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In the Literature

Families' Perception of End-of-Life Care for Patients With Serious Illness

Commentary on Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL. Quality of end-of-life care provided to patients with different serious illnesses. JAMA Intern Med. 2016;176(8):1095-1102.

> If 'progress' refers to the long-held Enlightenment idea and ideal that rationality and its tools can unequivocally improve life and reduce suffering, then 'postprogress' characterizes today's medicine….Postprogress suggests that technical ability and more and more interventions, while they extend wanted life for many, also bring with them existential quandaries about one's own relationship to medicine, to suffering, to more life, and of the apparent control that can be exercised over the timing of death.
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> -Sharon R. Kaufman, *Ordinary Medicine*[1]

During the last half century, many of the advances in medical technology, clinical medicine, and health care delivery that have helped maintain health and extend life may also have moved us further away from the "good death" that many of us hope for. This may be especially true for patients with advanced kidney disease. The now widespread availability of maintenance dialysis therapy means that many of these patients face a unique and challenging set of treatment decisions, including whether and when to initiate and eventually discontinue dialysis treatments.

WHAT DOES THIS IMPORTANT STUDY SHOW?

In a recent issue of *JAMA Internal Medicine*, Wachterman et al[2] provide novel information on patterns and quality of end-of-life care for patients with different health conditions. The authors conducted a retrospective study in a national cohort of patients (N = 57,728) who died in a Department of Veterans Affairs (VA) facility between October 1, 2009, and September 1, 2012. This work leveraged data from an ongoing VA-wide initiative to improve the quality of end-of-life care. As part of this effort, bereaved family members of patients who die in a VA acute- or long-term care facility are contacted by VA staff approximately 1 month after death and invited to complete a survey intended to measure the quality of end-of-life care. The survey used for this purpose, the Bereaved Family Survey, is an adaptation of an earlier instrument that was developed based on interviews with bereaved family members and expert opinion about the needs and expectations of veterans and their family members for end-of-life care.[3-5] Using select elements of the Bereaved Family Survey, which was completed for 34,005 (58.9%) cohort members, Wachterman et al compared family members' ratings of communication with health care providers, pain management, and overall quality of care provided near the end of life among patients with differing primary diagnoses (cancer, dementia, end-stage renal disease [ESRD] on dialysis therapy, cardiopulmonary failure, frailty, and other) associated with their terminal inpatient stay. The authors linked survey results with several putative process measures for quality of end-of-life care: palliative care consultation within the last 90 days of life, a do-not-resuscitate (DNR) order at the time of death, and site of death, including whether the patient died in an intensive care unit (ICU) or inpatient hospice.

After adjusting for patient demographic and clinical factors, the authors found that the services provided to patients near the end of life varied substantially according to their primary diagnosis (Fig 1). Compared with patients with cancer and dementia, those with end-organ failure (ie, ESRD and cardiopulmonary failure), frailty, or other serious illness were more likely to have died in an ICU (8.9%-13.4% vs 32.3%-35.2%) and were less likely to have received a palliative care consultation (61.4%-73.5% vs 41.5%-50.4%), to have a DNR order (93.5%-95.3% vs 83.9%-87.0%), and to have died in an inpatient hospice unit (32.3%-42.9% vs 20.3%-24.3%).

The Bereaved Family Survey results showed that for all diagnostic groups, the majority of bereaved family members reported that health care providers "always listened to concerns" (68.6%-73.8%), "always provided the medical treatment that patient and family wanted" (73.4%-80.4%), "always kept family informed about patient's condition and treatment" (63.8%-71.1%), and "always gave enough emotional support prior to the patient's death" (61.5%-67.5%). The percentage of patients with "frequent uncontrolled pain" ranged from 49.4% to 55.9% across groups. In all groups, more than half the family members rated the overall quality of end-of-life care as "excellent" (53.7%-59.2%). For most items, family member responses were more favorable for patients with cancer or dementia as compared with other conditions. Differences across conditions in family

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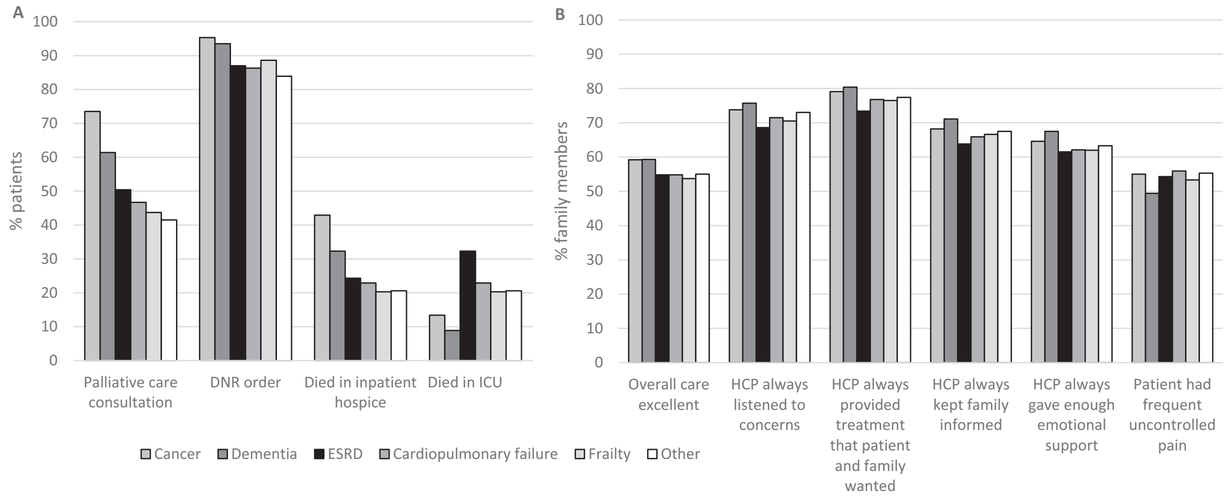

Figure 1. End-of-life care for patients with serious illness. (A) Patterns of care at the end of life. (B) Family members' assessment of end-of-life care. Abbreviations: DNR, do-not-resuscitate; ESRD, end-stage renal disease; HCP, health care provider; ICU, intensive care unit. Data from Wachterman et al.[2]

member ratings of overall quality of end-of-life care were no longer statistically significant after adjustment for receipt of a palliative care consultation, presence of a DNR order, and site of death, suggesting that these factors may play a mediating role.

HOW DOES THIS STUDY COMPARE WITH PRIOR STUDIES?

Several earlier studies in our own field have reported lower rates of hospice referral and higher rates of in-hospital death and use of intensive procedures (ie, cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition) among patients with ESRD as compared with the general population and those with cancer and heart failure.[6-9] Unlike these earlier studies, which differed from the current study in that they relied on literature comparisons with other conditions and used registry data to identify patients with ESRD, the current study suggests that health care use near the end of life may not differ substantially between patients with ESRD and those with cardiopulmonary failure.

The information provided by Wachterman et al about quality of end-of-life care for patients with a range of advanced illnesses is an extremely novel contribution. In our own field, very few studies have attempted to measure quality of end-of-life care among patients with advanced chronic kidney disease and most have been restricted to patients who discontinued dialysis therapy.[10-12] Thus, a lingering question raised by the aforementioned studies describing intensive patterns of end-of-life care among patients with ESRD is whether such practices reflect the goals, values, and preferences of patients and their families.

Although differences in patterns of end-of-life care (particularly site of death) may mediate the modest differences in responses to the Bereaved Family Survey among family members of patients with dementia or cancer versus other conditions, differences in patterns of end-of-life care in these compared with other conditions were far more marked than differences in responses to the Bereaved Family Survey.

There are several possible explanations for this apparent disconnect. First, it is possible that the Bereaved Family Survey may not capture all aspects of the end-of-life experience that are important to patients and family members. Supportive of this possibility, overall ratings of quality of end-of-life care were generally less favorable than responses to individual items on the Bereaved Family Survey. A related consideration is that survey responses of family members may not reflect patients' perceptions of their care.[13] Second, patterns of care prior to death may reflect patients' illness trajectories and whether death was perceived as imminent,[14] which might be expected to differ for patients with cancer and dementia versus organ failure, particularly organ failure[15,16] that has been treated with replacement therapy. A third and related possibility is that measures of health care use and treatment practices may be a poor marker for quality of care.[17-19] In other words, what is done—such as whether one receives a palliative care consultation, signs a DNR order, or dies in a hospice or ICU—may be less important in shaping patient and family experiences at the end of life than how things are done, something that may be impossible to capture using administrative data.

WHAT SHOULD CLINICIANS AND RESEARCHERS DO?

Consistent with prior studies,[20,21] these findings indicate that although many family members were