

# HOSPICE Management ADVISOR

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## Sincere efforts to reach African-Americans may not be enough

*Respect for heritage, spirituality, and leadership key to outreach*

Despite some hospices' sincerest efforts, a much smaller percentage of terminally ill African-Americans seek hospice care than do terminally ill white patients. While hospice leaders may think they understand the reasons behind this problem, few have thought that perhaps they are part of the problem.

According to the National Hospice and Palliative Care Association, only 8% of those cared for by hospices are African-Americans. That's far shy of the 12% that would be needed to match the proportion of African-Americans in the United States. By comparison, whites, who make the largest population of hospice patients, account for about 80% of both hospice patients and the total population.

Conventional wisdom regarding the underuse of hospice by African-Americans holds that, as a population, they misunderstand hospice care and mistrust health care providers in general. There is a feeling among African-Americans that hospice care is in some way substandard care or a form of withholding curative treatments that could rid them of their diseases.

While most people associated with hospice care would deny that this kind of discrimination takes place, one African-American hospice administrator says hospices must understand that these suspicions are real and are based on painful historical wounds that have been slow to heal.

"Mistrust exists because there is a history of African-Americans being denied care," says **Gregory Townsend**, program director for the Birmingham (AL) Area Hospice.

But historical circumstance isn't the sole reason for hospices' inability to reach terminally ill African-Americans. Hospices have done a poor job of educating the African-American population about hospice.

"When they get sick, they don't get the all the information they need," says Townsend. "Then when they are told there is nothing more that

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can be done for them and that they might want to consider hospice, they think care is being withheld from them.”

Townsend recalls the story of an African-American woman who was referred to another Birmingham-area hospice following a terminal diagnosis of cancer. After her physician informed her that they had exhausted every treatment that was available, a case worker mentioned hospice, but did not provide enough information about the kind of care she would receive there.

“People think that hospice is a place where they send people to die,” Townsend said. “She thought she would be away from home and away from her family. She called me to get a better explanation.”

How about the countless others who don't make that phone call to get better educated? Most will likely avoid hospice, believing that its services are reserved for those without hope. That's why it is incumbent upon hospices to go into African-American communities and provide education and solicit their help.

### ***Seek advocates from within the community***

Traditional methods of going into communities may actually be working against hospices. Sending an African-American hospice worker to give a talk to a local community group, for example, can be seen as condescending and self-serving, says the Rev. **Joseph Davis**, president of the National Black Church Family Council in Tuscaloosa, AL. Davis' organization is made up of Birmingham-area ministers who spearhead community service programs, including a health ministry that supplies volunteers who help provide care to the sick and elderly.

“You have to look for advocates in the black community to address their own neighbors,” Davis says. “Coming into a minority community, especially in rural areas, is a lot like being a missionary in a foreign country. The first thing you do as a missionary is show respect for the leaders of the community and show them you want to work with them.”

Townsend and Davis advise hospices to address the following issues in order to successfully reach African-Americans:

- **Make sure your hospice is a model of the community.**
- **Show respect for their cultural heritage and leadership of the community.**
- **Address unique spiritual needs.**

- **Take advantage of strong community ties.**
- **Enlist the help of those in the community.**

Like all other businesses, hospices have an obligation to ensure that those treating the community are a fair representation of the community itself. If the community is 20% African-American, then your staff should be 20% African-American. Caring about diversity in an organization is a big first step toward showing a community that the interests of minorities are important to you.

But that is only the beginning. Hospices cannot simply rely upon sending their own representatives, such as a nurse or social worker, into a community to provide hospice education. Even though a hospice is sensitive to a community's need to see someone of a similar racial background, that gesture doesn't go far enough, says Davis.

The barrier of mistrust is hard to breach because there is still a belief that the hospice worker is speaking to benefit the organization he or she represents, not to benefit the community. For that reason, typical public awareness programs have limited value in African-American communities.

But those same kinds of programs can have a greater impact when implemented in conjunction with community leaders, such as ministers and civic leaders. Further, Townsend says, hospices must be willing to listen more than they are willing to talk.

“You cannot come in and begin talking about what you are going to do to make their lives better,” Townsend says. “You need to let them tell you what they need for you to make their lives better.”

Spiritual care is a good example. While hospices are generally open to providing a wide variety of spiritual care through their own spiritual counseling, African-Americans have a rich spiritual heritage that is deeply rooted in community worship.

Davis resents the hospice notion that it can come into his church community and provide spiritual care. “Hospice is not the church,” he says. “Hospice is a community service.”

Still, addressing African-American communities' spiritual needs should be a priority, says Townsend. It's just that hospices have to address African-Americans' spiritual needs in a way that preserves the primacy of the community's existing religious framework, such as by creating a

*(Continued on page 76)*

## Symposium examines end-of-life care for blacks

Death and dying has been a fundamentally different experience for African-Americans over the past century than for whites or members of other ethnic groups in the United States, according to **Karla F.C. Holloway**, PhD, dean of the humanities and social sciences at Duke University in Durham, NC.

That experience, all too often marked by inadequate health care and violence, has in turn shaped a very different perspective about suffering, care, and mourning. According to Holloway, understanding these differences will be essential to improving end-of-life care, both for African-Americans and for other groups.

Holloway, who is William R. Kenan Jr. Professor of English and African-American literature, was the featured speaker May 24 at “Crossing Over Jordan: African-Americans and Care at the End of Life,” the second annual symposium of the Duke Institute on Care at the End of Life. “Crossing Over Jordan” examined end-of-life care in the African-American community from a variety of perspectives, including medicine, the humanities, and theology.

The day-long conference looked at bereavement, death, dying, and burial in black America in the 20th century. Holloway’s presentation, titled “My Memory Stammers, but My Soul is a Witness,” drew heavily from her new book, *Passed On: African-American Mourning Stories*.

Other featured speakers were: Richard Payne, MD, chief of the Pain and Palliative Care Service and Anne Burnett Tandy Professor of Neurology at Memorial Sloan-Kettering Cancer Center in New York, who discussed racial and cultural differences in health outcomes and attitudes toward end-of-life care; and The Rev. William C. Turner Jr., associate professor of the practice of homiletics at Duke Divinity School, who gave a theological perspective on the African-American community and care at the end of life, focusing particularly on the role of the African-American church.

The Duke Institute on Care at the End of Life, launched in January 2000, is an interdisciplinary

program that brings together scholars from throughout Duke and partnering institutions to conduct research, educational initiatives, and public outreach aimed at improving care for the suffering and dying.

“For this symposium, we wanted to bring together leading individuals from very different fields to talk about end-of-life care in the African-American community,” says **Keith Meador**, MD, director of the Institute.

The conference not only addressed the challenges that African-Americans face in improving care for the dying, but also the gifts and strengths that this particular ethnic community brings to the task of caring for one another at the end of life.

In writing her new book, Holloway researched African-American death, burial, and mourning practices, both in libraries and in the field. As part of her research, she interviewed black funeral home directors, attended their annual trade meetings, and visited the grave sites of famous African-Americans, such as singer Billie Holliday, jazz legend Louis Armstrong, and author Richard Wright.

### *Seeking out narrative of death and dying*

Holloway readily admits that such interests may seem odd for an English professor, at least initially. What draws her to the subject is a deep appreciation of and respect for “narrative.”

“If those moments of death and dying — both the outer contexts of care and the inner realms of spirit — are not narratively engaged, then we risk sculpting these ends of days to meet our own focused understandings,” she says. “I want to engage and explore a fuller story about death and dying, and the context of culture is one way to that story.”

Over the past century, Holloway says, the African-American narrative of death and dying has been marked more than that of other communities by violence — whether through lynchings early in the century, police shootings, or, more recently, retaliatory killings by warring gang members. At the same time, she says, the African-American narrative of death and dying has also been a story of great communal strengths that have been embodied in extraordinary practices of shared suffering and deeply held obligations of mutual care. ■

network of local ministers who will provide the bulk of spiritual care.

“People are more likely to listen to their minister because the church has always been the cornerstone of the African-American community,” Davis notes.

As hospices become more open to suggestions from those they are trying to serve, they will gain a greater understanding of the challenges that African-Americans face when confronted with a terminal illness. The uniqueness of the typical African-American approach to dealing with death and caregiving will become clear.

For example, African-American families care for their dying loved ones differently from the way white family members do. For hospices, this means:

- Families should be informed and counseled on the availability of services to assist with care in their communities.
- Health care professionals should monitor

patient and family caregiver needs for services throughout the illness.

- Community groups and agencies should focus on supplying support to African-American female caregivers (particularly daughters), because a much larger percentage of women provide care in African-American families than in Caucasian families.

- Because of their heavy involvement in providing care, informational classes, support programs, and booklets should be designed specifically to meet the needs of African-American women.

The bottom line, however, is for hospices to go into African-American communities and tailor these kinds of programs according to what community leaders say should be done.

“We’ve seen tremendous progress in Birmingham,” says Townsend. “Once a few people choose hospice and they begin talking about how great an experience it is, good news travels fast.” ■

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## Shortage of hospice nurses continues to worsen

### *Focus on retention strategy*

**J**ust when many thought the nursing shortage couldn’t get much worse, there is unsettling evidence that it is far from over. According to a national survey prepared by the Federation of Nurses and Health Professionals (FNHP), one in five nurses plans to leave the profession within five years because of unsatisfactory working conditions.

The survey, the results of which were released in April, included interviews of 700 current nurses and 207 former nurses, the FNHP said. Half of the current nurses said they have thought about leaving nursing. With nurses contemplating leaving the profession at such an alarming rate and a scant number of nursing school graduates on the horizon, the Bureau of Labor Statistics says 450,000 additional registered nurses will be needed to fill the present demand through the year 2008.

Of the nurses who told researchers they plan to leave, 75% said they could be persuaded to stay if certain improvements were made, including better staffing levels, more flexible schedules, and higher salaries, the nurses’ group said.

The implied message is for hospices to find

ways to pay nurses more, improve working conditions, and offer them a higher quality of life — both in the workplace and out of it — if they expect to compete in the labor marketplace. With hospitals having greater access to money compared to smaller, independently owned hospices, hospices are at a disadvantage if they cannot offer competitive salaries and higher staffing levels to attract a limited pool of prospective nurses and keep those already on staff.

Hospices don’t face competition just from hospitals and other segments of health care. They also run the risk of losing out to competing hospices that either have more resources or make the necessary sacrifices in order pay nurses more and offer them better benefits.

The National Hospice and Palliative Care Organization says hospices must implement innovative programs such as training student nurses in end-of-life care by affiliating with nursing programs. In this way, hospices can help to expose more nurses to the rewards of hospice nursing as well as providing an end-of-life care knowledge base for nurses, regardless of the health care segment in which they work.

But those kinds of programs will have little immediate impact and are certainly no help to hospices that find themselves cutting back on admissions or stretching their staffs to their limits in order to meet patient demand.

Surviving the nursing shortage requires a

two-pronged focus: nurse retention and nurse recruitment.

With many hospices trying to fill open positions, it's easy to lose sight of the importance of keeping nurses from leaving. While recruiting nurses is important, remember that nurses who are already on staff are often seasoned hospice nurses who possess on-the-job experience that cannot be replaced by new nurses who undergo a few hours of orientation training.

"We are in an all-out blitz to retain our nurses," says **Susan Lowell Butler**, vice president of communications and public engagement at the Hospice of Northern Virginia in Falls Church.

The Hospice of Northern Virginia is part of the competitive Washington, DC-area market. It must compete with a myriad of hospitals, physician offices, nursing homes, home health agencies, and hospices, to name a few.

Because of this situation, officials there do not harbor any illusions that any effort to retain nurses will be successful without a financial commitment. Butler says the hospice has made an effort to raise its salaries to be competitive with any institution in the Washington, DC-area.

"If hospices want to keep their staff and attract talented candidates, they are going to have to make a financial commitment," Butler says.

Last year, Hospice Atlanta faced an employment crisis of its own. A significant number of nurses and social workers left to take jobs with other institutions, including competing hospices that paid higher salaries.

"We are trying to address the salary issue," says **Pamela Melbourne**, RN, MN, director of clinical services for Hospice Atlanta. "But it is quite a challenge. The work that hospices nurses do should not be undervalued."

But salary is not the final word in retaining nurses. Salary combined with working conditions and quality-of-life issues will strengthen a hospice's standing with its staff.

Hospice Atlanta conducted an employee survey to determine what changes could be made to address staff concerns. Overwhelmingly, staff wanted a say in the direction of the organization, rather than having edicts handed down to them without their input.

Also, Hospice Atlanta found that nurses wanted more predictable schedules. So rather than requiring nurses to take on-call shifts, Hospice Atlanta is the process of hiring nurses whose specific job responsibility would be to handle after-hours and weekend calls.

At the Hospice of Northern Virginia, administrators are cognizant of the dangers of overloading their nursing staff. Administration emphasizes quality over quantity and supports the desire of nurses to spend more time with patients rather than cutting patient time short in order to make the next visit.

"They know that quality is as important as the number of patients that you see," says Butler. "A lot of nurses have come here because this is a return to real nursing, where you can build relationships with their patients. If you take that away from them, you'll lose those nurses."

### ***Give nurses real support***

In addition, nurses at the Hospice of Northern Virginia are showered with gestures of support, ranging from time off to attend nursing conferences to the use of laptop computers to reduce the burden of time spent performing tedious documentation tasks.

The Hospice of Northern Virginia also provides emotional support for its staff, recognizing that their professional caregivers need care too sometimes.

For example, the Hospice of Northern Virginia requires its workers to attend a support group twice a month. The support group is facilitated by an outside psychologist, and management personnel are not allowed to attend, which helps promote frank conversation without fear of reprisal.

Yet, some hospices find it impossible to require their busy nurses to attend support groups. Rather than making attendance a requirement, they place a priority on providing a formal outlet for nurses to express their emotions.

Other venues in which nurses can share their feelings include:

- **Interdisciplinary team meetings.** A great deal is discussed during team meetings, everything from the patient's progress to spiritual matters. The team meeting can also serve as a platform for nurses and others to share their feelings, especially following a difficult case. This allows a nurse to share his or her feelings with peers who can empathize with the emotions a troubled nurse is going through.

- **Patient memorial services.** Most hospices hold these services on a monthly basis to allow staff to recall patients who have died that month. The event gives staff a chance to share their feelings about their patients with colleagues (and sometimes family) of the deceased.

Experts agree that hospices should focus their recruiting attempts on the following two areas:

- Tout the high job satisfaction nurses will experience as a result of practicing hands-on medical care and developing close relationships with patients and families.
- Offer flexible working hours that will attract nurses who can't or don't want to work a traditional 40-hour week.

Job satisfaction can be the greatest selling point for a hospice, says **Metta G. Johnson**, RN, BSN, OCN, ACRN, executive director and owner of Haven House, an Atlanta-area hospice. Johnson and the directors of other Atlanta-area hospices would know. Because Georgia does not require a certificate of need to start a hospice program, competition is strong in Atlanta and surrounding counties. Not only are Atlanta-area hospices competing for patients, they are also competing for nurses.

### ***Be willing to look outside hospice***

Knowing that competition for hospice nurses is fierce, Johnson says she broadens her pool of prospective nurses by not limiting her search to those with hospice experience. Instead, her search includes all experienced nurses from a variety of disciplines.

To attract prospective nurses from outside hospice, the message of higher job satisfaction may have greater impact. Hospices should stress how hospice nurses can have a direct and immediate impact on patients and their families and recount the gratitude families have for hospice workers who helped them get through a difficult situation.

Still, money is a strong motivating factor. To help neutralize the money factor, providing employment that enhances quality of life beyond professional job satisfaction can go a long way toward persuading a nurse to join a hospice.

"I feel that an employer that is meeting an employee's personal and professional goals is the one with the most satisfied workers," says Johnson.

The best way to do that, says Johnson, is to offer a flexible hour and working arrangements.

At Haven House, Johnson allows nurses to work as many hours as they like, whether it's 20 hours a week or 40 hours a week. This attracts talented nurses, who, for example, cannot work a full-time job because they want to be home with children after school. Instead, hospice can offer that same nurse an opportunity to pursue her

professional interests while still being able to fulfill family obligations.

"You need to come up with creative scheduling," says Johnson. "Try to come up with a more flexible schedule that allows nurses to have a better quality of life and reduce burnout." ■

## **Target your marketing efforts at consumers**

### ***Focus on the public as well as professionals***

**F**or years, hospices have directed their marketing efforts at referral sources and other professionals who can persuade dying patients that hospices offer the best care for their terminal illnesses. But one Massachusetts hospice organization says hospices must expand their focus to include consumers.

Rather than relying solely on doctors, discharge planners, case managers, and ministers to affect hospice admissions, hospices should target consumers with a multimedia public awareness campaign to put them in a position to drive the demand for hospice care.

"Rather than focusing on just the professional model, we also used the maternity model that focused on women," says **D. Rigney Cunningham**, MSW, executive director of Hospice & Palliative Care Federation of Massachusetts in Norwood. "We felt that if we could take public support in the same way mothers changed maternity care, those with terminal illnesses could begin demanding hospice care."

In 1998, the Hospice & Palliative Care Federation embarked on a public awareness campaign, called Choosing Hospice, funded by a grant from the Robert Wood Johnson Foundation. The project built upon a 1996 *Boston Globe* supplement on hospice care and the growing discussion about end-of-life care.

Specifically, the project employed the following strategies:

- reprinted 107,000 copies of the *Boston Globe* supplement, which was originally published in June 1996;
- developed three public service announcements about hospice;
- published and distributed a hospice consumer guide;

- assembled a photography exhibit from photos taken for the *Boston Globe* supplement for use in community locations such as libraries, schools, hospitals, and museums;

- produced a 10-minute documentary film on hospice that can be used in conjunction with a speakers' bureau.

In short, Cunningham says, the federation set out to raise public awareness of hospice by implementing a multimedia approach. The hope was to create a model campaign that would raise awareness throughout the state with components that local hospices could use to raise awareness in their own communities.

"About a quarter of hospices have the resources to employ their own public relations, while the rest are unable to have someone focus on public awareness," says Cunningham. "We felt these hospices didn't have the expertise to raise public awareness in a time when end-of-life care was hitting the forefront."

The project was completed in 1999. Nearly two years removed, Cunningham has the benefit of time to look back at what worked and what didn't and offers her recommendations for hospices seeking to bolster hospice recognition in their own community.

"The model developed at the state level with dissemination at the community level was successful in creating high-quality and cost-effective public awareness," says Cunningham.

### ***Group utilized reprinted newspaper stories***

The written word was the foundation of the federation's public awareness campaign. Rather than trying to create a moving piece that embodied all that makes hospice care unique among health care, the federation received permission from the *Boston Globe* to reprint 107,000 copies of the Pulitzer Prize-nominated package of stories and photos.

Thirty-eight of 47 hospices in Massachusetts requested copies, ranging from as few as 100 to as many as 1,000. Hospices handed them out to physicians during conferences, grand rounds, and training sessions, as well as to lawmakers and the public during health fairs. Copies also were given to hospice volunteers, board members, donors, and new employees.

In addition to the reprinted newspaper stories, the federation produced a 16-page consumer handbook, which made it easier for hospices to engage the public in a uniform fashion, ensuring

the public received a consistent message.

The guidebook, *Choosing Hospice: A Guide to Hospice Care in Massachusetts*, covered the following topics:

- eligibility;
- why consumers should choose hospice;
- where care is provided;
- frequently asked patient questions;
- frequently asked family questions;
- financial arrangements, insurance coverage, and Medicare;
- reimbursement;
- resources.

Participating hospices were given 150 copies of the handbook free of charge. In addition, a CD-ROM version of the guidelines was offered, which allowed hospices to customize the guidelines to fit their individual organizations and print the guidelines at their own cost. Beyond the first free 150 copies each hospice received, hospices were responsible for the cost of additional reprints.

Sample press releases and public service announcements were made available to hospices to aid them in promoting the guidelines to consumers through local newspapers.

Both the newspaper supplement and guidelines were also distributed via a direct mail campaign that targeted all the usual professionals — HMO case managers and hospital discharge planners — because of their potential to refer patients to hospice.

To affect public awareness, the guidelines were sent to all 250 Massachusetts state legislators and to long-term care facilities. The newspaper supplement was mailed to colleges and universities, community clergy, and hospital chaplains in hopes they would be used as a teaching tool.

Aside from the stories contained in the *Boston Globe* supplement, the photos that accompanied the project were equally compelling. Using the published photos, as well as some that were not published, the federation created two 20-photo exhibits. Hospices were allowed to borrow the exhibit as part of their own public awareness efforts.

The photo exhibit was most commonly shown in public buildings, such as a post office or public library, and at educational conferences. In February 1999, the exhibit was used in conjunction with the release of the U.S. postage stamp that honored hospice care.

The exhibit allowed hospice to reach people who may never have considered hospice as a possible part of their distant future. Few hospices

took advantage of the exhibit, Cunningham says. Of the 10 hospices that used the exhibit, all were enthusiastic supporters of it as a public awareness tool.

No visual approach would be complete without a video. Following the release of the *Boston Globe* supplement, New England Cable Network produced a one-hour television show featuring Nora Lenihan, a 40-year-old cancer patient who was featured in the *Globe* project. The federation received permission to re-edit the program to reduce its running time to 28 minutes. The video was used as a community education tool by 42 hospices.

In addition to the media mentioned above, the federation also employed the following:

- an Internet web page, [www.hospicefed.org](http://www.hospicefed.org), as a means of further educating the public;
- public service announcements;
- speaker's bureau;
- print advertising.

The bottom line for Massachusetts hospices has been a 15% growth in hospice admissions. While Cunningham says the public awareness campaign cannot take complete credit for the increase, she believes the project played a large role. The debate surrounding end-of-life care and euthanasia, and Bill Moyer's "On Our Own Terms" series, were instrumental in getting hospice care to register on the radar screens of Massachusetts consumers.

While most items had some degree of success, Cunningham says the public service ads yielded disappointing results because the demand for television time usually relegated the ads to early-morning spots when most people were asleep. Also, technology-related approaches did not fare well. For example, the CD offered to hospices that would have allowed them to customize the consumer guidelines did not succeed because most hospices did not own the expensive publishing program needed to complete the project.

The lesson of the project, says Cunningham, is for hospices to shed old notions of how to raise public awareness. While physicians, discharge planners, nursing homes, and long-term care facilities should remain key targets of education and information, the public should not be ignored. Cunningham is an advocate of addressing consumers directly in hopes of prompting health care consumers to shape their own end-of-life care.

"What we tried to do was to present hospice as a brand name," Cunningham says. ■

## Get a grip on the proper way to wash your hands

*Experts come clean on their methods*

Everyone in the health care profession should know the importance of proper hand washing as a means of infection control. Even so, there are some gray areas regarding what constitutes proper hand washing, when it should be performed, and by whom. Do hospice workers fall under the same rules as home care aides? Can an antiseptic gel be used in place of soap and water?

We talked to a few experts in the field to get a better grip on the rules for hand washing. Here's what we learned:

### *Even speech therapists must comply*

"Every employee that enters a patient home should wash his or her hands prior to beginning the visit," according to **Kim Stout**, RN, BSN, home health director for McAlester (OK) Regional Health Center Home Health. Stout learned this the hard way. "We were given a deficiency by our state surveyor three years ago due to this very thing. Our speech language pathologist did not wash her hands. She did not touch the patient, but the surveyor stated that all home health employees are to wash hands using proper hand-washing techniques." The change in policy to reflect this, she says, has worked well for her agency since its implementation.

**Kathy Stockton**, RN, BSN, supervisor officer/performance improvement with Mercy Home Care and Hospice in Nampa, ID, says her agency also implemented a hand-washing policy after a Joint Commission on Accreditation of Healthcare Organizations survey. "It was recommended that we tighten our policy and make it uniform," she explains. "Up until that point, we had one that said nothing much more than 'you'll do it,' but nothing was spelled out."

Since that survey, Mercy Home Health has developed a written, formal policy that spells out exactly who should be washing their hands, when it should be done, and how. The new policy, Stockton explains, is used "for understanding of accountability so that all the staff are held to same standard. It's important staff understand that infection control is a really big item and that it's best to be proactive."

Stockton and Stout agree that everyone who enters a patient's home must wash his or her hands. As for what types of cleansers to use, Stockton says her policy "specifies the preference for soap and water as opposed to gel. You can use gels when there's no running water, but that's basically the bottom line. It's also allowed in cases where the practitioner feels the situation is such that washing hands in the patient's sink would be totally impractical."

However, using gel instead of soap is generally discouraged, she says. To get around the problems with using a patient's soap and/or towels, both Stout's and Stockton's agencies provide their staff with soap and paper towels. In the case of McAlester Home Care, germicidal hand wipes are provided. Like Mercy Home Care, however, Stout notes that the hand wipes are to be used only in instances where running water is not available.

Staff are required to wash their hands both prior to touching the patient and before leaving the home, Stockton says. "Getting staff to wash their hands with running water before leaving the home is more problematic because they would just as soon use the gel." She says using soap and running water is the biggest obstacle to compliance. "It's truly the problem child with the nonclinical staff. They understand why. It's just getting them to do it, and social workers have trouble understanding why it should be done before patient contact."

A good hand-washing policy also will point out that staff members should wash their hands for a minimum of 15 seconds, or about as long as it takes to sing your ABCs. It also should require employees to turn off the faucet using a paper or cloth towel.

For employees who wear a lot of rings on their fingers, care should be taken to clean around and under the jewelry. The same goes for women with long fingernails. Luckily for Stockton, "that's just not an issue for any of us. I imagine if the hospital with which we are associated implemented a specific policy with respect to this, we would, too, but so far, it's just not been much of a problem."

As for any advice to agencies looking to revise their hand-washing policies, Stockton says this: "Keep it as simple as you can. You want a policy that you can hold staff to, but on the other hand, you want to make it easy to understand and explain so that there are not too many opportunities for working around it." ■

## Pain management summit planned

The Joint Commission Resources of the Joint Commission on Accreditation of Healthcare Organizations has planned two seminars as part of its Second Annual Joint Commission Leadership Summit on Pain Management.

The seminars will be held June 25-26 in Phoenix and Sept. 20-21 in Atlanta.

Among the subjects to be covered are strategies for building institutional commitment to pain management, implementation of the Joint Commission's pain management standards as they relate to special populations and issues, techniques for teaching patients how to assist in managing their pain, and efficient and effective ways to define and assess the competency of clinicians involved in a multidisciplinary approach to pain management. The conferences will include poster presentations of good pain management practices from practicing clinicians.

To learn more or to register for either conference, send an e-mail to: [marktingcs@jclserv.jcaho.org](mailto:marktingcs@jclserv.jcaho.org), or call (630) 792-5800. ■

## News From the End of Life

### Lancet: Dying patients willing to tolerate pain

*Many fear side effects, addiction*

Most dying patients are willing to tolerate pain to avoid taking opioid medications and are willing to trade off pain relief to avoid side effects and a perceived (but unfounded) risk of addiction, according to a study published in the April 28 issue of *The Lancet*.

Among the key findings of the study are:

- Although the number of terminally ill patients suffering substantial pain remains too high, it is not as high as previously believed.
- Of 988 patients studied, nearly equal proportions of patients described their pain as severe, moderate, minimal, or non-existent.

- Roughly half of the patients studied had sought pain treatment from their primary care physician in the previous four weeks, yet 62% of these wanted no increase in their pain medication, regardless of their degree of pain. Their reasons were fear of addiction, dislike of mental or physical side effects such as confusion and constipation, and a desire to take no more injections or pills.

- African-Americans were found to be more likely to seek additional pain therapy and to be treated by pain specialists. Yet they were also more likely to refuse increases in their medication based on fears of addiction.

**Ezekiel J. Emanuel, MD**, one of the investigators in the study, says the real concern in treating end-of-life pain is whether patients who want treatment receive it. Emanuel, chair of the department of clinical bioethics at the National Institutes of Health, added that physicians must communicate more effectively that addiction to opioid pain relievers is a myth. ▼

## Study: Chemo given when patients don't respond

Many cancer patients receive chemotherapy at the end of life, even if their cancer is known to be unresponsive to drugs, according to a newly released study.

The study, involving cancer patients who died in Massachusetts in 1996, found a third of them received chemotherapy in the last six months of their lives. That finding "strongly suggests overuse of chemotherapy at the end of life," said researcher **Ezekiel J. Emanuel, MD**, chairman of the department of clinical bioethics at the National Institutes of Health.

Researchers found support for the growing view that oncologists continue to prescribe chemotherapy for too many cancer patients when clinical evidence indicates they are in terminal stages of the disease. There are no guidelines for appropriate use of chemotherapy at the end of life based on scientifically controlled trials

or consensus statements, Emanuel said.

Emanuel's team from Boston University and Stanford University linked information from death certificates in Massachusetts with Medicare billing records.

The researchers used standard textbooks to classify whether different cancers were generally responsive or unresponsive to chemotherapy. Responsive cancers in the study were breast, colon, and ovarian. Unresponsive cancers included gall bladder, kidney, liver, pancreatic, and melanoma. ▼

## Do Medicare rules block hospice access?

*Blame directed at payment system*

A recent report by researchers at Harvard Medical School, the Harvard School of Public Health, and RAND has found that many health care providers believe that Medicare regulations block them from providing good care to dying patients.

The study, led by **Haiden Huskamp, PhD**, assistant professor of health economics at Harvard Medical School in Cambridge, MA, appears in the May/June issue of *Health Affairs*.

In the first systematic interviews of health care providers regarding fee-for-service Medicare coverage and payment for end-of-life care, the providers said patients with particularly high-cost needs at the end of life sometimes have problems gaining access to nursing homes, hospitals, and home health care services. The researchers collected their data through structured in-person interviews of clinical and administrative staff members at hospitals, hospice agencies, home health agencies, skilled nursing facilities, and physician practices in six study sites around the country.

"Most interviewees praised the comprehensiveness of the Medicare hospice benefit, but many said that the level of hospice per diem rates — \$98.96 per routine day — don't support the

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relatively expensive services that some patients need, such as costly pain medications or palliative radiation or chemotherapy,” Huskamp says.

Patients who depend on a ventilator to breathe or have end-stage liver disease are sometimes denied access to local nursing homes, said one public hospital discharge planner. Patients needing particularly high-cost ancillary services including medications and lab tests also experience problems gaining access to nursing homes, according to some interviewees.

Providers expressed concern about the impact of the prospective payment system on home health agencies, one of the changes mandated by the Balanced Budget Act of 1997. Interviewees from one public hospital believed that local home health agencies were delivering lower-quality care and dismissing patients sooner than they should be because of the change in payment systems. Several physicians reported that concern over straining a hospice’s budget had prevented them from referring patients who needed expensive care.

The new system may result in an increased burden on families and in the “dumping” of sicker home health patients into hospices. Under the prospective payment system, “there is an incentive to provide less,” Huskamp says.

The research identifies specific barriers to care and suggests remedies that would not necessarily add costs to the system. The proposed solutions also are consistent with modifications made by the Balanced Budget Act. The study calls for further research in areas that pose particular problems for the millions of patients who need end-of-life care and who account for more than a quarter of the annual Medicare budget.

“The payment system was created almost 20 years ago, and the types of services that were used for end-of-life patients in hospice were different back then,” Huskamp explains. The researchers recommend a policy for increasing reimbursement in cases that require especially high-cost services. Since this revision might not be sufficient, they also recommend a study on the need for revising hospice rates.

Many of the providers interviewed said that the per diem hospice rates are also out of date because they do not factor in the steep decrease in the average hospice length of stay. In the past, higher costs associated with the first and last days of hospice care were balanced against days in between that cost less. With the national average length of stay having declined 27% from 1992

to 1998, the burden of the high-cost first and last days has increased proportionally. In response, the researchers recommend a higher per diem for the first and last days of hospice, with a possible reduction in the middle-of-stay per diem if a counterbalancing decrease were needed. ▼

## Nursing home patients in pain: Study

*Response ‘woefully inadequate,’ says author*

**A** new nationwide study shows that severe pain among elderly nursing home residents is prevalent, persistent, and poorly treated.

The authors of the first national look at pain management among this frail population say the findings underrate the true pain burden

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### Editorial Questions

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

experienced by the patients. They call untreated pain in nursing homes “an important national public health problem.”

Results of the study were published in the April 25 issue of the *Journal of the American Medical Association*.

“We believe the findings underestimate the actual pain burden,” said lead author **Joan Teno**, MD, associate director of the Brown University Center for Gerontology and Health Care Research. “Minimum Data Set data is collected by nursing home staff. It is based on staff perception, and staff routinely underestimate the pain burden of patients.”

The authors used the Minimum Data Set to examine the pain experience of more than 2.2 million people residing in U.S. nursing homes on or about April 1, 1999. They found that 41.2% of elderly nursing home residents who were in pain around April 1, 1999, still experienced moderate daily pain or excruciating pain 60 to 180 days later. Of individuals in a nursing home for between 2 and 6 months, one in seven had persistent pain. Nationwide, rates of persistent pain varied, with most states between 39.5% and 49.5%.

### ***‘Urgent work yet to be done’ in managing pain***

“Our findings demonstrate woefully inadequate pain management among a frail, old, and vulnerable population of Americans,” said co-author **Vince Mor**, PhD, director of the Department of Community Health at Brown Medical School. “Important ground has been gained in the last decade in pain management, but these results highlight the urgent work yet to be done.”

The study points to an urgent need for balance in public policy on pain management since recent public attention and policy have focused on the dangers of opiate prescription abuse, said Teno. “Recent media coverage has fed fears about opiate drug prescription abuse,” she said, “but that should not be a reason for leaving a vulnerable population in persistent severe pain. The focus must be on quality medical care that provides competent, compassionate, and coordinated medical care for frail, older Americans residing in nursing homes and treats drug abuse as well.”

The high rate of persistent severe pain has important policy ramifications, said **Karen Kaplan**, National Program Director for Last Acts, a coalition of more than 600 organizations united to improve end-of-life care. “Current regulations need to change to make pain a focus

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at all state and federal inspections of nursing homes to comport with the new standard of the Joint Commission on Accreditation of Healthcare Organizations,” she said. That standard says hospitals and nursing homes must recognize the right of patients to the appropriate assessment and management of pain.

“Persistent pain in nursing homes should be considered by regulators as an indicator of quality and reported publicly along with other indicators,” Teno said. “Federal and state nursing home surveyors should assess the quality of pain management at the time of annual inspection of nursing homes. We call on local Peer Review Organizations of the Health Care Financing Administration to work with nursing homes to improve pain management in the next decade.”

In addition, there is a need to enhance education of nursing home staff to give people the information and tools to improve their behaviors concerning pain management, Teno said.

She suggests that patients and family members ask a nursing home about its pain-treatment policy. “Ask if it regularly assesses pain as the ‘fifth vital sign.’ Also ask what efforts has the home taken to be more aware of and to improve pain management.” ■