



May 30, 2023

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8013
Baltimore, MD 21244

RE: CMS-1787: Medicare Program; FY 2024 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, Hospice Quality Reporting Program Requirements, and Hospice Certifying Physician Provider Enrollment Requirements

Dear Administrator Brooks-LaSure:

On behalf of the more than 37,000,000 Americans living with kidney diseases and the 21,000 nephrologists, scientists, and other kidney health care professionals who comprise the American Society of Nephrology (ASN), thank you for the opportunity to respond to the hospice request for information issued by the Centers for Medicaid and Medicare Services (CMS) in the *FY 2024 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, Hospice Quality Reporting Program Requirements, and Hospice Certifying Physician Provider Enrollment Requirements* proposed rule. ASN thanks you for the opportunity to comment on this immensely important issue for patients with End-Stage Renal Disease (ESRD) considering the use of hospice benefits.

Kidney diseases result in an enormous burden on individuals, their families, their communities, and the overall health care system. Kidney diseases are the tenth leading cause of death in the United States, and people with kidney diseases have a significantly higher risk of cardiovascular disease, kidney failure, and death. Individuals who progress to kidney failure often elect for kidney replacement therapy, including kidney transplant or dialysis. Individuals receiving dialysis have a five-year survival rate of less than 50 percent—worse than nearly all forms of cancer and may experience a high symptom burden associated not only with dialysis but also with the chronic conditions that resulted in kidney failure.

ASN's comment letter focuses on three areas:

- 1) Concurrent hospice and dialysis
- 2) Palliative approaches to dialysis
- 3) Upstream models of palliative care for kidney failure

Patient-centered approach

Nephrologists often find that seriously ill individuals who are nearing the end of life and are also on dialysis express goals and values that would be best aligned with concurrent hospice and customized dialysis. As patients develop and progress with comorbid conditions such as heart disease, vascular disease, cognitive impairment, cancer, or other illnesses, it is common for these individuals and their families to express preferences that dialysis treatments be shorter, less frequent, and more symptom-driven rather than scheduled. When this occurs, the main focus of all their medical care should be on their quality of life.

Yet the current care model views dialysis narrowly in terms of life prolongation rather than as a treatment that might be customized to treat symptoms and maximize comfort, aligning with the goals of hospice services. ASN believes that dialysis should be an option within hospice care as dialysis can and does reduce symptoms and enhance quality of life for patients with limited prognosis.

“Dialysis is a unique life-prolonging treatment with a predictably short prognosis after treatments cease. So, dialysis patients are forced to choose a path that likely will shorten survival in order to have access to the option of high-quality end-of-life services. Not surprisingly, few people on dialysis choose hospice, and those who do often delay hospice enrollment until very near the end of life, often in the setting of a hospitalization.”

Challenges with Providing Hospice Care for
Patients Undergoing Long-Term Dialysis
Jane O. Schell and Douglas S. Johnson

CJASN 16: 473–475, 2021. doi: <https://doi.org/10.2215/CJN.10710720>

This dynamic may explain why only one-quarter of dialysis patients receive hospice services compared with 50% of the general Medicare population, and of those that do, nearly half receive hospice for less than three days.

Barriers to a Patient-Centered Approach to Hospice for Dialysis Patients

There is a significant barrier for dialysis patients in terms of accessing hospice related to payment and reimbursement. Generally, the cost of dialysis (including transportation and of all the concurrent Part B and D medications/treatments) far exceeds a hospice provider's daily reimbursement. Technically, by regulations, situations do exist in which a patient can continue dialysis and receive hospice services, specifically if the hospice diagnosis is not related to the kidney disease. For example, a patient with metastatic pancreatic cancer who had pre-existing kidney failure related to diabetes and hypertension may be able to continue dialysis. However, hospice providers rarely accept the financial risk of caring for these individuals as Medicare payers often determine that kidney failure contributes to death, thereby rendering hospice providers

responsible for paying for dialysis and associated costs. This cost exceeds their reimbursement structure.

“The Medicare Hospice Benefit can cover both hospice and life-prolonging treatments for conditions unrelated to the hospice diagnosis. Hospices could then “carve out” dialysis so long as the ESKD diagnosis is unrelated to the hospice diagnosis; however, in practice, this happens rarely. Recently, the Centers of Medicare and Medicare Services (CMS) have moved away from the notion that a patient has one terminal condition contributing to his or her life-limiting prognosis. This has led to the expectation that hospices must be financially responsible for all conditions that contribute to the patient’s terminal prognosis, even those unrelated to the hospice diagnosis. Unsurprisingly, with this interpretation by CMS, most hospices typically only admit a patient with ESKD into hospice once the patient agrees to stop all dialysis treatments.”

Schell and Johnson

Hospices receive flat per diem rates that range between \$150 and \$200. Schell and Johnson explain further that most hospices cannot afford the base rate of dialysis (average approximately \$250/session) within their daily per diem rate and that only 1.1% of the country’s 4,515 hospices in operation have a daily census high enough to absorb these costs.ⁱ

Concurrent hospice and dialysis

The option for concurrent hospice care and dialysis may promote better access to comfort-oriented care for terminal dialysis patients. There are some pilot concurrent hospice and dialysis programs to try to address this issue. In Schell and Johnson’s concurrent model, they incorporated up to 10 hemodialysis treatments alongside hospice services, with a similar three-to-four-week timeframe for peritoneal dialysis patients. Interestingly, most patients who enrolled in hospice who were permitted to continue dialysis did not pursue any more dialysis. Of those who continued dialysis, almost all did so for only a few treatments. These examples of concurrent models, if regulated well, could be excellent initial options as they eliminate the need for a dichotomous decision about “stopping dialysis” in order to start hospiceⁱⁱ. It seems that the possibility of choice and a trial period provides a powerful incentive for deeper consideration of hospice, eliminating the large barrier of the current functional requirement to stop dialysis. However, regulatory action by CMS and Congress would need to extend such options to the broader Medicare population.

This adjustment must include transportation to and from dialysis. Currently, transportation to and from dialysis often accounts for the largest expense for concurrent hospice and dialysis. Related, there are racial inequities in who receives hospice among the dialysis population. Black and Hispanic patients are less likely to receive hospice compared to White patients. In addition to transportation, CMS should consider covering other ancillary services (e.g., home care) that are offered with hospice which may help decrease racial inequities in hospice care.

The Center for Medicare and Medicaid Innovation within CMS has explored innovative approaches on concurrent life-prolonging care and hospice in the Kidney Care Choices Model and the Medicare Care Choices Model. ASN encourages CMS to examine further innovative efforts throughout the Medicare population.

Education/Communications/Recommendations

There is a notable concern in the RFI questions around poor preparation of patients on dialysis and their families for what hospice is and whether dialysis treatments are consistent with and facilitate achievement of life goals. ASN believes education needs to be more upstream – where the conversations around dialysis and how it can contribute to achieving palliative goals should ideally occur. Patients and their care partners should be aware that they have a choice in how to manage their kidney disease. For patients and families considering concurrent care, access to palliative care consultation without affiliation to hospice would be ideal. CMS should align payment policy to support this goal.

For example, a previously functional patient on dialysis who experiences a progressive physical or cognitive decline after a heart attack may wish to continue dialysis for fluid management in tandem with hospice care, allowing maximum quality time with family and friends. In a case like this, continuing dialysis while they receive hospice aligns with the patient's goals. However, conversations about goals should occur before the patient enrolls in hospice and include contingency plans regarding care once dialysis no longer helps the patient meet their life goals. Among patients receiving maintenance dialysis who are considering or might be well served by hospice, it would be ideal for them to have a consultation with a palliative care clinician who is not affiliated with the hospice provider.

As CMS moves forward, ASN stresses that the agency should prioritize the importance of clear communication plans. Through shared-decision making, a cohesive goal-concordant plan can be made among patients, family members, hospice agencies and nephrologists to ensure high quality end-of-life care.

Additionally, ASN encourages CMS to support the following:

- 1) Broader coverage of concurrent hospice and dialysis (including transportation)
- 2) Patients' ability to dialyze in a dialysis center with palliative approaches to dialysis care, allowing flexibility in the dialysis prescription to achieve the patient's goals served with palliative or customized dialysis with hospice. This may involve exceptions to classical QIP measures.
- 3) Upstream models of care including palliative care to assist with symptoms and goals of care for patients receiving or planning for maintenance dialysis. This would improve the patient experience as well as promote more timely smooth transition to hospice services.

Ultimately, ASN urges CMS to consider both concurrent hospice and dialysis as well as more palliative/customized/"decremental" dialysis approaches, where the dialysis prescription is able to be modified and decreased over time according to patients' needs for symptom control. CMS should think differently about dialysis for patients in hospice – specifically, kidney replacement therapy should specifically be tailored to symptom relief and should focus on clinician judgement related to the amount of small molecule clearance needed compared to the average dialysis population, particularly given variation in dietary intake.

ASN strongly encourages CMS to pursue reforms that it has the authority to address. In the meantime, ASN will be discussing the need for statutory changes with members of Congress. ASN welcomes the opportunity to join CMS and Capitol Hill to advance this important issue.

Sincerely,

A handwritten signature in black ink that reads "Michelle Josephson". The signature is written in a cursive, flowing style.

Michelle A. Josephson, MD, FASN
President

ⁱ Challenges with Providing Hospice Care for Patients Undergoing Long-Term Dialysis
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