

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

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Older patients comprise the fastest growing population initiating dialysis. Many have coexisting conditions that affect their experience and survival. These patients spend their last days undergoing intensive therapies at a higher rate than with other life-limiting conditions. The majority of dialysis patients are hospitalized in their last month of life, where most will die (1). In our opinion, no population is more in need of quality end-of-life care than patients on dialysis.

Yet dialysis patients rarely receive hospice, a patient-centered approach to care that improves the quality of care near the end of life. The Medicare Hospice Benefit covers hospice services including expert symptom management and emotional and spiritual support through an interdisciplinary team for patients with a life expectancy of 6 months or less who are willing to forgo curative treatments (2). Only one-quarter of dialysis patients receive hospice services compared with 50% of the general Medicare population. The median length of hospice is 5 days for dialysis patients, much less than the 17.4 days for the general Medicare population (2,3). Even worse, almost one-half receive these services for 3 or fewer days and are as likely to be hospitalized in the last month of life as those without hospice (3).

The rigidity of the Medicare Hospice Benefit creates a clear barrier to providing people on dialysis with the full potential of hospice services, which ideally requires weeks of care. The requirement that beneficiaries revoke all life-prolonging care associated with the hospice diagnosis in order to receive hospice services forces patients with limited prognosis to decide between continuing life-prolonging treatments that may add time versus stopping these treatments to receive symptom-based care. 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.

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) has 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 (4). 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.

One solution to improve hospice utilization among dialysis patients is a patient-centered approach in which they could elect to receive both services. We have seen that this model of care leads to more timely hospice services that better align with patient and family preferences, and allows for a gradual and timely shift, rather than a forced transition into “comfort care” (5).

Through a partnership with a large nonprofit hospice organization in Western Pennsylvania, we have created a concurrent hospice and dialysis program for people on dialysis whose goals support comfort care yet would never have agreed to the traditional practice of stopping dialysis to begin hospice.

Concurrent care or open access is a blended model of care that promotes timelier hospice services to maximize patient symptom care, support, and end-of-life needs. The Medicare Hospice Benefit payment structure allows flexibility in terms of what is included in comfort care. Hence, a hospice can then view dialysis as a comfort-focused treatment and choose to cover a limited duration of dialysis alongside hospice services.

We have seen that the concurrent care model improves end-of-life outcomes. We anticipate that this approach to care will also reduce the cost of care at end of life. For other patients with high clinical needs, data suggest that early access to palliative and hospice services improves patient and family outcomes and decreases overall health care costs (6). These positive findings have led to increased efforts to test innovation in concurrent care in other disease conditions. In a Veterans Affairs study of patients with stage IV non-small cell lung cancer, concurrent care that includes cancer treatment and hospice services was associated with reduced aggressive care at end of life and demonstrated cost savings (7).

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However, most hospices cannot financially sustain concurrent care practices. Hospices receive a flat per diem rate (between \$150 and \$200/day) from Medicare to cover all services related to the terminal diagnosis (2). This rate includes services from the interdisciplinary team members, medications, medical equipment, and supplies. Most hospices cannot afford the base rate of dialysis (average approximately \$250/session) within their daily per diem rate (8). With these financial constraints, only hospices with a high average daily census (>500 patients) can afford to absorb the cost of providing concurrent care (9), and sadly, only 1.1% of the country's 4515 hospices in operation have daily censuses this high (2).

Our program allows up to ten palliative dialysis treatments paid for at a contracted rate by hospice. Dialysis treatments are often shortened, decreased to twice or once a week dictated by the patient's wishes, and kidney-specific medications that do not benefit symptoms or quality of life are discontinued. Our program offers concurrent services to patients with an estimated prognosis of short months to weeks, notably less than the standard hospice requirement. This time frame allows an earlier option for hospice services before patients become hospitalized and critically ill, and is also financially feasible for the hospice organization covering the dialysis treatments.

Our experience has taught us key lessons that may serve as a guide for others interested in developing a concurrent care program. Many patients received one to a few dialysis treatments, with a significant number receiving none, well short of the ten treatments allowed in the program. This indicates that the concurrent program likely provides a psychologic bridge for patients to enter hospice without the pressure to stop dialysis. This sentiment was reinforced by informal feedback from caregivers who participated in the program. One caregiver described the program as "allowing his body to make the decision" rather than forcing the patient to decide whether to stop. Despite receiving few to no dialysis treatments, patients gained additional time on hospice compared with national trends, allowing more complete employment of hospice services.

We have also learned the importance of care coordination and education needed to sustain a concurrent care program. To improve care coordination between hospice and dialysis teams, we established hospice and dialysis champions who serve as a point of contact for inquiries related to the program and care activities. We also created communication tools and feedback mechanisms to communicate modifications in the dialysis care plan or patient status. Finally, we implemented widespread education to equip the dialysis team with skills to address end-of-life needs for dialysis patients and their families.

Soon, innovation in kidney policy will create the possibility to provide concurrent care to dialysis patients. CMS has announced a benefit enhancement for concurrent dialysis for Medicare beneficiaries who elect the Medicare Hospice Benefit within the Kidney Care Choices (KCC) model (10). This benefit would waive the usual requirement of the Medicare Hospice Benefit that beneficiaries give up their right to life-prolonging care as a condition of electing the hospice benefit. CMS has supported similar innovations such as the Medicare Care Choices Model, an ongoing demonstration with 141 participating hospices testing the

effect of concurrent hospice and life-prolonging care on patient care, quality of life, and cost-effectiveness.

The proposed KCC benefit is not ideal. While the benefit promotes the practice of concurrent care, it does not include Medicare payment for both hospice and dialysis services. Instead, the Kidney Contracting Entity (KCE) will be required to pay for dialysis care with the hope that this payment will be offset from savings received if the overall cost of care is decreased. We are concerned that KCEs will be reluctant to engage in concurrent hospice and dialysis if they must pay the up-front cost for dialysis care with the hope that they will receive a portion of the savings to cover this investment.

As we look forward to participation in the KCC and Kidney Care First (KCF), we plan to implement our concurrent program in additional locations and partner with others interested in developing similar models. We plan to incorporate the perspectives of patients, families, and clinicians toward a model that may be evaluated with the goal of implementation on a broader scale. We hope with more promising data, the Center for Medicare and Medicaid Innovation will respond by expanding the current waiver allowing Medicare payment for both dialysis and hospice services. This revision would increase the likelihood that other KCEs will build a process to deliver concurrent dialysis and hospice care and, hence, improve the way we care for dialysis patients at end of life.

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