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State coalition explores ways to provide better end-of-life care

RWJF grantees begin tearing down the barriers to hospice care

Too many people die without the benefit of hospice or palliative care. This is a reality that hospices are all too familiar with. Now that they have crossed over into a new millennium, has end-of-life care improved significantly?

The short answer, unfortunately, is “no,” but end-of-life care advocates say more is being done in hopes of changing attitudes toward hospice and palliative care. For years, experts have complained that lack of training in palliative care among physicians and nurses has contributed largely to the fact that only one in three people who could benefit from hospice care actually do.

Consumers have done little to push physicians and nurses toward better end-of-life care. Without demand for hospice or palliative care, improved access and care have been slow in coming.

But recently, 23 coalitions of providers, insurers, and academics have undertaken efforts to reverse the trends that have been a hindrance to improved end-of-life care. Sponsored by the Robert Wood Johnson Foundation’s (RWJF) grant program, Community-State Partnership to Improve End-of-Life Care, these coalitions hope to draw a road map that provides a clear route to better end-of-life care.

One of those coalitions, Kentuckians for Compassionate Care, a partnership of 50 agencies and individuals, received a three-year grant of more than \$375,000 in January to coordinate a communitywide effort to engage senior groups, doctors, clergy, and policy leaders in efforts to improve care for all seriously ill and dying people in their state.

“By the end of the grant, we hope to have begun an avenue where every individual in the state of Kentucky has access to a good death,” says **Cynthia Ellis Keeney**, RN, project director.

The program, Journey’s End — A Kentucky Partnership for End of Life Care, has laid out a plan it hopes will raise awareness among health

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care providers, state lawmakers, and consumers, all of whom play a pivotal roles in improving care for those with chronic pain and terminal illness. The centerpiece of the project is a campaign to increase awareness among policy-makers, the public, and present and future physicians and nurses about the problems and barriers associated with the planning and delivery of quality end-of-life care.

To begin, investigators sought to identify barriers to good end-of-life care. Then, they developed programs designed to address each barrier. Among them are:

- **lack of palliative care education among physicians and nurses currently in school;**
- **lack of palliative care training among physicians and nurses currently in the field;**
- **lack of consumer demand for better of end-of life care;**
- **reimbursement methods that encourage inappropriate curative methods above appropriate palliative care.**

Reform for the dying

In January, project officials invited elected officials to a reception marking the coalition's grant acceptance. They used the opportunity to begin its campaign to educate elected officials.

Lawmakers were told how today's medical model fails to meet the needs of dying patients and their families. Left alone, the problem will only escalate as the population ages. The bottom line, elected officials were told: There needs to be broad-based policy reform to improve care of the dying.

They cited the following actions that should be taken:

- **Remove barriers to providing pain control, such as those that prompt physicians' fear of prosecution for using narcotics to treat pain.**
- **Require state-supported medical and nursing schools to include palliative care in their mandatory curriculum.**
- **Support mechanisms to facilitate carrying out patients' wishes outlined in advance directive documents across a variety of health settings.**
- **Identify access to quality end-of-life care as a health care priority in their state.**
- **Encourage the development of improved pain management assessment and treatment policies in nursing homes.**

In addition, resource materials, briefs, and issue papers describing project activities will be presented to state legislative members, state

officials, health work force regulators, health volunteers, and project partners.

Certainly, one of the linchpins to improving pain management and end-of-life care will be changing the attitudes of physicians and nurses who were trained in an era when death represented the enemy. Teaching physicians and nurses that comfort care is part of a patient's complete treatment has been slow to take root.

"No one wants to own up to the fact that we are all going to die," says **Lisa Spoden**, chairwoman of the Kentuckians for Compassionate Care. Spoden is also chairwoman of the Arlington, VA-based National Hospice Organization's Managed Care Task Force.

"All of us can benefit from more education," adds **Carla Hermann**, PhD, RN, associate professor at the University of Louisville's School of Nursing and a co-investigator for the partnership. "We know patients have a need for palliative care from the point of diagnosis."

To encourage physician behavior, Journey's End will implement a number of initiatives aimed at educating physicians and nurses, both in training schools and in the field. They include:

- **A peer resource network and toll-free Helpline.** Helpline will provide telephone consultation to physicians who are having difficulty managing pain and other symptoms in their terminally ill patients.
- **Education for Physicians on End-of-Life Care (EPEC).** An American Medical Association-developed training project designed to teach palliative care to physicians who, in turn, train their colleagues. EPEC training conferences will be offered to multidisciplinary teams of physicians and other support professionals (nurses, social workers, pharmacists, and clergy) at various sites around the state. **(See related story on p. 28.)**
- **Long-term care facility improvement.** The partnership plans to initiate pilot projects in six long-term care facilities to improve staff education through inservice training, encourage resident and family communication, and establish pain as the fifth vital sign.

Another component of their approach is to look at ways to remove payer-related barriers and ensure a seamless transition from curative efforts to palliative care. In cooperation with Louisville, KY-based Passport Health Plan, which provides coverage for Medicaid patients, the partnership will implement a coordinated care model.

The highlight of the model is the use of a nurse case manager who will act as a patient advocate

for terminally ill patients and as a liaison between physician and the patient and the patient's family. (See related story, below right.)

"I have long believed that our health care system is ill-prepared to give end-of-life care," says **Joyce Hagan Schifano**, BSN, MBA, president of Passport Health Plan.

Schifano says the model will promote timely referral to appropriate providers, including hospices, that have battled shortened length of stays. While the model is designed to promote smooth transitions into various segments of health care, Passport also hopes to show its managed care colleagues that better care can lead to lower costs, as well.

While physicians, nurses, government policies, and payers have played a significant role in failing to provide adequate end-of-life care, consumers have been just as culpable for fostering modern medicine's view on treating deadly diseases.

"It's going to take the kind of grass-roots effort among consumers who demand good end-of-life care the same way women demanded more personal birthing care," says Spoden. "We don't think people are demanding the kind of care they deserve."

It can be argued that the public's failure to demand better end-of-life care has contributed significantly to the lack of movement on all other fronts. As part of their project, Kentucky researchers will try to gauge public opinion by hosting five open forums where people can share their stories that illustrate both shortcomings and merits of current end-of-life practices and policies.

People's testimonies is not only expected to raise the public's awareness of poor end-of-life care, but can also have an impact on health care professionals and lawmakers, Spoden says.

Kentucky is one of a number of states that have received money from the RWJF to study ways to improve end-of-life care. About the same time the Kentucky coalition was awarded its most recent grant, four other states — Florida, Minnesota, New Hampshire, and Oklahoma — were also awarded.

Grants ranged from \$375,000 to \$450,000, covering two to three years. A description of each state plans follows:

- **A statewide partnership in Minnesota received a two-year grant of \$445,000 to improve care for terminally ill patients and their families.** The Minnesota Partnership to Improve End-of-Life Care will focus on changing the way insurers reimburse medical professionals for end-of-life planning conversations,

improving education opportunities for students in the health professions, and creating resource materials for consumers.

- **A statewide partnership in Florida received a three-year grant of \$450,000 to coordinate an effort to improve care for all seriously ill and dying Floridians.** The initiative involves Florida's state health and elder affairs agencies, as well as professionals, policy-makers, educators, and citizens.

- **A statewide coalition in Oklahoma received a 2½-year grant of \$375,000 to heighten awareness of the need for better care of the dying.** The coalition is one of 23 statewide partnerships to receive funding under a new program encouraging state and community groups to improve end-of-life care.

- **A New Hampshire group received a three-year grant of \$450,000 to lead a statewide advance care planning initiative.** The project is designed to improve the way consumers and the health care community understand and use documents, such as living wills, to help patients obtain the care and support they prefer when approaching death due to an incurable illness. ■

Taking away the reimbursement barrier

Imagine providing hospice services to a cancer patient who is still trying to beat the disease. Under today's current reimbursement regulations, it's difficult to fathom. But a small HMO in Kentucky is hoping it has found a solution to the financial barrier placed by payers that prevent access to palliative care and other services.

It's called coordinated reimbursement. At the heart of its design is a nurse case manager who watches over patients diagnosed with potential terminal illness and coordinates care from the curative stage to death, if necessary. The pilot program, the Continuum of Care Program (CCP), is part of the Journey's End project in Kentucky and is being undertaken by Passport Health plan, a 100,000 Medicaid-only member plan in Louisville.

By using a case manager, Passport officials hope to introduce palliative care and other services earlier in the disease process, recognizing that many patients are need of pain management from the point of diagnosis. Because many of the services are provided by hospice, including pain

management, are governed by six-months-or-less-to-live diagnoses, those services are most often not given.

“It seems to be the opinion of providers that the tail wags the dog, that reimbursement dictates care,” says **Joyce Hagan Schifano**, BSN, MBA, president of Passport Health Plan, which covers 15 counties surrounding the Louisville metropolitan area.

According to Schifano, CCP will focus on two major clinical initiatives: urging supportive care for patients earlier in their disease course and coordinating the care of diverse providers and caretakers.

A patient liaison

Case managers are nothing new to managed care, but Passport intends to use them as advocates for the patient and family. Often vilified for guarding the financial interests of their HMO, health plan case managers are often at odds with doctors and patients. Passport’s version of a case manager is more of a patient liaison, who will meet with the patient and family to discuss care goals and explain services that are available throughout each stage of treatment.

This will allow patients to access pain management or spiritual care, for example, while still undergoing curative treatment, such as chemotherapy. It also will help patients and family prepare for the inevitable when curative efforts fail.

“It’s my contention that if you provide the patient and family with support and care and when it comes time for the family to make a choice about continuing with curative care to the very end or choosing hospice, nine times out of 10 they will choose hospice sooner,” Schifano says. “Having worked with families in this position, I think all families are looking for is permission.”

In the end, the patient has been given access — without the constraints of reimbursement rules — to quality end-of-life care and the health plan, Schifano says, will have spent less on inappropriate curative efforts.

Journey’s End officials have high hopes for their reimbursement experiment. “I believe the reimbursement piece will be huge,” says **Cynthia Ellis Keeney**, project director.

If successful, they hope to use the model on a larger scale. Keeney estimates that to get a true indication of whether it is applicable on a large scale, they would need apply the model to five other states. ■

Teach MDs to spread palliative care message

KY coalition stresses interdisciplinary approach

One of the highlights to the Kentucky Coalition for Compassionate Care’s Journey’s End project is its training program for physicians and nurses. Education for Physicians on End-of-Life Care (EPEC) not only provides information for professionals, it relies upon doctors and nurses who have gone through the program to spread the gospel of palliative care.

“We all acknowledge that medical schools in this country don’t provide enough education on palliative care. EPEC fills that gap,” says **Mark Pfeifer**, MD, vice dean for clinical services at the University of Louisville’s School of Medicine and principal investigator for the Kentucky coalition.

We’re limited in our ability to reach all physicians and nurses, says **Carla Hermann**, PhD, RN, an associate professor with the University of Louisville’s School of Nursing and a co-investigator with the project. “It’s expensive to try and reach everyone. This works for us because we can train a few people who will train others.”

A good fit

EPEC was developed by the American Medical Association with the grant support of the Robert Wood Johnson Foundation. It was designed to educate all U.S. physicians on the essential clinical competencies required to provide quality end-of-life care.

Rather than reinvent a curriculum to teach physicians about end-of-life care, the Kentucky coalition chose to use EPEC because it fit with its education goals, Hermann says.

The EPEC curriculum consists of four 30-minute plenary modules and 12 45-minute workshop modules. Developers of the curriculum say its value lies, in part, in its practicality and portability. It teaches fundamental skills in communication, ethical decision making, palliative care, psychosocial considerations, and pain and symptom management, Hermann says. The workshop modules include:

- **Module 1: Advance Care Planning.**
 - Define advance care planning and explain its importance.
 - Describe the steps of the advance care

planning process.

- Describe the role of patient, proxy, physician, and others.
- Distinguish between statutory and advisory documents.
- Identify pitfalls and limitations in advance care planning.
- Utilize planning to help the patient put affairs in order.
- **Module 2: Communicating Bad News.**
 - Know why communication of “bad” news is important.
 - Understand the six-step protocol for delivering bad news.
 - Know what to do at each step.
- **Module 3: Whole Patient Assessment.**
 - Describe elements of suffering (physical, psychological, social, and spiritual).
 - Demonstrate ability to assess.
- **Module 4: Pain Management.**
 - Compare and contrast nociceptive and neuropathic pain.
 - Know steps of analgesic management.
 - Know use of adjuvant analgesic agents.
 - Know use of nonpharmacological approaches.
 - Know adverse effects of analgesics and their management.
- **Module 5: Physician-Assisted Suicide (PAS).**
 - Identify root causes of suffering that prompt PAS or euthanasia requests.
 - Define PAS and describe its current legal status.
 - Explain key steps for responding to requests.
 - Understand alternative strategies for addressing a patient’s suffering and fears.
- **Module 6: Anxiety, Delirium, and Depression.**
 - Identify major depression in patients facing the end of life.
 - Distinguish major depression from normal reactions.
 - Describe management plans for anxiety, delirium, and depression.
- **Module 7: Goals of Care.**
 - Name at least five potential goals of care that patients may have.
 - Identify clinical junctures at which priorities should be clarified.
 - Discuss how priorities should be determined.
 - Know how to assist the patient to identify reasonable goals.
- **Module 8: Sudden Illness.**
 - Describe the features of sudden illness that

require special skills.

- Know how to communicate effectively in the face of sudden illness.
 - Know how to guide decision making in the face of sudden illness.
 - Explain the benefits and risks of using a time-limited trial approach.
 - **Module 9: Medical Futility.**
 - List factors that might lead to futility situations.
 - Know how to assist in resolving each factor.
 - **Module 10: Common Physical Symptoms.**
 - Describe general guidelines for managing nonpain symptoms.
 - Explain the impact of symptom control.
 - Assess and treat each nonpain symptom.
 - Explain how the principle of double-effect applies to symptom management.
 - **Module 11: Withholding/Withdrawing Treatment.**
 - List medical orders relevant for terminally ill patients.
 - Apply this knowledge to clinical situations.
 - Describe common misconceptions about withholding or withdrawing therapy.
 - **Module 12: Last Hours of Living.**
 - Prepare and support the patient, family, and caregivers (professional and volunteer) through the dying process.
 - Assess and manage the pathophysiological changes of dying.
 - Identify and manage initial grief reactions.
 - **The plenary modules cover:**
 - I. Gaps in End-of-Life Care.**
 - Describe the current state of dying in America.
 - Contrast this with the way people wish to die.
 - II. Legal Issues in End-of-Life Care.**
 - Describe legal consensus points.
 - List common legal myths and pitfalls.
 - III. Elements of End-of-Life Care.**
 - Describe a conceptual framework for suffering.
 - Describe the elements of end-of-life care.
 - Define palliative care.
 - Compare and contrast palliative care to hospice care.
 - IV. Next Steps.**
 - List the important themes from the conference.
 - Identify barriers to good end-of-life care.
 - Develop potential solutions.
- While the AMA developed the training program for physicians, Journey’s End has not only

included nurses, but encouraged physicians who apply to take the course to recruit nurses and social workers to promote an interdisciplinary approach to improving end-of-life care.

Journey's End began training physicians and nurses using EPEC last fall. So far, a little more than a handful of physicians and nurses have gone through the program. Project officials hope to have as many as 70 EPEC-trained physicians and nurses by year's end, and 140 by the time the grant expires.

"The hope is that physicians and nurses will talk openly with their patients, so that the decision to move from a curative mode to comfort care is made in a timely fashion," Herman says.

Pfeifer says because the program is taught by physicians in a variety of specialties, it has the

potential for wide appeal among physicians because doctors tend to relate better to physicians in like specialties.

"It's not designed to create experts, but it educates physicians on the basics. Hopefully, it will generate a fair amount of enthusiasm so that they will share what they have learned."

Hermann stresses that EPEC is only part of its overall plan to educate physicians and nurses. The coalition also hopes to revamp the mandatory teaching curriculum in the state's medical and nursing schools.

[Editor's note: For more information about EPEC, contact: The EPEC Project, Institute for Ethics, American Medical Association, 515 N. State St., Chicago, IL 60610. Telephone: (312) 464-4979. E-mail: epec@ama-assn.org.] ■

Learn to spot spiritual conflict

Teach caregivers to accept patients' opposing views

As the 70-year-old man lay unconscious, hovering near death, his wife and family stood at his bedside. The wife, who was raised Lutheran, agonized over her husband's soul. He had never been baptized and she believed her husband would be go to hell unless the sacrament was performed.

The young hospice chaplain who was called to the family's home inquired about the man's wishes. The wife said he was active in the church, and on several occasions — usually when grandchildren were baptized — he would express a desire to do the same. He was to be baptized on several occasions, but backed out each time at the last minute. He was embarrassed because he was an adult accepting the sacrament, the wife told the chaplain.

Would the chaplain baptize her husband before he dies?

"The wife's religious belief taught her that you have to be baptized or you will go to hell," says the **Rev. Jeanne Brenneis**, MDiv, STM, chaplain with the Hospice of Northern Virginia and director of the Bioethics Center, both in Falls Church, VA, and the chaplain who was called to the home years ago. "He clearly did not want to be baptized when he had the opportunity."

But the wife persisted and Brenneis was left with the decision to either perform the sacrament

for the family's sake or follow the patient's life-long decision not to be baptized. Unable to ask the man what his wishes were, she decided to honor what the patient had wanted in his own lifetime. "What I did was do everything except the baptism," Brenneis recalls. "I told them in good conscience I couldn't give them exactly what they wanted. I don't think the family was very happy.

"I have talked with other chaplains since this happened and some said they would have done it. You could say it wouldn't do any harm, but it would be treating the sacrament lightly. I don't think there is a right or wrong answer."

Understand patients' wishes

In retrospect, Brenneis isn't sure if she would do things differently. But her story highlights the spiritual conflicts that can occur between dying patients and their families. With the many nuances family relationships can take, hospice workers must learn to spot potential conflict and work toward a resolution to ensure the patient's spiritual care is not undermined by family members who have conflicting views about spirituality and religion.

There are a number of situations in which family members can be at odds: children caring for a dying parent, a parent caring for a dying adult child, or a sibling caring for another sibling. Regardless of the familial makeup, hospice workers should approach resolving the conflict by helping caregivers understand the patient's wishes, says **Kevin O'Brien**, MA, director of education and

outreach services for the William Wendt Center for Loss & Healing in Washington.

Reasons for conflict

Simply enough, spiritual conflict can occur when one family member has an opposing religious belief from the other. But there can also be more complicated dynamics at work. Those types of conflict can manifest themselves in a number of ways: the ability to forgive particular family members, how medication should be used, and how much physical suffering should be endured.

A dying woman is compelled to reduce her pain medication, despite the objections of her husband, so that she feels lucid enough to pray continually in the days before she dies. At the root of this conflict is the woman's desire to exercise her religious practices and her husband's desire to make his wife comfortable.

Often, spiritual conflict is a symptom of a larger problem that needs to be resolved before the two sides can reach a spiritual understanding. For example, two siblings who worship under different denominations and caring for a dying parent may disagree about which sacraments and prayers to perform prior to their mother's death. Instead of spiritual issues driving the conflict, it may be the manifestation of a power struggle between the two siblings.

Be aware of underlying factors, Brenneis advises. "Don't get too distracted by spiritual issues. Look for underlying reasons."

In fact, Brenneis says conflicts that are truly about spiritual matters are often the most difficult to resolve. "When you start talking about religion, it can be an inflammatory discussion. You can get caught in a theology debate."

What hospice workers need to communicate to caregivers is that spirituality is an individual concept. Caregivers frequently make the mistake of assuming spirituality and religion are synonymous.

Hospice workers should counsel caregivers on the difference by explaining that religion is a set of standards and beliefs that accompany a religious practice, while spirituality is the collective wisdom an individual has gained over a lifetime about his or her own existence and place in the universe. Spirituality, caregivers must be told, is what gives meaning and purpose to life. While it is often the primary component of religion, spirituality can exist among those that do not have a set religion.

Consider this: A dying 30-year-old man tells his Catholic mother, who is his primary caregiver, that he doesn't want a priest to counsel him. Instead he wants to spend time in his garden. The mother needs to be counseled so that she can understand her son's view of his relationship with the universe and at some level she must learn to accept his wishes rather than impede his spiritual yearning.

O'Brien identifies three components to hospice workers must address to help resolve spiritual conflict:

- 1. understanding family relationships;**
- 2. taking a long-term approach;**
- 3. using prayer.**

Familial relationships provide the basic information from which the hospice worker will approach the conflict. For example, parents often view themselves as an authority, no matter the age of their children, and are unwilling to relinquish that authority. Grown children may have trouble asserting themselves when parents are imposing their beliefs on them. Or, just the opposite, adult children may show little respect for their parent's wishes and impose their own beliefs on the patient.

Identifying those dynamics at work will allow workers to get to the heart of the problem and come to a quicker resolution.

Power struggles among siblings can manifest themselves as spiritual conflict. A disagreeable and outspoken sibling can try to impose his or her religious practices as part of the struggle to gain control overall of the decision making responsibilities.

"Rather than avoid conflict, use it to your advantage," O'Brien advises.

Using conflict in controlled forms can help facilitate understanding on both sides, he says. For example, a parent and her dying adult child can re-enact religious rituals that were common when the child was younger, allowing mother and son to reconnect using shared pleasant experiences.

Opening a dialogue

Using the existing conflict allows the disagreeing parties to establish a dialogue, O'Brien says. But he reminds hospice workers that establishing a dialogue is only the beginning.

"It's not going to be resolved in single session," he says.

Prayer, plays an important role in bringing down barriers. O'Brien says. Often, the chance to

pray as a group will help heal the chasm that exists between family members. In cases, where family members have different views about God and the universe, a simple quiet pause that allows both sides to reflect upon their own beliefs is appropriate.

In instances where the patient refuses to accept religious practices of caregivers, Brenneis says praying with just the family is helpful. "It's important that you support the family," she says. "I have counseled families that conversions can occur during times when we think someone is gone."

If the patient can no longer make his or her own decision and family members want to impose their religious practices on the dying loved one, praying with the family in the presence of the patient is appropriate, as well, she says. "I feel saying a prayer won't harm the patient, but it certainly helps the family."

Brenneis is also sympathetic to the prevailing regulatory challenges the hospice industry faces and how that affects their time addressing every patient need. And O'Brien adds that hospice workers should be realistic about the results they should expect.

Today's industry trends suggest that most patients will be under hospice care for just a few weeks, sometimes just days before the patient dies. That leaves little time to tackle all spiritual conflicts between patient and caregiver.

"We get patients who are so much sicker these days," Brenneis says. "There can be so much anger and so little time. If there's an openness to talk about, then great."

"You can't expect to change relationships in such a short time," O'Brien adds. ■

Review the R's of your volunteer program

Programs provide meaningful experience

The importance of volunteers in a hospice program is undeniable. Without them, a hospice would have difficulty meeting the basic needs of its patients or it would go bankrupt trying. With that in mind, hospices would be well-served to review their recruiting, training, and retention efforts, to ensure the long-term success of their volunteer programs.

According to experts, hospice volunteer

programs require regular review and updating. Specifically, they should focus on:

- **Recruitment.** Attracting motivated individuals who fill specific needs within the hospice, including direct patient care, bereavement services, fundraising, and administration.

- **Retention.** Providing meaningful experiences and support for volunteers to keep them interested serving hospice.

- **Training.** Proving educational programs that educate volunteers on the hospice philosophy and clearly illustrate appropriate interaction between patient and volunteer, and family members and volunteer.

- **Recognition.** Showing appreciation for the work of volunteers both as an individual and as a group.

Recruitment tips

Attracting volunteers can be tricky for some hospices. Most hospice volunteers have had someone close to them benefit from hospice care. While grateful families can provide a well of potential volunteers, hospices run the risk of staffing their volunteer ranks with those using the experience to work through grief issues of their own. In most cases, hospices do not allow family and friends of recent hospice patients to volunteer until after a year has passed since the death of their loved one. That puts some pressure to recruit volunteers who know little of hospice or those who might be apprehensive about caring for the dying.

One recruiting challenge is a simple matter of geography. Depending on the location of a hospice, the challenges can vary. Hospice of Washington in Washington, DC, for example, competes with a wide variety of volunteer opportunities available in the nation's capital and surrounding communities.

"People can volunteer at the White House," says **Karen Jones**, senior director of community relations and the hospice's former director of volunteer services. "Being in Washington means there is a lot of competition for volunteers' time. So you have to provide something that is meaningful."

Hospices in rural areas, such as the Hospice of Central Iowa in Des Moines, covering a 19-county area, must find volunteers in the smaller surrounding communities to meet the needs of patients who are too far for urban-based volunteers to reach.

"When you cover a metropolitan area like Des

Moines — there really isn't a metropolitan area, it's all pretty rural — your approach needs to be different," says **Ann Cochran**, volunteer coordinator for the Hospice of Central Iowa.

There are the typical approaches to attracting volunteers — using available public service announcement spots on local television and in newspapers — but recruitment requires more than that shotgun approach.

Hospice of Washington uses its programs to attract volunteers. "If you have interesting programs, you will automatically have people eager to participate," Jones says.

To enhance the appeal of their programs, Hospice of Washington set out to create volunteer programs that touch upon a number of alternative therapies, services that many of its patients and families would benefit from, such as massage therapy. The idea is that by providing cutting-edge therapies, volunteers would be eager to participate.

It's a departure from the traditional approach to recruiting volunteers: taking potential volunteers and matching them to needs that exist within the hospice, including direct patient care.

Instead, Hospice of Washington developed outreach programs in which volunteers could apply their unique skills or explore burgeoning interests. For example, the hospice created an AIDS outreach program that involves a number of alternative therapies provided by volunteers. It also organized weekend retreats for its patients at nearby resorts where volunteers provide the bulk of care in a vacation setting. This doesn't mean it don't actively try to fill traditional volunteer needs, but its outreach programs reach those who may not have considered volunteering at its hospice.

"It hasn't been a problem recruiting," says **Sherry Peach**, director of volunteer services at Hospice of Washington. "It's actually worked out beautifully. Not only do the patients get a massage therapist, for example, but they also get a friend who will talk with them and hold their hand."

Hospice of Central Iowa has more traditional needs, but must meet them by treating each small community individually, says Cochran. While TV and newspaper ads successfully bring in volunteers within Des Moines and contiguous counties, filling the needs within small towns is challenging.

In those areas, Cochran relies on truly old-fashioned techniques. Church bulletins and small town publications advertise Hospice of Central Iowa's need for volunteers. Because churches, coffee shops, and taverns are traditional gathering

places in small towns, she is assured her call for volunteers will be seen by rural residents.

Often, these small communities — where a premium is placed on helping neighbors — take on the care of hospice patients as a community project, Cochran says.

Another recruiting challenge is convincing people that there is a place for their skills even if patient care isn't what interests them. "Anyone that wants to volunteer, you can find a place for them," says Cochran. "It's a matter of matching their skills and interests to your needs."

Teach the hospice's philosophy

Once the volunteers have been brought into the program, hospices need to have a curriculum in place that readies volunteers for their assignment. Part of that preparation, experts say, is for volunteers to be schooled in the hospice's mission.

"Everyone should be familiar with the hospice philosophy," says Cochran.

Fulfilling this requirement takes more than a few simple statements read by hospice employees or a couple of inservice sessions. Hospices need to develop a program that exposes volunteers to the interdisciplinary team approach to care and teaches volunteers' role on the team.

Traditionally, hospices approach this task by holding a series of one- to three-hour sessions during the week at a time convenient to most volunteers. Hospice of Washington officials don't think that's enough, and recommend a program that immerses volunteers in hospice education over a shorter, but intense, period.

"I bet I would be hard-pressed to find people who didn't have to miss a session," says Jones. "I don't think having volunteers for a couple of nights a week is comprehensive."

The problem with the consecutive-series approach, Jones says, is that they allow opportunity for volunteers to miss sessions because of competing demands, including family and work obligations.

At Hospice of Washington, volunteers are required to give two full Saturdays to training sessions. The training program covers:

- **the hospice's mission;**
- **the hospice's concept (the key features of the benefit, including palliative care over curative care);**
- **the medical perspective (interdisciplinary team approach and specific pain management methods);**

- **grief and bereavement;**
- **spirituality;**
- **caring for the family;**
- **patient care techniques;**
- **administrative requirements (documentation and confidentiality).**

After the volunteers complete the training program, they are assigned a mentor, an experienced volunteer. The volunteer follows his or her mentor during patient care for nine to 12 hours before deciding which area they want to volunteer.

Cochran says it is important for volunteers to work through their own feelings of death and grief. To do so, she recommends volunteers first be taught the signs and symptoms of dying and then understand their role when the patient shows those signs.

If a patient refuses to eat or drink, for example, the volunteer is told that those are signs of the body shutting down. Rather than intervening because food and water are basic needs, the volunteer understands the patient's body is preparing to die.

Yet the idea of allowing someone to refuse basic needs may be hard for some people. That's why Cochran has included a group discussion about death and dying into the training program at the Hospice of Central Iowa.

The group discussion allows volunteers to get in touch with their own views on death and dying and allows them to relate it to the hospice's mission. More importantly, they learn that their views should not be imposed on those they are trying to help.

"They have to be rooted in the fact that we provide comfort, not a cure, and understand why," Cochran said. "It's really important that boundaries don't get blurred. You have to make sure volunteers have worked out their own loss issues."

To reinforce those ideas, the group discussion includes exercises where the group tackles hypothetical situations and discuss right and wrong behavior. "We teach respect for different views and show them that it is normal for a dying patient not to want to eat," Cochran adds.

Because a hospice has invested its resources in

recruiting and training, it wants to be sure volunteers remain with the program. Of course, attrition will occur naturally, volunteers move away, change jobs, and family demands change. What hospices want to avoid are volunteers who burn out or become disillusioned.

At the heart of all this, Cochran says, is making volunteers feel appreciated and that their work makes a difference. At Hospice Atlanta, **Barbara Moore**, manager of volunteer services, says she makes an effort to speak with volunteers individually.

Because volunteers are required to undergo annual tuberculosis screenings, Moore says she uses the opportunity to meet with volunteers to ask them about their volunteer experience and thank them individually for their effort.

She also warns against demanding too much from volunteers. With growing needs, it's easy to keep asking the same volunteers to pitch in without taking into account their need for personal time.

"Don't let anyone feel guilty because they can't give more time," Moore says. ■

News From the End of Life

Chaplain protests combining nursing services

An Allentown, PA, hospice chaplain left her position in protest after the hospital that houses the program combined nursing services with its home health program, claiming executives made the decision for financial reasons, rather than the best interest of its patients.

The Rev. Ann Huey, who had 15 years of service with Lehigh Valley Hospice, argued that home health nurses and hospices nurses have distinct approaches to patient care. Using a home health nurse, she said, jeopardizes patients' ability to achieve a pain-free, spiritually fulfilling death.

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"With a dying patient and his family, we get one chance to do it right," Huey told the *Morning Call*, Allentown's local newspaper. "It's tough if folks are not wanting to be there. It's tough on caregivers and patients and family."

She also feared that financial pressures facing hospices will cause more hospices to go the way of Lehigh Valley.

Carol Schaffer, vice president of Lehigh Valley Health Services, which includes home care and hospice, says the move makes sense and will actually benefit patients. She told the newspaper that it was logical to train home care nurses in hospice care, because many of their patients need home care benefits early in their illness and that it would improve continuity of care. ■

News From Home Care

Study: IPS cuts HH access

Sixty-eight percent of all hospital discharge planners surveyed by George Washington University (GWU) researchers reported increased difficulty in initially obtaining home health services for Medicare patients since the implementation of the interim payment system (IPS).

In addition, respondents to the GWU Center for Health Services Research & Policy survey show that only 22% of them reported no change in difficulty finding home health services for their Medicare patients.

The latest findings of the study were included in the second phase of the two-part study that is measuring the impact of payment changes mandated by the Balanced Budget Act of 1997.

Home health industry advocates said the results were further evidence that Medicare patients have decreased access to home health services for the sickest patients. The study's authors shared their opinion.

"There is compelling evidence of differential treatment of sicker beneficiaries in response to financial incentives of IPS that suggest problems with access to and quality of home care services for this population, the study concluded. "These findings raise significant policy questions that should be addressed in evaluating IPS and any other payment system that may be developed." ▼

Risk areas for hospice, durable medical equipment outlined

Federal investigators still have their fraud and abuse sights set on durable medical equipment (DME) suppliers and hospice providers, a health care attorney told her colleagues during a January meeting of the American Health Lawyers Association.

There are a number of risk areas that hospices and DME providers need to be concerned with, says **Deborah Randall** of Arent Fox in Washington, DC. Specifically, hospices have 28 risk areas, while DME providers must be concerned with 47. So many, Randall says, hospices and DME supplier have difficulty keeping up with what investigators are taking aim at.

"When you look at the risk area, I think it is daunting to know what to pay attention to," Randall says.

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Editorial Questions

For questions or comments, call **Lee Landenberger** at (404) 262-5483.

Randall categorizes the risk areas:

1. **basic billing mistakes;**
2. **industry-specific risk areas;**
3. **certification and operational issues;**
4. **failure to self-report.**

It is the last item that Randall paid particular attention to. With the number of risk areas facing both industries, she says one common theme runs in them both is the Office of the Inspector General's compliance guidelines.

The guidelines say there is a duty to self-report violations or suspected fraud, a notion that she challenges. "I think every single case has to be examined on its own merits, she says. ▼

HH experts still fear Labor's opinion despite withdrawal

Although the Department of Labor has withdrawn its opinion that would have extended health and safety standards and record keeping to workers furnishing services in private homes, home health officials fear the issue is not dead.

In January, Department of Labor officials issued an opinion letter that extended Occupational Safety and Health Administration (OSHA) record-keeping and standardized requirements to workers providing services in a private home, sending a shock wave through the home health industry. Industry officials immediately spoke out against the letter, saying the opinion would impose OSHA requirements on home health work sites that were out of employees' control.

"While the letter opinion has been withdrawn, the notice of the withdrawal notes that the policy will be considered further and may be reissued in the future," says **Jim Pyles**, counsel for the Home Health Services and Staffing Association (HHSSA) in Washington, DC. "The policy seems to be in conflict with the ruling we obtained on behalf of HHSSA in a 1993 Seventh Circuit decision, which held that OSHA work site-related requirements cannot be imposed on work sites that are not under the employee's control."

Pyles said the advisory would have had a devastating impact on the home care industry if it had been allowed to stand. It would have required home health providers to assume responsibility for all potential of safety hazards in homes of any employees who take work home with them and in the homes of patients receiving care there. ■

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