

State Initiatives *in* End-of-Life Care

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Focus: Hospice Care—Part I

A Policymaker's Primer on Hospice Care



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Peggy Schaab, a registered nurse with The Center for Hospice and Palliative Care in Buffalo, N.Y., listens for the blood pressure of her patient, Helen Zimmer, in Zimmer's own home. Most Americans—including policymakers—mistakenly believe hospice is a place. More than 90 percent of American hospice care is provided in patients' homes, where nurses like Schaab and other hospice team members—including chaplains, social workers, and physical therapists—visit at least once a week, often more frequently, to check on patients and to train family members in giving palliative care. In 1999, nearly 2.4 million Americans died, less than 25 percent of the total at home; for the 700,000 who were served by hospice care, however, 78 percent were able to die either at home or under hospice care in the nursing home where they resided. For other myths and facts about hospice care, see p. 3.

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Hospice: A Service Most Americans Would Choose, If They Understood It

A large majority of Americans know precisely what they want when death seems near. According to a public opinion survey conducted for the National Hospice Foundation in April 1999 with people 45 and older,

- 83 percent want someone to make sure their wishes are known and enforced, and
- 85 percent want individualized pain control; a choice of care options; a team of professionals to carry out their choices; and emotional and spiritual support not only for themselves but also for their families.

Most of those surveyed, however, were not able to recognize that their desires could be fulfilled by hospice care: 80 percent did not know the meaning of the term “hospice,” and 90 percent did not know that Medicare pays for hospice, a statistic that did not vary by age, income, education, or race. Fewer than 10 percent of those surveyed knew that hospice provides pain relief for the terminally ill.

Essentially, most middle-aged and elderly Americans want hospice at the end of life, but they don't know that's what they want.



“Those who use the Medicare Hospice Benefit see it as setting the standard for compassionate, holistic end-of-life care. It provides the kind of care most of us would want when we face the end of our lives. The need to educate the public at large, as well as health care providers who advise us on our options, is very urgent.”

Senator Chuck Grassley (R-Iowa), Chair of Senate Special Committee on Aging's September 2000 Hearings on the Medicare Hospice Benefit

In the past 10 years hospice care has been in the public spotlight, but despite that publicity, studies show that more than three-quarters of the public—policymakers included—have an inaccurate understanding of hospice. Such misunderstandings have resulted in significant irregularities in the ways current policy, especially the Medicare Hospice Benefit (MHB), is interpreted and applied.

This Hospice Primer, the first in a two-part series about hospice, is designed to educate policymakers about what hospice is and, optimally, what it can do for dying Americans. The Primer will conclude by identifying policy controversies that prevent hospice from providing more and higher quality services—services that most Americans would choose. Part II in this series will explore the policy facts and controversies in more depth, as well as offering possible solutions and a research agenda. ■

Ten Myths and Facts about Hospice Care

Physicians, the general public, and those who create, interpret, and apply policy often harbor misconceptions about hospice. “People think good end-of-life care is only pain management. That’s not the end-all,” says Mary Labyak, MSW, Executive Director of The Hospice of the Florida Suncoast, the world’s largest nonprofit hospice and palliative care

center, located in Largo. “People need to understand that hospice is, in a larger sense, about living life to the fullest, and making sure life has grace and meaning. It’s also about how we help people make decisions at the end of life, and how we care for the entire family.”



Mary Labyak, MSW, Executive Director, The Hospice of the Florida Suncoast

Myth #1

Medicare provides only six months of hospice care, so enrollment should be delayed as long as possible.

Myth #2

All hospice care is the same.

Myth #3

Patients can't receive curative treatments while on hospice.

Myth #4

Hospice means giving up hope. Hospice workers help people die.

Myth #5

Hospice is useful only for heavy-duty pain medications.

Myth #6

You can't keep your own doctor on hospice.

Myth #7

Hospice is only for cancer patients.

Myth #8

Hospice is only for the sick family member.

Myth #9

Hospice is a place, so you must leave home to receive hospice.

Myth #10

Hospice is expensive.

Fact #1

Medicare law does not time-limit the hospice benefit, but Medicare regulations and their interpretations often discourage longer lengths of stay. Patients may enroll when their physician and the hospice medical director judge that the illness is terminal, with an estimated life-expectancy of six months or less.

Fact #2

Even in the same community, hospices may vary markedly, especially in the kinds of treatment patients can receive.

Fact #3

While the MHB requires beneficiaries to forego curative treatments, some hospices accept patients into their special palliative care programs when they prefer to continue receiving therapies directed toward reversal of disease and prolongation of life.

Fact #4

Hospice workers help people revise what they may hope for and help them achieve comfort when death is inevitable. They do nothing to hasten or prevent death.

Fact #5

Hospice care is designed to provide not only medical care but also social, psychological, and spiritual support given by an interdisciplinary team that includes a nurse, social worker, chaplain, and other professionals.

Fact #6

Most hospices establish working relationships with a wide base of referring physicians so that patients can keep their own doctors on admission to hospice care.

Fact #7

People who die from cancer are more likely to choose hospice care than are those who die of other conditions, but hospice care is now available to an increasing number of terminally ill people with noncancer diagnoses, such as congestive heart failure and chronic lung disease.

Fact #8

Hospice is designed to support all family members during the illness and to offer at least one year of bereavement support after a death.

Fact #9

In America, most hospice care is delivered in the home, though inpatient care is generally available (in hospitals, nursing homes and special settings) to serve those with no at-home caregiver, and those whose total care is overwhelming to families.

Fact #10

In general hospice costs less than hospital or nursing home care and saves significant money for Medicare (see p. 6).

What Hospice Is: Not a Place, But a Philosophy of Care

The term “hospice”—from the same linguistic root as “hospitality”—traces back to medieval times, when it referred to a resting place for weary or ill travelers. The word’s modern usage was coined in 1967 by Dame Cicely Saunders, a British physician and nun, who founded the first modern hospice, St. Christopher’s, in a London suburb.

Saunders introduced the idea of specialized holistic hospice care for dying people to the United States at a 1963 Yale University lecture to medical students, nurses, social workers, and chaplains. She showed pictures of terminally ill cancer patients, illustrating dramatic differences before and after patients received symptom control and social and spiritual support. Such interdisciplinary care is the hallmark

of hospice care. There are now 3,139 U.S. hospices. Three-fourths are nonprofit, but for-profit hospices are entering the industry faster than new nonprofits.

The Medicare Hospice Benefit (MHB) pays for 75 percent of hospice care, with private insurance covering 12 percent, and Medicaid and donations each covering about 7 percent, so public funds pay for most hospice care. Yet most beneficiaries still aren’t aware of the benefit. “Hospice is a no-cost item to an elderly patient and their family,” says Jon Keyserling, vice president of public policy for the National Hospice and Palliative Care Organization (NHPKO). “It’s paid-up health insurance.”

While the hospice philosophy remains consistent across the country, hospices may vary markedly, especially in the types of treatments patients can receive. Palliative treatments can be expensive. Smaller hospices with spartan community support are less likely to risk financial viability on patients who choose costly treatments or whose prognosis is lengthy enough to risk Medicare reimbursement denial. “Good hospices are accountable to HCFA’s criteria for terminality but are not driven by them,” says Jane Schafer, MA, Suncoast’s admissions director. “They are willing to stick their necks out for patients who might not meet all the medical criteria, but who meet other hospice criteria. If you live in that tension, you create open access. If you live in the black and white, your access is diminished.” ■

Characteristics of a High-Quality Hospice Program

The following characteristics of optimal hospice care come from a consensus statement of the National Hospice and Palliative Care Organization (NHPKO), as well as from statements made by leading hospice providers and researchers. Some hospices—especially those considered large, attracting 500 or more patients per year with diverse diagnoses—display many of these characteristics. However, about 60 percent of hospices in the United States are small, attracting fewer than 100 patients per year. Financial viability is a struggle for these hospices, and they find it harder to achieve these characteristics.

A high-quality hospice program does the following:

- Serves, above all, patients, families, and community, with sensitivity to different cultures, values, and beliefs
- Provides interdisciplinary teams of palliative care experts trained to give competent, compassionate, highly skilled, state-of-the-art care to dying patients
- Has a small patient-to-worker ratio
- Is responsive 24 hours per day, seven days per week
- Elicits and responds to patient and family needs and wants, and encourages involvement of patient’s own physician
- Conducts outreach to the entire community, including the traditionally underserved
- Does not discriminate in accepting patients based on their need for more aggressive palliative therapies, such as chemotherapy and radiation
- Shows willingness to accept referrals early in the illness trajectory, regardless of reimbursement likelihood
- Has well established, cooperative relationships with area hospitals and nursing homes
- Measures, monitors, and continuously improves its quality of care
- Produces accurate, reliable data about care, outcomes and costs
- Works—as part of the continuum of health care services—as an advocate, educator, and role model for quality end of life care in its community
- Earns community support.

“I’m as Content as I Can Be”: One Patient’s Experience of Hospice

Audrey Richardson was first diagnosed with breast cancer in 1997, when she was 73. Her doctor operated “and he said he got it all,” Audrey says. Then, in 1999, she began having pains in her chest. A biopsy was performed, showing the cancer had spread to her liver.

“A Stubborn Old Lady”

“They told me at that point that I had only three months to a year to live,” says Audrey, her eyes twinkling. “But I’m a stubborn old lady, and I wasn’t going to give in.”

Despite Audrey’s doctor’s estimate that she might have had longer than six months to live, he referred her to The Center for Hospice and Palliative Care in Buffalo, N.Y. Audrey says she was not intimidated at all by the thought of becoming a hospice patient, because she has been a financial supporter of her community’s hospice for years. “Who *doesn’t* know about hospice?” she asks rhetorically. “The one thing the people at hospice always say is that they won’t let you suffer. That’s what I wanted.”

Now 77, Audrey is still living with her cancer. Mother of three children and two stepchildren, all of whom live locally, she says her doctor calls her “Amazing Audrey” because she has outlasted his prognosis. “He can’t believe I’m still alive,” she exults.

Unexpectedly Discharged

Two months after Audrey’s first admission to hospice, she was discharged because her condition improved. The hospice was concerned she no longer met the HCFA criteria for terminality, even though the hospice and Audrey’s physicians—and Audrey herself—knew her condition



The Center for Hospice and Palliative Care

Audrey Richardson, 78, has for 20 months been a Medicare beneficiary of hospice. Without hospice, she says, she would not be able to live independently in her own home. “For people like me who don’t have a lot of money, it’s wonderful,” she says of hospice care. She is pictured here on her deck overlooking her garden.

would never be cured. If a patient experiences a sustained improvement, which sometimes happens when their symptoms are effectively treated and their caregivers receive a higher level of home support, the hospice may—ironically—be forced by the insurer to discharge the patient. Here’s why: when the dying individual receives expert palliative care and the whole family is emotionally and spiritually supported, symptoms—especially depression, and even perception of pain—are often alleviated. Patients and families commonly report great physical, psychological, and spiritual relief upon hospice admission.

“They Give Me Courage”

Audrey was readmitted to hospice in the fall of 2000 after a medical crisis sent her to the hospital. She has been a hospice patient continuously since then. With hospice care, her symptoms are being controlled enough for her to live on her own, cooking for herself and visiting her hairdresser each Thursday morning. But she retains considerable anxiety over the possibility, however remote, that she might be discharged again. She frequently notes how much her cancer has spread, where she can feel it with her fingertips, and how this is proof that she needs hospice care.

Audrey says her hospice has responded to her needs on holidays and weekends. “I called them one Sunday for more pain medication, and they were here in an hour,” she says.

Last year she recommended hospice to her 53-year-old niece, who was dying of lung cancer. “She died in their inpatient unit. The room was beautiful, like a hotel. You don’t have anyone yelling down the hall, the way you do in a hospital,” Audrey says. “She went to sleep very peacefully. It made me feel so good to see that, because I figure someday I’ll be there.

“They give me courage,” she says of her hospice team. She speaks of how comforting it was to plan for her care and even meet with the funeral director together with her family and her hospice social worker. “At first, [the terminal diagnosis] is such a shock, but they came in here and talked to me and my children, and we felt so much better. Of course, nobody looks forward to dying, but all I know is, I’m as content as I can be. And for people like me who don’t have a lot of money, it’s wonderful.” ■

Introduction to Major Hospice Policy Controversies

What follows are brief explorations of the major policy controversies currently affecting hospice quality and delivery. Part II of this mini-series will look at these facts and controversies—and some proposed policy ideas—in more depth.

Is Medicare Reimbursement Adequate?—The Biggest Hospice Policy Controversy

Hospice providers and HCFA agree that it's hard to say whether Medicare covers hospice's costs. There exists no nationwide standard or information database on the real costs of hospice—that is, what hospice should cost if done well (see box, p. 3). However, providers report that costs have skyrocketed since the 1982 inception of the MHB. Medical technology now treats illnesses that were considered untreatable 20 years ago. Interim results of a 2000 study by the actuarial firm Milliman & Robertson (M&R) shows drug costs have increased 1,500 percent over 1982 costs, and outpatient therapies (including palliative chemotherapy and radiation treatments) have increased 500 percent. Meanwhile, the daily reimbursement rate has only doubled.

“Our interim results show that current Medicare reimbursement is not adequate to cover the costs of care for hospice patients,” M&R reported in June 2000.

How MHB's Per Diem Works

The MHB was designed with a per diem to cover four levels of service, but more than 95 percent of patients are covered under the Routine Home Care level, which pays hospices about \$100 per day. The per-diem structure was based upon the idea that hospices attract diverse patient groups and that lengths of stay fall on a bell-curve, with most patients staying about six months

and small groups staying a very short or a very long time. Hospice services cost nearly twice as much during the first and last weeks of a patient's care as they do during the intervening weeks. The benefit was designed so that the reimbursements for patients at the bell curve's high point, whose average costs are less, would in the aggregate make up for the losses taken on patients at either extreme.

Hospices are drawing increasing numbers of short-term patients and

decreasing numbers of long-term patients, a trend attributed to

- public and physician misperceptions of hospice
- physicians' reluctance to talk about death and to prognosticate for a terminal illness
- physicians' concern about “losing” their patients to hospice
- Operation Restore Trust, the mid-1990s anti-Medicare-fraud campaign, whose investigation of a few hospices resulted in widespread concern about long-stay patients.

How Hospice Saves Medicare Money

Policymakers, physicians, and the hospice industry commonly accept the idea that, despite drastic increases in medical treatment costs over the past decade, hospice still costs much less to provide than hospital or nursing home care. Hospice involves less invasive technological intervention and, with timely referral, less staff time than acute care or skilled nursing. In addition, most hospice care is given at home. It would not be accurate to portray hospice as a cost-cutting measure, because palliative care at the end of life can require costly pharmacological and outpatient therapies. However, it is true that enrolling patients in a timely way under the MHB can help manage Medicare expenditures. As the figures below show, hospice saves Medicare significant money by preventing the medical crises that send patients to more costly hospitals and nursing homes. More timely referral might save Medicare even more money on unnecessary treatments. (All data courtesy of NHPCO.)

90 percent	Proportion of hospice care delivered in patients' homes (as opposed to more costly nursing homes or hospitals)
59	Average number of days spent under hospice care by average Medicare beneficiary enrolled in 1998 (the most recent year for which figures are available)
\$3,192	Medicare Part B dollars saved per Medicare hospice patient in the last month of hospice care
\$1.52	Medicare funds saved for every \$1 spent on Medicare hospice services
525,000	Number of MHB beneficiaries in 1999
\$1.675 billion	Medicare skilled-nursing and hospital reimbursements saved for patients enrolled on MHB in 1999

The Cost of Late Referral

The number of hospice patients doubled in the 1990s, but doctors simultaneously began to refer patients later in their illnesses. In 1992 the average length of stay was 74 days; just six years later it had decreased to 59. Median lengths of stay have decreased from 26 days to just 19. The most recent and comprehensive study of hospice patients found that 20 percent die within a week of enrollment—too little time for a patient to derive benefit from hospice—and that 80 percent die within three months—too little time, usually, for a hospice to recoup startup and ending costs. Late referral gives hospices too little time to evaluate patients and families and to develop and implement care plans.

With optimal referrals, “patients might receive hospice care for longer periods of time,” says Buddy Doyle, MS, a social worker and team leader at Suncoast. “But on the other hand, what is the cost of ongoing testing, curative chemotherapy and other treatments? The cost of extending hospice would be less than the cost of extending curative care.” Earlier referrals may result in savings that offset the expense of cure-oriented treatments.

The hospice per diem rate has been increased several times since MHB's inception in 1982 to keep up with inflation. But the only way it can be revised according to actual hospice costs is for HCFA to review services provided and attempt to capture accurate costs and fashion a rate accordingly. In 1999 HCFA began to require hospices to capture cost data and submit them for cost analysis and possible adjustment of the per diem rate; results are expected next year. “What we definitely need is a better way of thinking about hospice reimbursement,” says Thomas Hoyer, Director of HCFA's Chronic Care Policy Group.

Is the MHB's Six-Month Certification Rule Reasonable?

Medicare requires that all MHB patients be certified by their own attending physician and the hospice medical director as having a life expectancy of six months or less. This policy permits HCFA's fiscal intermediaries (FIs), who oversee MHB reimbursement, to review hospice documentation to determine whether a patient might live longer than six months and, if so, deny reimbursement. Medicine can treat—though rarely cure—chronic life-limiting illnesses for long periods of time, so currently about 7 percent of patients wind up on the MHB longer than six months.

“What we definitely need is a better way of thinking about hospice reimbursement.”

Thomas Hoyer, Director, HCFA Chronic Care Policy Group

There is great controversy over the six-month certification policy:

- Some researchers say this policy, depending on how it's interpreted and applied, can encourage physicians—who notoriously hate to prognosticate—to be more realistic and proactive with prognosis in terminal patients.
- Providers and some physicians say this policy is one cause of decreasing lengths of hospice stay because it discourages doctors from referring patients to hospice early.

Hoyer says HCFA's denial rate is less than 1 percent of cases; that Medicare law provides no penalty for physician error against this policy; and that this policy is a reasonable check against Medicare fraud. “Some illnesses may last a very long time, but the idea of end-of-life care is specific to a shorter period,” says Hoyer.

This hotly debated controversy will be explored in more depth in Part II of this mini-series.

Are HCFA's Local Medical Review Policies Fair?

Local Medical Review Policies (LMRPs) are hard-and-fast criteria that HCFA requires physicians and hospice directors to use to certify a patient as “terminal.” The LMRPs pertain to specific terminal diagnoses, such as lung cancer, chronic pulmonary disease, and Alzheimer's Disease. They were derived from hospice eligibility guidelines developed during Operation Restore Trust by the National Hospice Organization (now NHPKO) for use by hospices

and referring physicians. LMRPs go hand-in-hand with the six-month certification requirement, because both set criteria against which a hospice's patient documentation is reviewed by FIs when determining eligibility for reimbursement.

There is great controversy around the hospice LMRPs:

- NHPKO officials say their guidelines were never scientifically tested and were never meant to become encoded in public policy.
- Hospice providers say review criteria are needed, but that LMRP criteria are strictly medical and evaluate no psychological, social, or spiritual factors—so they do not reflect hospice services or philosophy of care.

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• HCFA's five regional FIs inconsistently interpret the agency's instructions about applying LMRPs. Thus, patients who qualify for hospice in Florida, for example, might not qualify in California. HCFA knows this occurs. "By the time we end up revising the Medicare reimbursement process, that won't happen any more, because that's inappropriate," Hoyer says.

What Can Be Done About Physician Ignorance of Hospice and Prognostication Errors?

Inaccurate or unjustifiably optimistic prognoses often lead to late hospice referral. A study by University of Chicago researchers released in June 2001 showed doctors often give terminally ill patients an overly positive estimate of life expectancy, and that a patient has less than a 40 percent chance of receiving an accurate prognosis in a terminal situation.

Physicians also delay hospice referral until patients are *in extremis* because they fear the following:

- The government will fine or investigate them or the hospice if the patient "lives too long."
- They will look incompetent if the patient lives longer than expected.
- Their hospice might be denied reimbursement and thus lose money.

Should Nursing-Home Patients Have to Choose Between Hospice and Skilled Nursing?

More and more Americans are spending their last days in nursing homes. When they enter a nursing home, patients are required to choose either the skilled nursing benefit or the hospice benefit; they cannot receive both. If they choose hospice, they must pay for their room and board out-of-pocket, a cost most cannot afford. Thus nursing home patients frequently forego hospice care.

The problems set out in this brief will be explored in greater detail in Part II of this mini-series. ■

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The following publications provided statistics cited here: "Barriers to Hospice Care: Are We Shortchanging Dying Patients?" Transcript of testimony on the Medicare Hospice Benefit, Sept. 18, 2000, www.senate.gov/~aging/hr59.htm

"Medicare: More Beneficiaries Use Hospice but for Fewer Days of Care," U.S. General Accounting Office Report, HEHS-00-182, www.gao.gov

Information About the Series

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