

# HOSPICE Management ADVISOR™

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## Can home health nurses provide hospice care?

*Blending services may help reduce length of stay*

**W**hen a longtime chaplain and administrator with Lehigh Valley Hospice in Allentown, PA, left her post in protest of staffing changes, the well-respected hospice found itself in the unenviable position of making internal changes under full view of the community it served.

**Ann Huey**, MDiv, the former administrator at Lehigh Valley Hospice, departed in December after 15 years as its chaplain when its parent, Lehigh Valley Hospital, decided to blend the nursing services of its hospice and home health programs, something it had been doing on a smaller scale with some of its remote offices. The move, hospice officials said, made sense from an economic perspective. But more importantly, it would improve quality of care by providing a seamless transition for home care patients who wanted hospice care. "One of the difficulties is that they [home health nurses] weren't trained for hospice care," she says.

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**Industry experts say economic pressures heaped on both the hospice and home health industry point to the possibility of more blended nursing services on an industrywide scale.**

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Her departure caught the attention of the local newspaper, and Huey expressed her concerns publicly and questioned Lehigh Valley Hospital's commitment to serving the terminally ill.

Lehigh Valley Hospice and its parent, Lehigh Valley Hospital, stand behind their decision and continue the effort to train home health nurses in hospice care. While officials are unapologetic about the changes, they acknowledge that a better job could have been done to keep staff,

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physicians, and the community aware of its changes to avoid misunderstandings or the appearance of valuing money over quality of care.

“We had to do a lot of customer recovery,” says **Bonnie Kosman**, MSN, RN, CS, CDE, administrator of Lehigh Valley Hospice.

According to the National Hospice and Palliative Care Organization (NHPO) in Alexandria, VA, nearly six in 10 hospices are owned by hospitals, home health agencies, nursing homes, or some other type of health care corporation.

The number of hospices and home health providers that blend their nursing services is unknown. But industry experts say economic pressures heaped on both the hospice and home health industry point to the possibility of more blended nursing services on an industrywide scale.

For example, hospices have been battling shortened length of service (LOS) with little success. In 1998 the national median LOS was 25 days compared to the 29 days in 1995, according to the NHPO. The national average LOS was 51.3 days in 1998 and 61 days in 1995. The emphasis has been to influence LOS by lobbying lawmakers to change reimbursement regulations, such as the required six-months-or-less terminal diagnosis. (See related story on Hospice Association of America’s legislative agenda on p. 40.)

### ***Industry trend***

The home health industry has been struggling with Medicare’s interim payment system, which reduced reimbursement by 15%. In October, a new Medicare payment system is set to begin. The prospective payment system will place greater emphasis on reducing visits rather than maximizing them.

The combined pressures on both segments of post-acute care seemingly beg home health and hospice providers to find joint solutions. Combining services is in the vanguard of innovative solutions.

One such innovative plan in Massachusetts combined hospice nurse services with home health visits. Hospice Care Inc. in Stoneham, MA, has been experimenting with contracting out its nurses’ services to a local home health agency with the hope that their presence would facilitate hospice admissions sooner in the dying process.

With its median LOS at 14 days and average length of stay 41 days, Hospice Care’s dwindling LOS is typical of the hospice industry. The two

most cost-intensive periods of care — program introduction and patients’ final days — were overlapping, often leading to care costs exceeding Medicare’s per diem payment without additional, less cost-intensive days to help offset the two cost-intensive periods.

By using a hospice nurse in a home care setting, the patient is given the opportunity to forge a relationship with a nurse that could potentially carry into the hospice setting.

Whether or not Huey agrees with her former hospice’s move to combine home health and hospice nursing services, experts agree that similar changes are eminent as both home care and hospice struggle to keep or increase their presence in health care’s continuum of care.

It’s a reality that many don’t seem to have a problem with, provided home health nurses are given the proper training. Blended nursing services allows an organization to consolidate fixed costs, such as rent; consolidate variable costs, including administration; and share resources, says **Karen Woods**, executive director of the Hospice Association of America in Washington, DC, which operates under the umbrella of the National Association of Home Care, also in Washington, DC.

Woods, who first worked for a freestanding hospice, says there is nothing inherently wrong with home health and hospice nurses sharing duties, but added that the organization must provide the needed support to help staff make the transition from home health to hospice and vice versa.

“The two clinical specialties can learn from each other,” says Woods.

### ***A matter of training***

But Huey argues that some home health nurses cannot provide adequate hospice care because caring for the dying requires special attributes, such as a willingness to accept death as a positive outcome and address patients and their families’ spiritual and emotional needs. Home care nurses, she says, are trained in the curative aspects of care rather than providing comfort to the dying and their families.

“Nurses don’t necessarily make the transition,” Huey says. “It confronts them with their own mortality.”

Huey’s act of protest is understood by industry experts and to some extent, agreed with, but none condemn the notion of combined nursing services. “There is an element of being called to do

hospice work,” says **David Abrams**, senior vice president of the Miami-based Hospice Foundation of America. “We would tend to agree that home care and hospice nursing services should remain separate because in practice it is difficult to make the switch. But theoretically it’s not impossible. You would have to look at it from an individual standpoint.”

Like many hospices, Lehigh Valley was struggling financially. The hospice and home care programs were housed in four branch offices. From the start of their operations, the two were already providing blended nursing services, says Kosman.

When officials compared the performance of the branch offices, it found that lengths of stay were dramatically different. In the offices where hospice nurses and home care nurses maintained separate patient populations, average hospice LOS was about 14 days, similar to the rest of the hospice industry.

But the numbers produced by the two branch offices where nurses provided both home care and hospice visits told a different LOS story. Rather than LOS hovering at about two weeks, patients were averaging four to eight weeks in hospice.

“What we heard from the offices that operated separate hospice and home health nursing services, home health patients who were eligible for the hospice benefit, 99% of the time the family didn’t want to give up the relationship with their home health nurse,” says Kosman. “In some cases, we had home health nurses providing care until the patient died.”

Huey acknowledges that LOS is a problem; hospices must find a solution so that they can remain viable. “To a degree, I do agree with [having to reach patients sooner],” she says. “For example, I think every hospice should provide pre-hospice palliative care. It honors the mission of hospice.”

### ***Forced to choose?***

Combining hospice and home health nursing services can lead to conflicts over which visit is more important, Huey says. She recalls a situation where an on-call nurse was forced to choose between visiting the home of a dying patient and a patient who needed antibiotics administered. The nurse chose to administer the antibiotics and the hospice patient passed away without a hospice worker present.

“It’s terribly unfair to make the nurse have to choose,” Huey says. “The home health patient

had an immediate medical need, but the family of the patient may have been distressed and needed the reassurance of the nurse.”

Incidents such as the one described by Huey are more a function of communication problems between nurses and their supervisors, Kosman says. If a conflict arises and the nurse advises her supervisor, arrangements can be made to accommodate both patients, Kosman says.

Aside from Huey, 10 nurses quit. Four have since asked to come back, Kosman says. “The 10 new nurses that we hired are adapting very well,” Kosman says. “That’s probably because they bought into the system right away without having anything to compare it to.”

Like Woods, Kosman firmly believes that home health nurses can provide high-quality hospice care given the proper training. She doesn’t agree that good hospice nurses have a higher calling.

“What Ann said about home health nurses not being able to provide quality hospice care left those who have done it extremely insulted,” Kosman says. “She didn’t give credit to those nurses who have done it day in and day out. I think some hospice nurses have become very comfortable in saying they have been called to their work. But I think that reflects their own needs. It’s been my experience that nurses who do say that they are the last to use the resources available to them and try to do everything on their own. I have seen home care nurses acknowledging that they can’t do it all and use other members of the interdisciplinary team.”

Without insider knowledge of what went on at Lehigh Valley, Woods’ take on the issue is that of resistance to change. “Change can be painful, especially if you’ve been in one place for a long time and are used to seeing things a certain way.”

### ***Softening the blow***

That’s why Kosman says better communication in the beginning would have gone a long way to softening the blow of change. Looking back, Kosman offers a few nuggets of advice for organizations going through similar changes:

- **Communicate changes with all your customers — the community, clinical staff, and referring physicians.** At first some physicians seemed reluctant to refer their patients to hospice because of the controversy, says Kosman. Yet, once physicians understood what the organization was trying to accomplish, many were eager to take part in helping home care nurses learn the

important aspects of hospice care.

- **Go slower with staff.** Allow for effective communication of the education process before sending them out on their own. Part of the education should be the communication how the change will effect them and what will be expected of each staff member. Lehigh Valley used the nurses who were already providing both hospice and home care service as trainer and mentors. Home health nurses performed joint visits with a hospice nurse to observe how things are done differently and help them adjust to palliative care.

- **Pay for inservice training.** “We knew we had to make a significant investment,” Kosman says. Nurses were required to participate in one-to 1½-hour training sessions twice a month where they learned the theory behind hospice care, the differences between palliative and curative care, and learned about documentation differences.

For those who are opposed to blending nursing services, Kosman says the demands on both industries requires both segments to look at care from a macro perspective.

“We’re looking at the big picture,” Kosman says. “Lehigh Valley Hospice is part of a larger organization that is committed to addressing care across the continuum.” ■

## HAA’s legislative agenda for 2000

### *Pain initiatives top the list of goals*

The Hospice Association of America (HAA) finalized its 2000 Legislative Blueprint for Action in February. It includes a list of its top 10 legislative issues. HAA president **Karen Woods** says the plan was developed with input from HAA’s members and reviewed by the National Association for Home Care’s Government Affairs Committee.

She says the 10 items were selected from a list of nearly 30 areas the association initially identified. Here is a rundown:

#### **1. Ensure access to medications necessary for pain control.**

“Congress should oppose any legislation that would directly or indirectly set limits or prohibit physicians from prescribing adequate and appropriate controlled substances for the management of pain related to terminal illness,” the HAA says.

According to Woods, this item flows from controversy about assisted suicide legislation earlier introduced in Oregon and elsewhere that the association feared could have had a chilling effect on doctors providing appropriate medication. “Anything that would deter a physician from providing appropriate medication needs to be looked at carefully,” she says. “Pain medication should be provided to terminally ill patients when needed, and physicians should not have to worry about the government accusing them of attempting to provide assistance of suicide.”

### *A stay of respite*

#### **2. Include in-home respite care in the Medicare hospice benefit.**

“Congress should establish a separate payment category in the Medicare hospice benefit for in-home respite care. Provision of in-home respite services would provide family relief and support while the patient remains at home,” says the HAA.

The Medicare benefit provides a stay of respite, but that respite has to be offered in an in-patient facility for a patient to qualify, notes Woods. “We are simply asking for a change in the wording of that that would allow for brief episodes of respite for the caregiver, where care could be provided in the patient’s residence instead of a facility.”

#### **3. Oppose decreasing hospice reimbursement for dually eligible patients residing in nursing facilities.**

“Congress should oppose any legislation that would decrease the reimbursement for hospice services for dually eligible patients residing in nursing facilities without appropriate data collection and analysis supporting such a change,” the HAA states. “Legislative changes to this area of hospice reimbursement prior to an in-depth study and analysis will, in effect, deny access to humane compassionate care for bona fide eligible terminally ill residents of nursing facilities.”

Woods notes that when Medicaid pays for nursing home room and board, patients can also access their Medicare benefit for hospice services. But she pointed to close scrutiny by the Department of Health and Human Services’ Office of Inspector General about the possibility of fraud. “That has led to some suggestion to eliminate that benefit,” she says. “We simply want a study to be completed before any change is made.”

#### **4. Protect hospices from the impact of sequential billing.**

“Congress should require the Health Care

Financing Administration to process and pay all clean claims as submitted regardless of whether previous claims have been processed, and pay interest on claims that are not processed in a timely manner," the HAA states.

Woods notes that sequential billing proved to be major burden on home health agencies when claims were pending. "We think hospice should bill in chronological order," she explains. "But if claims are reviewed, all billing subsequent to that should not be stopped, because that can have a devastating financial impact."

### **Clarification, please**

#### **5. Clarify the definition of hospice multiple sites.**

"Congress should clarify the definition of hospice multiple-site service area, establishing a uniform, reasonable, and up-to-date policy that focuses on the ability to provide quality care and positive outcomes rather than imposing arbitrary and ineffective time and/or distance requirements," the HAA says. "This definition should recognize the technological advances [communication tools that allow instantaneous information exchange by fax, telephone, beeper, cell phone, etc.] and provide efficient and effective ways to 'distance-manage' offices."

#### **6. Provide sufficient home care and hospice payments so that agencies can provide appropriate wages and benefits to clinical staff.**

HAA wants Congress to boost reimbursement under Medicare and Medicaid to allow for appropriate wage and benefit levels of all clinical staff for home care and hospice services. Woods contends there are already severe shortages of home health aides, which can have a major impact on how care is delivered.

She says HAA is looking at the whole issue of rates and how they are established. "Over time, there have been many changes in what is required to pay qualified staff," she explains. "Under current reimbursement systems, that means keeping an eye on payment rates so that you have enough money to provide the care that is required."

#### **7. Require demonstration projects to study special services and financing of end-of-life care.**

"Congress should enact legislation that would provide for demonstration projects to study special services and financing of end-of-life care in home care and hospice settings," the HAA says.

"Demonstration projects that study the special care needs of adult and children and evaluate the practices and procedures that will improve patient outcomes and resource utilization for end-of-life care would contribute valuable information about care needs and costs at the end of life."

#### **8. Ensure the portability of advance directives.**

"Congress should support legislation that ensures the portability of an individual's advance directive between health care facilities, as well as between states. An advance directive belongs to an individual and should not be interfered with or interrupted by the laws of any particular state or health care facility," the HAA says.

#### **9. Amend hospice core service requirements to permit the delivery of specialized nursing treatments under contract.**

Specifically, the association will urge Congress to amend the Social Security Act by including a provision allowing certain specialized high-tech nursing services to be provided by contract, under the direction and supervision of the hospice as necessary to meet the needs of the hospice patient.

#### **10. Congress should oppose implementation of penalties for erroneous certification of terminal illness.**

Specifically, it will also urge Congress to oppose the imposition of civil monetary penalties on physicians for false certification of eligibility for hospice care, which Woods say could inhibit doctors from authorizing appropriate hospice care out of fear of financial penalty. ■

## **Video has its place, but it is limited**

*Find balance between TV teachers, human contact*

**P**eruse the self-help section of your local video store and you will quickly realize how videos have become a medium for teaching everything from firmer tummies to better golf swings to fulfilling relationships. For those with a message or method, video is an efficient way to reach people in need of information.

Death — whether facing it or caring for those who are dying — prompts its fair share of questions from patients, their families, and health care providers. Like the rest of society, hospices use videotapes as a teaching tool. Videos are used to

train workers, inform referring physicians, and educate patients and their families.

Used properly, videos can supplement hospices' new employee training and help patients understand the hospice philosophy. "A new employee is required to be trained in so many things," says **Terri Dusek**, communications coordinator for the Hospice Austin in Austin, TX. "There are JCAHO [Joint Commission for the Accreditation of Healthcare Organizations] and OSHA [Occupational Safety and Health Administration] requirements. There is so much to learn that we have to use videos to cover everything. Videos are especially helpful in teaching patients and their families about hospice because it is such a new concept to them."

But because we have become so familiar with the medium, hospices run the risk of becoming too reliant on video presentations to get across their intended messages, says

**Joanne Sheldon**, MeD, RN, CRNH, education coordinator for the Hospice of the Western Reserve in Cleveland.

"I'm generally against using videos," Sheldon says. "Person-to-person communication is better. It gives you the opportunity for discussion."

Yet Sheldon admits that from a practical standpoint, training without videos is difficult, given the amount of information that hospices must convey to new employees, physicians, patients, and their families.

"I still believe that person-to-person teaching is the best. I will also admit that this is not always easy to accomplish," Sheldon says.

A few short years ago, Hospice Austin used videos exclusively for its new employee training. New hires took part in training at their convenience. When they chose to undergo training, they were escorted into a room with videotapes and written literature.

"It was horrible," says **Jane Scaff**, RN, CRNH, education coordinator for Hospice Austin. "Everything was a video, two solid days of video. We have revised our training since then."

Today, videos still play an integral part of their training, but they are used more strategically. Scaff says her hospice has gone from showing eight hours of video instruction to less than one hour over a more structured two-day training period.

"It's more important to use a lot of varied teaching techniques," Scaff says. "Videos are only

an element along with group discussions, overhead [projections], and flip charts."

Nothing, Sheldon says, replaces teaching face-to-face. "I have been in education for about six years with hospice and home care staff," she says. "I find that videos may be a good fill in for someone who is absent, but does not work too effectively otherwise."

Scaff says videos should be used in areas in which a hospice cannot provide personnel to deliver the information or message more effectively. For instance, she uses a video to explain cultural diversity. Despite her reluctance to show the video, she says, there isn't anyone in the organization who is qualified to discuss caring for people from a wide range of ethnicities, races, and religions.

Videos do have their advantages, Scaff says. If consistently shown, they become standardized sources of information. Trainers can be assured the same information is being given time after time.

In addition, some instructional videos can provide far more demonstrative information than a live instructor. For example, a video about back health and proper ways to lift patients can go over more scenarios involving patients than an instructor in a classroom and a video can do it in less time.

### ***See the bigger picture***

The key to using videos is to incorporate them into the larger training or education programs. "Videos should enhance the oral communication in your training," Scaff says. "Use them to improve your learning process."

If you use videos to train new workers or referring physicians, there should always be discussion beforehand, explaining what they will see and what they should expect to learn from the visual medium. A second discussion should follow after the completion of the tape.

Sheldon says hospices should provide:

- A discussion sheet to help students focus in on learning objectives.
- A list of objectives to make clear what students are expected learn from the video.
- A post-video questionnaire or test, to stress the learning objectives pointed out prior to the tape's showing.

"If I have a questionnaire or have a discussion

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**Used properly, videos can supplement hospices' new employee training and help patients understand the hospice philosophy.**

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group after viewing the videos with specific questions, I have found that most need much direction,” Sheldon says.

How you use videos in your education programs should be dictated by adult learning principles, says Scaff. Adult learning principles hold the following:

- Adults prefer flexible schedules that respond to their own time constraints.
- Adults learn better when learning is individualized.
- Adults prefer face-to-face learning rather than learning through the use of video or audio communication.
- Adults derive benefits from interaction with others who differ in age, level of experience, and professional preparation.
- Adult learners seem to learn better if there is an atmosphere of mutual helpfulness and peer support.
- Since adult learners are reluctant to take risks, the climate should be characterized by a sense of trust and acceptance.
- Adult learners appreciate the invitation to express their views and are open to the views of others.
- Adult learners bring clear expectations to the learning environment and expect instructors to accommodate those expectations.
- Adult learners derive the greatest benefit from instructional methods that assist them in processing their experience through reflection, analysis, and critical examination.
- Adult learners value teaching methods that increase their autonomy.
- Adult learners are motivated by practical how-to learning.

### ***Tailor your program***

As important as employing adult learning principles is tailoring your programs to fit the varying audiences you are training. For the most part, hospices will be training employees and volunteers during orientation and inservice; helping physicians understand aspects of hospice care, such as pain management; and educating patients and their families about hospice and its philosophy of care.

Each is a distinct population with different sets of learning objective and learning capabilities. If a hospice uses videos, the same video should not be used for all groups, generally speaking.

Here’s a look at how Hospice Austin uses

videos for each of the above groups:

#### **• Employees.**

While videos no longer dominate their new employee training program, it plays a powerful role in setting the stage for the orientation process. The first thing new workers do on their first day of orientation is watch a short videotape, “Walk Me to the Water,” an emotional series of black and white photographs of hospice patients with their fragile voices telling their own story.

“It sets the mood and gets them ready for a whole day of learning about the hospice philosophy,” Scaff says.

In this instance, the tape was used to provide an emotional spark in hopes of motivating new employees to enhance the learning process. The impact of the video, Scaff says, is something she could not reproduce with a live speaker.

“Someone always cries when we show this,” she says. “I can’t show them that kind of emotion, but that video can.”

The rest of the program is dominated by speakers from various departments and videos are used sparingly, mostly has how-to teaching aids, Scaff says. In each instance, videos are accompanied by pre- and post-tests to gauge how well students are learning. Handouts are usually given prior to the video to reinforce learning objectives.

She warns that overuse of videos in employee training accomplishes only one aspect of the training’s intended goals. While providing information is a key element to training, changing behavior is another.

Because hospice care requires an entirely different approach than other segments of health care, instructors during employee training should also be facilitating discussions to effect attitude changes about lofty topics such emotional and spiritual care.

#### **• Physicians.**

Hospice Austin uses videos even more sparingly with physicians. Because physicians are highly educated, a video must use the same language they use to be effective.

“We’re real selective in what we show,” Scaff says.

When choosing a video, hospices should consider how they educate physicians face-to-face. The most effective training includes a physician as the main speaker. “I always have a doctor standing next to me,” Scaff says. “They are not going to connect with me, a nurse, but they will connect with another physician.”

The same lesson should be applied to video use. The same video used to train workers will likely be without value to physicians.

Still the same principles of adult learning should apply, says Scaff. The purpose, goals, and objectives should clearly stated prior to showing a video with pre- and post tests given.

“I would never have them just watch a video,” she says.

### ***You can't replace human contact***

- **Patients.**

Given patients' and families' state of mind immediately following word of their terminal diagnoses, they have the least capacity to learn. It is common to have to repeat information before it is internalized.

Videos are perhaps most useful with this group. “Many times hospice is such a new concept, it's hard to grasp,” Dusek says.

To aid in this, Hospice Austin has a 14-minute video in which a bereaved family, physician, and nurse explain hospice care from their unique perspectives, giving prospective and new patients a glimpse at the kind of care they can expect to receive.

The complementary tape can also be shown to out-of-town family members who weren't present when clinical staff explained hospice care to the patient and present family.

Still Dusek stresses that the tape is only used to supplement information provided by physicians and hospice staff. “Nothing can replace human contact,” Dusek says.

She says there is also the danger that the video can do more harm than good. Before showing patient the tape, she allows enough time for the patient to grasp his or her terminal diagnosis, discuss treatment further with a physician, talk with a hospice nurse, and allow for family acceptance.

“When they're not ready, the video can cause them to go into denial and reject hospice care altogether,” Dusek says.

Hospice Austin also uses a videotape series, *Facing Death*, which it coproduced. The tapes cover the various aspects of dying, clinical, spiritual, and emotional. The tapes were intended for professionals, and patients and their families. However, patients and their families seemed to get the most use out of the series. Nurses, social workers, and chaplains now use the tape to pass along to family members to help them understand the dying process. ■

## **Poor pain management is deemed elder abuse**

### ***CA judge allows case to go to trial***

**F**ailure to treat pain in elderly patients can be considered a form of elder abuse, a California judge ruled in September. California Superior Court Judge Barbara Miller rejected defense motions to dismiss the elder abuse claims, allowing the first case of this kind to go to trial.

The case involves the care provided to William Bergman, an 85-year-old Californian dying of lung cancer. Bergman was admitted to Eden Medical Center in northern California complaining of intolerable pain. He spent five days in the hospital, where he was treated by Wing Chin, MD.

Using a 10-point scale, with 10 being the worst, nurses charted pain levels ranging from 7-10 throughout his stay. Bergman was later discharged to die at home. His family ultimately got another physician to prescribe pain medication that brought him relief. He died the next day.

### ***Providers put on notice***

The family filed suit in California state court asserting medical malpractice and elder abuse. The defendant physician and hospital repeatedly asked the court to dismiss the elder abuse claims, arguing that the plaintiffs were entitled only to the limited remedies available from a medical malpractice claim.

End-of-life advocates say the ruling will have an impact on pain management. Regardless of the trial's outcome, physicians will be aware that undertreated pain is grounds for legal action.

“This ruling will have a huge impact on end-of-life care, regardless of the outcome of this case,” says **Barbara Coombs Lee**, executive director of Portland, OR-based Compassion in Dying Federation, which is sponsoring the case. “California medical providers are now on notice: either treat dying patients properly or risk significant consequences.”

**Kathryn Tucker**, director of legal affairs for Compassion in Dying Federation, says the patient's family will be able to recover damages for Bergman's pain and suffering, which they would not be able to do under just a medical malpractice claim. The plaintiffs will also be able to recover attorneys' fees and avoid the cap on

damages in the medical malpractice statute.

“This exposes the defendant medical providers to significantly greater financial risk,” says Tucker. “The family and Compassion in Dying hope that with significant exposure for inadequate pain care, providers will be motivated to be more attentive to pain and work to see that it is treated properly.”

The surviving family originally filed a complaint with the Medical Board of California, which investigated and concluded that pain care was indeed inadequate. However, the board declined to take any action. The trial was expected to begin in March. ■

## HH and hospice patient: Elderly woman, widowed

### *A snapshot of the typical patient*

The typical home health and hospice patient is an elderly Caucasian woman between the ages of 75 and 84, widowed, and likely living in a private residence with family members, state the Atlanta-based Centers for Disease Control and Prevention.

For the more than 2 million patients served by home health and hospice, the most common primary diagnosis was disease of the circulatory system, which includes heart disease. Care most often consisted of home health skilled nursing services, says the report, which was released last December.

*Characteristics of Elderly Home Health Care Users: Data from the 1996 National Home and Hospice Care Survey*, looked at data from the 1996 National Home and Hospice Care Survey done by the National Center for Health Statistics.

### **Demographic characteristics studied**

Researchers sought to examine the demographic characteristics of home health and hospice patients and the services that were provided to them. The report looked at the data from two perspectives: current patients and discharged patients.

In 1996, there were an estimated 1.75 million elderly people — 65 years old and up — using home health care. The report found the following characteristics in current home health care patients:

- 70% were women;
- 47% were between the ages of 75-84 years old;
- 69% were white and 65% were non-Hispanic;
- 47% were widowed;
- 59% of the those widowed were elderly women, while 19% were elderly men;
- 92% were living in private residences;
- 50% lived with family members;
- 44% of elderly women lived alone, vs. 27% of elderly men.

Because elderly patients have a diminished capacity to perform normal activities of daily living (ADL), much of the care concentrated on helping them perform those basic tasks. Of all elderly current patients, 56% required help with at least one ADL. The most common type of help with ADLs included bathing and showering (53%), and dressing (46%).

Shopping for groceries or clothes, considered instrumental activities of daily living, was the most prominent service provided to those patients by agencies. Eighty-four percent required help. Twenty-three percent needed help preparing meals.

### **Discharged patients**

Discharge data was similar to current patient statistics. Discharges from home health and hospice (discharge as a result of death was included) in 1996 were also predominantly elderly white and non-Hispanic women who were mostly widowed.

The average length of service for elderly discharges was 107 days. Seventy percent of elderly patients used home health care services for 60 days or less. The average length of service for men was 104 days and 109 days for women. Lengths of service of more than 181 days were reported among 15% of elderly women and 9% of elderly men.

Heart disease, a leading killer of Americans, topped the list of most frequent primary diagnoses at discharge. Twenty-five percent of men and 32% of women had circulatory system diseases, which includes heart disease. Disease of the respiratory system was the next most common disease among men (13%), while injury and poisoning were the second most cited disease among women (15%).

Researchers say the recent statistics are consistent with the three previous home health and hospice surveys, with little change in the demographic of home health and hospice patients and the services they require. ■

### NHO adds 'palliative care' to name

To further remind health care providers and consumers of hospice's role in providing pain management to dying patients, the National Hospice Organization has changed its name to the National Hospice and Palliative Care Organization (NHPO).

"Hospice care and palliative care share the same core values and philosophies," said **Karen A. Davie**, NHPO president. "Adding palliative care to our name — as many hospices have already done — reflects the natural evolution in end-of-life care and fosters recognition of the role of hospices in providing such care."

#### *Broadening its role*

The Alexandria, VA-based organization represents nearly 2,500 hospice care programs and thousands of professionals in the United States. It is the largest nonprofit membership organization for hospice and palliative care.

The name signals the NHPO's intention to broaden hospice's role in end-of-life care. Currently, hospice care is provided to more than half a million Americans each year. Hospice care offers a patient-centered, team-oriented program of expert medical care, pain relief, and emotional support for individuals confronting terminal illnesses and for their families. It is provided in patients' homes or a home-like setting.

"Our vision is to extend and expand comprehensive comfort care beyond the limits imposed by Medicare's six-month prognosis requirements and potentially into populations still pursuing curative treatments," said Davie. "In order to enhance quality of life, hospice programs encourage access to care earlier in a patient's illness or

disease process. The name change more accurately reflects the range of care and services our members provide, but the principles of hospice care and the programs we represent remain the same."

The World Health Organization defined palliative care in 1990 as addressing not only physical pain, but also emotional, social, and spiritual pain to achieve "the best quality of life for patients and their families." Hospice care professionals and volunteers provide services that address all of the symptoms of a terminal illness — ranging from physical to emotional to spiritual — with the aim of promoting comfort and dignity and living as fully as possible at life's end. ▼

### Children with cancer endure pain needlessly

*Suffering could be eliminated, journal says*

Children dying of cancer endure pain needlessly, according to a study published in the Feb. 3 issue of *The New England Journal of Medicine*, but through better effort from families, doctors, and the institutions where children are treated, unnecessary pain can be eliminated.

The researchers, led by Joanne Wolfe, MD, MPH, a children's cancer doctor at Dana-Farber Cancer Institute in Boston, interviewed the parents of 103 children who died of cancer between 1990 and 1997.

The study found:

- 89% of parents reported their children suffered "a lot" or "a great deal" in their last month of life from pain, fatigue, or difficulty in breathing.
- Almost 80% of the children suffered from pain, and efforts to eliminate pain worked only 27% of the time.
- When curative efforts continued longer than reasonable hope remained, treatments that could

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better relieve pain and other symptoms began too late.

- Pediatric oncologists were sometimes unaware of the extent of the children's suffering.
- Pain and other end-of-life symptoms were more likely to be dealt with successfully if the primary care physician remained involved in the child's care. ▼

## JAMA: Texts offer little end-of-life instruction

*Researchers find 2% devoted to care of dying*

Leading medical textbooks give little or no helpful information on caring for seriously ill patients at the end of life, according to a study published in the *Journal of the American Medical Association (JAMA)*.

The research analyzed coverage of 13 key end-of-life topics in 50 best-selling medical textbooks. Researchers from the University of California, San Francisco (UCSF), found that half of the key topics were not contained in the books, minimal content was found in one-fifth of the topics, and helpful information in fewer than one-fourth of the topics. On average, textbook indexes cited only 2% of their total pages as pertinent to end-of-life care.

"I'm afraid the textbooks we researched received a failing grade," says **Michael W. Rabow, MD**, assistant clinical professor of medicine and lead author of the UCSF study. "That is troubling, because if end-of-life material is not in the books, there's a good chance medical students won't learn it and physicians won't do it. Even more experienced doctors refer to these texts when caring for their patients."

### All elements addressed

This study is the first to assess end-of-life content in books from a wide range of medical disciplines. The 13 topics identified by researchers as important to end-of-life care address all elements in the standard physical, psychological, and social model of health. These included management of pain; management of symptoms other than pain; psychological issues such as depression; social and demographic issues such as family, gender and race; spiritual issues; and ethics,

law, and policies regarding the end of life. Those topics were chosen based on position statements from major national and international medical organizations.

Researchers found the textbooks with the least information on end-of-life care were in surgery; infectious diseases and AIDS; and oncology and hematology. Textbooks with the highest percentage of helpful information were in family medicine and primary care; geriatrics and psychiatry.

### Social, spiritual issues got least coverage

The topics receiving the least adequate coverage were social, spiritual, ethical, and family issues, as well as physicians' responsibilities after a patient dies. Specialty textbooks with information about particular diseases often contained little or no helpful information on caring for patients dying from those diseases.

"Physicians must be able to talk about death, and must be able to reassure our patients that they will not die alone and in pain," Rabow says.

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#### Editorial Questions

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

“Providing quality care for those at the end of life is part of how physicians can heal.”

Rabow notes that some encouraging changes are already occurring, partly because of studies like this and new standards of competence for physicians in end-of-life care from national professional licensing bodies and accrediting organizations. According to the *JAMA* article, publishers have already commissioned updates of end-of-life care content in textbooks in nursing, pediatrics and psychiatry, and in two medical textbooks. Among the changes are new chapters devoted to end-of-life care. ■

## News From Home Care

### Confidentiality will have a large cost to industry

Confidentiality legislation that would require providers to track all disclosures of health record information could cost health care providers a total of \$40 billion over five years, according to a House subcommittee estimate.

The Department of Health and Human Services estimates that patient confidentiality regulations will impose a cost of \$3.8 billion on the health care industry. But House Ways and Means Health Subcommittee chairman Bill Thomas (R-CA) cited estimates at a hearing before his subcommittee in February that place final costs of the proposed legislation to be 10 times greater than the \$3.8 billion price tag originally given.

Industry experts say retraining employees, hiring privacy officials, upgrading systems, and tracking disclosures represents a massive reorganization among providers. “At first blush, this standard seems to a perfectly reasonable common-sense provision,” says **Alissa Fox**, executive director of the National Blue Cross Blue Shield Association, of the provision that calls for providers disclose only minimum information. “This standard would require a massive reorganization of workflow, as well as a possible redesign of physical office space, and would jeopardize the timeliness of patient care, benefit determinations, and other critical elements of the health care system.” ■

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