CMS.

| Table 1. Examples of approaches to common issues among maintenance dialysis patients in the current disease-focused dialysis delivery model versus a palliative approach to dialysis care model |
|---------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| **Issue**                                                    | **Current Disease-Focused Metrics for Conventional Delivery of Dialysis Care**                        | **A Patient-Centered Palliative Approach to Dialysis Care**                                                      |
| Vascular access                                              | Creation and maintenance of an AV fistula                                                                 | Central venous catheter acceptable                                                                                 |
|                  | Target small solute clearance based on current standards (Kt/V > 1.2 for HD and Kt/V > 1.7 for PD), intensifying the dialysis prescription as needed to achieve targets | Lower clearance acceptable if changes in dialysis prescription increase demands inconsistent with patient preference |
| Cardiovascular disease                                       | Treat CV risk factors, potentially targeting BP and dyslipidemia                                           | Tolerate hypertension to avoid symptoms; no indication for dyslipidemia treatment                                |
|                  | Dietary counseling; binders to control hyperphosphatemia; vitamin D analogues with or without calcimimetics for secondary hyperparathyroidism | Limited restrictions; more permissive hyperphosphatemia and hyperparathyroidism                                    |
| Mineral and bone disorder                                    | Encourage dietary protein intake while limiting potassium (if HD), sodium, and phosphorus intake              | Reduce dietary restrictions                                                                                        |
| Nutrition                                                   | Routine monthly laboratory tests                                                                            | Minimal necessary                                                                                                  |
| Laboratory monitoring                                       |                                                                                                              |                                                                    |

AV, arteriovenous; HD, hemodialysis; PD, peritoneal dialysis.
Improving knowledge gaps in this area would require incorporation of skill sets into training program curricula for fellows (such as NephroTalk) and could be achieved through continuing medical education requirements for practicing nephrologists (52). Dialysis social workers and nursing staff may be tasked with following up with end-of-life discussions, the assignment of health care proxies, and completion of living wills, but nephrologists must remain primarily responsible for discussion of prognosis and goals of care with patients and families. Involvement of the dialysis team can facilitate the implementation of a palliative approach into dialysis care (41,53).

**Recommendation #2: Develop Metrics for a Palliative Approach to Dialysis Care**

Although important guidelines, working group publications, and initiatives focusing on palliative care in the ESRD population have increased awareness among nephrology providers, additional research and evidence is needed to inform appropriate standards of care for patients undergoing a palliative approach to dialysis care (51,54,55). Many questions remain unanswered, including better identification of patients who could benefit from a palliative approach, dosing and timing of dialysis, optimizing symptom management, and establishing patient-centered goals of care. Nevertheless, given the magnitude of burdens associated with dialysis near the end of life, implementing a palliative approach to dialysis care based on expert opinion is reasonable (56,57). Codifying quality metrics for a palliative approach to dialysis care could alleviate concerns of substandard care that does not align with the current disease-focused metrics, thereby promoting patient goals and improving utilization of appropriate services near the end of life.

Key domains for a palliative approach to dialysis care include elicitation of patient goals of care; physical, psychological, and spiritual symptom management; patient and caregiver satisfaction; and caregiver support. Potential metrics within these domains are summarized in Table 3.

**Table 2. Proposed recommendations and barriers addressed**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Barriers Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nephrologists and nephrology fellows should develop expertise in discussing prognosis and goals of care</td>
<td>Nephrologists often lack skills to address prognosis and goals of care for patients with ESRD</td>
</tr>
<tr>
<td>Develop metrics for a palliative approach to dialysis care</td>
<td>Infrequent end-of-life discussions among dialysis patients</td>
</tr>
<tr>
<td>Determine the fiscal impact of a palliative approach to dialysis care</td>
<td>Current standard-of-care metrics disease-focused rather than patient-centered</td>
</tr>
</tbody>
</table>

**Table 3. Key domains and suggested quality metrics for a palliative approach to dialysis care**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Potential Metrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elicitation of patient goals of care</td>
<td>Documentation of discussion of prognosis</td>
</tr>
<tr>
<td>Physical, psychological, and spiritual symptoms</td>
<td>Frequency of documentation in medical orders, such as POLST, of patient goals of current care and preferences for life-sustaining treatments at the end of life</td>
</tr>
<tr>
<td>Caregiver support</td>
<td>Frequency of documentation of symptoms by the dialysis care team</td>
</tr>
<tr>
<td>Patient and caregiver satisfaction</td>
<td>Change in symptom scores over time</td>
</tr>
</tbody>
</table>

POLST, Physician Orders for Life-Sustaining Treatment.
therapy and rehabilitation. Current practices of aggregating data for all dialysis patients regardless of their goals of care misrepresent the delivered quality of care as reported on public reporting sites, discourage a palliative approach and may have negative financial consequences for dialysis providers (45,51). A failure to implement a separate reporting mechanism representing achievement of standards specific to patients choosing a palliative approach could lead to dialysis providers “cherry-picking” and, worse, subjecting patients nearing the end of life to unwanted and possibly detrimental treatment.

Conclusion
A palliative approach to dialysis care could be an important aspect of treating selected patients on maintenance dialysis. As a patient-centered rather than disease-oriented approach to the delivery of dialysis care among patients with limited life expectancy, a palliative approach to dialysis care could alleviate the suffering of such patients. Much work is needed to facilitate incorporation of this approach into the existing dialysis delivery infrastructure in the United States in order to realize its most effective use.

Acknowledgments
V.G. was supported by grant 1K23-DK093710-01A1 from the National Institute of Diabetes and Digestive and Kidney Disease and by the Harold Amos Medical Faculty Development Program of the Robert Wood Johnson Foundation. L.M.C. and M.G. are supported by a grant from the Patient Centered Outcomes Research Institute on Shared Decision-Making and Renal Supportive Care. V.G., M.J.F., J.P., and R.M. are members of the Dialysis Advisory Group of the American Society of Nephrology. D.W. was a member of the Dialysis Advisory Group at the time of manuscript conception, and S.V.J. and M.J.G. are members of the Geriatric Nephrology Advisory Group of the American Society of Nephrology (ASN). The opinions expressed in this manuscript are those of the authors and not necessarily the opinions of their institutions or of all the members of the ASN. The members of the ASN’s Dialysis and Geriatric Nephrology Advisory Groups and Communication Committee reviewed this manuscript prior to submission.

The following were the members of the Dialysis Advisory Group of the ASN at the time of writing this editorial: Gregory L. Braden (Springfield, MA), Christopher Chan (Toronto, ON, Canada), David Charytan (Boston, MA), Michael J. Fischer (Chicago, IL), Jennifer E. Flythe (Boston, MA), Vanessa Grubbs (San Francisco, CA), Adriana Hung (Nashville, TN), Frank Hurst (Silver Spring, MD), Mark Lukasiewski (Washington, DC; ASN Staff), Rajnish Mehrotra (Seattle, WA; Advisory Group Chair), Timothy W. Meyer (Palo Alto, CA), Sharon M. Moe (Indianapolis, IN; ASN Council liaison), Amy Barton Pai (Albany, NY), Jeffrey Perl (Toronto, ON, Canada), Shuvo Roy (San Francisco, CA), Michael J. Somers (Boston, MA), Isaac Teitelbaum (Denver, CO), and Leslie Wong (Cleveland, OH).

Disclosures
V.G. received investigator-initiated research funding from Valeant Pharmaceuticals. S.V.J. received investigator-initiated research funding from Fresenius and speaker fees from Amgen. J.P. received speaking honoraria from Baxter Healthcare, Amgen Canada, and DaVita Healthcare Partners; consulting fees from Baxter Healthcare, Shire, Takeda, Janssen Inc.; and research support from Baxter Healthcare. D.W. received research funding from Dialysis Clinic, Inc. and was site principal investigator for clinical trials by Keryx (completed) and Janssen. R.M. received grant support and/or honoraria from Baxter Healthcare and DaVita.

References
22. Davison SN, Jhangri GS, Johnson JA: Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis
42. Centers for Medicare & Medicaid Services: Final CY, End-Stage Renal Disease Prospective Payment System. 2013, pp 1352–F2012
58. Agraharkar M, Barclay C, Agraharkar A: Staff-assisted home hemodialysis in debilitating or terminally ill patients. Int Urol Nephrol 33: 139–144, 2002
Published online ahead of print. Publication date available at www.jasn.org.