



# Hospice Use Among Patients With Cancer: Trends, Barriers, and Future Directions

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Patients with advanced cancer and their families frequently encounter clinical and logistical challenges related to end-of-life care. Hospice provides interdisciplinary and holistic care to meet patients' biomedical, psychosocial, and spiritual needs in the last phases of life. Despite increasing general acceptance and use among patients with cancer, hospice remains underused. Underuse stems from ongoing misconceptions regarding hospice and its purpose, coupled with the rapid development of novel anticancer treatments, such as immunotherapies and targeted therapies, that have changed the landscape of possibilities. Furthermore, rapid evolutions in how end-of-life care is structured and reimbursed for will affect how oncology patients will intersect with hospice care. In this review, we explore the current and future challenges to greater integration of hospice care in the care of patients with advanced cancer and propose five recommendations as part of the path forward.

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## INTRODUCTION

Most patients with advanced cancer and their families face complex care needs during the end of life (EoL). Patients commonly experience many symptoms, including pain, fatigue, depression, and anxiety, and may struggle to maintain autonomy, dignity, and a sense of control.<sup>1-3</sup> Caregivers and families may also struggle to cope with disease-related changes, experience spiritual or emotional distress, and shoulder the physical and financial burdens of caregiving.<sup>4,5</sup>

A robust evidence base demonstrates that hospice use alleviates symptom burden, decreases the frequency of hospitalization and invasive procedures, and increases concordance with patient EoL preferences.<sup>6</sup> Hospice focuses on holistically helping patients focus on care that matters to them, often shifting away from unnecessary or unhelpful measures. However, hospice remains underused; an estimated 43% of eligible patients do not receive it.<sup>7</sup> Hospice is used less frequently by men, racial and ethnic minorities, and individuals of lower socioeconomic status.<sup>8,9</sup> Cancer remains the primary diagnosis among hospice recipients<sup>8</sup>; among patients with terminal cancer, only 25% die at home.<sup>10</sup> The aforementioned discrepancies persist in the cancer context, as women outstrip men, and communities with higher African-American

or Hispanic concentrations or low-income individuals see lower hospice use (potentially partly because of disparities in medical infrastructure or localization of hospice providers).<sup>9</sup> Salient to the current era of rapidly emerging novel anticancer treatments, patients with cancer and oncologists face the daunting task of navigating prognostic uncertainty.<sup>11-13</sup> Consideration of hospice use improvement strategies is paramount, especially as the hospice landscape changes.<sup>14-17</sup> Herein we describe hospice use trends among patients with cancer, barriers to hospice access, challenges for integrating hospice into cancer care, and offer five recommendations for future directions.

## HISTORICAL AND CURRENT HOSPICE USE TRENDS

Over the past two decades, hospice use across all diseases has increased sixfold,<sup>6</sup> and 48.2% of Medicare beneficiaries receive hospice.<sup>8</sup> However, high volumes of care do not necessarily equate to maximum care value. Although the mean length of stay (LoS) of hospice patients has increased from 54 days to 86 days over the past decade, the median LoS remains around 17-18 days.<sup>16</sup> Furthermore, hospice use for 3 days or less increased from 22.2% in 2002 to 28.4% in 2009,<sup>10</sup> and one half of patients enroll in hospice late (ie, weeks or days before death) and are unable to benefit from the full scope of hospice

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services.<sup>11,16</sup> Late hospice enrollment challenges hospices to formulate comprehensive care plans in limited time while shouldering large up-front admission costs.<sup>18</sup>

Among patients with cancer, enrollments are also often late, with 15.5% of patients with cancer transitioning within the last 3 days of life<sup>10</sup> and 30% within the last 7 days.<sup>19</sup> Moreover, the median LoS among patients with cancer is only 14.5 days, shorter than that of their counterparts without cancer.<sup>20</sup> Importantly, although patients with cancer who enroll in hospice for longer than 1 week experience a duration-dependent increase in quality of life (QoL), late enrollees are unable to receive the maximum benefit of hospice services, because those who enroll for a week or less have comparable QoL scores to patients who do not enroll in hospice.<sup>21</sup>

### BENEFITS OF HOSPICE USE

Hospice services provide great value when patient preferences shift toward prioritizing QoL over potentially life-prolonging measures. Hospice use among patients with cancer is associated with reduced pain intensity, symptom burden, and psychological distress; improved QoL; decreased usage of aggressive care; and increased likelihood of death in a location of preference (most often at home).<sup>6,21-23</sup> Conversely, patients with cancer who disenroll from hospice exhibit an increased likelihood of hospitalization, admission to the emergency room (ER) or intensive care unit (ICU), and in-hospital death.<sup>24</sup> Likewise, patients who never enrolled in hospice have more ER visits, hospitalizations, and noncancer clinic visits, in addition to decreased median survival after their last cancer treatment.<sup>25</sup> Furthermore, caregivers of patients receiving hospice care exhibit less severe depressive symptoms, fewer mental health issues, diminished grief, and a lower risk of death during bereavement periods.<sup>21,22,24</sup>

Cost savings borne by health systems, payers, and patients are an additional benefit. From 2002 to 2009, patients with cancer incurred a mean per capita cost of \$74,212 in cancer-related expenses during the last 6 months of life, primarily attributed to acute inpatient expenses, which rose precipitously from \$1,785 in the sixth month before death to \$20,559 in the last month before death. Hospice use decreases costs by 13% to 20% for patients with cancer and their families.<sup>18</sup> Conversely, hospice disenrollment increases per capita costs by \$124 per day.<sup>24</sup> Thus, earlier hospice use provides patients and their families with holistic and improved management of EoL care and mitigates potentially low-value resource use and associated stress.

### BARRIERS TO HOSPICE USE

Despite the overwhelming benefits, four barriers to use remain. First, some patients and their families are reluctant to acknowledge illness severity, reflecting the societal and cultural challenges of having difficult conversations related

to death and dying.<sup>13,23,26</sup> The language of cancer treatment reflects this, as patients willing to undergo treatments (even of questionable efficacy) are sometimes labeled fighters, with the journey often considered a war. Patients may perceive that discussing death and dying issues with their oncologists may signal weakness, failure, or a character flaw.<sup>13</sup>

Second, patients may also misperceive hospice as the relinquishment of hope, a restrictive or permanent care option (without an ability to disenroll for new clinical trials), suited for only the last days or hours of life, or disruptive to ongoing patient-provider relationships.<sup>13,26,27</sup> Insufficiency in hospice knowledge abounds. Per a recent survey, 62% of respondents were unaware that most hospice benefits preclude concurrent curative care, 57% of respondents were unaware that hospice continues to support families after the patient's death, and 33% did not realize that most insurance covers hospice.<sup>27</sup> These misperceptions may be related to the paucity of noncommercial, patient-facing resources about hospice. Currently, there are few patient decision aids that provide comprehensive, timely information to patients on eligibility, hospice services, family support, patient rights, and Medicare coverage. Internet searches for hospice resources often yield fragmented results.<sup>6</sup> Greater development and dissemination of hospice resources are needed to facilitate and supplement goals-of-care conversations throughout various stages of illness progression.

Third, inadequate or late communication of care preferences among patients, caregivers, and clinicians can delay hospice use. Patients and caregivers may look to providers to initiate goals-of-care conversations at early stages in the illness trajectory.<sup>18</sup> However, when providers do not clearly initiate conversations on illness progression, patients and their families report a gap between understanding and expectation.<sup>23</sup> Consequently, patients may exhibit unrealistic optimism toward extended life expectancy, deferring hospice use despite eligibility or necessity.<sup>22,23</sup>

Fourth, determination of patient eligibility for hospice is challenging for clinicians. The nature of cancer care is complex, with ever-moving prognosis targets related to rapid escalation of drug approvals. Achievable outcomes are changing quickly; only a few years ago, with some exceptions, the majority of all-comer patients with solid tumors did not experience a consistent and durable response.<sup>28-30</sup> Even as response rates evolve, it is unlikely that oncologists will be able to provide absolute assurances regarding medication efficacy and duration of effect. Furthermore, the inflection point of when a patient is no longer responsive to disease-modifying treatment is variable.<sup>11-13</sup> Survival time estimation is a difficult skill, with one study suggesting that clinicians are correct in only 20% to 30% of cases. Errors tend to favor overestimation.<sup>11,18,31</sup> Consequently, survival overestimation is closely associated with markers of more aggressive, disease-focused treatment

before death.<sup>31</sup> Clinicians' investment in patients may also facilitate overly optimistic outlooks that limit prognostication.<sup>13</sup> In addition, clinicians and hospice agencies may worry about the consequences of long hospice LoS because of early referral, with concerns about audits and other corrective action from perceptions of not meeting local coverage determination requirements.<sup>11,13</sup> As the anticancer medication armamentarium expands, prognosticating using the best available evidence and balancing potential adverse effects, patient preferences, and opportunity costs (eg, home-based comprehensive care from hospice) are important, yet ever-complex skills.

### PAYMENT CHALLENGES RELATED TO ROUTINE INTEGRATION OF HOSPICE INTO CANCER CARE

Medicare reimbursement for hospice is improving; however, the fundamental challenge of integrating hospice into everyday cancer care remains. Before 2016, the Medicare Hospice Benefit was a flat per diem rate of approximately \$151, as reported in 2012, and Medicare imposed an aggregate spending cap of \$24,500 per hospice agency.<sup>16</sup> Thereafter, Medicare adopted a cost-saving tiered reimbursement strategy because patient care needs are greatest at the initiation and conclusion of standard hospice enrollment periods.<sup>14</sup> Despite this switch and increased hospice financing, current reimbursement rates are insufficient to offset the costs associated with concurrent use of hospice services and intensive supportive care, such as regular blood transfusions and palliative radiation. Limiting hospice to patients who must refuse disease-modifying (albeit, palliative) therapy enforces an artificial distinction between curative and palliative modes of care<sup>16</sup> and places inevitable pressure on both patients and physicians to choose, or refer, hospice at the correct time. This pressure can obfuscate decision making and delay hospice election.

In the 1990s, some large hospices began experimenting with the open-access model of concurrent care with upstream enrollment and concurrent disease-modifying and palliative care. By 2009, 29% of hospices reported open-access implementation; however, two thirds of those restricted chemotherapy and radiation services. Some insurance companies have also begun implementing concurrent care programs and, in 2015, the Centers for Medicare and Medicaid Services (CMS) began a 5-year concurrent care demonstration, the results of which are pending. Thus, despite efforts to implement concurrent care, current data are inconclusive regarding the benefits for patients with cancer specifically.<sup>32</sup>

Much can be learned from concurrent care implementation in Veterans Affairs (VA) medical centers (VAMCs). With the Comprehensive End-of-Life Care Initiative, which supplemented concurrent care with upstream palliative care consultation infrastructure, hospice use among veterans increased by 20% to 42%, compared with only 16% among nonveterans. Among VA patients with cancer,

68% currently use hospice and 25%, concurrent care.<sup>33</sup> The proportion of VAMCs offering high levels of concurrent care has likewise grown, from 20.0% to 43.2%.<sup>34</sup> This growth has yielded several benefits.<sup>19,34-37</sup> Among patients with stage IV non-small-cell lung cancer, veterans treated at VAMCs with the highest hospice availability were more than twice as likely to receive concurrent chemotherapy or radiation. Veterans with the highest potential of concurrent care were one third less likely to receive aggressive treatments and 22% less likely to be admitted to an ICU in the 6 months after diagnosis, compared with those with the lowest concurrent care potential.<sup>19,35</sup> Greater concurrent care was associated with increased hospice use.<sup>34</sup> Importantly, these patients also incurred an estimated \$266 lower daily cost in days 8-30 after diagnosis and a \$187.25 lower daily cost for up to 180 days.<sup>19,35</sup> Furthermore, patients receiving concurrent care exhibit improved QoL because of enhanced symptom management, preservation of hope, and relationships with clinicians, and a gradual transition phase.<sup>36,37</sup> Nonetheless, the VA system is unique in terms of patient population and integrative coverage of services. Given the higher costs of aggressive services under Medicare, sometimes-uncoordinated care for patients with comorbidities, and the lack of a uniform incentive for providers, the feasibility of concurrent care translation to non-VA settings and the extent of coverage for expensive novel anticancer therapies remain indeterminate.<sup>19,33,35</sup>

Another impediment to integrating hospice into routine cancer care is that hospice has traditionally remained excluded from the Medicare Advantage (MA) benefits package. Complex coverage requirements have prompted recommendations for hospice inclusion in MA plans by 2021. The carve-in would facilitate more gradual transition into hospice.<sup>15,17</sup> The move is consistent with recent substantial and parallel growth of both MA and hospice enrollments and with Medicare's emphasis on eliminating payment silos, decreasing care fragmentation, and providing patient-centered care.<sup>17</sup> It could further incentivize MA plans to develop robust serious-illness strategies that support beneficiaries through EoL. Nonetheless, no clear constituency among hospice and Medicare beneficiary advocacy organizations exists as a driving force for policy change.<sup>15</sup> In addition, it remains unclear whether such a market structure may encourage MA plans to include only a subset of local hospice agencies or hospices providing a less robust set of services in contracted networks, potentially limiting choice and quality for beneficiaries. MA plans' unfamiliarity with the hospice model may further complicate this. Importantly, carve-in necessitates continued improvement and use of EoL care quality measurement standards. The National Quality Forum EoL care measures and the Hospice Quality Reporting Program represent good first steps; however, limitations, such as little variation in distinguishing high-quality care, persist. Integration of EoL care quality metrics in MA plan

assessments warrants consideration.<sup>15,17</sup> Last, how carve-in would affect hospice reimbursement rates, benchmark and risk adjustment payments for MA plans, and palliative care programs warrants additional investigation.<sup>15</sup>

### RECOMMENDATIONS FOR FUTURE DIRECTIONS

Considering the barriers to hospice use and the upcoming changes in hospice reimbursement, action will be needed from an array of stakeholders, including patients, caregivers, providers, cancer organizations, hospices, and policymakers, to maximize hospice enrollment (Table 1).

First, patients and caregivers must be adequately informed about their EoL care options and engaged in the decision-making process. Technological applications provide an accessible, affordable, and comprehensive avenue.<sup>38,39</sup> Such tools have demonstrated usability and efficacy in increasing knowledge about, and willingness to accept, palliative care among patients with cancer.<sup>40</sup> Similar tools could prove effective in the hospice context. A recent study showed that 78% of hospice informal caregivers were receptive to the idea of mobile health applications as educational tools.<sup>38</sup> New applications should be designed to comprehensively provide patient- and caregiver-tailored information about hospice services, eligibility criteria, and Medicare coverage. They should also use assessments to gauge patient and caregiver preferences for EoL care. These tools may have the potential to dissolve misperceptions about hospice; facilitate patient-family and patient-physician communication about hospice; and increase the efficiency of, and retention rate after, hospice referral and onboarding visits.

Second, oncologists should further build, practice, and refine patient-centric communication skills to achieve earlier and more regular establishment of goals of care. The patient-oncologist relationship is unique, given the

complexity, uncertainty, fear, and stigma surrounding cancer. There remain important opportunities to reflect on communication practices to prevent overwhelming patients with medical or technical information, asking close-ended questions, and failing to respond to patient emotions.<sup>41,42</sup> Most, but not all, patients with cancer prefer forthright prognosis delivery while preserving hope, active participation in a shared decision-making process, and autonomy.<sup>41</sup> This can be accomplished while acknowledging the uncertainty of the future and skillfully navigating seemingly uncharted territories using open-ended discussions focused on preferences and values.<sup>42</sup> Using evidence-based communication training tools, including VitalTalk; Reframe, Expect Emotion, Map Future, Align Values, Plan Treatments (REMAP); Set Up, Assess Perception, Obtain Invitation, Give Knowledge, Address Emotion, Summarize (SPIKES); and the Serious Illness Care Program (SICP); can help.<sup>43</sup> For example, SICP use has yielded significantly earlier, more comprehensive, more values-oriented, and a greater number of per-patient goals-of-care conversations for patients with terminal cancer.<sup>44</sup> SPIKES, meanwhile, has demonstrated efficacy in increasing oncologists' confidence in disclosing unfavorable outcomes to patients.<sup>45</sup>

Third, to provide objectivity in the timing and nature of goals-of-care discussions, clinicians must increasingly use validated prognostic and treatment risk tools. Specifically, cancer-specific comprehensive geriatric assessments (CGAs), which have been adapted to 15- to 30-minute procedures reliant on self-reported measurements, can detect vulnerabilities otherwise overlooked in routine oncology visits, including poor physical functioning, poor nutritional status, falls, depression, and cognitive impairment, all of which exhibit worse outcomes among patients with cancer, and predict survival expectations among older patients. Recently, there has been increasing awareness of the need to perform CGAs for older (70 years of age and

**TABLE 1.** Recommendations for Increasing Timely Use of Hospice Care for Patients With Cancer

Recommendation	Description
Build and scale hospice-preparatory materials	Web and mobile applications that provide information on hospice while soliciting patient care preferences can easily reach patients and facilitate and activate engagement in end-of-life decision-making processes.
Refine oncologist-patient communication strategies related to goals-of-care conversations	Oncologists should consider strategies that address hospice referral as a positive transition point, emphasize shared decision making, and share an open-ended menu of possibilities for patients. Systematic communication tools merit greater use among oncologists.
Regularly determine usage of standard criteria for patient hospice eligibility	Comprehensive geriatric assessments and chemotherapy toxicity risk assessment metrics should be used adjunctly with routine prognosis estimations that are based on functional status and other factors to more robustly predict patient risk for acute hospitalization or other complications in response to treatment prolongation or changes in treatment trajectory.
Test models for closer integration of hospice care into routine cancer care	Given the impending hospice carve-in into Medicare Advantage plans, cancer organizations and policymakers should explore the applicability of concurrent care models.
Embrace increased focus by all stakeholders on end-of-life care metrics	Oncology practices and hospice organizations must be responsive to increased attention by payers and regulators on quality measures and payment related to performance on end-of-life metrics such as hospice referral rates, hospice length of stay, and patient experience scores. The continued development of quality improvement programs that focus on addressing opportunities in these areas is paramount.

older) patients with cancer.<sup>46,47</sup> A recent case study of a patient with acute myeloid leukemia highlighted the efficacy of CGAs in modifying therapy regimens and living accommodations.<sup>48</sup> Another study involving various cancer types has associated CGA administration with patient preference for less intensive treatments (eg, less intensive surgeries, and radiotherapy instead of chemotherapy).<sup>47</sup> Additional related resources, including the Chemotherapy Risk Assessment Scale for High-Age Patients and the Cancer and Aging Research Group tools, can provide toxicity risk predictions when beginning a new line of treatment.<sup>46</sup> Although an association between CGA administration and hospice use remains unproven, CGAs and related tests can improve prognostication and warrant consideration for more regular implementation in the oncology clinic.

Fourth, given the impending MA hospice carve-in,<sup>15</sup> cancer organizations should prepare for a tighter integration of hospice and cancer care. To date, there is no standardized model of concurrent care delivery because of payment and regulatory restrictions. However, cancer organizations could look toward VA-based cancer institutes to understand concurrent care implementation. In the VA model, hospices generally provide primary care, order medications, and manage symptoms, whereas ambulatory cancer centers manage complex care needs, such as palliative chemotherapy and radiation, and communication during hospitalizations. Importantly, VAMCs feature dedicated liaisons (usually nurse managers, oncologists, or palliative care physicians) to coordinate said care and educate patients.<sup>37</sup> Despite the aforementioned differences and uncertainties regarding alteration of coverage expansion, non-VA cancer organizations may benefit from considering aspects of the VA model of liaison dedication and care allocation.

Fifth, given the rapid shift from pay-for-volume to pay-for-value, oncology practices must embrace more regular inclusion of EoL quality metrics and performance improvement. Quality measures, including annual hospice

enrollment rates, hospice referral rates, mean and median LoS, and patient- and family-rated QoL, are increasingly measured by clinicians, administrators, payers, and regulators. Certain initiatives have preliminarily demonstrated the usefulness of such measures. The CMS Oncology Care Model, which provides 6-month episode- and performance-based payments after chemotherapy initiation, has encouraged participating oncology practices to adopt innovative features, including patient education modules, dashboard systems to communicate quality metrics to providers, and committees for treatment risk assessment. This has promoted increased advanced care planning documentation, decreased ER visits, and more integrated provider collaboration.<sup>49</sup> Likewise, the Innovative Oncology Business Solutions Community Oncology Medical Home (COME HOME) model, which emphasizes enhancing triage pathways, outpatient access, and treatment standard adherence, has promoted fewer ER visits and 30-day readmissions and decreased per-capita costs.<sup>50</sup> These efforts represent a good first step; however, all stakeholders in the oncology ecosystem should be committed to continued review and scrutiny of practices related to EoL and hospice care and should proactively consider continuous quality improvement programs emphasizing said areas.

Hospice is an evidence-based, widely available care delivery mechanism to improve the later experiences of patients with advanced cancer. Despite its benefits, hospice remains underused, requiring efforts from patients, providers, and policymakers to implement innovative technology applications, refine oncologist-patient goals-of-care communication, and use a more comprehensive prognostic armamentarium. Furthermore, the landscape of hospice payment is evolving, as integration of hospice care into routine cancer care becomes more feasible. Ultimately, a multidisciplinary set of solutions is needed for the path forward.

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## AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

##### Hospice Use Among Patients With Cancer: Trends, Barriers, and Future Directions

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