

cians typically receive little to no training in the use of medications for pain and symptom management and thus rely on a presumed level of expertise on the part of the hospice nurse. Given the current nursing shortage, however, such an assumption of competency may or may not be well founded. Attending physicians should routinely evaluate recommendations and should have a low threshold for reviewing cases with the hospice medical director.

As a patient's disease progresses, the hospice plan shifts to accommodate decreasing independence, alterations in symptoms, and changing psychosocial needs. In Mr. G.'s case, the realization that his symptoms could be managed at home lessened his anxiety, which in turn decreased episodes of chest pain. Flash pulmonary edema occurred less

frequently; during one such episode, he received intravenous furosemide in his home, since he wanted to avoid further hospitalizations. During 4 months of hospice care, Mr. G.'s condition gradually deteriorated, with increasing weakness, dyspnea, and cardiac cachexia. Near the end, his family and friends gathered, and he died peacefully with his wife and nurse at his side. Despite his family's grief, they expressed their appreciation that Mr. G. had maintained a reasonably high quality of life and had died in his home as he had wished.

With the growing number of baby boomers seeking more control over all aspects of their health care, the use of hospice care will probably continue to increase. It is especially important, therefore, that physicians become more familiar with what

hospice care offers and work to overcome barriers in talking frankly with patients about what lies ahead.

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## Letting Go of the Rope — Aggressive Treatment, Hospice Care, and Open Access

Alexi A. Wright, M.D., and Ingrid T. Katz, M.D., M.H.S.

More Americans are choosing hospice for end-of-life care, but ironically, hospice patients increasingly are forced to give up effective palliative treatments along with aggressive medical intervention. For Joanne Doolin, a 64-year-old mother of three who spent her last 2 years of life fighting colon cancer that eventually made it impossible to eat, enrollment in hospice care involved a difficult trade-off: with only a few weeks left to live and her daughter's wedding approaching, Doolin was forced to choose between entering hospice care

and continuing to receive total parenteral nutritional support.

Unfortunately, treatment options are often limited by the economic constraints of hospice care. The hospice that was the closest to Doolin's Boston-area home would accept only patients willing to forgo life-sustaining treatments, including chemotherapy and parenteral nutrition. It cares for only about 20 patients at a time with three nurses, a manager, a part-time chaplain, and a medical director who works there one morning a week. As a small program, it can-

not negotiate pricing or spread the cost of expensive medications across many patients. A few large hospices offer what is called open-access care, which allows patients to add hospice care to their current medical treatment, but this option is not available in Massachusetts.

The Medicare hospice benefit reimburses hospices on a per diem basis, paying fixed inpatient and outpatient fees regardless of services provided. Despite adjustments for inflation, the fees have not kept up with the cost of cutting-edge palliative treat-

ments. Many patients who meet the criterion for hospice care — having less than 6 months to live — still opt for palliation from oral chemotherapies, radiation, antiemetics, or blood transfusions. But these treatments can cost more than \$10,000 per month — too much for most hospice programs (see Table 1).

Although some observers worry that nationwide open access could bankrupt Medicare, most agree that per diem reimbursement rates remain unacceptably low: in 2006, hospices were paid an average of \$563 per patient per day for inpatient care (which

represents 2.7% of Medicare's total hospice payments) (see Table 2). The average outpatient fee was \$126 for a typical day of care, an amount that must cover nursing care; contributions from social workers, chaplains, and volunteers; and all drugs and durable medical equipment, as well as 13 months of bereavement support.

Despite differences among hospice programs, patient and family satisfaction is high; in 2005, one third of the 2.4 million Americans who died were receiving hospice care.<sup>1</sup> The largest proportion of patients

had cancer, although patients with dementia, heart disease, and fatal lung conditions are increasingly entering hospice care. Diane Meier, director of the Center to Advance Palliative Care at the Mount Sinai School of Medicine in New York, argues that “palliative care and hospice are the only medical disciplines where nurses and physicians focus on the whole person.”

Most patients, however, wait until the last few weeks of life to enroll. In 2005, the median hospice stay was 26 days. One contributing factor is late referrals by oncologists, who routinely

**Table 1. Approximate Costs of Drugs Commonly Used by Hospices and Oncologists for Palliative Treatment.\***

Class and Drug	Dose/24 Hr	Price \$
<b>Emergency hospice pack</b>		
1-night supply of morphine oral concentrate, lorazepam, haloperidol, prochlorperazine, and Senokot		50.00
<b>Pain relief and laxatives</b>		
Morphine oral concentrate	200 mg	186.00
MS Contin generic	200 mg	294.00
Oxycodone ER	160 mg	562.20
Fentanyl patch	100 µg	533.60
Senna	2 tablets	6.60
<b>Antiemetics, anxiolytics, anticholinergics</b>		
Lorazepam	6 mg	115.20
Prochlorperazine	20 mg	53.70
Haloperidol oral concentrate	2 mg	22.56
Scopolamine patches	1 patch	9.18†
Ondansetron	8 mg	1,113.90
<b>Oral chemotherapy and supportive care</b>		
Temozolomide	200 mg	1,867.40
Capecitabine	2500 mg	1,883.70
Erlotinib	150 mg	3,906.60
Zoledronic acid	4 mg	824.56
Erythropoietin	40,000 units/wk	2,504.00

\* Prices represent estimates for a 1-month supply of medicine at average wholesale price (Medi-Span, <http://www.medi-span.com>, accessed July 27, 2007). Many hospice programs, hospitals, and physicians are able to negotiate lower prices than those listed here; some hospices negotiate a fixed daily rate per patient to cover all necessary medications.

† Each patch lasts 72 hours. The patch is given very close to the end of life.

Table 2. Medicare Hospice Payment Categories and Rates, Fiscal Year 2006.\*

Type of Care	Base Payment Rate \$	% of Days
Home care on a typical day	126/day	93.0
Home care during periods of patient crisis	31/hr	4.1
Inpatient care for a short period to provide respite for primary caregiver	131/day	0.2
Inpatient care to treat symptoms that cannot be managed at home	563/day	2.7

\* “Home care during periods of patient crisis” is defined as crisis care delivered in the home for 8 or more hours within a 24-hour period beginning at midnight; care must be delivered by a nurse for more than half of the hours to qualify for this level of payment. The minimum daily payment rate for such care is \$246 per day and the maximum is \$738 per day. Data are from the Medicare Payment Advisory Commission (MedPAC).

overestimate patients’ lifespans.<sup>2</sup> Many patients are referred only when no other option remains.

In addition, many patients fear that they will not receive enough medical services in hospice care. “It felt like I was trading in the Lamborghini of medical care for an old pick-up truck driving down a rutted road,” said one patient with cancer. Optimal end-of-life support often necessitates careful titration of opioid, antipsychotic, and anxiolytic drugs, which can sometimes require a doctor’s presence. But few patients ever meet a physician after enrolling for hospice care; there are no rules mandating the degree of physician involvement. Medicare does not even collect information on the number, frequency, or duration of visits or on which personnel provide which aspects of care. Each hospice program decides what services to offer, and family members often must fill in the gaps.

Like most patients with terminal illness, Joanne Doolin chose ongoing medical treatment over hospice. She entered a bridge-to-hospice program that provided

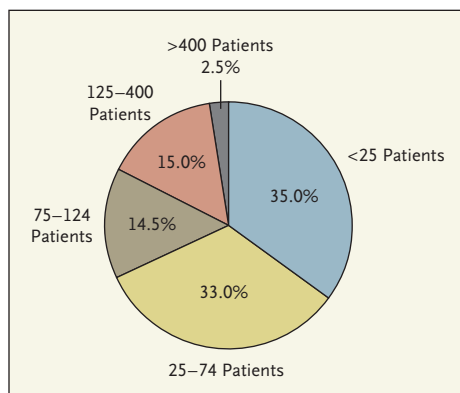
home nursing care and access to an infusion company for nutrition until she was ready for hospice care. She spent more than a month at home, visited her favorite casino, and attended her daughter’s wedding. But then Doolin’s health suddenly deteriorated, and she needed urgent medical care and pain management. Her family contacted the bridge program’s hospice but could not enroll her in time. During Doolin’s last few hours, care was provided by a haphazard mix of people, including her family, a covering oncologist, a pharmacist, and compassionate local firefighters. One year later, Doolin’s family is still angry over the forced choice between parenteral nutrition and hospice care. They believe she would have suffered less in an open-access hospice program.

The disconnect between pre-hospice and hospice care seems absolute to physicians as well. The Medicare hospice benefit “is so restrictive,” says Thomas Smith, chair of the division of hematology–oncology and palliative care at Virginia Commonwealth Uni-

versity–Massey Cancer Center, in Richmond, “that it requires divorcing yourself from your patient’s care because you can’t be their cancer doctor anymore. As soon as you enroll in hospice, there goes your Aranesp, your Zometa, and your Zofran. . . . I can’t do anything but adjust pain meds and hold hands. These are wonderful things to do, but they won’t keep my office running.” Many hospice directors counter that oncologists abandon their patients when they can no longer visit the office.

A few large hospices and insurance companies are trying to prevent these situations with open-access programs. Last year, Capital Hospice, based in Washington, D.C., paid for palliative chemotherapy, radiation, dialysis, blood transfusions, parenteral nutrition, antibiotics, and other expensive intravenous medications. With an average daily census of 606 patients, the program can spread out the expense. President and chief executive officer Malene Davis likens open access to “two ropes hanging from the ceiling. We’ve asked people to hold on to the aggressive-treatment rope with both hands,” she says, “but when they go on hospice we tell them to let go completely. Open access gives people the choice to let go of active treatment with one hand and grab on to the hospice rope until they feel comfortable letting the other hand go.”

The large insurance company UnitedHealth offers a basic open-access hospice benefit to nearly 26 million members and a smaller hospice program in 11 cities that includes physician home visits and reviews of care. A com-



#### Size of Hospice.

Data are from the National Hospice and Palliative Care Organization.

pany spokesperson says that the cost is negligible as compared with the cost of its other programs. In 2004, Aetna started its Compassionate Care Program, which uses *International Classification of Diseases, Ninth Revision*, codes and pharmaceutical information to identify members with terminal illnesses; the members are then contacted by nurse case managers, who offer emotional support, care coordination, and information about end-of-life planning and symptom relief. Early results suggest that members appreciate the additional support that tailored case management provides; more members are enrolling in hospice, and the program is reducing rates of unnecessary hospitalizations.

But these programs remain the exception. According to the Center for Medicare and Medicaid Services (CMS), only 2.5% of the country's 4100 hospices have an average daily census above 400 — commonly considered the minimum requirement for open

access (see pie chart). Elsewhere, patients and hospice directors must make tough choices.

The only randomized trial to date examining standard cancer care both with and without hospice support showed no significant difference in survival rates, but it did show significant improvements in quality of life when cancer care and hospice care were combined. Preliminary analysis revealed a 27% cost reduction in the combined-care group, which received less chemotherapy and diagnostic testing and required fewer hospitalizations.<sup>3</sup>

Nevertheless, many experts worry that open access may be prohibitively expensive. A 1990 study showed that most patients with cancer would choose to undergo toxic chemotherapy despite marginal potential benefits<sup>4</sup>; a study in 2004 reported increasingly aggressive care at the end of life.<sup>5</sup> Patients with congestive heart failure also face difficult choices, since life-sustaining medications can cost \$1,300 per day. "Whoever wrote [Medicare's hospice] policy has never taken care of sick patients," argues Diane Meier. "Our patients are fighting for their lives and will do anything to extend the length of time they live, as long as they have some quality of life."

CMS foresees an annual increase of 9% in hospice spending over the next decade, which will outpace increases for hospitals, physicians, skilled nursing facilities, and home health services. Many expect closer scrutiny of hospice reimbursements

by Medicare, particularly for patients with dementia or other illnesses, who often live with the disease for more than 6 months. "Baby boomers are going to want everything — from death coaches to powerful drugs," says Davis, "but we've got to begin grappling with tough choices if we're going to stay in business for \$150 a day."

Some choices will undoubtedly involve better definitions of palliative treatment. Currently, oncologists focus on how well a tumor responds to chemotherapy, but they will soon have to examine improvement of symptoms and quality of life to justify treatment costs. Meanwhile, patients will simply have to hope for access to a hospice that is large enough to help them.

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