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INVITED COMMENTARY

Can We Begin With the End in Mind? End-of-Life Care Preferences Before Long-term Dialysis

Aligning patients' preferences with the care patients receive at the end of life is a national priority.[1] Although some preferences are common among patients and their families, the factors that contribute to high-quality care at the end of life vary considerably across individuals. Values and preferences may be elicited through flexible approaches to shared treatment decision making. Despite greater patient and family satisfaction with high levels of shared decision making,[2] end-of-life decisions are often incomplete, especially in acute care settings.[3] When end-of-life discussions do occur, patients are more likely to prefer less aggressive care, perhaps because they develop more realistic views about the benefits, or lack thereof, from aggressive therapies near death.[2]

Addressing end-of-life concerns has always been an important part of treating patients with end-stage renal disease (ESRD), particularly among older patients. Although long-term dialysis does not restore normal life expectancy for patients with ESRD, it has added countless years of incremental survival for millions. With improvements in medical technology and therapies that are keeping more people with other chronic conditions alive, indications for long-term dialysis have expanded dramatically to include a growing number of patients who develop kidney disease as a complication of an underlying disease. As a result, a worldwide increase in ESRD has been fueled by the aging of the population and by the rising prevalence of diabetes and hypertension. In many countries, older patients now make up the fastest growing segment of the dialysis population. In the United States, the rate of patients 75 years or older starting on dialysis has almost tripled over the past 2 decades from 550 to 1550 per million.[4] Despite the hope for longer survival that dialysis may offer, the 5-year survival rate among US patients 75 years or older is approximately 15%.[4] Therefore, older patients who develop ESRD must try to optimize their quality of life while living with a grave, life-limiting chronic disease, often against a background of comorbid conditions and functional status limitations. Consequently, although dialysis offers the potential for increased survival, it may do so with tremendous limitations in quality of life and survival, especially among older patients.

Decisions to withdraw dialysis have become more common in clinical practice as a greater number of older patients discover the trade-off between survival and quality of life that dialysis can entail. Clinical practice guidelines designed to assist in the care of older patients with ESRD have outlined approaches to shared decision making for the withdrawal of dialysis, time-limited trials of dialysis care, and approaches to initiation of palliative care.[5] However, there is wide regional variation in rates of dialysis discontinuation among older patients receiving dialysis that is independent of patient characteristics, suggesting that practice pattern variation is related to variation in physician practice styles.[6] These patterns mirror those related to various other assessments of treatment intensity at the end of life.

In this issue of the *Archives*, Wong et al[7] expand on previous observations among older adults undergoing dialysis by examining health care resource use at the end of life, including hospitalization, intensive care unit admission, and use of intensive procedures. Using Medicare claims data to examine health care resource use in the last month of life for almost 100 000 patients 65 years or older who died within 3 to 5 years of starting long-term dialysis, they found that 3 out of 4 patients were hospitalized, almost 50% were admitted to an intensive care unit, and 3 out of 10 patients received an intensive intervention (mechanical ventilation, cardiopulmonary resuscitation, or a feeding tube). This level of intensity of care is striking and highlights the potential limitations of this therapy on patients' quality of life near death. Although intensity was found to be related to some differences in patient characteristics, important differences were more strongly related to regional patterns in Medicare expenditures during the last 6 months of life, suggesting that these regional factors dominate individual patient preferences.[8]

When patient preferences are specified, these wishes are usually respected, resulting in fewer health care interventions at the end of life.[2] Advanced care planning and shared decision making regarding end-of-life care not only would lead to better patient quality of life but also may have the additional benefit of better quality of life among surviving caregivers.[2] Therefore, an important initial step in addressing these concerns includes the implementation of policies that support appropriate advanced care planning and shared decision making regarding end-of-life care long before such decisions are necessary.

The Medicare Improvements for Patients and Providers Act of 2008 added kidney disease education services as a covered benefit under Medicare Part B for beneficiaries diagnosed as having advanced chronic kidney disease.[9] Under this benefit, Medicare covers up to 6 sessions of predialysis education and counseling to help patients delay dialysis and to prevent kidney disease com-

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plications. However, the benefit does not currently require completion of advanced care planning during these sessions. One potential solution to facilitate improved quality of life near death for patients who are receiving long-term dialysis would be to add advanced care planning as a requirement to the kidney disease education benefit. Alternatively, end-of-life discussions and advanced care planning could be reimbursed separately, similar to predialysis educational counseling, or it could be required as part of monthly dialysis management fees. Facilitating discussions about treatment goals and preferences early and throughout the course of long-term dialysis may substantially improve quality of life for patients and their loved ones. Also, by facilitating these discussions at the beginning of dialysis, we can help to ensure that patients do not receive unwanted, expensive, and invasive care at the end of life.

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RESEARCH LETTERS

Comparing Physician-Reported Cancer Management Plans With Medicare Services Received

The National Oncologic PET Registry (NOPR) was developed to provide evidence on the effectiveness of position emission tomography (PET) in the detection, diagnosis, and clinical management of certain cancers, and has been used to inform Medicare coverage policy for PET.[1-3] The NOPR collects data regarding the intended management strategy reported by physicians before and after PET, with a change in intended management suggesting "added clinical value" from the PET scan.[4] The NOPR does not collect data on the management plan actually implemented. To determine whether physician-reported management plans in NOPR reflect actual services received, we compared the physician-reported NOPR management plan with services provided according to Medicare claims data. As the first study, to our knowledge, using linked NOPR and Medicare data, this comparison provides information on whether physician-reported data in NOPR reflect the care that is ultimately provided to patients.

Methods. We conducted a retrospective cohort study using linked cancer registry, NOPR, and Medicare data for Medicare patients in North Carolina and California who received NOPR-documented PET scans from May 2006 through December 2008. Patients with a new primary diagnosis of pancreatic adenocarcinoma or renal cell carcinoma from 2003 through 2007 were identified. Of the 683 eligible PET scans for these cancer cases, we excluded 194 (28.4%) because of nonconsent, noncontinuous Medicare fee-for-service coverage, or death within 30 days of PET scan.

From the post-PET NOPR survey we identified the referring physician's planned management following the PET scan. Using Medicare claims data, we identified management services received in the 30 days following the PET scan based on all diagnosis and procedure codes found in claims. For the NOPR vs Medicare comparison, we categorized management strategies as observation, additional imaging, biopsy, or treatment (eg, surgery, chemotherapy, and/or radiation). In the Medicare data, observation was defined as having no subsequent claims for cancer-related imaging, biopsy, or treatment in the follow-up period.

We assessed the agreement between post-PET NOPR physician-reported intended management and post-PET Medicare services using Cohen κ and calculated the proportion of NOPR post-PET intended management strategies provided based on Medicare data. Since the NOPR allows the referring physician to select 1 intended management strategy (observation, additional imaging, biopsy, or treatment) yet multiple treatments, we also created a variable indicating any treatment.

Results. We identified 489 PET scans for 325 patients. Agreement of post-PET management strategies in NOPR and Medicare services received ranged from poor ($\kappa = 0.06$) for additional imaging to fair ($\kappa = 0.49$) for surgery (**Table**). In 21.3% of scans, NOPR physicians indicated planned subsequent treatments that were not found in Medicare claims. Conversely, 11.3% of scans had Medicare claims for treatments after the PET that were not indicated in NOPR as the intended management strategy.

The proportion of NOPR-reported management plans that could be matched to a corresponding Medi-

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