

HOSPICE Management ADVISOR

Integration • Outcomes • Managed Care • Medicare Compliance • Risk Management • QI • End-of-Life Care

INSIDE

■ **An outline for cooperation:**

When hospices and hospitals cooperate, end-of-life care is enhanced. A New York City center has guidelines on making this happen 15

■ **Advance directives:**

Hospices should partner with nursing homes to ensure patients document their wishes for end-of-life care 16

■ **Guest Column:** Author of CAPC-NHPCO monograph on inpatient palliative care shares his insights about this growing trend in end-of-life care . . . 19

■ **News From the End of Life:** Poor pain management caused by poor adherence to pain medication regimens; negative effects of caregiving last for years; faith-based volunteers and clergy need more training in end-of-life care 22

FEBRUARY
2002

VOL. 7, NO. 2
(pages 13-24)

Hospice involvement key to success of inpatient palliative care

Cooperation with hospitals can foster transition into hospice

It wasn't long ago when hospices looked on suspiciously as hospitals began talking about providing better end-of-life care within their own facilities, with some hospitals even laying the groundwork for palliative care units. Hospice leaders wondered out loud if hospitals were treading on hospice territory. Hospices and trade associations rallied to remind people they have been providing palliative care for more than two decades. To drive that point home, many hospices and associations added "palliative care" to their organization's name.

It seems, however, suspicion is giving way to partnership. Hospitals are realizing that they don't have to reinvent end-of-life care. For their part, hospices understand that by sharing their expertise, they can improve the quality of care of patients in hospitals, a population that has been difficult for them to tap into in the past.

"Several years ago, it was a shock to the hospice industry to see the end-of-life care wave that was sweeping across the country as if it were something new, and we had been doing it for more than 20 years," says **Mary Labyak**, MSSW, LCSW, president and chief executive officer of Hospice of the Florida Suncoast in Largo, FL.

"Since then, there has been a lot of dialogue between hospices and hospitals," Labyak says. "We are at a different point now and we have an opportunity to deal with each other differently."

Last August, Forsyth Medical Center in Winston-Salem, NC, opened an 11-bed acute palliative care unit to serve terminally ill patients who have chosen to stop aggressive, curative treatment. Hospital administrators decided to dedicate a portion of the facility to palliative care, in part because too many of the hospital's dying patients were on a waiting list for hospice, and most died before getting an opportunity to benefit from hospice care.

Before the opening of the hospital's inpatient facility, terminally ill

NOW AVAILABLE ON-LINE: www.ahcpub.com/online.html
Call (800) 688-2421 for details.

patients in need of acute palliative care services had to be spread out among beds in the hospital's intensive care unit and other areas.

It was ventures such as these that would cause hospice administrators to shiver at the notion of having to compete with a hospital. Treating dying hospital patients in an inpatient palliative care unit could mean those patients would likely not be referred to a hospice's own inpatient facility or its home care program.

"The hospitals in our area have been very supportive of hospice," says **Joann Davis**, chief executive officer of the Hospice and Palliative Care Center in Winston-Salem. "They are competitive with one another, but not with us."

But that was never the intention of Forsyth Medical Center's program, says **Sylvia Beane**, RN, nurse manager at Forsyth Medical Center. "This new unit gives Forsyth Medical Center an opportunity to identify patients who can benefit most from palliative care services: patients with cancer, patients with chronic degenerative diseases, patients dying in the ICU on ventilators," Beane says.

"Our patients are not looking for a cure for their illnesses," she continues. "Our goal is to help these patients to live life to the fullest up until the last minute of life. The needs of these patients are great. Often the patient and his family feel guilty because they are not fighting anymore. We'll address not only their physical needs but their emotional and spiritual needs as well."

Hospital officials instead view the palliative care unit as a transitional setting to help move patients from the hospital to the hospice. The inpatient unit is for patients who are no longer seeking aggressive care and treatment for their terminal illnesses but who still need the services of an acute care hospital.

"These patients need a higher level of care than they can receive at home or in a hospice facility, or they are not strong enough to be transferred to a hospice facility," Beane says. "The new unit will also help ease the waiting list at hospice."

Interest in establishing hospital-based palliative care programs is growing as a result of public and professional recognition of the need to improve care of the seriously ill and dying. Few hospital-based programs offer dedicated units like this one. At 11 beds, Forsyth Medical Center's acute palliative care unit will be one of the largest hospital-based units in the country, says Beane.

In addition to the pride hospital officials exude

when talking about their inpatient palliative care unit, they also acknowledge that it could not have been done without the help of the Hospice and Palliative Care Center, which is located just down the road from the hospital. The center provided a lot of the expertise needed to establish policies and procedures for caring for dying patients who no longer want curative care.

Before the hospital and hospice agreed to collaborate on an inpatient care unit, a symbiotic relationship already existed. Both the hospice and the hospital understood the value of sharing expertise. It was common for hospice nurses to be in the hospital providing consultation to hospital staff and teaching ill patients about hospice. The hospice medical director has also been available for consultation.

Hospice shared routine order sets

As both organizations began exploring the creation of a palliative care unit in the hospital in January 2001, one thing became clear early on: The hospital would not have to go through the time-consuming task of developing palliative care procedures and protocols.

"We knew they were the experts," says Beane. "It was a collaboration from the start."

The hospice readily shared its routine order sets, which helped hospital staff develop plans of care for their palliative care patients. This also facilitates a smoother transition into hospice care, because the care can be easily coordinated with care the patient will receive through hospice.

There is no one model for hospice-hospital palliative care ventures. They can range from full partnerships to hospices simply providing clinical consultations, says Labyak. How the two sides work together is a function of the trust and understanding that have been cultivated prior to the decision to establish an inpatient palliative care unit.

But hospitals and hospices that collaborate should adhere to general principles of palliative care programs, Labyak adds. **(For a step-by-step approach, see story, p. 15.)** Hospices and hospitals must establish palliative care programs that emphasize the following:

- physical, psychological, social, and spiritual support to help the patient and family adapt to the anticipated decline associated with advanced, progressive, incurable disease;
- a full array of inter-institutional and community resources (hospitals, home care, hospice,

long-term care, adult day services) that promote a seamless transition between institutions/settings and services;

- an environment that supports innovation, research, education, and dissemination of best practices and models of care.

The power of cooperation should not be taken lightly or dismissed as sugar-coated rhetoric. Consider that the Forsyth Medical Center and the Hospice and Palliative Care Center began planning the inpatient palliative care center a year ago. In less than a year, the hospital had all its policies and procedures in place and hospital space dedicated, allowing the center to begin treating patients in September.

“This was never about competition,” Beane says. “We realized that the care of these patients is different and that it is about living well while you are dying. We knew hospice had the experts. We would have had a unit without hospice help, but I don’t think it would have been as successful, and if we didn’t already have a good working relationship, there would have been a lot of misunderstanding and backpedaling.” ■

Steps for creating an in-hospital program

A step-by-step approach

While hospices bring a wealth of palliative care expertise, they need to cooperate with their hospital partners as they go through the process of establishing an inpatient palliative care program. To provide direction to hospitals and hospices that are collaborating in establishing an inpatient program, the New York City-based Center to Advance Palliative Care (CAPC) has outlined the following step-by-step approach:

1. Identify institutional leaders and initiate a strategic planning process.

Strong, effective leadership is the key ingredient for successful development of palliative care programs. Identify key stakeholders and champions among the hospital/health system staff and from the community.

2. Conduct an institutional and community needs assessment for palliative care services.

Developing a new clinical service requires an organized process, convincing data, and

demonstration of a compelling unmet patient need within the institution as well as the community. Begin this analysis by interviewing potential stakeholders. Assess their interest and needs. Elicit their support and identify opportunities for collaboration.

3. Survey the community for competitive palliative care services.

Specifically look at:

- length of time in operation;
- reputation and ability to meet patient needs;
- gaps in existing palliative care services;
- potential collaborative opportunities.

4. Profile hospital patient population and demonstrate an unmet patient need.

Look at the patient population that will benefit most from palliative care. For example, demonstrate the costs to the hospital for failing to institute appropriate services and discharge options for vulnerable, seriously ill patients, many of whom are dying. Graphically illustrate the scale of unmet patient need with data such as:

- total number of hospital deaths annually by age group and insurance status;
- causes of death by Medicare DRG;
- locations of deaths (e.g., medical/surgical unit, ER, ICU, etc.);
- length of stay in hospital and in ICU by DRG, among patients who die in the hospital;
- discharge information (destination);
- number of patients with advance directive, health care proxy, and/or DNR order.

5. Conduct focus groups.

Further define your patient population and its needs by convening several small focus groups to reveal additional reasons for instituting a palliative care program. Focus groups to convene include:

- physicians;
- nurses, social workers, pharmacists, and chaplains;
- patients in specific diagnostic groups;
- family and caregivers.

6. Develop a mission statement, goals, and objectives for the palliative care program.

With your research completed, develop a compelling mission statement and goals and objectives that reflect and reinforce unmet need. Establish short-term (12 months) and long-term (three years) program goals that are as specific and measurable as possible. Goals to consider include:

- patient/caregiver satisfaction;
- physician and staff satisfaction;

- growth in patient volume;
- financial performance;
- impact on length of stay in hospital and in ICU;
- innovation/research;
- awards/recognition.

7. Decide on the range of services to offer.

The range of palliative care services offered will depend on such variables as:

- gaps in existing community services;
- type of population to be cared for (e.g., complex tertiary-care referral populations vs. small community hospital populations of mostly elderly and chronically ill);
- location in the hospital where most patient deaths occur;
- inpatient hospital bed constraints.

8. Select a delivery model.

This can include a consultation service, a dedicated inpatient unit, a combined consultative and geographic unit model, a combined hospice palliative care unit (with or without a contract with a community hospice), or a hospital outpatient palliative care clinic. (For more information on these models, check out the CAPC web site at: www.capcmssm.org/topic/5/.)

9. Determine funding sources.

Medicare and Medicaid are the primary payers for palliative and hospice care. Medicare is the benchmark for rates paid by private insurers for these services.

10. Develop a public relations and communications plan.

Identify both internal and external audiences to whom you will promote the new service.

Activities may include:

- program brochure and direct mail campaign;
- educational programs for referring physicians, families, and patients;
- local news and human interest stories;
- public relations and fundraising events.

11. Develop an operations plan.

Identify all the resources/costs required to put the program into operation, including:

- administration and management team;
- community advisory group;
- staffing;
- space renovation and rent;
- capacity (number of beds/patients per staff unit);
- medical and office equipment and supplies;
- medical records;
- quality assurance;
- public relations/communications.

12. Develop a financial plan.

Using cost estimates from the operations plan, develop a financial plan including a three-year proposed program budget of revenues and expenses. Project estimated revenues from all funding sources, based on anticipated patient utilization and service volumes.

13. Recruit a skilled interdisciplinary team.

Once your program is approved, recruit a skilled interdisciplinary team from the outset. For a dedicated inpatient unit, the team should include a physician, a nurse, a social worker, and/or a bereavement or pastoral care counselor. If having a dedicated bereavement staff is not possible, the palliative care service should be able to refer families to affiliated bereavement program staff. Other experts who can make a significant contribution to the team include patient advocates, chaplains, pharmacists, pain experts, rehabilitation experts, and psychiatric consultants.

14. Develop a patient database to measure quality and outcomes.

Clinical data, patient and family assessments, and financial information should be collected in easily accessible and usable databases. It is also important to track and evaluate all program research and educational activities. Data such as these help quantify the importance of the program and are critical to demonstrating the program's benefit to the hospital's mission and reputation. ■

Advance directives needed in nursing homes

Patient preferences vary by region

Nursing homes can help patients decide and document how they wish to be cared for in the event of a serious illness, according to a recent study. With that finding in mind, the relationships hospices have with nursing homes may very well dictate whether nursing home patients receive complete advance directive guidance that includes care wishes for both chronic and terminal stages.

Expressing preferences for end-of-life care in advance directives can help patients and their families deal with questions that may arise when

an elderly person becomes seriously ill, such as whether or not to resuscitate, and the kind of care the patient wishes to receive following a terminal diagnosis. Nursing home residents also must decide on palliative care options available to them before their illness turns into a terminal condition.

Today, about 1.5 million people reside in nursing homes in the United States, and many have chronic disorders, researchers report in the May issue of the *Journal of the American Medical Directors Association*. These chronic illnesses are often directly linked to their deaths, making it important to for those patients to document their care wishes in the event they cannot tell physicians and medical staff how they want their final weeks of care carried out.

“Addressing patient and family desires for treatment is important for maintaining the dignity and comfort of any patient,” says **Vincent W. DeLaGarza**, MD, of Johns Hopkins University in Baltimore.

DeLaGarza and his colleagues reviewed medical charts of more than 4,000 nursing home residents in a managed Medicare program in six states. They found that in 1996, 73% of patients or their families had discussed their preferences for treatment in the event of a serious illness. The following year, the nursing homes participating in the study made efforts to increase the number of patients with advance directives. These initiatives included staff educational programs and letters to health care providers.

By 1997, 85% of more than 6,500 patients surveyed had advance directives. Patients’ preferences for their end-of-life care varied by geographic region. For example, 8% of patients in Minnesota said they would want CPR, compared with 29% of those in Georgia. Similarly, 87% of patients in Georgia said they wished to be hospitalized, compared with 57% of those in Minnesota. Overall, 62% of patients wished to be hospitalized.

The reasons for the geographic variation are not clear, but the researchers suggest they may reflect racial preferences, which have been documented in previous studies. Nonetheless, the variation in patient preferences and the fact that more than one-third of patients did not want to be hospitalized underscores the need for patients to state their wishes explicitly in letters or discussions with family members and health care providers, researchers concluded.

The need for advance directives in nursing

homes is an opportunity local hospices must seize, according to **Cherry Meier**, RN, MSN, long-term care manager for the National Hospice and Palliative Care Organization in Alexandria, VA, and director of public affairs for Vitas in Austin, TX.

“The need for information about advance directives is one of the reasons why nursing homes invite hospices in,” Meier says.

But nursing home-hospice relationships can be delicate, Meier warns. Not all nursing homes are receptive to hospice offers to share expertise. There is still a lack of understanding between nursing homes and hospices. And while nursing homes have a learning curve, so do hospices, says **Christine Johnson**, RN, MS, executive director of The Inn at Barton Creek, an assisted living facility in Bountiful, UT.

Johnson speaks not just as a nursing home administrator, but also as an expert in nursing home-hospice relationships. In 1997, after a number of nursing homes in Utah complained that there seemed to be an unusual push for hospice services in nursing homes, she co-wrote the Utah Health Care Association’s guidelines for delivering hospice care in a nursing facility.

While hospices have an expertise in educating patients and families on advance directives, the scope of their expertise may be limited to only end-of-life questions, rather than issues surrounding a chronic illness. Nursing homes, on the other hand, focus on treatment issues.

Nursing homes focus on treatment issues

Understanding nursing home concerns will give hospices a helpful perspective when they discuss advance directives with nursing home staff. This includes recognition that nursing homes are often concerned with intermediate conditions while hospices focus on terminal conditions. And the biggest of those terminal care issues is palliative care, which includes symptom management and emotional and spiritual care.

Both Meier and Johnson agree that hospices and nursing homes usually will not come together to promote advance directives outside of previously established cooperation. The value of hospice and nursing home cooperation in educating patients and their families about care options is that it ensures that their decisions are honored and promotes a seamless transition from nursing home care to hospice care when appropriate.

But to foster greater cooperation, hospices must address nursing home needs, not in one single area such as advance directives, but from a more global perspective.

Johnson identifies 10 areas in which nursing homes and hospices can become entangled in conflicting policies and regulations. They are as follows:

1. Coordination of billing. The two organizations need to work out who is going to bill for which services. This includes understanding the responsibilities of clinical management of the patient and being able to distinguish routine care provided by nursing home staff.

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

3. Resident assessment. Hospices must cooperate with nursing home staff to ensure timely completion of the minimum data set, either by agreeing to complete the form based on a working knowledge of the patient or providing the needed information to nursing home staff responsible for completing the form.

'Work toward mutual support'

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

5. Professional communication. To facilitate the coordination of care plans, standard mechanisms need to be in place to notify each provider of changes in the care plan or changes in

the patient's condition. Johnson suggests each organization designate one staff member as the person to call when changes are made and to coordinate how the changes will be handled. For example, a hospice might designate the on-call nurse as the liaison so that the nursing home is assured of reaching a nurse who is able to make sure changes are noted and care is provided in a timely manner.

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

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

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

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

10. Nursing home staff training. Hospices need to establish a collaborative training program with their nursing home partners. Hospices often treat facility staff training as a work in progress, says Johnson. For training to take root, hospices must make sure nursing home administration is taking part. High-level management participation means there is a greater likelihood that the concepts taught will remain with the organization despite the high turnover rate of nurses and aides.

“Both sides must be open so that some degree of rapport is developed,” says Johnson. “If you have common principles of practice and come to an agreement on how to perform these practices, then it all flows.” ■



Hospice vs. palliative care: What's the difference?

Hospice industry shifts focus

By **Larry Beresford**
Alameda, CA

Palliative care, a term that is strikingly unfamiliar to the health-consuming public but increasingly prominent for hospices, hospitals, and other health providers, was a central theme of the recent National Hospice and Palliative Care Organization (NHPCO) Management and Leadership Conference.

Titled “Hospice and Palliative Care: Evidence, Advocacy and Action,” the Dec. 3-5 conference in Arlington, VA, featured presentations on outpatient palliative care programs, hospital-based consulting services, new policy proposals, and research on palliative care trends and initiatives. I co-presented one of the sessions, addressing hospital-hospice collaboration in palliative care development, based on my research for a project sponsored by NHPCO and the Center to Advance Palliative Care (CAPC) at the Mount Sinai School of Medicine in New York City. (The fruits of that project include a technical assistance monograph on hospital-hospice partnerships, now available

on the two sponsoring organizations' web sites [www.nhpc.org and www.capcmssm.org] and soon to be mailed to all provider members of NHPCO.)

Just as important as the palliative care content presented at NHPCO's conference was the growing comfort level with the concept, as evidenced by attendees from hospices around the country — some of whom previously may have feared it as a threat to hospice's primacy in the delivery of end-of-life care. However, the actual nature and forms of palliative care are less clear, which can be seen in the careful attempts to define it in many of the conference presentations.

Two years ago, NHPCO changed its name from the National Hospice Organization, mirroring similar changes by the national organizations for hospice doctors and nurses, by several state hospice organizations, and by increasing numbers of local hospice programs. However, hospice professionals may well wonder whether adding “palliative care” to the names of hospices and hospice organizations acknowledges the existence of two distinct, parallel models of end-of-life care. Or does it point instead to a new, comprehensive, integrated care model in which hospice is part of a broader continuum of end-of-life care? And is the new focus on palliative care good for patients — and for hospices? The jury is still out on some of those questions, but I believe some important implications are starting to emerge:

1. Hospice currently is the only large-scale, national provider of end-of-life care, even though palliative care development is under way in hundreds of hospitals across the country. U.S. hospices served 700,000 terminally ill patients in 2000, according to NHPCO data, representing one-quarter of all Americans who died from any cause that year. The number of hospice admissions continues to rise, even though providers complain about the problems resulting from short lengths of stay. It only makes sense for existing hospice programs to play a significant role in new palliative care development, based on their broad experience in caring for dying patients.

2. Hospice is palliative care, as hospice standards have emphasized since the movement's early days, but not all palliative care is hospice. There are many reasons — regulatory, financial, institutional, cultural, or personal — why some patients with life-threatening illnesses and a need for palliative support might not be enrolled in

hospice care, even when they have fewer than six months to live. Meanwhile, some hospices are developing new palliative care service lines while insisting that Medicare's definition of hospice care does not encompass all that hospice is or should be. However, even the broadest definition of hospice cannot incorporate all current palliative care development, and not all patients who need palliative care can or will choose the hospice option.

Earlier access to palliative care a challenge

3. Palliative care is an appropriate service from the point of diagnosis of a serious or life-threatening illness, according to the latest definitions, but palliative care providers are challenged to promote access earlier in the disease trajectory. Palliative care often struggles with the same issue that hospice has long faced: a tendency for physicians and other health professionals to view it as an end-of-life or even brink-of-death service. Evidence from the field highlights the need for educating referral sources to recognize the value of specialized attention to seriously ill patients' and families' needs for symptom management and psychosocial-spiritual support simultaneous with aggressive, disease-modifying therapies.

4. Reimbursement and regulation for palliative care remain big question marks. Currently, there is no reimbursement stream or regulatory structure explicitly addressing palliative care — with the exception of hospice — although palliative care can be covered through other reimbursement categories such as physician consultant visits or hospital diagnosis-related groups. But if reimbursement for palliative care were to be enacted, many innovative palliative care programs that now survive on grants, philanthropy, and institutional subsidies are poised to take advantage of it. Evidence is starting to emerge suggesting that palliative care programs can generate cost savings for hospitals by reducing lengths of stay and substituting supportive care for futile, aggressive treatments. But such evidence is still sketchy and hard to pin down.

5. The hospital remains a major site for the provision of end-of-life care, with half of all deaths occurring in the acute hospital setting. Community hospices often have little influence on what happens in the hospital, and results from the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments demonstrated that many patients dying in the hospital receive less-than-optimal care.

Together, those five implications point to an unmistakable conclusion: Hospices and hospitals need to find ways to work together to meet more of the palliative care needs of seriously ill patients who are dying in the hospital or who aren't eligible for or enrolled in hospice care. Simply put, hospices need to go where patients are dying if they are to fulfill their larger mission of service to the community, while hospitals should be drawing upon hospices' experience and skills in end-of-life care.

I visited 10 sites of hospital-hospice collaboration in the course of researching the NHPCO/CAPC monograph on hospital-hospice partnerships. What I found at those sites of active partnering is the emergence of new, experimental, ad hoc programs incorporating inpatient hospice or palliative care units; inpatient and outpatient consulting services; liaison nursing, coordination, and case management; research and education initiatives; and a variety of other activities.

Hospice presence affects hospital culture

In some of those partnerships, the hospice is leading the innovation by introducing new concepts and new services to the hospital. In others, the hospital is driving the innovation while drawing upon a community hospice in an advisory or consultative capacity. In many cases, an expanded presence for interdisciplinary hospice and palliative care within the hospital is influencing medical culture and symptom management practices more broadly within the institution, often resulting from mere proximity and a higher profile for appropriate end-of-life care.

A major focus at many of the sites was the development of inpatient hospice units. These units provide the general inpatient care needed by the hospice's caseload and also expand access to the hospice benefit for patients who are dying in the hospital. There are various avenues to collaborative inpatient development, depending on local circumstances, but often the hospice unit provides a beachhead for expanded collaboration on other fronts.

Well-placed champions within the hospital, mutual trust, and close personal relationships between individuals at each partnering organization were all important to successful collaboration. The partnerships also provided opportunities for physician leaders to play an expanded role in end-of-life care and for the exploration of specialized programming addressing the needs of special

patient populations ranging from seriously ill children to patients with HIV/AIDS, congestive heart failure, chronic obstructive pulmonary disease, or Alzheimer's disease. But the collaborations required financial support in the form of foundation grants, community donations, medical fellowships, and institutional subsidies, in addition to whatever reimbursement was available.

More research and more demonstration projects are needed to document the forms of collaboration between hospices and hospitals (as well as their value). At the sites I visited, hospice and hospital partners say they are responding to unmet needs in their communities and improving end-of-life care overall. They also say hospice's expertise in symptom management and interdisciplinary care is slowly infiltrating into the medical culture of larger institutions without diminishing its direct role in providing end-of-life care.

The partners say introducing palliative care to patients and families earlier in the course of an illness, before a hospice referral would be considered appropriate, can have a secondary effect of more and earlier referrals to hospice care. This comes about not by pushing an explicit agenda of earlier hospice referral but by starting the conversation with patients and families about their values and goals for treatment and introducing them to palliative care concepts earlier in the course of their illness. The opportunity is expressed by a slogan used at one of the sites: "Hope for the best; plan for the worst."

Then, when a hospice referral becomes appropriate, it can be a more natural and seamless transition. Ultimately, they suggest, hospice will take its rightful place in the broader care continuum as the most intensive form of palliative care. One hospice medical director described it as "the jewel in the crown of palliative care," providing the gold standard for palliative care, a center of excellence, and a force for change in the hospital. If such an effect can be documented on a larger scale, the logic of hospices and hospitals developing closer partnerships in palliative care will become inescapable.

[Editor's note: Larry Beresford, an independent journalist specializing in end-of-life care, is the primary author of Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Services, published in December 2001 by the Center to Advance Palliative Care. Contact him at 1089 Park Ave., Alameda, CA 94501. Telephone: (510) 864-2446. E-mail: larryberesford@hotmail.com.] ■

Disaster Planning and Bioterrorism: Is Your Hospital Ready?

Wednesday, March 6, 2002 • 2:00-3:00 p.m. EST

Presented by Bettina M. Stopford, RN and
Robert E. Suter, DO, MHA, FACEP

To easily attend this **audio conference**, you simply phone in from your home or office, whichever is convenient for you.

Sponsored by the publisher of *Emergency Medicine Reports, Hospital Infection Control, Hospital Employee Health, ED Management, ED Nursing* and others.

**Educate your entire staff for one low fee!
Just \$29 for your entire facility for subscribers
to one of AHC's publications and \$299
for nonsubscribers.**

You will learn:

- How to satisfy JCAHO requirements for emergency preparedness.
- Ways to expedite communication among your clinicians for identifying and reporting disease clusters or symptoms of bioterrorism in a timely manner.
- Protocols for patient management, including increased patient flow, isolation, transport, placement and discharge.
- How to manage the decontamination process to prevent further spread and whom to consult to determine if decontamination should even be considered.
- Strategies and steps to take for triage and to safely house a large number of affected individuals.
- And more

Plus, your staff can earn valuable CE or CME

Each listener has the opportunity to earn approximately 1 nursing contact hour or up to 1 AMA Category 1 CME credit.

We know the unthinkable can happen — make sure you and your staff are prepared.

Call (800) 688-2421 or
(404) 262-5476 to register now!

You also may register on line at www.ahcpub.com
(Priority code 55001)

Accreditation Statement

American Health Care Accredited + is a credit + d + a + a provider of continuing education in training by the American Nurses Credentialing Center's Commission on Accreditation. Provider approved by the California Board of Registered Nursing, Provider # Number + CEP 10864 for approximately 1 nursing contact hour.

American Health Care Accredited + designate + this continuing medical education activity for up to 1 hour in Category 1 credit toward the ANCC Physician's Recognition Award. Each physician should claim only those hours of credit that he/she actually spent in the educational activity. American Health Care Accredited + (AHC) is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

At the conclusion of this teleconference, participant + will + able to understand current requirements for disaster planning/bioterrorism and offer suggestions for satisfying those requirements.

Poor regimen adherence leads to poor pain care

Addiction fears not the problem

Lack of adherence to pain medication regimens and inadequate analgesic prescriptions are the main reasons cancer patients do not achieve adequate pain relief, according to researchers at the University of California San Francisco (UCSF).

In one of the first studies to observe cancer patients in their homes, researchers at the schools of nursing, medicine, and pharmacy at UCSF studied whether cancer patients were adhering to the around-the-clock and as-needed pain management regimens prescribed by their doctors. The results of the study were published in the Dec. 1 issue of the *Journal of Clinical Oncology*.

"The old message was that people weren't taking their pain medication because of fear of addiction," says **Christine Miaskowski**, RN, PhD, professor and chairwoman of the department of physiological nursing at UCSF. "Our study debunks that explanation, and found that the side effects caused by most opioid analgesics were a key reason why cancer patients did not adhere to their pain medication regimen."

Side effects, such as constipation and sedation, deterred patients from taking their pain medications. Patients in the study told researchers that they would rather experience pain than deal with the side effects of the analgesic medications. This finding is unfortunate, because side effects like these can be proactively treated.

According to an accompanying editorial by **Jamie von Roenn**, MD, professor of medicine at Northwestern University in Chicago, "Lack of adequate knowledge or assessment of pain management by physicians is suggested by the pattern of analgesic prescriptions. Effective pain

management requires repeated assessment and adjustments in dosage."

The randomized five-week study included 65 adult oncology patients with baseline pain and evidence of bone metastases. On a daily basis, patients rated their level of pain intensity and recorded their pain medication intake. Adherence rates for opioid analgesics prescribed on around-the-clock and as-needed bases were calculated weekly.

Overall adherence rates ranged from 84.5% to 90.8% for around-the-clock opioid analgesics and 22.2% to 26.6% for as-needed analgesics. There were no significant changes in adherence rates, pain intensity, or duration of pain during the course of the study.

Federal guidelines recommend that all cancer patients with chronic cancer pain be prescribed an around-the-clock analgesic regimen, as well as a short-acting supplement for breakthrough pain. However, not all patients received both types of medication. In the study, 13.9% of patients were prescribed opioid analgesics on an around-the-clock basis, 56.9% were prescribed opioid analgesics on an as-needed basis, and 29.2% were prescribed both around-the-clock and as-needed analgesics.

"Poor adherence, may, therefore, in part reflect the lack of relief from inadequate analgesic prescriptions," says von Roenn. ■

Caregiving negative effects can last years: Study

Depression rate didn't drop

The negative psychological impact of caregiving for a spouse with Alzheimer's or other forms of dementia continues for years after the spouse dies, new research suggests.

The study by researchers at the Houston VA Medical Center and The Ohio State University in

COMING IN FUTURE MONTHS

■ Tips for making the best use of the Internet

■ Building strong community awareness programs

■ New developments in pain management

■ Proven hospice marketing strategies

Columbus found that, even three years after their spouse had died, former caregivers still showed levels of depression and loneliness similar to those in current caregivers.

For example, 41% of former caregivers showed mild to severe depression at two to three years after their spouses' death — not significantly less than the 43% depression rate among current caregivers.

“One assumption has been that the psychological health of caregivers would improve once the burden of caregiving ends,” says **Susan Robinson-Whelen**, PhD, the lead author of the study and an assistant professor of physical medicine and rehabilitation at Baylor College of Medicine in Houston. “However, we found that the negative effects of long-term caregiving for a spouse with dementia may continue well beyond the caregiving years.”

The study appears in the December issue of the *Journal of Abnormal Psychology*.

The researchers studied 49 former caregivers, 42 continuing caregivers, and 52 noncaregiving control participants. The former and current caregivers all cared for a spouse suffering from some form of dementia, such as Alzheimer's disease. All the participants were assessed on a variety of psychological measures for four years. The former caregivers were tested once before the death of their spouse and three times following the death.

The most striking finding was that levels of depression did not significantly improve even two to three years after caregiving duties ended, says **Janice Kiecolt-Glaser**, PhD, who is a professor of psychiatry at Ohio State. While many of the former caregivers showed evidence of relatively mild depression, it was still enough to impair their well-being, she said. Researchers were also concerned that the depression had not significantly decreased over time.

Kiecolt-Glaser notes that the control group in her study — those who had never been caregivers — had a depression rate of only 15%, compared to the rate of over 40% for former and current caregivers. “We didn't see the improvements you would hope and expect to see after caregiving has ended,” she says.

Results also showed that former caregivers experienced fewer negative moods — such as guilt and anger — than did current caregivers, and did not differ significantly from non-caregivers in such negative mood states. However, former caregivers did not see a similar return to

normal in how often they felt positive emotions, such as energy and enthusiasm. Even two to three years after caregiving ended, former caregivers reported fewer positive mood states than non-caregivers.

Moreover, former caregivers also showed higher levels of loneliness than did non-caregivers. “Most studies suggest many widowed people see improvements in their psychological health after a year or so of the death of their spouse,” Robinson-Whelen says. “However, the former caregivers in this study still had relatively high levels of depression and loneliness, even several years after the death of their spouse.”

The former caregivers who were most likely to report psychological problems were those who said they often had recurring, unwanted thoughts about their caregiving experiences, or who said they tried to actively avoid such thoughts. Former caregivers who reported less social support from family and friends also were

Hospice Management Advisor™ (ISSN# 1087-0288) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Application to mail at periodical rates is pending at Atlanta, GA 30304. POSTMASTER: Send address changes to **Hospice Management Advisor™**, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291, (customerservice@ahcpub.com) **Hours:** 8:30 a.m.-6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday, EST.

Subscription rates: One year (12 issues), \$319. Outside U.S., add \$30 per year, total prepaid in U.S. funds. Two to nine additional copies, \$191 per year; 10 to 20 additional copies, \$128 per year. For more than 20 copies, call customer service for special handling. Missing issues will be fulfilled by customer service free of charge when contacted within one month of the missing issue date. **Back issues**, when available, are \$53 each. (GST registration number R128870672.)

Photocopying: No part of this newsletter may be reproduced in any form or incorporated into any information retrieval system without the written permission of the copyright owner. For reprint permission, please contact American Health Consultants®. Address: P.O. Box 740056, Atlanta, GA 30374. Telephone: (800) 688-2421. World Wide Web: <http://www.ahcpub.com>.

Opinions expressed are not necessarily those of this publication. Mention of products or services does not constitute endorsement. Clinical, legal, tax, and other comments are offered for general guidance only; professional counsel should be sought for specific situations.

Editor: **Eric Resultan**, (770) 329-9684, (eric_resultan@msn.com).

Vice President/Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@ahcpub.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@ahcpub.com).

Managing Editor: **Robin Mason**, (404) 262-5517, (robin.mason@ahcpub.com).

Production Editor: **Brent Winter**.

Copyright © 2002 by American Health Consultants®. **Hospice Management Advisor™** is a trademark of American Health Consultants®. The trademark **Hospice Management Advisor™** is used herein under license. All rights reserved.



Editorial Questions

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

more likely to show signs of depression or other problems.

One area where former caregivers did show significant improvement was stress: After three years, former caregivers showed levels of stress very similar to those of non-caregivers. "You would expect that once the daily constant demands of caregiving were over that stress would go down," Robinson-Whelen says.

She says it is not known whether these results would apply to caregivers who cared for spouses with problems other than dementia. However, caring for a spouse with dementia may create special problems that make adjustment following death more difficult, she said.

"Caregiving, especially for a spouse with dementia, is very difficult and the effects can linger for years," she says. "Former caregivers need more attention given to their needs." ■

End-of-life volunteers need more support

Reaching out to the terminally ill and their families is a common practice and a high priority among most faith communities, but preparation and comfort levels for this kind of ministry can limit the care they offer.

A study by the New Hampshire Partnership for End-of-Life Care suggests more support is needed for volunteers and clergy who are attempting to reach out to the terminally ill.

"This is important work that is very difficult because of the different physical, emotional, and spiritual dimensions involved," says **Shawn LaFrance**, project director of the Partnership. "It's great to see so many people involved in end-of-life care, but it also tells us that we can do more to support these volunteers and clergy members in helping the terminally ill and their families."

The study is the result of a survey of more than 200 faith communities in New Hampshire. The study showed that more than 1,500 lay members of responding congregations are involved in providing spiritual support to the terminally ill, yet, clergy members report that only 7% of these individuals are "very prepared" to do so; half are somewhat prepared and 16% are not prepared. ■

EDITORIAL ADVISORY BOARD

Consulting Editor:

The Rev. Jeanne Brenneis,
MDiv, STM
Director, Bioethics Center
Chaplain, Hospice of Northern Virginia
Falls Church, VA

Gretchen M. Brown, MSW
President and CEO
Hospice of the Bluegrass
Lexington, KY

Pamela S. Melbourne, RN, MN
Director of Clinical Services
Hospice Atlanta
Atlanta

Earl Ash Evens, MSW, MBA
President and CEO
AdvaCare Inc.
Pittsburgh

Peggy Pettit, RN
Vice President
Patient/Family Services
Vitas Healthcare Corporation
Miami

Marilyn Hannus
Director
Hospice of Cape Cod
Yarmouthport, MA

Claire B. Tehan, MA
Vice President, Hospice
Hospital Home Health Care
Agency of California
Torrance, CA

Bonnie Kosman,
MSN, RN, CS, CDE
Director of Patient Care
Lehigh Valley Hospice
Allentown, PA

No easing of inspections for nursing homes seen

Proposed federal regulations that would have reduced the frequency of nursing home inspections will not be implemented.

President Bush has rejected a proposal from the Centers for Medicare and Medicaid Services (CMS) to soften nursing home inspection requirements and limit penalties. Previous reports indicated that the president favored allowing so-called "good" nursing homes to be inspected less frequently.

Under the rejected proposed CMS plan, "bad" nursing homes eventually would have been inspected twice as often as those that had good compliance records and would have been subject to stricter inspection criteria. ■

Newsletter binder full?
Call **1-800-688-2421**
for a complimentary
replacement.

