High-quality, patient-centered care at the end of life is achieved when medical treatment aligns with patient preferences and goals of care. Despite most patients expressing wishes to die at home and with less aggressive care, many patients spend their final days in the hospital, and nearly 60% die in acute-care settings. Goal concordance is often used as a quality measure to evaluate the delivery of end-of-life care for patients with serious illness. Family members and surrogate decision-makers can provide important insight on whether health care was concordant with patient wishes in the last stages of life. However, the extent to which older patients with serious illness are being provided with goal-concordant care has seldom been explored.

We congratulate Glass et al on their study measuring how well end-of-life wishes of decedents aged 65 years or older were met in the last year of life. This cross-sectional survey found that among 715 next of kin of patients who died in the Kaiser Permanente Southern California integrated health system, 601 (88.9%) believed that patient wishes were met. Overall, 554 patients (84.1%) completed an advance directive; and 133 of 156 next of kin (85.3%) were satisfied with the way the patient died. These findings provide promising evidence that the quality and provision of end-of-life care can be more goal concordant and patient centered than many previous studies suggest.

Glass and colleagues also used a unique subcomparison of high-cost and low-cost users to examine family perceptions of goal concordance and satisfaction with patient care. Although family members of high-cost users were somewhat less satisfied with patient care compared with other decedents, most respondents (250 of 332 [80.1%]) still believed that end-of-life care for high-cost users was concordant with patient wishes. Interestingly, within the high-cost user group, 71 (26.8%) felt that the amount of care provided was, in fact, too little. In a health care system where intensive therapies at the end of life are perceived to be an indicator of lower quality and poor patient care, findings from this study point to the importance of redefining how we conceptualize health care utilization as a quality measure of goal-concordant care.

Prior research has shown that patients with a billed advance care planning (ACP) encounter were more likely than those without these encounters to receive hospice services and less likely to receive any intensive therapies, such as chemotherapy. However, as we increasingly recognize, end-of-life care is much more nuanced than defining more hospital and intensive care unit (ICU) care as bad and more hospice and palliative care as good. Patients with ACP encounters were also more likely to be admitted to the hospital and an ICU and, in part because of this, accrued higher health care costs compared with their counterparts. However, despite a higher likelihood of hospitalization and ICU admissions, patients with ACP encounters were indeed less likely to receive many intensive therapies.

The assumption that high costs at the end of life are an indication of aggressive and discordant care may not be an accurate representation of the care being delivered. Hospitalizations can be linked to symptom management or further clarification around goals of care. In these cases, health care utilization may be concordant with patient preferences at the end of life and represent high-quality care. There is also growing recognition of the diversity of beliefs and values at the end of life. A study examining patient preferences for end-of-life treatment found that Black and Hispanic respondents were more likely to express preferences for intensive treatment at the end of life and were more likely to prefer to die in hospital. These effects may in part explain the high concordance
rates found among high-cost users in the study by Glass et al,2 where nearly half of Hispanic decedents (65 of 138 [47.1%]) and more than half of Black decedents (54 of 88 [61.4%]) in the study population were included in the high-cost user group. Although the proportion of White and Black decedents among the study population was broadly representative of the sociodemographic composition of Kaiser Permanente plan members and the US Census population in Southern California, Hispanic decedents were fairly underrepresented (19.3% among study population vs 45.2% Kaiser Permanente plan members and 43.3% general census population).5 Targeted research studies with specific racial/ethnic groups can further the interpretation of these findings.

Efforts to engage patients and families in ACP have increased in recent years as a way to promote concordance among patient values, wishes, and medical treatment. Glass et al2 found that although most decedents (80%-90%) discussed end-of-life care preferences with next of kin or completed an advance directive, only 338 (57.1%) of those who said they would like to die at home did so. Moreover, 38% to 43% of patients who received cardiopulmonary resuscitation, mechanical respiration, and/or artificial feeding reportedly did not want it.2

Factors that may be associated with residual discordance between patient preferences for end-of-life care and the medical treatment provided are not well-understood. A limitation of the study by Glass et al2 is the unknown timing of ACP activities, which may have taken place too early or too late to be actionable. Quality of communication was also rated lower among those who reported goal-discordant care compared with those who did not.6 Strategies aimed at improving communication between surrogates and health care teams may help to achieve goal concordant care. Clear communication regarding patient preferences and how they translate into specific medical treatments—and how those treatments relate to broader goals for care—may help to avoid discordance between ACP and medical care provided.

Glass and colleagues2 focused on an older (ie, ≥65 years) population, who comprise 73% of all deaths in the United States.7 However, surrogate perceptions around goal-concordant and goal-discordant care and recall bias may not always be an accurate reflection or representation of the beliefs and experiences of decedents. Another important limitation is the inclusion of only insured individuals receiving care within a large integrated health system. While the generalizability of these findings to other health systems and contexts is unknown, these findings offer an example worth dissecting for other systems where goal concordant care is less common.

Particular nuances of this integrated health system may have influenced results in ways that are not representative of the typical end-of-life experience across the United States. Survey respondents were recruited from Kaiser Permanente—a large, well-established, stable integrated health system with common treatment pathways and a comprehensive electronic medical record. This may provide opportunities for scheduled ACP discussions with primary or specialist clinicians in a way that is shared across the system. It also provides a mechanism for quality improvement as well as best practice initiatives and incentives for quality, service, and patient satisfaction that may not exist across more diffuse models of health care.

Understanding the key differences, enablers, incentives, and forcing functions that drive the delivery of goal-concordant care within this health system may help to identify promising practices that can be used in other models across the United States. Quality of care should be evaluated in a way that reflects the complexity of patient wishes and experiences at the end of life. A better understanding of the relationship between health care utilization and delivery of goal-concordant care—and factors associated with these successes—should be at the core of our efforts.
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