

# State Initiatives in End-of-Life Care

Issue 17, November 2002

Focus: Hospice Care—Part II

## Barriers to Hospice Care and Some Proposed Policy Solutions



Kristin Petersen

*High-quality hospice care provides interdisciplinary teams of experts trained to give compassionate, highly skilled palliative care to dying patients. Hospice provides more than just medication or technological intervention—above all, it asks its workers to forge relationships with patients, families, and community, with sensitivity to different cultures, values, and beliefs. But all too often, the reimbursement system rewards invasive, high-tech treatments far more readily than human interaction.*

*Here, Ailene Josephs, RN, of Forbes Hospice, Pittsburgh, talks with an actively dying cancer patient as his wife looks on. Several hours after this photograph was taken, this patient died at home, as he and his wife had wished. Surveys have shown that more than 90 percent of Americans would prefer to die at home. However, because of barriers to hospice access and inadequate reimbursement, less than 20 percent of Americans get their wish. This policy brief explores those barriers in depth, as well as some proposed policy solutions.*

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## Hospice: A Service That Satisfies— But Is Unavailable to Many Dying Americans

Because the American health care model treats death as a failure, the health care industry commits most of its technical and scientific resources to fighting it—and its reimbursement and regulatory schemes to rewarding that fight and penalizing failure. One result is that 28 percent of Medicare dollars spent on any single patient is invested in delaying death in the last year of life, and half of that sum in the last month of life.

Medicare is the most important source of health insurance for Americans at the end of their lives. It is used by 85 percent of people who die in the United States each year. Yet Medicare, like all medical reimbursement plans, typically focuses more on delaying death rather than supporting quality of life at life's end. Despite the creation of the Medicare Hospice Benefit (MHB) 20 years ago and the growth of hospice as a movement, the following facts remain:

- More than 80 percent of people eligible for Medicare don't know it offers a hospice benefit.
- Those who eventually receive hospice usually suffer too long from uncontrolled pain and symptoms before being referred.
- The average Medicare hospice patient's length of stay has decreased from 70 days at the Medicare Hospice Benefit's inception in 1983 to about 36 days in 2000, with more than half of hospice patients staying less than 25 days and more than one-quarter staying less than a week.
- Since 1998, nearly one-and-a-half times as many hospices have been going out of business annually than opening their doors.

The MHB pays for hospice services for people with terminal illnesses but limits eligibility to those with prognoses of six months or less. In general, this makes hospice more accessible to patients

dying of cancer, but less accessible to many who have terminal illnesses with lengthier or less predictable courses, such as AIDS, Alzheimer's disease, and progressive, fatal organ disease, according to Marilyn Moon, a Medicare expert at The Urban Institute and author of the recent study, "Medicare and End-of-Life Care." Patient access to hospice, Moon adds, is thus undermined by a persistent focus on prognosis rather than quality of life, inscribed in many federal and state policies, coupled with public ignorance about hospice and cultural denial of death.

One-fourth of Medicare spending goes toward end-of-life care, a percentage that has remained stable for years. By contrast, MHB spending accounts for less than 1 percent of Medicare's annual budget. This means Medicare is spending a lot of money in the last year of life on curative care for patients who have no hope of living for a long time, instead of on hospice care that focuses on comfort (usually at lower cost). This also means nearly half of Medicare beneficiaries die in the hospital, and another quarter die in nursing homes instead of at home, where the vast majority of hospice care is given and where most Americans want to die.

Hospices have long asked Congress to bring MHB per diems in line with actual costs. With budget constraints in mind, recent studies suggest other modest regulatory or legislative changes that would remove barriers to hospice access and improve patients' chances of getting their wish to die at home. This brief will explore the major policy barriers to patient access and the financial viability of what is universally recognized as the gold standard for end-of-life care. ■



*"The Medicare hospice benefit has not been updated since it was enacted over 20 years ago, and it is time for Congress to focus on how to improve end-of-life care and make it accessible across the board."*

Sen. Ron Wyden (D-Ore.)

# Primary Policy Promoters and Barriers to Hospice Access and Quality

In the 20 years since the MHB was enacted, hospice has grown from a community-based service staffed by volunteers to a professional health care sector reimbursed by government programs. Hospice enrollment has grown from 1,000 admissions in 1975 to more than 700,000 in 2000: one out of four Americans dying of any cause receives hospice. Such statistics prompted the Medicare Payment Advisory Commission (MedPAC) in 2002 to conclude that Medicare beneficiaries easily access hospice care and that the MHB is working as it should. Yet today's hospice patients are receiving about half the number of days of

care they did 20 years ago, making it more difficult for hospices to remain in the black. Also, the MHB is one of Medicare's smallest programs, accounting for just 2 percent of total payments. "Our nation spends an enormous amount of money to provide care at the end of life, yet few Americans access hospice care when they need it, or even know what hospice is," says Sen. Ron Wyden (D-Ore.), who in 2001 proposed hospice demonstration-project legislation.

Many in hospice think the six-month certification rule is the greatest access barrier. "I think providers focus on the

six-month rule as the problem when the barriers that are outside their control are more complex than that," says Jonathan Keyserling, JD, vice president of public policy at the National Hospice and Palliative Care Organization (NHPCO). Lack of access also results from "the cultural bias in medicine that hospice equals failure and the public's lack of a general awareness that hospice is available."

Explored below from both sides are the three policies most often cited as barriers to hospice access. Other policy barriers are explored beginning on page 4.

## Policy Promoters

### Medicare Per Diem, Not Fee-for-Service, Payment Plan

Hospice is widely acknowledged to be the first managed care program in the United States, and a very successful one at that. One aspect of its success is the per diem reimbursement scheme, which lets hospice manage each patient's care from enrollment through either the patient's death or termination of enrollment. This allows some hospices to go beyond the required services and lends flexibility not possible through a fee-for-service scheme.

### MHB's "Unlimited" Hospice Benefit

Medicare law does not time-limit the hospice benefit. Each patient may be recertified for an unlimited number of six-month terms, provided two physicians certify the patient as appropriate for hospice care and likely not to live past six months if the illness runs its normal course. Within the past two years, HCFA and CMS have issued a number of statements encouraging physicians not to feel unduly restricted by the six-month certification rule, recognizing that prognosis is an inexact science, reassuring physicians and hospice providers that doctors are expected to comply with this rule only by using their "best clinical judgment" when prognosticating, and stating that physicians will not be scrutinized over patients who outlive six-month prognoses.

### The MHB Helps Hospices Meet Patients Where They Live

Unlike European hospice programs, the MHB does not require patients to enter a hospice inpatient facility. The MHB's "routine home care" level pays for care in a variety of settings, including a patient's own home, a relative's home, or a nursing home. If the patient is only eligible for Medicare, the MHB pays the hospice for care delivered at home or a nursing home. If a nursing home resident is dually eligible for Medicare and Medicaid, the patient's hospice care is paid for by Medicare and the nursing home room and board is paid for by Medicaid. This is beneficial for all nursing home residents: a recent Brown University study showed that when hospice care is provided to a fraction of residents, all the residents in that nursing home receive better care.

## Policy Barriers

### Inadequate Medicare Per Diem Payment Rate

In the 20 years since the MHB was instituted, the gap has greatly increased between actual costs and MHB reimbursement levels. Drug costs in particular are estimated by one actuarial study to have increased by 1,500 percent, with an average per-patient-per-day cost of more than \$15, while the MHB daily medications allowance is \$2.48. Most hospices absorb the difference through charitable contributions and community support.

### Six-Month Prognosis Certification Requirement

During the 1990s' antifraud campaigns, the government required some hospices to repay millions in reimbursements for patients who outlived their six-month terms. The Department of Health and Human Services has expressed concern that because of the prognosis difficulties this rule places on physicians, and because of physicians' logical perception that this rule limits the MHB, patients are either not being referred to hospice, or are being referred too late in their illnesses for hospice to do much good. "We're the only area in health care where you have to evaluate the condition and decide what is needed before you even refer," says Mary Labyak, MSW, executive director of The Hospice of the Florida Suncoast, the world's largest program dedicated to palliative care. "If a patient has heart problems, you don't decide how to do a bypass and then refer to the cardiologist"—you refer first and trust the specialist to chart the treatment course, she says.

### Hardship for Nursing Homes and Their Residents

Nursing home residents eligible only for Medicare must pay their own nursing home room-and-board costs—which can be astronomical. Hospice advocates consider this a severe deterrent to electing hospice for the growing numbers of elderly dying in nursing homes. For dually eligible nursing home residents, the MHB pays for hospice costs and Medicaid pays for room and board at 95 percent of the nursing home's rate, forcing hospices to produce the other 5 percent out of their pockets. This places additional burden on hospices' already stretched financial resources.

## Other Policy Barriers to Patient Access and Hospice's Financial Viability

### Medicaid Payment for Hospice

Medicaid pays for care for about 8 percent of hospice patients, and many inconsistencies are built into this benefit, according to independent researchers Jane Tilly and Joshua Wiener of The Urban Institute. Tilly and Wiener further note that the 30 percent of dying patients who qualify for both Medicare and Medicaid—“dual eligibles”—are less likely to enroll in hospice than those who do not have Medicaid because of the laws' confusion.

### Hardships of “Pass-Through” Payment

The way Medicaid pays nursing homes for hospice patients also causes difficulty. Medicaid considers the hospice the primary caregiver and the nursing home the supplier of room and board—defined to include help with activities of daily living, medication management, supervision, cleaning the room, and prescribed therapies. Medicaid law requires states to pay hospices at least 95 percent of the nursing home's room-and-board rate—potentially saving the state some money.

This payment system causes several problems. Aside from hospice's need to make up the other 5 percent of the room-and-board rate (see p. 3), there are delays and disruptions in payment that occur when patients enroll in hospice and Medicaid switches from paying the nursing home to paying the hospice. This further reinforces the nursing home's incentive to keep the patient off hospice care.

### Hardships for Nursing Home Residents under the MHB

Medicare reimburses nursing facilities for nursing home residents' room and board under the Skilled Nursing Facility (SNF) Benefit. But when patients enroll in hospice, the beneficiary becomes liable for these costs. Tilly and Wiener concluded that this reimbursement structure creates a financial incentive for terminally ill patients discharged from hospitals to choose, at least at first, the SNF Benefit—despite its curative and rehabilitative nature—over the MHB, which may be more helpful but does not cover room and board.

These policies also create financial incentives for nursing homes to keep residents off of hospice and send them back to the hospital, says Suncoast's Labyak. The SNF Benefit “pays for 21 days in a nursing home,” she says, “then there's a co-pay for days 22 to 100. Then the patient spends down their assets [by paying for nursing home room and board out of pocket] until they reach Medicaid eligibility. Then the patient has a bad episode and goes to the hospital; when they're discharged into the nursing home they go back on Medicare for 100 days, then back on Medicaid. But Medicaid's payments are much lower” than Medicare's, so the nursing home's incentive is not to put the patient on Medicaid hospice; it is to send the patient back to the hospital somehow, so when they're discharged they go back on Medicare—“to ‘skill them,’ as they say,” Labyak notes. “At the very time they need us most, they don't get us.”

## Hospice Care in the Nursing Home

Nursing home residents at the end of life sometimes have a difficult time accessing hospice care because of confusing and burdensome requirements surrounding hospice care delivered in long-term care facilities (see above).

Brian Weichelt, right, did not encounter these difficulties. Diagnosed with end-stage cirrhosis of the liver, at the time of this photograph he was in the middle of his second six month term on hospice and was not expected to live more than six months. It is common for patients with chronic, fatal organ disease such as cirrhosis to live much longer than their physical condition indicates, and after Weichelt's first six-month eligibility

term expired his eligibility was renewed, since his physicians certified that he still met the conditions of eligibility.

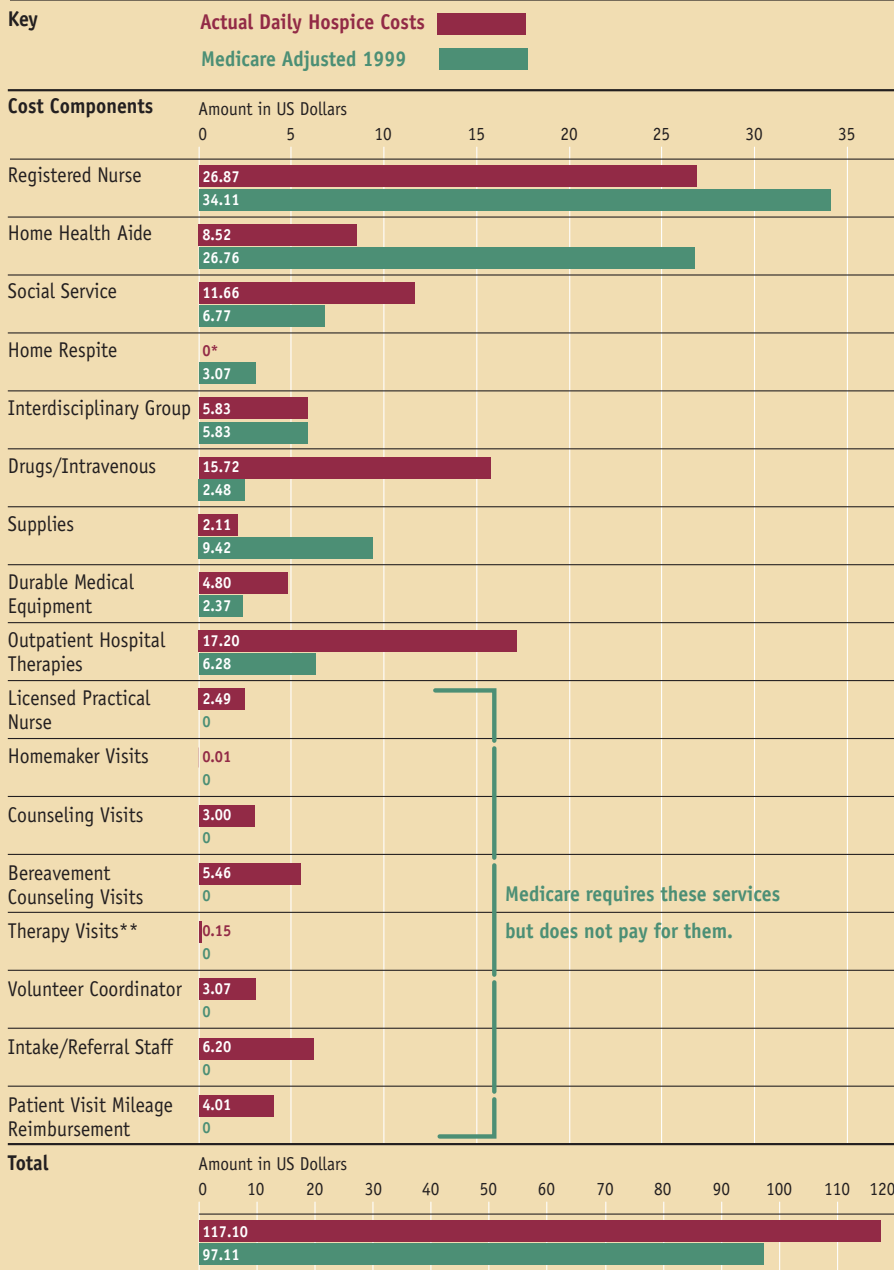
Chronic organ failure requires demanding hospice care: Rodgers visited Weichelt at least three times a week to drain his abdomen of fluid and control his other symptoms. Since Rodgers is also a Catholic nun, she is able to offer spiritual support to patients who desire it.



*Jeanne Rodgers, RN, a nurse with Forbes Hospice, Pittsburgh, checks the vital signs—including pain—of Brian Weichelt, 65, at his nursing home. Weichelt died in January 2002, during his second six-month hospice term.*

Jim Juckis

## What Hospice Costs, and What Medicare Pays For



\*Home Respite costs are reflected in Registered Nurse and Home Health Aide costs.

\*\*Therapy Visits include Physical, Speech, Occupational, and Respiratory Therapies

These charts illustrate the comprehensive range of hospice routine home care service, which comprises the vast majority of hospice care delivered under the MHB. Green bars show the reimbursement rates the MHB currently assigns to the components of hospice care that it considers reimbursable. Red bars show the actual costs of these components—and others—as estimated by a 2001 actuarial evaluation of the MHB completed by Milliman

USA Inc. As the graph illustrates, there are many service components that are required by the MHB but are not paid for by it (see also sidebar, p. 7). During the preparation of Milliman’s study, Congress enacted an interim 5 percent increase in the MHB reimbursement rates, but those working in hospice say that ever-rising costs—especially drug costs—erode some, if not all, of this reimbursement increase. (Sources: NHPCO; Milliman USA Inc.)

### CMS Survey Inconsistencies

The frequency of surveys and the Centers for Medicare Services’ (CMS’s) evaluation of whether patients are eligible for hospice have varied dramatically among regions. Surveyors often lack an understanding of end-of-life care and frequently expect to see assessments, interventions, and goals that are curative or rehabilitative in nature.

The frequency of and level of citations in the typical survey in some CMS regions also have changed dramatically. In some regions, surveyors are citing hospices with multiple deficiencies and threatening closure, while in other regions the same observations lead to suggestions for improvements with no citation documented. Tilly and Wiener note that hospices facing these unpredictable and difficult surveys have had to shift their focus away from working for positive patient and family outcomes to complying with administrative processes and red tape.

Finally, Tilly and Wiener add, CMS has given hospices arbitrary boundaries for service areas that preclude many rural patients from having access to hospice care.

### Regulations Placing Hospices in Financial and Ethical Hardship

Some CMS regulations put hospices in financially and ethically untenable positions. For example, CMS requires hospices to equip themselves to resuscitate all hospice patients lacking a signed do-not-resuscitate order. Yet the MHB does not reimburse hospices for the large costs of these skills and equipment, putting a further financial burden on hospices. Also, this requirement directly conflicts with the MHB rule that patients electing hospice forgo all curative treatment, potentially placing hospices in the ethically untenable position of being required to provide what their mission deems as standard care.

# Proposed Policy Changes to Improve Access and Financial Viability

“A careful look at end-of-life care ought to explore both hospice and traditional care settings to find areas of improvement,” notes Urban Institute Medicare researcher Marilyn Moon. The changes suggested below come from hospice advocates and independent researchers as well as the recent MedPAC report. Among the ambitious propos-

als are recommendations for changing hospice reimbursement rates and methods. “Even with attention to budget constraints,” Moon adds, “a number of improvements could be made through either regulatory or legislative changes on a modest scale.”

## Rethink Hospice Reimbursement

Not one of the modest proposals, but hospice advocates and independent researchers suggest ways payment could be changed to improve patients’ access and hospices’ financial viability.

### Make MHB’s Per Diem Reflect True Costs

The 2002 MedPAC report urged CMS to review the per diem’s capacity to cover costs of care. Beginning in 2001 CMS asked hospices to collect cost data, and these are starting to roll in, says Thomas Hoyer, director of CMS’s Chronic Care and Policy Group. He says, “We can probably learn what the average daily cost is on prescription drugs”—the cost that providers say has most dramatically increased. He notes, however, that CMS expects many of these initial data to be inaccurate; he also notes that, in any case, revising the per diem can only be done through an act of Congress. Furthermore, Hoyer believes hospices have not made the case that they’re not able to cover their costs on the current per diem. But Jay Mahoney, president and CEO of Summit Business Group, which conducted focus groups for MedPAC, disagrees: “I’m uncertain what kind of case has to be made. How many hospices would have to go out of business before the conclusion could be drawn that these hospices are underpaid?”

### Pay a Higher Rate for First and Last Days

“I would say our costs for the first and last days are about \$300 to \$400 each,” says J. Donald Schumacher, PsyD, CEO of The Center for Hospice and Palliative Care and the incoming president of the NHPCO. Says Mahoney: “It is much more difficult for a hospice program to provide the best services it can in a period less than 90 days.” Because lengths of stay have drastically decreased, “a higher per diem in the last seven to ten days of life might be appropriate . . . ensuring that payments for those with very short stays are adequate for their more intensive needs,” writes The Urban Institute’s Moon.

## Adopt an Outlier Policy for High-Cost Patients

Hospitals and other health care organizations routinely allow for “outliers” among their populations—those patients whose costs of care lie outside the average. “An outlier policy is a very useful one in payment reform—I agree with that,” says CMS’s Hoyer. “But none of these policies could be enacted immediately,” because they require an act of Congress.

### Re-examine the Medicaid Hospice Benefit

Ensuring that all states’ Medicaid programs include hospice would eliminate the policy that directly bars Medicaid beneficiaries in six states from receiving hospice. Also, eliminating the “pass-through” and requiring states to pay nursing homes directly for the room and board of hospice patients would alleviate confusion and aid the financial stability of hospices—but to the burden of nursing homes, unless and until Medicaid is required to pay the full room-and-board costs for nursing home residents receiving hospice.

### Re-evaluate Eligibility Requirements

Though many in hospice say that providers focus too much on this policy as a barrier to access, two recent studies have articulated the difficulties this policy places on providers, physicians, and patients alike. The 2000 Benefits Improvement and Protection Act (BIPA) requires the Secretary of Health and Human Services to study the appropriateness of the six-month certification rule.

On the other hand, many in hospice say the requirement to forgo what is often perceived as curative treatments spurs patients to delay hospice care until all hope for cure is lost. Mahoney says that focus groups conducted for the MedPAC report showed there are many patients who are appropriate for hospice but who never choose it, and having to forgo curative treatment, particularly chemotherapy, was one of the reasons. “Patients and families want the choice; they want to take that chance,” says Mahoney. “Their doctor

might tell them the chemo gives them a one in ten shot of living longer: Who doesn’t think they’re going to be that one? Physicians are hard put to say no.” And yet they must if the patient is to be eligible for hospice. Such patients—and there are many of them—are generally not going to elect hospice. “This creates a problem of access—these patients could benefit from hospice care, but it is either not presented as an option to them or they do not choose it,” Mahoney says.

## Educate Physicians and Beneficiaries

To overturn misconceptions about the MHB, Moon notes, Medicare could fund seminars and continuing education courses to clarify hospice benefit regulations and to publicize existing policies that few physicians know about, including their ability to recertify hospice patients who survive longer than expected. Better consumer information about all existing Medicare-funded end-of-life care choices, including the MHB, could be provided to beneficiaries, 80 percent of whom are unaware of the MHB. Doctors and attorneys, who play an intimate role in end-of-life care planning, should be included, says the NHPCO’s Keyserling. “The vast majority of people dying in America are elderly and covered by Medicare, so a public information campaign should be initiated or supported by the government,” he says.

## Consider Demonstration Projects

CMS-conducted demonstration projects could—temporarily and in a limited fashion—lift current reimbursement and eligibility policies in order to test potential adjustments in those areas. Trial changes to hospice reimbursement—to account for patients with short stays, or for those who need unusually costly palliative treatments—could reveal useful solutions to the difficulties with the current per diem that hospices report. Trial changes in the eligibility rules could test how it might work to allow hospice care to be available to a wider range of beneficiaries.

# The Hospice Consult: A Plan to Bring Palliative Care into Patients' Lives Earlier

Hospice providers have proposed an idea that they think may improve the current system more quickly than it could take to revise provisions of the MHB: the hospice consult. Hospice providers believe this would reach further back into the illness trajectory than hospice has been able to, given the policy and cultural barriers that many agree have reduced the average length of time hospice patients receive care.

## How It Would Work

The plan would give attending physicians authority to organize a series of consults with a team of palliative care experts. The consults could include a palliative care doctor, a nurse, and a social worker. It could take place as soon as a patient is diagnosed with a life-limiting illness, regardless of prognosis. The meetings could take place in any setting—in patients' own homes, nursing homes, or assisted living facilities, for example.

Currently, only physicians can provide such consultations to non-hospice patients, and they can receive reimbursement only under Medicare Part B. For many years, physicians with palliative care expertise and concern have been using this method to give this care to non-hospice patients in nursing homes and hospitals. But currently there is no way to get payment for the other members of an interdisciplinary palliative care team—those

*Continues on page 8*

## Bereavement Counseling—One of Several Services Medicare Requires but Doesn't Pay For

Many patients and families don't know that hospice serves the family as well as the dying patient—for example, Medicare-certified hospices are required by Medicare law to provide a year of bereavement counseling to survivors. Medicare, however, does not reimburse for this. A recent actuarial study of the MHB estimated that the per-patient-per-day cost of this service is \$5.46. When multiplied by the number of hospice patients receiving care per year, the total amount hospices have to raise in charitable contributions to cover the cost of this single service is nearly \$4 million.

Similarly, there are a number of other services Medicare requires but does not reimburse for. These include:

- physical, occupational, speech, and respiratory therapy visits
- counseling/chaplain services
- homemaker services
- the work of intake and referral staff



*Hospice nurse Ailene Josephs pays a visit to a bereaved man whose wife has recently died under the care of Forbes Hospice. She offers comfort as they look at photographs of his wife.*

Kristin Petersen

- volunteer coordinators' work (hospices are required to provide a certain proportion of their services through volunteers)
- licensed practical nurses and nurse practitioners, which rural hospice depends upon

Rural hospice programs face special challenges. One-fourth of Medicare beneficiaries live in rural areas and are served by rural hospices, which comprise nearly one-third of all hospices. Rural hospices deal with more frequent and difficult social issues—including profound poverty, illiteracy, alcoholism, drug abuse, domestic violence, and staff safety—all of which affect the way care is delivered. Their

costs are higher, and their reimbursements are often lower. There are fewer charitable organizations in rural areas, and with an average of just five patients per day, rural hospices daily live close to the margin and must make every penny count. Rural hospices face the following special challenges created by policy barriers:

- vehicle mileage, which Medicare does not pay for, is higher than in urban areas
- resulting higher costs in routine and emergency delivery of medicine, supplies, and equipment
- dependence upon tele-medicine, whose infrastructure—beepers, cell phones, etc.—is not reimbursed by Medicare

## The Hospice Consult: A Plan to Bring Palliative Care Into Patients' Lives Earlier

Continued

who work together to provide the multifaceted attention that hospice has established as the hallmark of top-flight palliative care.

The hospice consult would not require patients to abandon curative therapies, but rather proposes to combine these with palliative care and advance care planning. "Part of the hospice consult is, 'OK, you can hold onto your curative wishes and your treatment, but you have to understand that you also need to make some plans—both for your curative wishes and because your life may now be more limited,'" Keyserling says.

At so early a stage in the illness trajectory, many patients who would qualify for a consult would not meet the six-month prognosis the MHB requires. For this reason hospice advocates have envisioned the consult as a separate Medicare program outside of the MHB, says Keyserling.

### Who Would Qualify, and When

The hospice consult would apply to patients in the early stages of life-limiting illnesses who are not yet eligible for hospice but whose diagnoses obviously indicate the need to make plans, and whose treatments—aggressive chemotherapy and radiation, for example—may necessitate pain and symptom control. Hospice and other palliative care teams are qualified to consult about this type of symptom control, but they are not permitted to do it or be paid for it—so, often, patients don't receive it. Schumacher says the hospice consult could also benefit patients "the second time around—when a life-limiting cancer recurs."

"If the patient is well and not very symptomatic yet, the hospice medical director might say, 'Here are some of the things that have happened to other people in the past. If any of these things should happen to you, we're here to help you.' So the patient has a safety net," Schumacher says.

Suncoast's Labyak adds, "The group of people who unilaterally get closed out of hospice is when Medicare pays for the nursing home." With a hospice consult, she says, "These patients could get a visit or two from a palliative care team to get them on a good pain regime."

### Making the "Palliative Care Lesson" Systemwide

A version of the consult has been included in a Medicare provider bill that may be acted on by Congress. Critics have raised questions about the consult's potential to divert patients toward hospice programs and away from palliative care specialists in hospitals and other inpatient units. Hospice has responded to these criticisms by emphasizing that the consult proposal, as it has been drafted, "will not preclude practitioners already providing these services," Keyserling says.

"With 6,940 hospitals, 20,000 nursing homes, and about 6,000 home health agencies, it's not likely that the government will shift all that [palliative care] business over to hospice," CMS's Hoyer notes. "The likelihood is that it will be a systemwide move. It needs to be that everyone learns the palliative care lesson." ■

# State Initiatives in End-of-Life Care

## Information about the Series

"Hospice Care—Part II: Barriers to Hospice Care and Some Proposed Policy Solutions" is the seventeenth in a series of briefs profiling promising new policies and practices in end-of-life care.

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