

HOSPICE Management ADVISOR

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Lessons in helping others cope with death: What hospices learned from Sept. 11 terrorist attacks

Apply their knowledge to your own bereavement programs

It has been 10 months since two planes toppled the World Trade Center towers and a third plane slammed into the Pentagon. In the hours that followed, hospices mobilized to offer bereavement services to the thousands of people who lost loved ones during a long morning of terror that claimed more than 2,000 lives.

While grief cast a pall over the entire nation, nowhere was it more palpable than in the two cities where the acts took place.

Without hesitation, hospices in those areas worked the phones offering counseling services to swamped emergency agencies trying to cope with the onslaught of assistance requests. Hospice workers immediately began treating families, friends, and co-workers of those killed. The approach made sense. After all, hospices help families cope with loss on a daily basis. While hospices have a wealth of experience in bereavement care, many learned that there are significant differences between treating grief following an expected death and treating grief resulting from a sudden, unexpected death. Those same differences were magnified by the immense scale of the devastation.

"It's different," says **Kathy McMahon**, president and chief executive officer of the Hospice and Palliative Care Association of New York State in Albany. "You need a different set of skills to handle traumatic death than you would to deal with an expected death."

The New York hospice trade association acted as a clearinghouse for bereavement services in the first few days following Sept. 11 and has continued to work with local hospices that are still dealing with victims of the terrorist attacks. In recognition of the long road to recovery the victims face, the hospice association recently accepted a \$50,000 grant from the United Hospital Fund to explore ways to improve bereavement

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care in cases of traumatic death.

In short, New York hospices hope to learn from their own experience. While few could have imagined the scale of the community's grief, New York City-area hospice staff say there are lessons that can be applied to traumatic grief caused by less sensational circumstances, such as suicide and automobile accidents.

For hospices that do not offer bereavement services to families whose loved one died outside the hospice setting, New York's and Washington, DC's trial by fire is good place to find model programs to start community bereavement programs. The same can be said for hospices that want to improve their current community grief programs.

In addition, the response to the terrorist acts also provides a blueprint for hospice response to community crisis. According to White House officials, future terrorist attacks are likely, which should prompt hospices to form action plans in the event of further attacks. Action plans are also important for other community crisis situations, such as school shootings and other events that lead to significant loss of life and community-wide shock.

Hospice Care Network

Hospice Care Network in Westbury, NY, was already operating a full-service bereavement program prior to Sept. 11. Its community grief program provided services to those grieving loved ones following fatal automobile accidents, murder, and suicide, among other causes. But none of that prepared them for what they faced immediately following the attacks — and what they're still facing today.

"I thought we were versed in traumatic grief," says **Mary Gravina**, LSW, director of bereavement services and pediatric programs at Hospice and Palliative Care Association of New York State. "But we were in no way prepared. We found a grief of a magnitude we had never seen before. It was worlds apart from grief we had seen among hospice families, and even different from other traumatic death cases."

The most notable difference was the lack of closure and finality victims' families faced, says Gravina. With many families unable to locate the body of their deceased, the bereaved were unable to close out the event and move into the bereavement process. The same can be said for the attention paid to victims' families and the sense of

duty that many family members showed by attending community events that honored those who were killed. The hectic pace and media spotlight stunted their grief until attention turned away from the victims months later and family members found themselves overwhelmed by their grief.

Yet, Gravina noted parallels between normal traumatic grief cases and the extreme situation brought on by a massive terrorist attack. "It was a tremendous learning experience," she adds.

The lessons learned by Hospice Care Network can be applied to both community crisis situations and individual cases of traumatic death. According to Gravina, the hospice learned about:

- the need to partner with community groups in anticipation of catastrophic community events;
- the need for ongoing training specific to traumatic death, such as post-traumatic stress syndrome;
- the importance of victims sharing their stories with one another in group sessions.

With so many people eager to help, emergency services on Sept. 11 were overwhelmed with volunteers. With expertise in bereavement, the Hospices of the National Capital Region in Fairfax, VA, the largest hospice organization in the Washington, DC, area, found it difficult to integrate its services with services being provided by emergency services agencies, says **Robin McMahan**, LCSW, BCD, senior advisor for grief and loss for the Hospices of the National Capital Region.

The experience taught leaders of the hospice to take a proactive approach — that is, to have systems, policies, and partnerships in place prior to any community catastrophe. Hospices of the National Capital Region has since designated an emergency responder whose job is to make the initial contact with the agency responsible for handling the crisis.

VNS Hospice Care

Like Hospice Care Network, VNS Hospice Care provides bereavement care to families outside the hospice setting. Shortly after Sept. 11, the hospice was asked to provide counseling services to firefighters who lost family and colleagues in the towers' collapse. "We've got families 'decompensating' out there," hospice workers were told by a firefighter's union representative. In addition to the firefighters, a law firm near the twin towers that had employees

who lost family members asked hospice counselors to provide bereavement services.

“We weren’t prepared,” explains **Jeanne Dennis**, MSW, executive director of VNS Hospice. “Nothing compared to what we experienced. There were so many layers of grief. We were concerned for all our patients below 14th Street, we had staff that had family that worked in the World Trade Centers, and the community was calling upon us to help.”

What they learned was that while there were plenty of counseling services available to families, the level of expertise was not equal across the board. “What we know is that there are many mental health counselors out there, but not everyone has been trained in post-traumatic intervention,” Dennis says.

Apply themes in traumatic situations

While there is a need for training outside bereavement care for anticipated deaths, experts say there are themes that can be applied in traumatic death situations. Most hospice programs approach bereavement care by applying a set of goals that are laid out in a bereavement care plan. These goals may call for bereavement professionals to help grieving patients:

- to express all the feelings over the loss: anguish, longing, relief, anger, depression, numbness, despair, aching, guilt, confusion, and often unbearable pain;
- to let the nonnegotiable and excruciating reality sink in that the grieving patient will never again be in the physical presence of the deceased loved one;
- to review the relationship from the beginning and to see the positive and negative aspects of the person and the relationship;
- to identify and heal unresolved issues and regrets;
- to explore the changes in family and other relationships;
- to integrate all the changes into a new sense of oneself and to take on healthy new ways of being in the world without the person;
- to form a healthy new inner relationship with the person and to find new ways of relating to him or her.

In addition to these goals, Dennis says, trauma situations call for “grief debriefing” training. Hospice workers need to be trained in breaking the news of a family member’s death and how to handle the shock that ensues. Grief debriefing

also includes taking care of practical matters that hospice workers don’t normally have to address following an anticipated death. “You’ve got to roll up your sleeves and do all the practical stuff like making sure they get home, that children are cared for, for example,” she adds. “Be prepared to move into a chaotic situation.”

Longer healing process

Of all the differences between the two types of grief, time is perhaps the most significant. Families being cared for under hospice while they prepare for the death of a loved one from a terminal illness have the opportunity to prepare, which helps to soften the blow brought on by the patient’s death. While everyone is different, the bereavement process can last one to two years. In traumatic situations, that time period could extend well beyond two years. Hospices must be sure they have the resources for sustained treatment programs.

“We don’t want to make people dependent on grief counseling, but you have to be prepared to treat traumatic grief patients for a long time,” says McMahon.

In traditional hospice situations, those suffering from grief are exposed to the following over a one-year or two-year period:

- **Group-oriented bereavement counseling.** Isolation and guilt are among the emotions the bereaved endure. Group counseling provides the understanding and support from others that may be missing. In addition, the support of those who have gone or are going through the same process can help those grieving the loss of a loved one understand their own emotions and feel normal.
- **Individual grief counseling.** While group counseling is perhaps an efficient way to counsel more than one grieving person, many require individual counseling to deal with the emotions surrounding their grief.
- **Community services.** Nonprofit groups exist in many communities. Hospices should be aware of the available services that could benefit the survivor.

For the most part, the same services are provided to traumatic grief patients. However, hospices must be aware of the subtle and not-so-subtle differences that come into play. For example, group counseling should not integrate traumatic loss patients with those whose loved ones died during hospice care. Traumatic loss patients often have a more profound story to tell that may cause others

in the group to trivialize their own loss.

For example, a man whose wife died in the World Trade Centers shared his story with others in the group. His story was followed by a woman whose husband died from cancer. She began her story with, "My husband only died of cancer."

McMahon offered the following tips:

- Work on coping strategies from the beginning of treatment.
- In cases of newsworthy events, protect patients from gratuitous coverage and teach them how to cope in those situations, including knowing when to turn the television off.
- Set up a private ritual on the anniversary of the death and the days leading up to the anniversary. Try to surround patients with people who support them and insulate them from other distractions.
- Be aware of other significant dates that can send patients into an emotional spiral.

In many ways, there isn't a great difference in treating anticipated grief and traumatic grief. But where there are differences, experts agree, having the expertise can prove critical. "We anticipated that there would be more parallels," says Gravina. "The difference between the two is that losing someone to cancer or some other disease is like getting punched in the gut; losing someone under traumatic circumstances is like getting punched in the gut and not seeing it coming." ■

Misuse of OxyContin stalls effective pain care

Fear of scrutiny can lead to underuse

In the vast expanse of cyberspace, there is a photo of Eddie Bisch, a cherub-faced 18-year-old with blue eyes and cropped platinum-blond hair. The picture shows him dressed in a tuxedo, mingling among family and friends during a family wedding. As it turns out, the picture would take on a higher meaning as it captured the face of an Everyboy, whose boyish features belied his fate.

But just months after the snapshot was taken, Eddie and friends spent an evening popping Xanax, drinking beer, and splitting a 40 mg tablet of OxyContin. On Feb. 19, 2001, Eddie Bisch

became the 21st person to die from an OxyContin overdose in three months.

The growing number of Eddie Bisches has caused law enforcement to step up their efforts to combat OxyContin abuse. Caught in the middle are the thousands of patients who suffer from chronic or disease-related pain but who don't receive adequate pain relief because physicians are unwilling to prescribe the drug or refill prescriptions out fear of being labeled dope dealers.

The federal Drug Enforcement Agency (DEA) has tried to placate physicians by acknowledging that OxyContin and similar drugs are valuable tools that physicians should use when appropriate. Still, the DEA blames OxyContin for 464 drug overdose deaths in the past two years, and there is talk of placing tighter restrictions on prescription and use of the drug.

Father aims to hamper street trade

Even Eddie Bisch's father doesn't have a problem with OxyContin when prescribed by a physician for a patient suffering from severe pain. But he has nothing but resentment for those who hand out prescriptions knowing that the person he or she is writing it for intends to use or sell the drug for illicit purposes.

As a memorial to his son, Bisch built a web site (www.oxyabusekills.com) to remember Eddie and others who died as a result of oxycodone overdose, and to warn others of the dangers of using the drug outside of its intended use.

"When Eddie died I lost about a year and a half of my life," says **Ed Bisch**, Eddie's father. "By putting up this web site, my goal is to slow down the street supply of Oxy."

Like hospices, Ed Bisch has found himself in the middle of a controversy he neither started nor wants to be a part of. He vigorously denounces physicians who prescribe the drug indiscriminately or illegally. But his stance has caused some to see him as an adversary to the pain management movement.

"I was shocked by the amount of hate mail I got from people who said I was making it harder for them to get the drugs they need for pain. I'm not against Oxy for severe pain. If I get cancer and I'm in pain, I'll take it and I'll be glad to take it."

Sadly, stories like the Bisches are becoming commonplace. Diversion of the prescription medication has prompted law enforcement officials to step up their efforts to root out rogue physicians

who see the latest drug craze as an opportunity to make a fast buck. Other physicians fear guilt by association. If they prescribe the drug, say some physicians, then it could lead to scrutiny, and perhaps unfair prosecution.

Before OxyContin was national news, the pain management movement was enjoying momentum, with more and more physicians and nurses taking the time to educate themselves about available drugs and therapies to improve patient outcomes and improve quality of life. It seems, however, that the momentum has slowed or been halted.

"Patients with true needs are being denied access [to OxyContin]," says **Marc Hahn, DO**, president of the Glenview, IL-based American Academy of Pain Medicine and dean of the Texas College of Osteopathic Medicine in Fort Worth, TX. "Whether we're losing ground, we don't know for sure."

Earlier this year, the American Medical Association released its "Annual Review of State Pain Policies: 2001," which found a steady adoption of state pain policies that ease constraints surrounding the use of opioid analgesics for the treatment of pain. While state regulators are taking unprecedented steps to help physicians provide relief to cancer patients and others suffering from chronic pain, pain remains inadequately managed, due in part to concerns about addiction and legal sanctions, according to pain policy expert **Aaron M. Gilson, PhD**, chief policy researcher and assistant director of the University of Wisconsin Pain & Policy Studies Group in Madison.

In 1998, the Federation of State Medical Boards developed model guidelines that encourage the use of controlled substances for pain therapy and provide physicians guidance for use of controlled substances. The policy was disseminated to medical boards in each state. The new report found that state policies addressing the appropriate use of controlled substances for pain management increased from six in 1989 to more than 80 in 2001, with some states having more than one policy.

The new report also found that since 1998, 22 states have developed policies addressing the use of controlled substances for pain that are based on the federation's model guidelines. However, some state policies contain language that has the potential to impede the use of opioid analgesics and restrict patient access to adequate pain management, says Gilson.

Gilson has also reviewed trends in medical use of particular drugs to determine if the heightened attention surrounding the need for effective pain management is increasing the use of these medications. "According to our data, medical use of morphine in the U.S. has increased almost 2,000 percent since 1980. This suggests that it's being used more and more, not only to treat cancer pain but also to treat other types of chronic pain," says Gilson. "However, patients are still experiencing inadequate pain control due to practitioner fear of investigation and discipline, as well as patient and practitioner concerns regarding addiction."

While the DEA acknowledges the value of OxyContin for patients in severe pain, many doctors are worried about prosecution and have adopted a "better safe than sorry" attitude. The challenge for hospices is how to bring physicians back to prescribing the drug when it is appropriate.

Older physicians unused to such scrutiny

Just a few miles away from where Eddie Bisch died, Taylor Hospice in Ridley Park, PA, has had to face just that sort of challenge. Physicians have told hospice officials that they have been subjected to inquiries regarding their prescribing patterns by law enforcement agencies, including the DEA.

"We deal with a lot of older physicians who are not used to this kind of scrutiny," says **Janet Le, CHPN**, clinical director for Taylor Hospice. "What we tell them is that as long as they show documentation, they should be okay."

In another part of metropolitan Philadelphia, **Tina McMichael, MSN**, the director of Hospice of the VNA of Greater Philadelphia, says the limited number of inner-city physicians with ties to the larger hospitals have showed little trepidation in prescribing OxyContin and other opioids for their hospice patients.

"We've got a good medical director who has done a good job of helping to educate referring physicians, and our referring physicians seem to be enlightened," she says.

While the two hospices have had starkly different experiences with their referring physicians, there is a common denominator that explains the absence of problems in one and the solution to the other's problems: physician education.

Both hospices stress pain protocols developed by Hospice Pharmacia in Philadelphia,

a supplier of pain drugs to hospices. In addition, there is ongoing education lead by hospice medical directors.

Clinical staff at Taylor Hospice guide referring physicians in improving documentation. The hospice stresses thorough pain assessments and keeping a record of the pain patients report by using pain scales and including detailed notes of pain symptoms, such as grimacing, restlessness, and agitation, in the patient record.

"We've worked one on one with our physicians, and they have become more familiar with documentation and are more confident about prescribing pain drugs," Le says.

Still, if physicians are not comfortable with prescribing OxyContin, the hospice suggests other equally powerful drugs, such as morphine or Percocet, which require more frequent doses than the time-released OxyContin.

Hahn says the way to gain back the momentum of the pain management movement is through better education and improved tracking systems to better distinguish between compliance and abuse.

Hospice Pharmacia, which works with both Taylor Hospice and the VNA Hospice, has about 40 peer-reviewed pain management protocols covering most kinds of pain, which in some cases direct physicians to rely less on opioid drugs than on adjuvant therapies such as nonsteroidal anti-inflammatory drugs in order to control a patient's pain.

"The protocols drive people to use pain medication in steps," says **Calvin Knowlton**, PhD, chief executive officer of Hospice Pharmacia.

Hospice Pharmacia also provides technology that helps both physicians and the DEA track prescriptions. The firm offers a referral access system that tracks physician prescribing patterns by the DEA number assigned to prescribers. The system allows physicians to review their own referral patterns and review their own clinical practices if they notice any deviation from the norm.

From his home in a working-class neighborhood in Philadelphia, Ed Bisch will continue his crusade against OxyContin abuse. But he is quick to praise physicians who prescribe the drug to the thousands of people who are in extreme pain, which is a far cry from his healthy, athletic son and his friends whose pill-popping habits could be traced to a physician who wrote illegal prescriptions while his license was suspended.

"It's literally a bad dream, and I'm just starting to wake up from it," says Bisch. ■

Report from UK shows abuse of bereaved children

Study says small number of children are at risk

Some children who suffer the loss of a mother or father are being abused or neglected by the remaining parent, according to a study by children's charity ChildLine in London. The organization has called for urgent research into the subject after an investigation of existing studies on bereavement found virtually no mention of any association with abuse.

Esther Rantzen, ChildLine's chairman, says the report showed for perhaps the first time that there is a small number of children for whom the death of a parent or guardian means the child is deprived of their "protector" within the family. "The sexual abuse that follows causes these already vulnerable children additional pain and betrayal, on a scale too profound for most of us to imagine," she says.

The report, by ChildLine counselor and retired pediatrician **Sheila Cross**, MD, was based on a 10% sample of 2,619 calls made to the charity during a two-year period ending in March 2000. The subjects were young people, the majority aged 11 to 16, who had been bereaved.

The study found that 5% of callers mentioned abuse or neglect as another problem in their lives. The report said many young people of all ages believed that their ill treatment was related to the surviving parent's inability to cope with their own distress and frequently said that their father or mother had been drinking heavily since their partner died.

Where a bereaved child spoke about sexual abuse taking place for the first time following a bereavement, children were sometimes told that they must take a mother's place or that the abuse was intended to comfort them.

In some instances, the death of a caregiver had removed the child's protector (usually the mother) and the abuser had seized an opportunity that had not previously existed.

The report found that 43% of children in the study called ChildLine because a parent had died. These children described the pain of loss and their difficulty in coming to terms with a new pattern of life.

More than 21% of children in the study called because of the death of a grandparent, and 15%

called after their pet had died.

Nearly a third (31%) of callers in the sample spoke of a violent death, and a small number had witnessed it — most of them in road accidents. One had watched helplessly as someone took their own life, and two had witnessed a murder. ■



Sept. 11 aftermath shows the value of simply asking

Just give people a chance to give

By **Spencer Levine**

Director of Communications

The Hospices of the National Capital Region
Fairfax, VA

As the first anniversary of the Sept. 11 terrorist attacks approaches, the media relations wheels of every hospice should begin turning. The terrible emotions that are sure to resurface on that day will not be limited to people in the affected areas, and providing the emotional support for which hospice is acclaimed should not be limited either. Therefore, the challenge will be to find effective and affordable ways to let the community know hospice is there to help.

The medium with the highest potential impact is often television. Not coincidentally, that is often the most expensive medium in which to advertise or attract public attention.

Even though the federal government requires little of broadcast stations in the way of free public service announcements (PSAs), the good news is that broadcast and cable stations do seem to want to do things they perceive as helpful to the communities they serve. However, before they will give you free air time, you will probably need to meet specific requirements, such as having a message that spotlights programs, services, activities, or issues of community interest, and/or you must be a nonprofit, tax-exempt community group or organization. The requirements may vary, so it is definitely worth contacting your local stations about eligibility for free public service air time to promote a particular event or service.

For example, in the weeks preceding the first anniversary of the terrorist attacks, any hospice offering free counseling to the community after what is likely to be non-stop television news coverage with countless replays of those horrific images of last Sept. 11 should consider approaching local broadcast and cable stations NOW for free public service time in the fall to inform your community that counseling is available.

In fact, you might find, as we did, that your organization's grief and loss counselors are seen as a valuable resource to the station in terms of its news coverage for this anniversary or other traumatic events that can leave your community with an open wound.

Arranging for free air time is often less of a challenge than actually producing the public service announcement. Some television stations will offer to do it for you, though they may balk at allowing a competing station to use the same PSA. Other stations have neither the time, interest, or resources to do the production.

Sept. 11 had a profound effect on our service area, which includes the Pentagon and the part of suburban Maryland in which most of the Pentagon casualties lived. I knew I would have little difficulty getting air time for a PSA to announce our plans to continue to provide free counseling to the community through the holiday season. However, I did not have the slightest idea how I would pay for its production. Washington, DC, is too large a media market to count on any particular station to produce a PSA for all of the other stations to use. I decided that because I could not afford to pay someone to produce our PSA, I'd have to find someone who could.

I am not a development professional. In fact, I was uncomfortable asking a co-worker to borrow money for lunch one day after discovering in a checkout line that my teenager had secretly raided my wallet during the night. Still, armed with only the nobility of my mission, I set out to find someone to underwrite production of our public service announcement, even though we would be unable to acknowledge their assistance in the PSA they made possible. To do so would make the announcement a commercial, rendering it unsuitable for free public service air time.

What I learned was literally worth almost one hundred thousand dollars. Established donors and local businesses want to help you promote services that they see as crucial in a crisis. All you have to do is ask.

We checked our donor base and found the

owner of a local media production company. I know television production is expensive, so I expected “the ask” to be tough, the answer disappointing.

I said, “I want to do a PSA so people in our community will know we will continue to offer free counseling through the holidays. I don’t have any budget for this. And I can’t mention your company’s name in the spot or it won’t be considered a public service.”

I was stunned by his response: His offer to provide us with anything we need went far beyond any commitment I had expected. But his explanation is the real lesson to be learned.

Our benefactor said to me what we have been saying in the media all along. By getting involved, taking action, participating in this project, he said, his employees have a chance to do something personally and professionally to aid in our community’s healing. For him, that was worth far more than his company’s name in the spot.

We have been telling the public through the media that this kind of empowerment should not be underestimated. Now I know that to be true by experience.

I am suggesting to other hospice professionals that the same advice applies. While we hope and pray there will never be another experience like Sept. 11, we know there will always be disasters, both natural and man-made, after which the community involved will need our help to heal.

While we were fortunate enough to have the owner of a television production company among our donors, the point is that he would have helped us anyway. He saw the value to the community in promoting our services and the value to his company in providing employees a chance to get actively involved in healing the community.

There are few towns across the country without access to television, so production companies will likely be nearby. That is the first place to ask for help to promote your services. If a production company cannot donate all of its services, perhaps it can donate some of its services or reduce its prices. It might also put you in touch with other production professionals, such as cameramen, actors, and writers who might donate their services individually.

If all else fails and you must pay the full cost of production, pooling donations from several hospice supporters or local businesses solicited expressly for this purpose will enable each to contribute a manageable amount, the sum of

which would cover the production costs. And they may thank you for providing a way to help your community.

We have found success in thanking our benefactors in a variety of ways: public acknowledgement in a news conference, placing articles in the local paper, an invitation to a special hospice event to be thanked publicly, and a mention in our donor publication that reaches the local business community.

Hospices need not wait for a tragedy to occur before they collaborate with a local production company or solicit donors or businesses for a special project. Even when there is no emergency forcing you to get your message out right now, local businesses might just be looking for a way to demonstrate to present and future clients their commitment to the community and to local charity.

All you have to do is ask.

(Editor’s note: The Hospices of the National Capital Region, celebrating its 25th anniversary this year, comprises Hospice of Northern Virginia, Hospice Care of DC, Hospice of Prince George’s County, Hospice of Suburban Maryland, and the Halquist Memorial Inpatient Hospice Center. The writer was formerly a network television producer, radio writer, and newspaper reporter. His e-mail address is Slevine@thehospices.org.) ■

Docs don’t know Medicare home health rules

According to the Office of the Inspector General’s report, “The Physician’s Role in Medicare Home Health 2001,” 50% of physicians surveyed say they are not clear about the definition to apply when certifying medical necessity for a patient, and 3% say they are unclear on the Medicare criteria for “homebound.”

Many physicians also say they are not able to provide the level of oversight expected of them for Medicare home health patients. 83% of the respondents understand that Medicare expects them to make sure that only medically necessary services are on the plan of care, but only 48% say they are able to ensure this is the case.

Although home health staff are struggling to understand the rules for the home health

prospective payment system (PPS), physicians are even less aware of the requirements. In fact, 60% of the physicians surveyed said they had never heard of PPS.

To view the full report and recommendations, go to <http://oig.hhs.gov/oei/reports/oei-02-00-00620.pdf>. ■

News From the End of Life

Series offered on caring for terminally ill patients

Research indicates that quality end-of-life care has been sorely lacking in the United States. Ongoing surveys reveal that nurses feel inadequately prepared to care for dying patients. To address this knowledge gap, the *American Journal of Nursing* (AJN) is publishing a bimonthly palliative nursing care continuing education series.

The series represents a broad outreach to clinical nurses across all specialties that deal with end-of-life care. AJN, the official journal of the American Nurses Association (ANA), currently reaches about 342,000 nurses in diverse settings and positions.

The series of bimonthly articles will present a broad review of best research and practices in end-of-life care using actual case studies to improve the way nurses care for the dying and their families. The series debuted in the May 2002 issue of AJN, and the leading article provides an overview of palliative nursing care.

Specific topics that will be covered in the series include pain management, symptom management, cultural considerations in end-of-life care, ethical and legal issues, preparation and care for the time of death, achieving quality of life at the end of life, and grief, loss, and bereavement.

"Every nurse at some point is confronted with end-of-life care issues. Nurses need to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death," says **Betty Ferrell**, PhD, RN, research scientist at the City of Hope National Medical Center in Los Angeles and one of two

editors of the series. "This new series will teach nurses how to manage the many physical and psychological issues facing patients and families throughout a life-threatening illness."

The series builds upon the End-of-Life Nursing Education Consortium (ELNEC) project, an initiative of the American Association of Colleges of Nursing and City of Hope to improve nurses' breadth of knowledge on end-of-life care. Previous efforts of ELNEC include the development of a curriculum and eight corresponding courses to educate faculty, continuing education providers, and state boards of nursing representatives on end-of-life care.

Continuing education contact hours will be available for each article. All articles in the series will be posted on the Internet at www.ajnonline.com and www.nursingcenter.com. ▼

Study: Cancer patients need more services

A new study reports that patients who suffer from breakthrough pain in cancer, which affects as many as two-thirds of cancer patients, require increased medical services that result in higher medical costs than cancer patients without breakthrough pain.

The research, published in the *Journal of Pain*, found that patients with breakthrough pain are more likely to be hospitalized more frequently and have more doctor visits — two markers for increased medical costs — than cancer patients without breakthrough pain.

Patients who suffered from breakthrough pain incurred costs of approximately \$12,000 a year on medical services specific to their pain (hospitalizations, emergency room and physician visits), while patients who did not have breakthrough pain, but still experienced pain, incurred costs of approximately \$2,400 a year.

"Breakthrough pain is an often overlooked consequence of cancer. We know that it can significantly impact quality of life and recovery, but this is one of the first studies to demonstrate a relationship between breakthrough pain and the increased need for medical attention, resulting in higher medical costs," explains lead investigator **Barry Fortner**, PhD, of the department of psychology

and cancer symptom research at the West Clinic in Memphis, TN, and adjunct professor at the University of Memphis.

Breakthrough pain is a flare-up of pain characterized by rapid onset, severe intensity, and short duration. It occurs despite effective control of pain with scheduled analgesics used to control pain around the clock.

While data are limited on the prevalence of breakthrough pain, it is estimated that as many as 67% of those being treated for cancer pain experience breakthrough pain. The pain can be spontaneous and unprompted, or it can be brought on by an action as simple as swallowing, coughing, or moving. Breakthrough pain generally has the same source as persistent pain; causes can range from the cancer itself to cancer treatments.

According to the findings, more than half of the patients surveyed (53%, 527 patients) had experienced pain since being diagnosed with cancer. Of these, 49% (256 patients) had taken an analgesic on a regular schedule to treat their pain, 63% (160 patients) of whom suffered from breakthrough pain (BTP).

All patients who experienced pain were asked about the need for any of three medical services because of pain: hospitalization, emergency room visits, and doctor visits. On average, BTP patients were significantly more likely to experience pain-related hospitalizations and physician office visits than non-BTP patients. Thirty-seven percent of BTP patients (59 patients) vs. 23% of non-BTP patients (20 patients) reported pain-related hospitalizations. Fifty-six percent of BTP patients (90 patients) vs. 37% of non-BTP patients (33 patients) visited their doctor because of pain.

"Less than one-third of cancer patients in the study reported taking medication on a regular basis to treat their pain, and of these individuals, more than half reported suffering from breakthrough pain," says Fortner. "This situation is of major concern, especially since we have widely accepted treatment strategies to effectively control cancer pain, including one particular treatment designed to help manage breakthrough pain," he adds.

While the authors note that patients who

reported having breakthrough pain may actually have been suffering from uncontrolled cancer pain in general, Fortner says the study results signal a need to look more carefully at how breakthrough pain is being assessed and managed among cancer patients. ▼

HHS awards new Native American grants

Health and Human Services (HHS) Secretary **Tommy G. Thompson** has announced \$27.6 million in grants to support community programs and services for tribal elders and their caregivers. This amount reflects an 8.5% increase in funding for fiscal year 2002 and includes 10 tribal organizations receiving federal funds for aging services for the first time.

"The services provided through these grants are helping to improve the lives of our most revered citizens. We know that serious health disparities continue to plague Native American communities, and lack of access to health and social services remains a challenge," Secretary Thompson said. "This program is a vital component of our prevention and education efforts to reach out to vulnerable communities."

Administered by HHS' Administration on Aging (AoA), the 236 grants awarded to tribal organizations will provide nutrition and supportive services to Native American elders to help them to remain independent and healthy. In addition, 177 Native American Caregiver Support Grants, available under the new National Family Caregiver Support Program, will support the caregivers of American Indian, Alaskan Native, and Native Hawaiian elders. Of that number, 68 tribal organizations will receive critical caregiver support services for the first time.

Since 1978, AoA has funded federally recognized tribal organizations for nutrition and supportive services provided to approximately 250,000 Native American elders, who are among the most disadvantaged populations in the

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nation. The Native American Caregiver Support Program, created in 2000 as part of the new National Family Caregiver Support Program (a new component of the Older Americans Act) provides support to the caregivers of elders who are chronically ill or have disabilities.

The program includes information, assistance, counseling, training, and respite among its list of services available to family caregivers struggling to care for family members.

"We know that an increasing number of Native American elders need assistance, and most prefer to remain in their homes, communities, and on reservations. Our programs help to promote independence, well-being, and positive lifestyles while preserving the heritage of the Native American culture," HHS Assistant Secretary for Aging **Josefina G. Carbonell** said. ▼

Helping caregivers to communicate with MDs

The National Family Caregiver's Association (NFCA) 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, yet they receive no formal training or support in their roles. The program, called "Communicating Effectively With Healthcare Professionals," provides family caregivers with the skills and tools they need to help their loved ones get better care.

NFCA kicked off the project with an informative "train-the-trainer" conference on March 9-10 in Arlington, VA. The forty-seven pre-selected attendees were introduced to a curriculum including 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 from as far away as Alaska included representatives from the American Red Cross, area agencies on aging, health systems, volunteer 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. The project was made possible by a

grant from the Jacob and Valeria Langeloth Foundation. The National Alliance for Caregiving provided assistance to NFCA in the development of the project.

"One of the greatest challenges family caregivers face is ensuring that a loved one is receiving the best medical care," says **Suzanne Mintz**, president and co-founder of NFCA. "This is a daunting task when working with a myriad of health care professionals, providers, insurers, and other medical organizations. 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."

NFCA is a grass-roots organization created to enable, educate, support, and advocate for the millions of Americans who care for chronically ill, aged, or disabled loved ones. For more information on the program, contact NFCA at (800) 896 3650 or at info@nfcacares.org. ▼

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Editorial Questions

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

Assisted living facility pays \$1.5 million for hiring felon

A Virginia jury has found Summerville Assisted Living facility in Woodbridge negligent for not properly caring for a former patient, and has awarded the patient \$1.5 million.

The jury deliberated for fewer than 90 minutes. Barbara Crowe, daughter of the patient, 83-year-old Margaret Noel, filed suit last year on behalf of her mother, who was living in the facility's Alzheimer's wing when she fell and broke her hip in 1999. **Jeffrey J. Downey, JD**, attorney for Crowe, said Summerville's negligence was exemplified by "an utter disregard for the safety of their residents, especially their vulnerable Alzheimer's residents who were placed in the hands of a convicted felon, who received a few hours of video training and was placed on the floor caring for some 15 to 20 residents."

Evidence also showed that staffing levels were not based on the needs of the residents, but on the corporate budget, which did not take into account the acuity of the residents.

Downey says the verdict reflects a complete rejection of the notion that Alzheimer's patients can't experience pain and suffering, a notion he says is often articulated in settlement discussions if not in court. ▼

Most support caps on pain and suffering awards

The vast majority of Americans support medical liability reform, including a cap on pain and suffering awards, according to a survey released by the Health Care Liability Alliance (HCLA).

Donald J. Palmisano, MD, JD, secretary-treasurer of the American Medical Association (AMA), says the survey results show that the American people support the health care community's drive for liability reform. Palmisano is a founding member of HCLA and a member of its board.

"Liability reform is one of the AMA's top legislative priorities, and these survey results show the vast majority of Americans support liability reform as well," he says. "An overwhelming 78% of Americans say they are concerned about the impact rising liability costs have on access to care,

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and 73% support a law that caps pain and suffering awards."

Palmisano says the AMA has always held that patients who have been injured through negligence should be compensated fairly, but, unfortunately, the current liability system has failed patients. The United States has created a liability lottery, he says, where select patients receive astronomical awards and many others have problems accessing care because of it.

"We will never have true access to care for all unless the hemorrhaging costs of the current medical liability system are addressed," he says. "The new survey shows that 71% of Americans agree that one of the primary reasons health care costs are rising is because of medical malpractice lawsuits. The spiraling costs generated by our nation's dysfunctional liability system are borne by everyone. We need a system that ensures fair compensation and puts an end to the liability lottery." ■

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