

## VIEWPOINT

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## A Policy Prescription for Hospice Care

Since the founding of the inaugural hospice in the United States in 1974, there has been substantial growth of the hospice movement, with an estimated 1.6 million patients receiving hospice care in 2014.<sup>1</sup> Hospice aims to meet the needs of patients with life-limiting illnesses through expert symptom management, provision of home-based care, and facilitation of caregiver support. An important contributor to the expansion of hospice was the Medicare Hospice Benefit, created by Congress in 1982, which enabled older US adults to receive hospice care. Paradoxically, some of the requirements of the benefit also created barriers to enrollment. To limit Medicare costs during the enactment of the hospice benefit, eligibility was restricted to individuals with an estimated life expectancy of 6 months or less, and individuals had to be willing to forgo all treatment directed at their underlying disease. As science and clinical care have advanced over time, what is appropriate for end-of-life care in 2016 is very different from 1982. These enrollment requirements result in underuse of hospice and instead contribute to excess use of hospital care and intensive care at the end of life.

These barriers to hospice enrollment are particularly relevant for patients with hematologic malignancies such as acute myeloid leukemia, the myelodysplastic syndromes, lymphoma, and multiple myeloma. Approximately 57 000 individuals in the United States die as a result of hematologic cancers each year, and an estimated 70% are in the Medicare population ( $\geq 65$  years old).<sup>2</sup> This patient population has been shown to have the lowest rates of hospice use in oncology, and when patients with hematologic malignancies enroll in hospice, they are likely to do so within 3 days of death.<sup>3</sup> Admission to hospice within 3 days of death is considered to be an indicator of suboptimal end-of-life care because such a short time frame limits the opportunity for patients and their families to fully benefit from the symptom management and psychosocial support that hospice provides.

In addition, patients with hematologic malignancies have high rates of intensive care near the end of life. For example, in one study, 84.5% of 290 adults 60 years or older with acute myeloid leukemia were hospitalized within 30 days of death, and 61% died in the hospital.<sup>4</sup> Although attitudinal factors involving patients and physicians, such as equating hospice use to "giving up," likely contribute to underuse in this population, these factors are inextricably linked to wide-reaching system-level factors related to the Medicare Hospice Benefit.

As a specific example, the fact that the reimbursement structure of the hospice benefit is insufficient for hospices to provide blood transfusions discourages patients with advanced hematologic cancers from receiving hospice care. The requirement for patients to forgo disease-directed therapy creates an artificial dichotomy between hospice care and disease-directed

care that is palliative and does not account for many treatments or procedures whose purpose is simply to help patients feel better (eg, blood transfusions, radiation, or drainage of excessive fluid from the abdomen). For example, consider a 66-year-old patient with a myelodysplastic syndrome who has been receiving routine transfusions of red blood cells and platelets to alleviate the cytopenias characteristic of this disease. The patient experiences improvement in fatigue from the receipt of red cells and reduction of bleeding episodes from the receipt of platelets, but his disease subsequently progresses rapidly and his prognosis is less than 6 months' survival. How is this patient going to be able to choose hospice when the transfusions that have palliated his symptoms and possibly improved his quality of life will no longer be accessible?

Interventions are needed to increase access to hospice services. Previous efforts have focused largely on addressing patient and physician factors thought to be barriers, such as educating patients and physicians about the usefulness of hospice. Although these efforts are necessary for improvement, they are not sufficient. The vast majority of US residents prefer to die at home, and hospice offers the opportunity to actualize this preference. Physician surveys also show that most perceive hospice care to be beneficial. In a national survey of 349 hematologic oncologists conducted by researchers at the Dana-Farber Cancer Institute earlier this year,<sup>5</sup> the majority of respondents (93%) agreed that hospice care is helpful. Unfortunately, such strong agreement with the general philosophy of hospice does not readily translate into practice, as demonstrated by the low rates of hospice use among patients with hematologic cancers. To bolster current efforts for improvement, policy prescriptions are clearly needed.

Policies that address eligibility barriers have the potential to substantially increase access to hospice services. Some hospice organizations and commercial insurance companies have begun to find innovative ways to address these barriers, and their approaches are instructive. In 2005, Aetna launched a pilot comprehensive case management program and expanded hospice benefits for patients with advanced illness. Specifically, the company extended the definition of terminal illness from 6 months to 12 months and allowed patients to continue to receive some types of antineoplastic treatment while also receiving hospice services. Compared with the 387 patients in the control group, the rates of hospice use among the 387 patients in the expanded hospice benefits group increased from 27.9% to 69.8%, and the average length of stay also increased from 21.4 days to 36.7 days. Although patients had access to disease-directed treatment while receiving hospice care, acute and critical care use decreased.<sup>6</sup> Specifically, the proportion of patients with emergency

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department visits decreased from 15.2% in the control group to 9.8% in the expanded hospice benefits group. Similarly, acute hospital admissions decreased from 40.3% to 16.8%, and intensive care unit admissions decreased from 23.0% to 9.6%. These data suggest that the additional services provided effective symptom management in the home setting, reducing the need for acute care in emergency departments and hospitals.

Some hospices also offer an “open-access model” that allows patients to receive hospice care while still receiving additional treatments that palliate symptoms (eg, palliative radiation, blood transfusions), even if such treatments are considered disease-directed. Indeed, in the aforementioned survey of hematologic oncologists, 60% reported that they would refer more patients to hospice if transfusions were allowed. However, the fact that Medicare reimburses hospices on a per diem rate, regardless of the types of services provided, makes it difficult for most hospices to provide such open-access care even if they desire to.

To have a wide-reaching and sustainable influence on the number of patients with blood cancers who access hospice, there needs to be progression from silos of innovative strategies to system-wide policies that benefit patients regardless of whether they live in areas with open-access hospices. Specifically, a policy that redefines the eligibility criteria for the Medicare Hospice Benefit to allow concurrent palliative disease-directed care would enable more patients to seek hospice. In addition, access to resources such as transfusions triggered by symptoms (fatigue, bleeding) would be aligned with the mission of hospice care to enhance the quality of life for patients at the end of life. With restructuring of the eligibility criteria to allow concurrent care, increases in hospice reimburse-

ment rates would also be necessary to ensure that hospices can provide the additional palliative services (eg, transfusions) that some patients need.

Expanding hospice access to patients receiving palliative disease-directed care may be cost neutral or even cost saving through increases in home-based care and reduced use of other intensive medical services. Acute hospitalization is the largest component of Medicare spending for patients with advanced cancer (48%),<sup>7</sup> and these expenditures are likely more pronounced for patients with hematologic malignancies, among whom both acute and terminal hospitalizations are high.<sup>4</sup> It thus stands to reason that expanding hospice services to patients receiving disease-directed care could be financially feasible, given the potential to decrease hospital-related costs.

In the spring of 2014, the Centers for Medicare & Medicaid Services announced a demonstration project to provide a new option for Medicare beneficiaries with life-limiting illnesses to receive hospice care along with concurrent disease-directed care.<sup>8</sup> This project recognizes that for patients entering hospice, there is an implicit promise that their symptoms will be effectively managed, which sometimes requires access to disease-directed therapy. This initiative has been met with great enthusiasm and the model was expanded from 30 to 141 hospices, with services slated to begin January 2016. This is a step in the right direction and will provide important data to help with redefining the Medicare Hospice Benefit, such that desire to receive disease-directed therapy is not mutually exclusive with enrolling in hospice. Increasing hospice use will require such forward-thinking policies that make it easier for physicians to recommend hospice and for patients to choose it.

#### ARTICLE INFORMATION

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