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


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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 cannot negotiate pricing or spread the cost of expensive medications across many

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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 treatments. 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](#)).

View this table: [Table 1. Approximate Costs of Drugs Commonly Used by Hospices and Oncologists for Palliative Treatment.](#)

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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.

View this table: [Table 2. Medicare Hospice Payment Categories and Rates, Fiscal Year 2006.](#)

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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.¹ 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 overestimate patients' lifespans.² 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 University–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 company 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

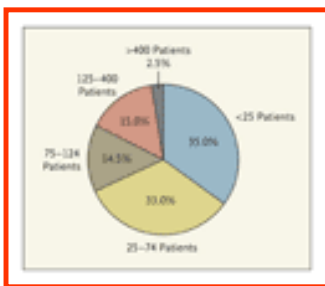
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and pharmaceutical information to identify members with terminal illnesses; the members are then contacted by nurse case managers, who offer emotional support, care coordination, and information about end-of-life planning and symptom relief. Early 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.



Size of Hospice.

Data are from the National Hospice and Palliative Care Organization.

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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.³

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 benefits⁴; a study in 2004 reported increasingly aggressive care at the end of life.⁵ 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.

Source Information

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An [interview](#) with Dr. Timothy Quill, director of the Center for Palliative Care and Clinical Ethics at the University of Rochester, can be heard at www.nejm.org.

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