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Beyond enrollment: Providing the highest quality care within hospice

Katherine A. Ornstein, PhD¹ and Diane E. Meier, MD^{1,2}

¹Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York

²Center to Advance Palliative Care, New York, New York

The Institute of Medicine report *Dying in America*¹ highlights the fact that multiple transitions between health care settings at the end of life, including high rates of hospitalizations, can fragment care delivery and burden patients and families. Hospice care, which has had rapid growth in recent years,² aims to provide care that ameliorates symptoms and attends to the psychosocial needs of patients and their families while reducing unneeded and unwanted medical interventions including hospitalization. Evidence to date suggests that hospice has positive effects on patient quality of life, and caregiver outcomes.^{3,4} By effectively reducing ED visits and subsequent hospitalizations, hospice may result in other

Contact: Diane E. Meier, MD, Center to Advance Palliative Care, Icahn School of Medicine at Mount Sinai, 55 W. 125th Street, Suite 1302, New York New York 10027, T: 212 201 2675, F: 212 426 1369, diane.meier@mssm.edu.

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downstream benefits for patients (avoiding fragmentation, hazards of hospitalization, and untreated symptom distress) and families (via caregiver assessment and support as well as long-term bereavement support), even beyond a patient's death.⁵

Two studies in this issue of JAGS examine hospitalization, ED usage, and other healthcare transitions for patients with serious illness at the end of life who are enrolled in hospice. Obermeyer et al⁶ finds that the vast majority of individuals with poor prognosis cancer visited the emergency department in the last 6 months of life. Using coarsened exact matching to create pairs of Medicare beneficiaries who did or did not enroll in hospice, Obermeyer et al. determines that those decedents who did not use hospice were significantly more likely to visit the ED in the last week of life. Furthermore, there were fewer hospital admissions following ED visits for the hospice group. This study suggests that, overall, hospice is successfully reducing ED visits and hospitalizations, at least for patients with cancer. Similarly, in a previous study of patients with poor prognosis cancer, Obermeyer et al⁷ found that patients who received hospice care also had lower total expenditures over the last year of life than patients who did not use hospice.

In contrast, Wang et al⁸ report that among all hospice decedents in the United States in 2011, 10% had at least one and more than 6% had two or more transitions after enrollment, the majority to hospitals. The sheer number of transitions after enrollment in hospice documented by Wang et al. is concerning. Wang's figure delineating multiple transitions makes it clear that a subset of patients experience a complex and highly fragmented journey following their enrollment in hospice. Transitions of care, including hospitalizations, at end of life create discontinuity, risk from the hazards of hospitalization, and, importantly, may limit access to potentially important palliative care services such as expert symptom control, communication about what to expect and how to handle it, and continuity of reliable care relationships at a very vulnerable time. While challenging for all families of patients with serious illness, care transitions may be especially complicated for caregivers of dying patients who need to be prepared and know what to expect as death approaches, and require support from professionals with expertise in the unique challenges of care during the last few weeks of life and the active dying phase.

But do these transitions after hospice enrollment necessarily reflect the failure of the hospice system to meet the needs of patients and their families? Unfortunately, these data, while impressively culled from administrative claims, county and hospital referral region level data, do not tell us why these transitions are occurring. Critically, they are unable to provide any information about patient or family preferences for care, nor the immediate precipitants of their decision to go to the hospital. Possible reasons include (but are not limited to) poorly controlled symptoms, caregiver exhaustion, or anxiety about the imminence of death. Although hospice is required to provide 24/7 availability, responsiveness to phone calls, staffing, and availability to come to the house vary widely from hospice to hospice. Hospices also differ in their ability to prepare family caregivers on how to respond should (predictable) but severe symptom distress develop. During a pain or dyspnea crisis, waiting more than a few minutes for a call back is too long. Thus hospital use among hospice patients may reflect a need for more immediate or intense palliation and/or the provision of other necessary and appropriate medical care, an inference supported by the fact that cancer

patients on hospice – a group with a high burden of distressing physical symptoms - were most likely to transition to hospice, compared to other diagnostic categories. The variation based on primary diagnosis, i.e., patients with cancer have more transitions to hospital, also may suggest that the intense relationships with hospital based oncology specialists may cause patients and families to feel safest among these familiar providers. Hospitalization could also reflect a change of mind towards preferences of families and patients for life-prolonging care.

The significant hospice-level variation in likelihood of hospitalization, however, suggests that high rates of transitions to hospitals reflect system level failures. For example, the finding that hospices with a lower average daily census and those that have been in operation less than 10 years are most likely to have patients hospitalized suggests that some hospices simply have not developed the resource capacity required to adequately meet patient's needs. Researchers have successfully used administrative data to demonstrate that hospice length of stay, disenrollment, and care patterns vary on individual, hospice, and geographic levels.⁹⁻¹² Now that heterogeneity in hospice care has been established, we have to focus on understanding exactly why such variations exist and what can be done from a policy and regulatory standpoint to reduce fragmented care and unnecessary transitions. Hospice quality measures need to be expanded to incorporate claims based data on care pattern variations so that hospices can be held accountable for fragmented care and unnecessary transitions. Although it is likely that the level of after-hours attentiveness required by some dying patients and their families is not routinely available, hospice quality measures, including frequency of skilled visits, wait time for retuning phone calls, and number and type of care transitions, will help us move to a better understanding of the variation in hospice quality and its predictors. Furthermore, data from the new Medicare Care Choices Model demonstration project,¹³ will allow us to determine whether access to both disease treatment and hospice simultaneously will modify reliance on 911, the ED, and the hospital for after-hours crises.

We must consider how we can continue to reduce fragmented care and unnecessary transitions for patients with serious illness both within and outside of the hospice setting. It is possible that as Medicare begins payment for advance care planning discussions and they become more standardized throughout medical practice, patients and families will be more likely to get the care they want. We also must continue to increase access to palliative care earlier in the disease course. Interestingly, Wang et al finds that states with highest access to palliative care in hospitals have 40% fewer transitions to hospital within the hospice setting suggesting that the more opportunity for palliative care throughout the care spectrum, the greater likelihood that hospice can truly achieve its goal. The nationwide increase in assumption of financial risk for patients resulting from a number of policy levers (e.g., growth in ACOs, Medicare Advantage, Medicaid managed care, and penalties for 30 day readmissions, hospital mortality, and poor satisfaction) will also support greater access to palliative care service delivery that meets high risk patient's needs at home and in community settings, rather than forcing them to rely on 911 calls after hours.

Evidence to date suggests that hospice improves patient and family-reported of quality of care, and in so doing is associated with reduction in ED visits, hospitalizations, consequent

stresses, and their related costs. But we need to do more than just expand the hospice benefit- we have to ensure that hospice is providing vulnerable dying patients and their families with the high quality care they want and deserve. This means reducing unnecessary and undesired care transitions within the hospice setting. The use of hospice quality measures that focus on identifying and addressing the root causes of transitions is key to ensuring that this most vulnerable of all groups of patients and families receive the highest possible quality of care.

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