

# HOSPICE Management ADVISOR

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## Conflict between hospice, nursing homes can impede end-of-life care

*Each side must understand the other and be willing to cooperate*

Almost any way you approach it, referrals from nursing homes are difficult to come by. There is the clash of organizational cultures, the pass-through payments, and other reimbursement concerns that create barriers.

Medicaid recipients living in nursing homes are especially vulnerable to being excluded from hospice care, and an emerging reimbursement trend in some states is removing what little financial incentive nursing homes have to refer their patients to hospice care.

In states like Kentucky and Pennsylvania, dying patients, who often require the most intensive care, are treated as outlier cases and are being excluded from the nursing homes' case-mix adjustment formula. The effect is to lower the reimbursement that a nursing home receives for a patient.

In recent years, Medicare established a prospective payment system — much like the diagnosis-related groups implemented in hospitals in the early 1980s — for post-acute providers, including nursing facilities. The idea was to move away from cost-based reimbursement, which encouraged spending, to a system that pays on a per diem that is adjusted based on case mix and regional wage differences. The reasoning behind the change, which was part of the 1997 federal Balanced Budget Act, was to encourage cost-effectiveness among home health agencies, skilled nursing facilities, and other long-term care facilities.

State-sponsored Medicaid programs soon followed suit, adopting either the same case mix adjuster used by Medicare (the Resource Utilization Group System III) or one of their own. But in an effort to further wring out greater efficiency, some states are removing hospice patients from the case mix calculation, says **Cherrie Meier**, a nursing home consultant for the National Hospice and Palliative Care Organization in Alexandria, VA, and director of public affairs for Vitas Healthcare Corp. in Austin, TX.

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Each day of payment is based on an assessment of the patient's clinical and functional status using the Minimum Data Set assessment tool. Case-mix adjustment accounts for the fact that providers treat patients with varying degrees of severity. The higher the severity, the greater the per diem amount paid to the provider for caring for the patient.

Employing a case-mix adjuster encourages nursing homes to take on the sickest patients, rather than dump them in other institutions or admit them to a hospital. Because dying patients require greater amounts of skilled nursing, nursing homes are reluctant to refer the patient to hospice and lose out on revenue.

The outlier exemption from case mix adjustment is only the latest in a number of disincentives that have plagued the nursing home/hospice relationship. Others include:

- **Pass-through provision.** Because Medicare and Medicaid are averse to paying two providers for the care of one patient, Medicare and most Medicaid payers reimburse hospices for the universe of care provided to a nursing home patient. Included in the payment is the nursing home portion for room and board. This often leads to slower payment compared to direct payment from Medicaid as a result of electronic filing of required documentation.

- **95% reimbursement for room and board.** Hospices are paid 95% of the cost of room and board, which they are expected to pass along to the nursing home. Unless the hospice is willing to chip in the last 5% to cover the entire cost of room board, nursing homes are often unwilling to discount the cost of the patient's stay.

- **Culture and organizational clashes.** There seems to be an underlying mutual misunderstanding between nursing homes and hospice. For example, hospice staffers sometimes view nursing homes as lacking in end-of-life care training, despite the belief among nursing home personnel that they too are providers of end-of-life care.

Because of the last reason, nursing homes have balked at making hospice referrals, says **Susan Polniaszek**, senior reimbursement policy analyst for the American Association of Homes and Services for the Aging in Washington, DC. "I don't think the money issue is a reason," she says. "Nursing homes do palliative and end-of-life care. In some cases they don't need to refer a patient to hospice. Other nursing homes don't understand hospice care, and hospice doesn't understand nursing homes."

Still, hospices need to find a way to surmount the economic and social barriers that exist. A 1998 five-state study underscored the need for hospice expertise in nursing homes. It showed widespread untreated pain among elderly nursing home residents with cancer, especially among the oldest and minority patients.

The study, which was published in the *Journal of the American Medical Association*, concluded that there is room for dramatic improvement when it comes to treating and managing pain in nursing home populations.

Researchers examined data collected on 13,625 cancer patients ages 65 and older discharged from hospitals to 1,492 nursing homes from 1992 to 1995. In total, 4,003 patients reported daily pain. Of those, 16% received a simple analgesic such as aspirin or acetaminophen. Thirty-two percent were given codeine or other weak opioids, and 26% received morphine. However, 26% of patients with daily pain received no analgesics, not even an aspirin or acetaminophen tablet.

Patients who were 85 or older and experienced daily pain were about 50% less likely to receive any analgesic than those ages 65 to 74 years. Only 13% of patients ages 85 years and older received codeine or other weak opiates or morphine, compared to 38% of those ages 65 to 74 years.

African-Americans were 50% less likely than whites to receive any analgesics. Although not statistically significant, a similar trend in the data was noted for Hispanics, Asians, and American Indians.

### ***Hospices, nursing homes should join forces***

For Meier, the answer lies in convincing Medicaid officials in the 38 states that currently offer a hospice benefit to review their policies and make the needed changes to enhance the transition between nursing home and hospice care. Also, hospices and their state hospice organizations should join forces with nursing home trade groups to lobby for changes at the state level, Meier adds.

While changing Medicaid rules and regulations will ultimately lead to greater opportunity for referrals, true improvement will not come until hospices take the time to understand their nursing home counterparts.

"Hospices must understand that nursing facilities are the most regulated industry next to the nuclear industry," says Polniaszek. "The contract between the hospice and the nursing home

must be spelled out so that both sides know who is responsible for what. And hospices must understand that no matter who has [clinical management] of the patient, the nursing home is physically liable for that patient.” (See **sample contract, p. 100.**)

A dialogue between hospices and nursing homes is the first step to expanded referrals, says Polniaszek. Hospices must understand that nursing home staff not only lack training in palliative care, but strict regulations prevent them from using drugs the same way hospices use them.

In addition to regular inservice training, hospice workers need to have an ongoing training component. For example:

- Bring written literature about your hospice and its mission to the nursing home when visiting a patient. This will help educate new nursing home employees who have not yet had hospice inservice training.
- Invite nursing home staff to your hospice’s hospital inservice training.

- Make your palliative care services available to nursing homes. Even though a hospice cannot receive payment unless the patient has a terminal illness diagnosis, this gesture creates excellent goodwill, which can lead to future referrals.

Hospices, too, could benefit from some education. Nursing home staff often are frustrated by hospice staffs’ seemingly cavalier attitude toward nursing home policies. For instance, hospices sometimes do not appreciate the strict schedule of patient assessments required by Medicare. The Minimum Data Set (MDS), a lengthy patient assessment form, must be completed every 30 days for the first 90 days of care and every 60 days after that. Even though the hospice owns clinical management of the patient, the nursing home still must complete the MDS because the patient is still a resident of the nursing home. Because hospice is providing a significant portion of the care, hospice input and assistance are needed to complete the assessment. ■

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## Traps to look for when coordinating care

*10 areas require particular attention*

While better cooperation among hospices and nursing homes will result in better end-of-life patient care, there are snares and traps awaiting any cooperative effort. Here are 10 areas where nursing homes and hospices can become entangled in conflicting policies and regulations:

**1. Coordination of billing.** The organizations need to decide who will bill for which services. This includes understanding the responsibilities of clinical management of the patient and distinguishing routine care provided by nursing home staff.

**2. Patient self-determination and advance directives.** Both organizations are responsible for ensuring the patient’s rights to informed consent are being respected. To ensure the patient’s wishes are being carried out, nursing homes are required to inform patients of their right to formulate an advance directive that establishes special power of attorney, a living will, and a medical treatment plan. For the hospice’s part, it should ensure that an informed consent form specifying the type of services that could be provided by the hospice is obtained for each patient.

**3. Resident assessment.** Hospices must cooperate with nursing home staff to ensure timely completion of the Minimum Data Set (MDS), either by agreeing to complete the form based on a working knowledge of the patient or by providing the needed information to nursing home staff responsible for completing the MDS.

**4. Comprehensive care plans.** While both hospices and nursing homes have care plans, they come with different requirements. For example, nursing homes are required to review and update their care plans every 30 days for skilled-nursing patients and quarterly for long-term care patients. Hospices do not have the same requirement. The result can be two care plans for one patient evolving in two very different ways. Both organizations must strive to coordinate their care plans so that they account for each other’s goals and are updated at the same time.

**5. Professional communication.** To facilitate coordination of care plans, standard mechanisms should be in place to notify each provider of changes in the care plan or changes in the patient’s condition. Johnson suggests each organization designate a staff member as the person to call when changes are made and to coordinate how the changes will be handled. For example, a hospice might designate the on-call nurse as the liaison so that the nursing home is assured of reaching a nurse who is able to make sure changes are noted

and care is provided in a timely manner.

**6. Interdisciplinary team.** Both nursing homes and hospices use a variety of disciplines to treat their patients. Each organization depends on the interaction of these disciplines to help determine the best course of care. When a hospice comes into a nursing home, the need to recount observations and communicate changes in care does not diminish. There is a need for both interdisciplinary teams to work together. Johnson suggests that each organization include a representative from the other's team to act as a liaison between the two groups.

**7. Physician services and visits.** Hospices need to teach nursing homes that physician-directed interdisciplinary care is an essential component of hospice. The nursing home physician must clarify his or her role with hospice, including whether that physician or the hospice medical director will certify the care plan and services to be provided.

**8. Medications.** This area has the greatest potential for conflict. Nursing homes must follow specific regulations for certain drugs, such as psychotropic and anti-psychotic drugs. Before nursing homes can use them, there must be a specific diagnosis, such as depression or mental illness. Hospices, on the other hand, use some of these drugs routinely as part of their pain management arsenals. A conflict can arise when a hospice has placed a resident on one of these drugs to manage pain, but a nursing home nurse refuses to administer the drug because the patient doesn't have the required diagnosis. If the nursing home nurse would have been properly educated about the hospice's pain management plan and told why the drug in question was being used, the patient would not have been forced to suffer needlessly while the two sides straightened out their differences.

**9. Clinical records.** When a hospice comes in to treat a nursing home resident, it must establish a patient record. But that record also represents care delivered while the patient is a resident of the nursing home. Nursing homes and hospices must agree on how they will share their records, including which organization keeps the original copy.

**10. Nursing home staff training.** Hospices need to establish a collaborative training program with their nursing home partners. Hospices often treat facility staff training as a work in progress. For training to take root, hospices must make sure nursing home administration is taking part.

With high-level management participation, there is a greater likelihood that the concepts taught will remain with the organization, despite the high turnover rate of nurses and aides. ■

## Include these items in nursing home contracts

*Agree on terms at the outset*

While good communication will enhance the hospice/nursing home relationship, a good contract is the foundation. To avoid misunderstandings, the contract should be as specific as possible so that both sides have a clear picture of their responsibilities.

Below is an outline of the key elements of a contract that was developed by the Wisconsin Department of Health and Family Services. While not intended to be a cookie-cutter contract, it touches on most of the items that should be agreed upon in a hospice/nursing home contract.

### 1. Recitals

**2. Definitions** (particularized to individual needs and terminology)

- Attending Physician
- Care Manager
- Covered Services
- Facility
- Hospice
- Hospice Care
- Hospice Medical Director
- Hospice Services
  - Routine Home Care
  - Inpatient Respite Care
  - Continuous Care
  - Inpatient Acute Care
- Informed Consent
- Interdisciplinary Group
- Non-covered Services
- Nursing Home Medical Director
- Patient Care Management
- Plan of Care
- Residential Hospice Patient
- Respite Care
- Room and Board Services
- Other Pertinent Definitions as Identified by

the Parties

- Bed Hold

### 3. Eligible Residents (criteria)

- Medicaid Eligible
- Medicare Eligible
- Medicaid/Medicare (dual eligibility)
- Private Insurance or HMO
- Private Pay
- Other Pertinent Sections As Identified by the Parties

### 4. Coordination of Services

- Admission Procedures (general process, written orders, authorizations)
  - Patient Care Management (decision process, delegation of responsibility)
  - Continuity of Care (transfers between levels of care, actions requiring patient notice)
  - Communication Process (detail the process generally and for emergencies)
    - notification of MD (change of condition, death, etc.)
    - notification of hospice
  - Interdisciplinary Team Meetings
  - Quality Assurance/Performance Improvement
- Drugs and Pharmaceuticals
- Medical Equipment and Medical Supplies
- Transportation and Ambulance
- Family Services and Bereavement Care
- Other Pertinent Sections as Identified by the Parties

### 5. Hospice Duties, Responsibilities and Services

- Hospice Services (general coverage under Routine Home Care), Access and Availability
  - Provision of Core Services
  - Compliance with Law (including licensure, staff qualifications)
  - Hospice Patient Care Management
  - Management of the Terminal Illness: Plan of Care
    - Medical Order: Responsibilities of Attending Physician
    - Medical Order Procedures
    - Documentation (clarification of respective duties, location of original medical record)
    - Confidentiality of Medical Record
    - Orientation and Education
    - Other Pertinent Sections as Identified by the Parties

### 6. Facility Duties, Responsibilities and

### Services

- Facility Services (generally, room and board, specific services, plan of care, cooperation with hospice in identified areas, bedhold policy)
  - Compliance with Law (including licensure, staff qualifications)
  - Availability of Nursing Home Care (hours of care, adequate services, personnel)
  - Documentation (clarification of respective duties, location of original medical record)
  - Facility Staff Privileges: Hospice Medical Director
    - Access to Documents (medical/business records, federal record retention requirements for facility, subcontractors)
    - Orientation and Education
    - Other Pertinent Sections as Identified by the Parties

### 7. Financial Responsibility

- Responsibility of the Hospice
- Responsibility of the Facility
- Reimbursement
  - Medicaid Patients
  - Medicare Patients
  - Medicaid/Medicare Patients
  - Private Pay/Insurance Patients
  - Purchase of Services by the Hospice from the Facility
  - Other Pertinent Sections as Identified by the Parties

### 8. Insurance and Indemnification

- 9. Joint Review of Hospice Services (quality, appropriateness)

- 10. Compliance with Government Regulations (caregiver background checks, nurse aide registry, corporate compliance, etc.)

### 11. Relationship Between the Parties

### 12. Conflict Resolution Process

### 13. Term of the Agreement (length, renewals)

- 14. Termination of the Agreement (for cause/without cause, events precipitating regulatory implications, resident transfers and single-case continuation agreements, resident notice timeframes)

### 15. Amendments to the Agreement

**16. Notice Requirements** (form, method, and delivery)

**17. Miscellaneous** (including non-discrimination policy)

**18. Other Pertinent Sections as Identified by the Parties**

**19. Appendices** (if desired, may include references to provider policies, clinical protocols and procedures) ■

## Hospice Medicare benefit in need of changes

*MedPAC changes offer new hope*

In 1977, Hospital Home Health Care in Torrance, CA, began offering hospice services under the limitations of the home health Medicare benefit. That meant the home health agency provided home visits to dying patients who only had skilled nursing needs and were homebound. Clearly, this limited the number of terminally ill Medicare patients they could serve.

On the other hand, volunteer hospices did not rely on Medicare for reimbursement and were not subject to its regulations. Still, those same hospices, regarded as a novelty in the early days, struggled to raise enough money to care for more than a few patients at a time. Hospitals also tried opening inpatient hospice units. But for all their efforts, hospital hospice staff knew that many dying patients were going home to die rather than spending their last days in institutional surroundings.

Whether its leaders knew it or not, the hospice industry — barely a decade old in the United States at the time — was at a crossroads. Hospices were mostly either tiny volunteer organizations or branches of home health or hospital programs struggling for credibility. Change was set in motion in 1980 when 26 hospice programs took part in a Medicare hospice demonstration project that wound up largely defining how hospices are reimbursed today.

September marks the 20th anniversary of the Hospice Medicare Benefit, and for better or for

worse it remains the most important development to take place in the industry since hospice was brought to the United States in the early 1970s.

“Physicians began to take notice,” says **Claire Tehan**, MA, administrator for TrinityCare Hospice in Torrance, CA. Tehan was hospice director of Hospital Home Health Care during its participation in the demonstration project in the early 1980s. “We gained a lot of credibility with physicians. It was such a boost for us.”

“It allowed us to take a part of the population — those who were dying at home — that we couldn’t reach, provide care, and get reimbursed for it,” says **Nancy Warner**, MHA, RN, chief executive officer of Orleans-Essex Hospice in Newport, VT, which was one of four Vermont hospices that participated in the first hospice demonstration project.

“Our excitement was for the patient,” says **Judy Naghorn**, MSW, a social worker with Unity Hospice in Green Bay, WI. Naghorn started with Unity as a volunteer in the 1980s, when it was Bellin Hospice, an inpatient program under Bellin Hospital.

“We sensed that a lot of people could be helped at home,” says **John Machek**, MDiv, chaplain with Bellin Hospital. “But it was difficult to reach people at home because the homebound requirement was interpreted so strictly.”

### ***The good, the bad, the ugly***

After two decades of being beholden to Medicare’s regulations, those who took part in the original demonstration that started it all say the Medicare hospice benefit was the best thing to happen to hospices.

“Absolutely. The hospice benefit has been a good thing,” says Warner. “I feel that the conditions of participation [COPs] are not burdensome. The COPs give plenty of leeway for a hospice to come up with a care plan that is best for the patient.”

Certainly, hospices have much to be grateful for. They are less strictly regulated than some health care providers, such as nursing homes, for example. Most of the elements of hospice care that the original participants value highly — an interdisciplinary approach, spiritual care, and the use of volunteers — remain part today’s benefit.

There have been changes, though, some of which threaten the survival of many hospices. During the demonstration project, no certification of terminal illness was required. It wasn’t until the

Hospice Medicare Benefit was enacted in 1982 that the terminal illness requirement was included. "I remember people staying a lot longer back then — months, it seemed — rather than the few days we see now," says Tehan.

At the time, the certification seemed appropriate, but as therapies have improved, more patients are pinning their hopes on curative efforts. The result has been a steadily declining length of service since the benefit was enacted.

In addition to declining length of service, reimbursement for hospice care has failed to keep up with the changing times, including new pain relief therapies and the costs of drugs and supplies.

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, commissioned actuarial firm Milliman & Robertson to study hospice reimbursement. The 2000 study compared cost data from when the Medicare Hospice benefit was first established to cost figures from 1998-1999. The study pointed out a number of areas in which Medicare has failed to keep up with hospice costs:

- **Patients are enrolling in hospices later.** With patients electing the hospice benefit closer to the time of death, there is less revenue opportunity for hospices. According to the study, the average length of service has dropped to 40 days, while the original Medicare hospice benefit set the original rate based on a 70-day length of service.

- **New technology has increased costs.** Advances in technology, breakthrough therapies, and prescription drugs have increased the cost of hospice care far beyond Medicare's annual market basket update, which is used to determine annual reimbursement increases. While the hospice per diem rate has doubled since the early 1980s, prescription drug costs, for example, have risen 1,500%, from about \$1 of the per diem rate in 1982 to \$16 of the per diem rate in 1999.

- **The use of outpatient hospital therapies has increased.** Palliative care chemotherapy and radiation treatment now costs more than \$17 per day. Medicare originally allotted about \$3 of the per diem reimbursement to cover this component.

In 1982, when hospice care was added to the Medicare benefit, the routine home care rate was set at \$41.46 per day. At the time, the reimbursement rate did not include an annual inflationary update. It wasn't until subsequent congressional action that a specific rate increase was included when legislation tied it to the hospital market basket.

While those who took part in shaping the Medicare Hospice Benefit agree that it has largely been a boon for the hospice industry, there is equal consensus regarding a need for change.

"[The Hospice Medicare Benefit] worked for a while," says Tehan. "But what has changed is the courses of therapy; they are a lot more expensive. How we are reimbursed needs to be revisited."

Chief among the issues that must be reviewed are the eligibility requirements for hospice, specifically the need for a terminal illness certification by a physician, and more timely access to hospice care.

Last June MedPAC, Congress' advisory panel on health care delivery and financing, asked the U.S. Department of Health and Human Services (HHS) to evaluate the adequacy of Medicare's payments to hospices for providing end-of-life care to patients and families. In its hospice report, MedPAC made two specific recommendations to HHS, which administers the Medicare program:

1. Evaluate hospice payment rates to ensure they are consistent with the costs of providing appropriate care.
2. Research differences in the care and resource needs of hospice patients and determine whether a case-mix adjusted payment system for hospice is feasible, and study ways to establish a high-cost outlier policy.

### ***NHPCO advocates palliative care consultation***

The NHPCO recently stepped up its efforts to improve the benefit by lobbying lawmakers to include palliative care consultations as part of the hospice benefit. The concept calls for the development of a series of palliative care consultations that could take place as soon as a patient is diagnosed with a life-threatening illness. At this early stage in the progress of the disease, the patient would probably not meet the hospice eligibility requirement that he or she must have a prognosis of six months or less to live. Under the palliative care consultation concept, a patient would not have to waive curative care in order to take advantage of this consultation.

One thing that will not change, despite the grumbling of hospice workers, is the need for documentation. Pioneers of the benefit say it's a small price to pay for the credibility the benefit has brought the industry.

"When you take money from the government, you're going to be regulated," says Tehan. ■

# Hospice and Medicare: 20 years of growth

*It began as a cost savings initiative*

Hospice was made eligible for Medicare reimbursement under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), about 10 years after hospice was introduced in the United States. While the first standards for hospice care were formulated in 1974 by a committee of the International Work Group on Death and Dying, Medicare did not have any formal standards for the treatment of the terminally ill, nor did it offer reimbursement for services related specifically to palliative care.

Governmental initiatives and not-for-profit foundation funding fueled the spread of hospices across the country. Typical of this trend were grants to three hospice demonstration projects in 1978 by the National Cancer Institute to study costs of care and types of care provided. Eventually, this led the Health Care Financing Administration (HCFA) to initiate its own research and demonstration studies to examine the costs, benefits, and feasibility of having Medicare pay for hospice care.

The Robert Wood Johnson Foundation and the John A. Hartford Foundation also supported early hospice research. The W.K. Kellogg Foundation in 1981 awarded a grant to the Joint Commission on Accreditation of Hospitals to investigate the status of hospice in the United States and develop standards for accreditation.

Congress in 1982 introduced hospice into the Medicare program as a cost-savings provision after a Congressional Budget Office study asserted that hospice utilization would result in sizable savings over conventional hospital care. Because the benefit was created so quickly and represented a new area of health care, two special provisions were included in the legislation. First, a sunset provision stipulated that without congressional intervention, the law would expire in November 1986. Second, an evaluation of the impact of the benefit was mandated.

Initially, Medicare's hospice benefit consisted of three benefit periods, with a lifetime limit of 210 days of coverage. Patients who lived longer but who still required hospice services were cared for by the hospice without charge to Medicare or the patient as a condition of providers' participation

in the program. Further, if patients were unable to pay for services, the hospice was not allowed to discharge them on that basis. The belief was that by putting hospice providers at risk for delivering services after a given length of time, they would only enroll seriously ill beneficiaries, despite the difficulties of predicting survival.

According to Medicare, the benefit was limited to 210 lifetime days for several reasons. First, the limit was consistent with results from the National Hospice Study, which found that more than 95% of the 15,000 patients in the study were on hospice for fewer than 210 days.

Also, hospice was cost-effective for shorter episodes, which Medicare considered to be stays lasting up to 100 days. The saving associated with reduced hospital use in the last weeks of life was offset by the cost of additional services in longer hospice episodes.

Recognizing the difficulty of making a prognosis of six months or less, Congress later repealed the 210-day limit for services furnished on or after Jan 1, 1990. Four benefit periods replaced the 210 days: The first two were limited to 90 days each and the third period to 30 days, while the fourth period was unlimited. However, beneficiaries could have no more than four benefit periods.

The original Hospice Medicare Benefit (HMB) established four graduating levels of hospice care that are still used today: routine home care, continuous home care, inpatient respite care, and general inpatient care. The 1982 HMB also established another fixture of hospice care — the interdisciplinary team: physician, registered nurse, social worker, and pastoral or other spiritual counselor. The HMB called for the collective team, including the patient and family, to participate in assessing, coordinating, and providing the appropriate palliative and supportive care to hospice patients and their families.

That concept now is one of the hallmarks of hospice care. The hospice team helps establish the patient's plan of care, providing or supervising hospice care and services and periodically reviewing and updating the care plan. The interdisciplinary team also manages the patient's discomfort and symptom relief. Implicit in the interdisciplinary team concept is the idea of communication among the team members, and among team members, the patient, and the patient's family, to ensure continuity of care. Unlike multidisciplinary care, in which each area decides what is best from within its own

discipline, everyone on the hospice interdisciplinary team offers input on all issues facing a patient.

The original hospice legislation required hospices to use volunteers and to keep records tracking their use. TEFRA also required hospices to track any cost savings or expansion of care provision facilitated by the use of volunteers. Volunteers were considered key to the hospice movement. Although the number of volunteers hospices used varied markedly, proponents thought that volunteers' continuous involvement was important in preserving the hospice philosophy. The final hospice regulations contained a requirement that volunteer efforts should account for at least 5% of total hospice personnel efforts. This requirement was added because HCFA said the intent of the law was to develop standards to monitor the level of volunteer activity so as to prevent substantial diminution of the proportion of volunteers.

### **20/80 provision emphasizes home care**

The hospice benefit was designed so that most services were provided in the patient's home. To support this focus, TEFRA contained a 20/80 provision, which limited a provider's total inpatient care days to 20% of all care delivered during a year by a given hospice. This provision did not apply to each individual, because some patients might need to stay far longer in an inpatient setting. The provision was intended to control costs, prevent the program from becoming an exclusively inpatient model, and preserve hospice's philosophy of care in a home environment.

Another major provision of the original Medicare hospice legislation was that hospices assess families' bereavement needs. Although payment stops at the time of death, hospice providers have always been required to provide bereavement services for up to one year following the death of a patient.

In 1986, the Consolidated Omnibus Budget Reconciliation Act (COBRA) repealed the sunset provision for Medicare's hospice benefit included in TEFRA. In addition, COBRA stated that terminally ill patients residing in nursing facilities could elect Medicare hospice care and be paid Medicare's routine home care rate. COBRA also gave states the option of adding a hospice benefit to their Medicaid programs. Today, 38 states have hospice Medicaid benefits. ■

## **Study: Cancer pain undertreated in minorities**

*More than a communication problem*

Yet another study suggests that minorities are poorly cared for at the end of life. Cancer pain among minorities often goes undertreated compared to cancer pain among whites, according to the study, which was published in the April 15 issue of the journal *Cancer* (2002; 8:2295-2304).

Researchers talked with 31 cancer outpatients, 17 of whom were Hispanic and 14 African-American. Many of the participants told researchers that they didn't understand the best way to use pain medications or that they hadn't been warned in advance about possible side effects and how to control them.

Researchers also found that 75% of the patients said they experienced severe pain. While they got information from many sources, patients told the researchers that doctors are the most frequent and most trusted sources for information regarding cancer and cancer-related pain.

"There seems to be a problem in communication," said lead author **Karen O. Anderson, PhD**, at M.D. Anderson Cancer Center in Houston. "Patients may be reluctant to talk about their pain. Doctors and nurses don't always do a good job of asking about it."

In this study, some patients didn't want to discuss their pain because they felt they should be able to bear it. Others were concerned about the potential for addiction. Some patients stopped taking their medicine because of unpleasant side effects. For example, pain medicine often causes constipation. "They should have been warned about this [constipation]," Anderson said. "They should have been given steps to prevent it. Often [doctors] use a high-fiber diet, mild laxative, or stool softeners to prevent these problems."

Communication is only part of the problem, says **John Finn, MD**, medical director for Hospice of Michigan in Detroit and a pain management expert. "The issue is fairly more complicated than lack of communication," he says. "What is evident is that minorities do get worse treatment than everyone else."

The study alludes to two other important factors: patient reluctance to take pain medication and physicians' lack of training in pain management.

Finn suggests that understanding cultural differences among African-Americans, Hispanics, Asians, and whites leads to an appreciation of the complexity of addressing pain management among minority groups.

For example, among African-Americans, there often is a mistrust of the health care system. He suggests that communication between African-Americans and their physicians may be hampered by an assumed mistrust. Physicians must make a stronger effort to explain courses of treatment and listen to patient concerns in order to gain their trust.

Inner-city pharmacies contribute to the pain management divide. Many pharmacies in impoverished neighborhoods do not stock narcotic drugs out of fear of being robbed or burglarized. This contributes to reduced access to pain management drugs among minorities, who often are the majority in such neighborhoods. In addition, people living in high-crime neighborhoods are reluctant to keep these drugs at home for the same reasons pharmacies do not stock them.

Also, the way health care providers measure pain is an issue. Rather than arbitrarily choosing an unacceptable level of pain for the entire population, health care providers need to gauge pain on individual preferences. For example, if five of 10 people report pain of more than a 5 on a 1-to-10 scale, it would be reported that half the patients were made to endure moderate to severe pain. Instead, providers should consider an individual's tolerance for pain, which is often based on cultural factors. For example, Hispanics, with their deep roots in Catholicism, may be willing to endure higher degrees of pain. Also, fear of addiction is prevalent among minorities.

### **Not the first study**

This study follows another study that concluded that minorities are significantly less likely to receive appropriate pain medication for a number of painful conditions, including cancer-related pain. Literature suggests that physicians evaluate pain equally, whether you're African-American, Hispanic, or white, but for some reason, there

appear to be differences in prescribing practices, says **Stacie Pinderhughes**, MD, assistant professor of geriatrics at the Mount Sinai School of Medicine in New York City.

Pinderhughes says a 1997 study on undertreatment of cancer pain, published in the *Annals of Internal Medicine*, found that 65% of minority patients did not receive guideline-recommended analgesic prescriptions, compared to 50% of non-minority patients.

She also points to a 2000 study published in the *Annals of Emergency Medicine* that examined African-American patients and non-Hispanic white patients who presented to the emergency room with fractures. African-American patients were 66% more likely to receive no pain medication for their fractures than their white counterparts, she says.

Pinderhughes says three types of factors can affect access to opioids for minority patients: patient factors, provider factors, and system factors. Two examples of patient factors are fears of addiction and fears of judgment. Typical patient fears might be "Will I become a drug addict?" or "Will my sister or daughter think I'm a drug addict?" Pinderhughes explained.

There are also fears of not wanting to distract a physician from the primary problem. "If I'm an elderly African-American woman with cancer, I may not want to tell my doctor about my pain, because I may be fearful that my doctor will not focus on treating my cancer," Pinderhughes says.

Limited access to opioids in neighborhood pharmacies is yet another major patient factor for minorities, according to Pinderhughes. In the 2000 study, a group led by **Sean Morrison**, MD, at the Mount Sinai School of Medicine, examined the percentage of pharmacies in New York City neighborhoods that stocked adequate opioid pain medications. The group found that residents of predominantly minority neighborhoods were much less likely to have access to pain medications, because the neighborhood pharmacies did not stock them.

While the variability pharmacy stocks of opioids is considered a patient factor, Pinderhughes says it also can be considered a system factor.

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A negative personal experience with addiction in family members is another example of a patient factor that may affect willingness to request pain treatment.

Pinderhughes characterizes the medical community's lack of education and discomfort associated with prescribing pain medications as provider factors. Medical students only recently started receiving mandatory training in the principles of pain management, she says. "I graduated from medical school in 1994, and I didn't get one class on the benefits of pain management," she notes.

Today, more programs teach clinical competencies in pain management and palliative care. Still, Pinderhughes says some physicians may be reluctant to prescribe pain medications because they may not know how to prescribe them, or they may be uncomfortable with managing potential side effects. ■

## News From the End of Life

### Leaders trained to link caregivers, providers

The National Family Caregiver's Association (NFCFA) in Kensington, MD, has launched an innovative program to help family caregivers communicate effectively with health care professionals. Family caregivers provide over 80% of all home care services, but they receive no formal training or support in their roles. The NFCFA program provides family caregivers with the skills and tools they need to help their loved ones get better care.

NFCFA kicked off the project with an informative "train-the-trainer" conference in March in Arlington, VA. The 47 preselected attendees were introduced to a curriculum that included effective communication techniques that utilize role-playing to help caregivers practice what they are learning in real-life situations such as a doctor's office or emergency room. Participants came from as far away as Alaska and included representatives from the American Red Cross, Area Agencies on Aging, health systems, voluntary health agencies, and other health care and

faith-based organizations.

Newly trained leaders return to their communities to conduct workshops with family caregivers using the manual designed specifically for the trainers and integrated with the caregiver curriculum and support tools guide.

"One of the greatest challenges family caregivers face is ensuring that a loved one is receiving the best medical care. This is a daunting task when working with a myriad of health care professionals, providers, insurers, and other medical organizations," says **Suzanne Mintz**, president and co-founder of NFCFA. "This program helps family caregivers feel more confident and capable when serving as the voice for a chronically ill, aged, or disabled loved one. It helps them be better advocates for their own needs as well."

NFCFA is a grass-roots organization created to educate, support, and speak up for the millions of Americans who care for chronically ill, aged, or disabled loved ones. NFCFA reaches across the

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Editor: **Eric Resultan**, (770) 329-9684, (eric\_resultan@msn.com).  
Vice President/Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@ahcpub.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@ahcpub.com).  
Managing Editor: **Robin Mason**, (404) 262-5517, (robin.mason@ahcpub.com).  
Production Editor: **Brent Winter**.

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#### Editorial Questions

For questions or comments, call **Glen Harris** at (404) 262-5461.

boundaries of different diagnoses, different relationships, and different life stages to address the common needs and concerns of all family caregivers.

For more information on Communicating Effectively With Healthcare Professionals, contact NFCA at (800) 896 3650, or send an e-mail to [info@nfcacares.org](mailto:info@nfcacares.org). ▼

## Project seeks applications for palliative care grants

The Project on Death in America, in collaboration with the Emily Davie and Joseph S. Kornfeld Foundation in Brooklyn, NY, is seeking proposals from new or established palliative care fellowship training programs for funding support of individual fellowships in palliative care. The goal of this jointly funded fellowship program is to train physicians in the principles and practice of palliative care, to help build the capacity of fellowship programs, and to help establish palliative medicine as a recognized subspecialty of medicine.

The initiative is open to palliative care fellowship training programs, but not to individual applicants. Up to six two-year palliative care fellowship program awards will be available, with funding to begin July 2003.

Each award must be used to support the clinical or research training of palliative care fellows, with preference given to clinical training. Selected programs will receive up to \$75,000 a year for two years, for a maximum total of \$150,000. Eighty percent of each year's award must be applied to the stipend of one or more fellows, with a maximum of 20% of the total of each year's award available to the program and its director to support educational meetings, conferences, and expenses directly related to the fellowship training program.

Palliative care fellowship training programs may re-apply every year for one two-year award. The selected institution's palliative care fellowship program and its training director are responsible for identifying, selecting, monitoring, and evaluating fellow candidates. Candidates must be board-eligible in a residency program approved by the Accreditation Council for Graduate Medical Education (ACGME).

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To be eligible for funding, applicants must meet the following criteria:

- Programs must be affiliated with an accredited medical school that provides an ACGME-approved residency program or equivalent.
- Programs must demonstrate efforts to conform to the fellowship standards promulgated by the American Board of Hospice and Palliative Medicine.
- Programs must be in the United States.
- Programs must demonstrate evidence of ongoing institutional commitment to palliative care, and of cross-disciplinary collaborations.

For details of application procedures, contact the Project on Death in America at (212) 548-0344. ■

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