# The Debate in Hospice Care

Improving end-of-life care has been an important issue in the oncology community as well as in the health care arena in general. The American Society of Clinical Oncology recently collaborated with the Education in Palliative and End-of-Life Care (EPEC) project to develop and disseminate EPEC-Oncology (EPEC-O), a comprehensive curriculum designed especially for oncology clinicians. In addition, earlier this year, the American College of Physicians issued a clinical practice guideline on evidence-based interventions to improve palliative care at the end of life.[1] The guideline notes the critical elements for end-of-life care as being support for families and caregivers; continuity of care; attention to well-being, including existential and spiritual concerns; and support for function and survival duration. The very elements of EPEC-O and the American College of Physicians guideline are at the core of the hospice movement that began more than 30 years ago.

Hospice care has become a complex issue, and the recent explosion in the number of for-profit hospices has set the stage for debate about how to best care for individuals at the end of life in terms of both quality of life and cost effectiveness. Passionate proponents of mission-driven hospices argue that the tax status of a hospice can influence the services provided because of differences in priorities (ie, shareholders *v* patients). For-profit hospices argue that their tax status allows better access to capital to enhance care. That theory has led several nonprofit hospices to change their tax status.

Several questions have been raised during this recent debate. Has the philosophy of hospice changed? Has tax status affected the quality of hospice? Are the economic incentives driving patient selection by hospice providers fair? Do patients enrolled in hospice receive the care that meets their needs? A review of the history of hospice and emerging trends in its use and practices may provide some answers.

## History of Hospice

The first hospice home care program in the United States was Connecticut Hospice (funded by the National Cancer Institute), which began in 1974, some 7 years after Dame Cicely Saunders established the first hospice, St Christopher's Hospice, in London, United Kingdom. The number of hospice programs in the United States has grown steadily since 1974, increasing to more than 4,500 programs in 2006.[2] The greatest growth has been in the number of for-profit hospices. Over the past decade, the number of for-profit hospices has increased nearly fourfold.[3] Between 2001 and 2003 alone, the number of for-profit hospices increased 25%, compared with an overall 8% increase in hospice programs.[4] One study found that 91% of 44 new, freestanding hospices that opened between 2002 and 2003 were owned by for-profit organizations.[5] As a result, for-profit hospices now account for 46% of the total number of programs.[2]

The use of hospice in the United States has also increased. According to the National Hospice and Palliative Care Organization, the number of people using hospice increased from 495,000 in 1997 to 1.3 million in 2006—an increase of 162% during 10 years.[2] Patients with cancer once comprised the majority of patients receiving hospice care and while it remains the top diagnosis among hospice enrollments, its percentage is decreasing. In 2006, cancer accounted for approximately 44% of the diagnoses. The steady decrease in cancer diagnoses reflects lower cancer-related mortality rates as well as an increased awareness about hospice among people with other chronic conditions. The decrease may also represent an increasing tendency of individuals with cancer to choose potentially curative treatments rather than hospice.

Treatments given with potentially curative intent are not allowable under the Medicare Hospice Benefit (MHB), the primary payer for hospice care in the United States. The MHB was enacted by the US Congress in 1982, and nearly 93% of US hospices are now certified by the Centers for Medicare and Medicaid Services to file for reimbursement under this benefit.[2] Spending on hospice through MHB has increased from $1.9 billion in 1995 to $8.1 billion in 2005.[6]

Several criteria must be met to be eligible for the MHB, including patient eligibility for Medicare Part A and certification by both the patient's physician and the hospice medical director that the survival prognosis is 6 months or fewer if the illness were to run its natural course.[7] Centers for Medicare and Medicaid Services–certified hospices are mandated to provide a core of services that include nursing care, social services, physicians' services, short-term inpatient care, counseling, home health aide services, therapy (physical, occupational, and speech-language), medical appliances and supplies (including drugs and biologic agents), respite care for family caregivers, and family bereavement.[7]

Most patients (84%) receiving hospice services are covered by the MHB.[2] Health maintenance organizations and private insurances reimburse costs for approximately 8% of hospice users,[2] and these payers may not cover all hospice services, especially counseling or bereavement services. Some commercial insurers do not cover any hospice care. Medicaid provides coverage for approximately 5% of hospice users, but this coverage is not available in all states.[2]

## Ineffective Use of Hospice Services

Despite the growth in hospices and the creation of reimbursement benefits, hospice has been both underutilized and may be used ineffectively. The National Hospice and Palliative Care Organization estimates that 36% of all individuals who died in 2006 were enrolled in a hospice program.[2] In addition, the median duration of hospice services decreased from 26 days in 2005 to nearly 21 days in 2006, and approximately 25% of individuals in hospice were enrolled for less than 1 week.[4] Reports have indicated that the stays for patients with cancer are shorter than those for patients with other diagnoses.[4] These statistics highlight a tendency for both physicians and patients to defer hospice until a point when death is imminent.

"Hospice is not just about managing death," emphasizes Craig C. Earle, MD, MSc, Dana-Farber Cancer Institute (Boston, Massachusetts). "High-quality palliative care can be of great benefit to a patient, and that benefit accrues over time." Hospice is beneficial in several realms, including the patient's quality of life, patient and family satisfaction, and cost effectiveness.[8–12] One study even indicated that hospice significantly extended survival for patients with lung, pancreatic, or colorectal cancer compared with patients who did not receive hospice care.[13]

The Medicare Payment Advisory Committee (MedPAC) has also noted that the opportunity for a comprehensive palliative care program increases with longer hospice stays.[4] Researchers have found that services as bereavement counseling, palliative care, and respite for caregivers was experienced by patients and families who used hospice for at least 7 to 8 weeks[12] and that the maximum benefit of hospice is achieved by a stay of 80 to 90 days.[8]

The cost savings of hospice has been documented in several studies. A meta-analysis published in 1996 indicated that the use of hospice saved as much as 40% of health care costs during the last month of life and 17% over the last 6 months.[10] In a later study, the health care costs specifically for patients with cancer were 13% to 20% lower for those who had received hospice care than for those who had not.[11] Similar findings were reported in 2007: hospice use was found to significantly reduce Medicare costs during the last year of life by an average of $2,309 per hospice user.[12] In addition, Medicare costs were reduced further the longer an individual was enrolled in hospice. Cost savings were more pronounced for patients with cancer than for patients with other diagnoses, especially for longer stays.[12]

Despite the benefits in terms of both quality of life and cost effectiveness, hospice referrals have historically been made too late. The barriers to timely referral have been researched and well documented and are related to physician and patient attitudes as well as the reimbursement structure itself. Among the most commonly cited patient-related barriers are denial of health status, desire to exhaust all treatment options, a negative perception of hospice, and patient demographics.[8,14] Physician-related barriers include a reluctance to discuss hospice because of fears about the patient's reaction, difficulty in prognosis, feeling of professional failure, and loss of control.[8,15–17]

Paradoxically, the very advances in treatment that have enhanced cancer care and survival have created perhaps the most important barrier to the effective use of hospice. Mintzer and Zagrabbe[18] noted that 26 cytotoxic chemotherapy agents, monoclonal antibodies, and molecularly targeted agents have been approved by the US Food and Drug Administration over the past decade. These new treatments provide new options—and continued hope—for patients, even though the clinical response and survival benefit associated with these agents are typically low. Those authors postulated that as the number of new anticancer therapies increases, the average number of days in hospice would decrease.[18]

The findings of several studies support that hypothesis. Earle et al[19] found that between 1993 and 1996, there were significant decreases in the average number of days between the start of the last unique chemotherapy regimen and death and between the last dose of chemotherapy and death. In addition, data indicated that nearly 19% of patients received chemotherapy within the last 14 days of life.[19] This increased use of aggressive treatment over the past few years demonstrates the decision-making challenges inherent in an oncology world distinguished by research advances: neither patients nor physicians want to "give up."

## An All-or-None Decision

What patients are required to give up in order to enroll in hospice is not only curative-intent therapy but also palliative treatments, such as radiation therapy, chemotherapy, transfusions (blood and platelets), and total parenteral nutrition. These treatments are considered to be "usual" rather than "aggressive" to patients with cancer,[20] but many of these options fall in the gray zone between disease-directed therapy and palliative care and, as such, are not covered by the MHB. However, studies have demonstrated significant benefits in terms of symptomatic relief from many treatments considered to be disease directed. For example, several trials have shown that radiation therapy provides effective relief of cancer-related symptoms.[21] This creates a decision-making challenge. "It's an all-or-none decision," notes Dr. Earle. "Patients are asked to give up on everything else."

Most oncologists and other health care professionals agree that the all-or-none philosophy of the MHB is outdated, as significant advances in treatment have been made since the crafting of the legislation.[22] Adding to the problem is that the fixed rate of the MHB lacks the flexibility to address the costs of actual care. The benefit currently provides reimbursement on a flat per diem rate of $135.29 for routine home care and $601.02 for general inpatient care, regardless of the actual costs of care.[23] The actual costs of treatments commonly used for palliative care range from $6.60 for two Senna tablets to $3,906.60 for a one-month course of erlotinib.[24] An 8-mg dose of an antiemetic (ondansetron) can cost upward of $1,100.[24]

The category of oral chemotherapy and supportive care is associated with the highest costs, with a weekly dose of erythropoietin costing $2,504, temozolomide and capecitabine each costing nearly $1,900,[24] and a course of palliative chemotherapy for colon cancer estimated at $30,000.[19] The cost of palliative radiation therapy is also high and was reported to be a barrier to its use by 64% of hospice providers.[21] The prohibitive cost led to such treatment being used for only 3% of hospice patients, despite a much higher percentage of patients who would benefit.[21] The bottom line is that without reimbursement, hospices cannot afford to provide complex and/or costly treatments. Without such treatments, patients feel they cannot afford to opt for hospice.

## Open Access Model of Hospice

The open access model of hospice was developed to help individuals avoid the "terrible decision" between palliative care and hospice. An open access hospice provides treatments that palliate symptoms and enhance the quality of life, even if the treatments are considered to be disease directed. The decision for a hospice to follow an open access model can be risky, as the cost for a patient is increased without an accompanying increase in reimbursement. In addition, Medicare may consider the treatment too aggressive or "not hospice appropriate" and disallow coverage. Nonprofit hospices are at risk for financial survival, and for-profit hospices are at risk for narrower profit margins. Thus, even with open access, individuals considering hospice can find themselves in another abyss: nonprofit hospices cannot afford to provide expensive treatments, and for-profit hospices may decline admission to individuals who require or want treatments that are costly.

Whether the open access model of hospice care can be sustained remains unclear. As more and more individuals opt for both costly treatments and hospice care, the financial strain may be too much for both nonprofit and for-profit hospices. Alternatively, cost-effective changes in the selection of patients and the delivery of care may compromise patients' access to high-quality hospice care.

Research has shown wide variation in the admission practices as well as the breadth of services for both types of hospice (nonprofit and for-profit). In a survey of 100 hospices in California, 63% reported that admission was denied on the basis of at least one of seven restrictions.[25] Among the restrictions were chemotherapy (48%), total parenteral nutrition (38%), radiation therapy (36%), and transfusions (25%).[25] In another study, data on more than 9,000 discharged hospice patients indicated that only 14% of hospices provided care across five key categories of palliative care (nursing care, physician care, medication management, psychosocial care, and caregiver support).[26] Approximately one-third of the hospices in the study provided patient and family services in one or two of the key categories.[26]

## A Competitive Arena for Hospices

The exponential growth in for-profit hospice programs and the increasing desire for costly treatments have created a competitive arena for hospices. The advantage for most nonprofit hospices is their name recognition and foothold in the market gained through longevity. Economies of scale and better access to funding associated with for-profit hospices give them an edge.[25,27]

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Small programs or programs in rural areas may not be able to contract with the services necessary to provide complex hospice treatments. Economies of scale place larger hospices in a better position to offer a wider range of services or expensive services. Larger hospice size has been associated with less restrictive admission practices.[25] An average daily census of more than 400 is considered to be the minimum requirement for open access, yet only 2.5% of the country's hospices are of this size,[24] most of which are for-profit. In addition, for-profit hospices have been found to be significantly less likely to admit patients with shorter, less profitable, expected lengths of stay.[27] Lastly, higher profit margins enable for-profit hospices to market more aggressively to draw in more enrollees.

No studies published to date have provided evidence of a difference in the quality of care according to the profit status of hospices. However, the findings of two studies suggest that the range of services offered by for-profit hospices is narrower than the range offered by nonprofit ones.[3,5] In one of these studies, the services most often lacking were those that are considered as "noncore" or more discretionary according to federal regulations.[3] In the other study, newly established hospices, 91% of which were for-profit, offered fewer radiation therapy and imaging services than existing (freestanding) hospices.[5]

## Addressing the Challenges

Some proposed solutions have the potential for addressing the current challenges surrounding hospice care. The fixed daily payment system of the MHB encourages hospice providers to admit patients who will have the lowest daily costs. Thus, a reimbursement policy that reflects actual costs could represent a solution, but such a change is unlikely. MedPAC has recommended that hospice services be evaluated to ensure that the payment system is accurate. In addition, MedPAC has made several suggestions, including adjustment of payments to reflect factors such as diagnosis, case mix, and length of stay or staggered payouts to meet the increased costs associated with the beginning and end of a hospice stay.[4] Considering reimbursement for some costly treatments separate from basic hospice services may also help patients maintain palliative therapy and enroll in hospice.[25]

Some private health insurance companies have stepped forth to help ease the difficult decision for patients by allowing them receive treatments and hospice care concurrently. UnitedHealth offers a basic open-access hospice benefit as well as a smaller hospice program in 11 cities.[24] Aetna has developed a Compassionate Care Program that provides emotional support, care coordination, and information about end-of-life care and symptom management. Kaiser Permanente established its Palliative Care Project, an interdisciplinary home-based health care program, to help patients receive curative therapy while gradually transitioning to receive more palliative care.

Another potential solution is a “bridge,” or a program that enables patients to receive hospice services earlier than can be provided under the MHB. Bridge programs are based on the concept that palliative care experts have long advocated that end-of-life care can be enhanced by better integration of palliative care throughout the continuum of care. Preliminary reports have shown these programs to be effective.[28,29] For example, a phase III trial at the University of Michigan Comprehensive Cancer Center demonstrated that conventional oncology management plus hospice enrollment and support was associated with a better quality of life and a cost savings of 27% compared with conventional oncology management alone.[29]

Community oncologists can also have a substantial effect on the quality of hospice care by providing more timely referral. Honest communication with patients about the benefits of continued aggressive treatment for advanced disease, discussion of hospice services early in the course of disease, and emphasizing that patients will not be “abandoned” by their medical care provider can help patients be more open to the idea of hospice as an option.[17]

Oncologists must learn to recognize their own professional limitations and gain a clearer understanding of when the benefits of hospice care outweigh the benefits of active, curative treatment. More timely referrals not only provide patients with optimum hospice care but also helps both for-profit and nonprofit hospice programs remain financially stable by balancing costs over time and patients. Lastly, community oncologists should become aware of the admission practices and range of services provided by the hospices in their area so that they can help their patients find end-of-life care that best meets their needs.

The questions posed earlier remain difficult to answer. Advances in cancer therapies—both curative and palliative—have made treatment decisions a challenge for patients as well as physicians. An open access hospice model has the potential of eliminating an either-or decision for many individuals but is a potential threat to the economic viability of both nonprofit and for-profit hospice. Regardless of tax status, hospices must remain driven by a mission to help individuals maintain a better quality of life while dying. An ultimate solution will depend on several factors, including evaluation and modification of payment systems and innovative palliative care programs.

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