

# HOSPICE Management ADVISOR

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## Hospice opportunities abound, especially in palliative care

*NHPCO conference highlights opportunities for the future*

National Hospice and Palliative Care Organization (NHPCO) president **J. Donald Schumacher**, in office just one year, portrays the U.S. hospice industry and its trade organization as on the move, with opportunities on the horizon.

Schumacher's remarks were made during his opening address at the Alexandria, VA-based NHPCO's 18th Management and Leadership Conference, "Hospice & Palliative Care: Expanding Our Future," held Sept. 7-9 in Phoenix.

In his upbeat plenary presentation and a subsequent interview with *Hospice Management Advisor*, Schumacher described a number of initiatives being planned for NHPCO (**see story, p. 123**), while challenging NHPCO members to keep pace with the national organization's momentum by expanding access for patients in need of end-of-life care and by paying attention to the quality and consistency of hospice care (**see story, p. 124**). He also pointed to recent growth in the organization's membership and its tally of 885,000 terminally ill patients served by U.S. hospices in 2002, up 14% from 775,000 patients served in 2001.

For the first time since 1999, hospice length of service also went up, albeit slightly. According to adjusted data from NHPCO's National Data Set, the national average length of stay in hospice in 2002 was 51 days,

This issue of *Hospital Management Advisor* includes coverage of key events and insights from the 18th annual conference of the Alexandria, VA-based National Hospice and Palliative Care Organization, held Sept. 7-9 in Phoenix. Our coverage includes expert opinions on what may lie in the hospice industry's future, a look at the call for quality assurance initiatives, and insight into how one book is leading to changes at many hospices.

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up from 48 in 2001. The median rose from 20.5 to 20.9 days in the same period — a step in the right direction, but still too short to provide optimal care to many hospice patients. Schumacher said he believes hospice length of stay is continuing to rise, thanks to more aggressive outreach and open admission policies by many hospices and the efforts of palliative care programs to encourage more timely referrals to hospice.

## **Palliative care goes mainstream**

Numerous presentations and conversations among the 1,275 registered attendees at the NHPCO conference confirmed that non-hospice palliative care programs are becoming a mainstream strategic direction for America's hospice industry. However, there remains a distinct lack of consensus about what palliative care is, how it differs from conventional hospice care, why palliative approaches are needed to supplement

hospice care, and who should be providing these services.

"Palliative care essentially is hospice with a longer tail, covering a longer time frame," Schumacher told *Hospice Management Advisor*. The majority of American hospices still only provide hospice care, which is a form of palliative care but not the only one, he explained. From the point of diagnosis of a serious, life-threatening condition, patients often need a palliative care consultation "to help them get their feet on the road, if you will, toward the hospice door."

Such consultations could be provided by hospice team members, inpatient team members, nursing homes, or home health agencies. "But they are all, essentially, creating a pathway to end-of-life care. If the patients do, in fact, recover, then great. They go on their way," he said. But many palliative care patients eventually will qualify for hospice — and will have a better understanding of the hospice approach when its time comes.

However, Schumacher also issued a sharp rebuke to those who wish to marginalize hospice's role in end-of-life care or offer palliative care as a substitute for hospice. "We are focused on expanding hospice and end-of-life care. We're no longer content to sit in the back row while other providers eat our lunch ... leaving hospice in the dust," he said. "The feelings I've had for years about hospice being relegated to the back of the bus are shared by a lot of our members," Schumacher said. He added that members have told him they want to see NHPCO reclaim the initiative for hospice as the leader in end-of-life care.

"We want to integrate palliative care and palliative support into the hospice industry," he said. Alluding to America's air traffic controllers, who made a difficult decision to shut down the nation's airspace on the morning of Sept. 11, 2001, Schumacher said that if palliative care models are not provided in collaboration with existing hospice providers, "we'll shut down palliative care's airspace."

## **Varieties of palliative care**

Various forms of palliative care were highlighted at the Phoenix conference, including partnerships between hospices and hospitals, described during a Center to Advance Palliative Care (CAPC)-sponsored pre-conference seminar, and a number of end-of-life demonstration

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### **Editorial Questions**

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

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Other sessions described a palliative home care insurance product developed by Community Hospice in Albany, NY, in collaboration with an HMO and three home health agencies; direct-to-consumer marketing of palliative care by Hospice of the Florida Suncoast in Largo; and programs targeting cardiology, pediatrics, and veterans.

In Buffalo, NY, Support Blue is the name for a palliative care consultation benefit developed by the local Blue Cross health plan and the Center for Hospice and Palliative Care. The insurer pays for up to six palliative care consultation visits for commercially covered patients. The program already has been shown to reduce utilization of emergency room, intensive care, and overall hospital services.

Another profiled palliative care consultation service, offered by Palliative Care Center of the North Shore, Evanston, IL, made 5,380 billable consultations in 2002, 83% of them in 13 area hospitals and the rest in patients' homes, using a team comprising physicians, nurses, nurse practitioners, social workers, and a hospital liaison, as well as administrative support staff.

Hospice of the Bluegrass in Lexington, KY, is continuing to expand its palliative care consultation service, which is jointly staffed with three Lexington hospitals. Eliminating the service's

operating deficit on physician billing income has proven elusive, however, reported **Susan Swinford** of Hospice of the Bluegrass. Swinford said the hospice hopes to finally reach a break-even point for palliative care based on increased volume of visits at more sites.

Palliative care "is something we have to do. Ultimately, it's important to our success, and important to the patient and family," noted **William Finn**, CEO of the Buffalo hospice. But he cautioned conference attendees to think carefully about how palliative care services fit with the other services they provide.

Palliative care is a positive and growing part of the health care system, added **Amber Jones**, consultant with CAPC. "If hospice doesn't rise to the opportunity to provide [palliative care], somebody else will. Why would we not do that?" she told *HMA*. Hospices will need to learn new ways of linking with other providers such as hospitals, and this kind of collaboration may be more challenging than many realize.

"In my recent experience, hospice doesn't go with the patient often enough," Jones said. Instead, hospice needs to find reasons to say "yes" to patients instead of "no," even if that means providing simultaneous palliative and curative care — which is not what many hospice professionals expected to be doing when they came into the field. ■

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## NHPCO leader outlines upcoming initiatives

*Grants sought to help finance efforts*

Signs of forward motion for the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, were cited during its recent Management and Leadership Conference, held Sept. 7-9 in Phoenix.

Under the leadership of president **J. Donald Schumacher**, NHPCO is pursuing a number of new initiatives, with several large foundation requests pending to help pay for them. They include:

- developing legislative language for federally funded hospice demonstration projects;
- increased partnering with other national organizations;
- promotion of a new membership category in

NHPCO for non-hospice palliative care programs (this new category already has 49 members in operational and planning stages of providing a variety of services, including teaching, in a variety of settings);

- a plan to offer free individual memberships in NHPCO's National Council of Hospice and Palliative Professionals to staff and volunteers of NHPCO provider hospices;
- efforts to assemble "a stable of well-known hospice spokespersons" for national media outreach;
- a proposed Global Leadership Center for Care at the End of Life.

The last initiative is a centerpiece of NHPCO's new strategic plan, which is still under development but could be rolled out as soon as January 2004, Schumacher said. The Global Leadership Center would be separate from NHPCO's existing member services, and could include specific offices addressing diversity, HIV/AIDS, grief and loss, children and adolescents, executive

leadership training, and consumer issues. "All of these offices ultimately will be able to develop support for global activities," he said.

What will this proposal center mean to America's hospices? "Eventually, it will mean more research, more education, and more opportunities for us to fund programs around the world and around the country," Schumacher told *Hospice Management Advisor*. "We would not only raise money for our own benefit, but also do requests for proposals to manage other foundations' money to help fund new programmatic initiatives around the country. So what it means to your readers is this: Pay attention. Stay tuned. You may see some opportunities to participate in this discussion."

Hospices are reaching out to physicians and capturing more of the terminally ill patients in their communities, which is reflected in new data showing a slight increase in overall lengths of stay. More hospices are open to enrolling patients receiving radiation and chemotherapy "as a transition from aggressive care to terminal care," he said.

One rural hospice professional commented during a session at the Phoenix conference that his hospice had admitted 18 patients receiving chemotherapy since Jan. 1. Sixteen of them chose to stop the chemotherapy within three weeks of their hospice admission, based on dialogue with the hospice team.

Schumacher told a story about a medical center physician who had to call eight local hospice programs before finding one willing to admit a terminally ill cancer patient who required intravenous administration of pain medications because he had lost the ability to absorb drugs enterally due to a tumor in his gut. "That kind of thing should not happen. That is our problem. We have made our situation worse because of our fears and anxieties. It's time for hospice programs to start taking some risks," or else risk losing ground to palliative care alternatives, he asserted.

"There are some people who will never accept hospice care. So hospices need to find ways to serve them with palliative care consultations. We are, however, the experts, with the team experience and the management expertise. We're the ones that need to be doing the bulk of palliative care," Schumacher said. "Take out of your vocabulary, 'I can't do it,'" he exhorted attendees. "You have to trust a little bit some of the things we'll be urging you to do. We can't be defined by a narrow box any longer." ■

## Steps to boost quality advocated at conference

*Concerns must be addressed, officials say*

Participants at the 18th Management and Leadership Conference of the Alexandria, VA-based National Hospice and Palliative Care Organization (NHPCO), held Sept. 7-9 in Phoenix, said that while they were looking forward to growth and expanded opportunities, they also were looking back at the problem of inconsistent care and concerns about the quality of hospice care.

Anecdotal reports of such quality concerns were widely discussed at the conference, along with fears that just a few high-profile hospice scandals could seriously jeopardize hospice's current favorable standing in America.

"We have enjoyed a very good reputation in our communities, and we want to see that continue," NHPCO chairwoman **Maureen Hinkelman** said during an open forum at NHPCO's conference about how to tackle quality concerns. All regions of the country are reporting concerns about hospice quality, she added. "We want to open the dialogue and begin to address the issue ourselves."

Among the suggestions to emerge at the forum were greater emphasis on business ethics, revisiting hospice's core values, publication of a national hospice quality report card, and mobilization of hospice executives who could visit hospices under NHPCO's sponsorship to consult on quality improvement. It was also pointed out that providers have a responsibility at the local level to forthrightly address reported quality concerns among their neighbors.

"When I hear about horrible hospice care, it hurts us all. I feel there has to be some saber rattling," said **Martha Barton** of Pikes Peak Hospice in Colorado Springs, CO. "I think it's frightening, it's growing, and it's deepening."

Concerns about quality come in a variety of forms, according to NHPCO president **J. Donald Schumacher**, so there is no single way to address them. "NHPCO members are very concerned about the variability in quality. There is bad hospice care out there, and I think we need to stop it. All hospices are going to get painted with the brush of bad apples," he said.

"My issue is not with the ownership or tax status of a hospice, but with the quality of care it

provides," Schumacher said. "To be sure that the care being provided is good and that everybody who needs the care gets it — that's our job." He suggested that a new approach to hospice accreditation, perhaps provided by an organization that is affiliated with or closely related to NHPCO, may be needed. In addition to some new form of accreditation, what's needed is a combination of more education for providers, a Good Housekeeping-type seal of approval for hospice, and more hospices doing quality self-assessment, he said.

"I loved the suggestion at the forum this evening of giving some of the senior people in the industry who may be retiring some time at NHPCO's sponsorship to go around and help hospices develop their programs," Schumacher said.

NHPCO has developed a self-assessment quality initiative called the Quality Partners Program, which so far has about 200 participating agencies. To be identified as a Quality Partner, a hospice completes and submits the 2002 National Data Set Survey and a Standard of Practice Self-Assessment questionnaire, which is based on NHPCO's hospice standards. ■

## ***Good to Great* author inspires reflection**

*Do you have the right people on the 'bus'?*

Although he did not make a physical appearance at the 18th Management and Leadership Conference of the Alexandria, VA-based National Hospice and Palliative Care Organization (NHPCO), held Sept. 7-9 in Phoenix, management expert and author **Jim Collins** nonetheless exerted a powerful presence. Having consulted previously with NHPCO and with a number of leading hospice executives, Collins seems to have been adopted as the unofficial management guru for America's hospices.

Collins' 2001 management guide, *Good to Great: Why Some Companies Make the Leap and Others Don't*, has become a publishing sensation, directly inspiring several presentations at the Phoenix conference and helping to shape NHPCO's strategic planning process. Collins

also addressed attendees through a videotaped conversation with NHPCO president **J. Donald Schumacher**, recorded at Collins' management laboratory in Boulder, CO.

*Good to Great* builds on research for Collins' previous management bestseller, *Built to Last*, and summarizes common traits of 11 elite companies that made substantial, dramatic, sustained improvements in financial performance. The book emphasizes a few key themes from these elite companies, including the role of the "level five" leader in guiding the transition. According to Collins, level five leaders are personally selfless but have an indomitable will to achieve the organization's goals.

Each *Good to Great* company also established a culture of discipline built around its "hedgehog concept," which is a single, simple, unifying organizational mission that can be found in the overlap between the company's passion, what it can do better than anyone else, and what drives its "economic engine." Great companies were willing to confront the "brutal facts" of their environment and to make sure that they had the right people in the right seats.

### ***Not another management fad***

Given the varied management trends, fads, gurus, and organizing principles that have swept through America's business community in recent decades, it is striking how thoroughly Collins' concepts have come to dominate the conversations of leading hospice executives. **David English**, CEO of the Hospices of the National Capital Region in Falls Church, VA, offered personal testimony regarding the appeal of Collins' ideas in a presentation on how his agency applied the principles in *Good to Great* to its operations.

"The passion I have for Jim Collins and the concepts in *Good to Great* are so important to me that they have become a significant part of my life," English said. Based on a careful reading of the book while on vacation in 2001, he came to realize that three of the six members of his agency's executive team were not the right fit for where the hospice needed to go in pursuit of its hedgehog concept. But before he could act on that realization, English needed to go to his board of directors and ask them if they thought he was the right person to be driving the bus and if they were all in the right seats.

"The *Good to Great* concept allows you to ask that question," English related. "One of the most

significant things I learned from the book is that as an organization evolves, a person may be the right person today but not the right person a year or two from now. We had developed leaders with vision, passion, and enthusiasm. Unfortunately, that doesn't mean they were the right people on the bus."

In early 2002, the Hospices of the National Capital Region adopted a strategy of creating an internal *Good to Great* culture. Its hedgehog concept, found at the confluence of the "three circles" — what the agency is passionate about, what it can do better than anyone else, and what drives its economic engine — is now used by the hospice in making key strategic decisions. "Anything that doesn't fit our hedgehog concept, we will not do," English said.

This approach also required empowering staff, encouraging vigorous debate, planning for leadership succession, and improving metrics—what the hospice measures to help shape its strategic decisions. The concept can also be applied within individual departments as well as across the organization as a whole.

"We have actually changed the culture of our executive team, although implementing it across the organization has been a longer process," he said. The reshuffled executive team put together a position paper outlining the agency's reorganization with *Good to Great* concepts and is developing a "Three Circles Institute." "We're going to retrain every person in our organization around our culture, values, mission, and what the three circles mean. We also told our staff we expect them all to have the same passion for the work they do," English said.

### ***Confronting the brutal facts***

In his videotaped presentation for the NHPCO conference, Collins summarized the challenge facing the hospice industry as the need to clarify the distinction between its why or core mission and how that mission is carried out, which is subject to modification as needed. The industry also needs to define "an economic engine that leaves hospice in control of its own economic destiny."

Collins urged attendees to fearlessly confront the "brutal facts" of their present circumstances. One of those brutal facts is the Medicare hospice benefit, which Collins says has been more of a burden than an advantage to the growth of hospice. "It has allowed you to be intellectually

undisciplined about your economic engine," he explained. "I would challenge hospice to figure out how to make its economics work such that you can take or leave" Medicare's reimbursement for any given patient.

Based on a personal hospice experience in his own family, Collins said the core mission of hospice care is "to add humanity, meaning, and graciousness to the experience of dying." Hospice's why, he added, is "to make the process of dying a fully human, engaged process that, in and of itself, has its own redeeming value for all concerned." ■

## **Two new TV ads readied for national release**

*Ads designed to increase public awareness*

The Alexandria, VA-based National Hospice and Palliative Care Organization (NHPCO) and the National Hospice Foundation (NHF), NHPCO's development arm, are rolling out two new television public service announcements (PSAs) to increase consumer understanding of the special care hospice provides. State hospice organizations across the nation, in partnership with NHPCO and NHF, are distributing these PSAs to television stations as part of an ongoing public awareness initiative. Televised PSAs carry important messages to the public via a medium accessible to most Americans.

This initiative, developed and launched by NHF, has featured televised messages from Matt Lauer, Elizabeth Dole, and others sharing their personal stories about hospice. The two previously released PSAs, "Mrs. Dole" and "My Father," have grossed more than 45 million viewer impressions and have aired over 22,500 times since they were released in January 2003. This represents approximately \$4 million worth of broadcast air time.

While hospice usage in the United States has been steadily increasing in recent years, more public awareness, education, and outreach are necessary. The NHPCO reports that an estimated 885,000 patients were served by hospice providers in 2002, representing an increase of almost 15% over the 775,000 patients served in 2001. Yet 34% of hospice patients die within seven days or less after admittance, often an inadequate time

for the patient and family to take full advantage of the range of services hospice provides.

The two PSAs being distributed during October and November, "My Husband" and "My Wife," were developed by NHF and the creative agency Arnold & Associates of Alexandria, VA. The 60-second spot "My Husband" received a prestigious 2003 ADDY Award. Sponsored by the American Advertising Federation, the ADDY Awards honor excellence in advertising and cultivate the highest creative standards in the industry. There were over 60,000 entrants in the 2003 ADDY Awards competition.

Distribution of the new PSAs has been coordinated to coincide with National Hospice Month in November. This year is the 25th anniversary of National Hospice Month, a time when hospice providers across the country focus on community outreach and education. The messages of these new ads reinforce the patient-centered philosophy of care and the ongoing bereavement support provided to families by hospice organizations. ■

## Studies show pain disparity among minorities

*Research on minorities examined*

An African-American patient is more likely to endure disease-related pain than his or her white counterpart. Experts in end-of-life care have noted this fact for years, and now a recent University of Michigan research study has drawn a similar conclusion. The study report, written by a panel of top pain experts and based on a survey of more than 180 pain-related studies from a broad range of specialties, documents a phenomenon that pain specialists have long suspected but still don't fully understand.

The authors and researchers with the American Pain Society (APS) pulled together research on racial and ethnic disparities in the perception, diagnosis, and treatment of pain in treatment locations ranging from emergency departments to cancer clinics. They studied conditions ranging from chronic pain to acute pain induced in laboratory experiments.

Their conclusions were published in the September issue of the journal *Pain Medicine*.

"Across the board, and consistently, there are racial and ethnic differences in pain," says lead author **Carmen R. Green, MD**, an anesthesiologist and pain management specialist at the University of Michigan Health System in Ann Arbor and chairwoman of the APS special interest group on racial and ethnic disparities in pain. "There's much we still don't understand about why these health disparities based upon race and ethnicity exist, so more research is needed. We hope our work will increase awareness of this issue among patients and providers alike."

The new paper echoes the recently published findings from the Institute of Medicine's (IOM) panel on health disparities, which collected evidence of racial and ethnic differences in many areas of medical and surgical care.

The IOM panel's report included some perspective on differences in emergency and cancer pain treatment. But the new paper goes further by including data from more fields, including chronic pain and disability, and considering pain medication access issues. It also offers recommendations for future research.

Also, the journal *Cancer* published a study earlier this year noting the disparity in pain management. According to the journal, cancer pain among minorities often goes undertreated compared to cancer pain among whites. The results of the study were published in the April 15 issue of the journal.

Researchers talked with 31 cancer outpatients, 17 Hispanic and 14 African-American. Many of the participants told researchers that they didn't understand the best way to use pain medications or that they hadn't been warned in advance about possible side effects and how to control them.

Researchers also found that 75% of the patients said they experienced severe pain. While they got information from many sources, patients told the researchers that doctors are the most frequent and most trusted sources for information regarding cancer and cancer-related pain.

Researchers of the study published in *Pain Medicine* found more examples of studies that support the theory that minorities are less likely to receive adequate pain management than whites.

**Knox Todd, MD, MPH**, of the Rollins School of Public Health at Emory University in Atlanta, who co-authored the latest study, looked at emergency medicine studies that showed Hispanics with broken bones in their arms or legs were twice as likely as non-Hispanic whites to go without pain medication in their emergency department visits, even

after differences in language, gender, and insurance status were taken into account.

Another study co-author, **Karen O. Anderson**, PhD, of the M.D. Anderson Cancer Center in Houston, cited studies of cancer pain. One study showed that Hispanics and African-Americans with cancer were less likely to be assessed for pain and did not receive the level of pain medications recommended by the World Health Organization. Another study showed that African-American cancer patients in nursing homes had a 64% greater chance of receiving no pain treatment than did non-Hispanic whites.

The report also draws on Green's work in the area of chronic pain, including her recently published findings that, regardless of their age, African-Americans with chronic non-cancer pain from any source suffered more psychological and physical effects than non-Hispanic whites with chronic non-cancer pain.

### ***Pain tolerance varies by ethnicity***

In addition to these clinical pain studies, the authors describe the racial and ethnic differences in pain sensitivity and pain response that have been found in numerous experiments. For instance, scientists using pressure, heat, or cold to induce pain have found that African-Americans and Hispanics tend to have lower thresholds of pain tolerance. Other studies have found that pain-study participants from Nepal and India had higher pain tolerances than Western counterparts.

Taken together, these findings suggest that something in the brain's pain-processing and pain-killing systems may vary by race and ethnicity. But more studies are needed to know for sure, writes co-author **Roger Filligim**, PhD, of the University of Florida College of Dentistry in Gainesville.

Researchers also examined how communication between patients and health care providers, and the social context of their interaction, can influence pain diagnosis and treatment. They cite a number of studies showing that African-Americans and members of other racial and ethnic minorities are consistently undertreated for pain across a range of conditions, from cancer and chest pain to post-surgical and chronic lower-back pain.

Access to pain medications can also vary by race and ethnicity, the authors find. They note findings that pharmacies in neighborhoods with

large minority populations tend not to carry narcotic pain medicines such as morphine out of fear of being robbed or burglarized. This contributes to reduced minority access to pain management drugs. In addition, people living in high-crime neighborhoods are reluctant to keep these drugs at home for the same reasons pharmacies do not stock them..

Past studies have cited a sense of mistrust toward the health care system among African-Americans. Studies suggest that communication between African-Americans and their physicians may be hampered by that mistrust and that physicians must make a greater effort to explain courses of treatment and listen to patient concerns in order to gain patients' trust.

Also, the way health care providers measure pain is an issue. Rather than arbitrarily choosing an unacceptable level of pain for the entire population, health care providers need to gauge pain on individual preferences. For example, if 10 people report varying degrees of pain, half of them more than a 5 on a 1-to-10 scale, it would be reported that half the patients were made to endure moderate to severe pain. Instead, providers should consider an individual's tolerance for pain, which is often based on cultural factors. For example, Hispanics, with their deep roots in Catholicism, may be willing to endure higher degrees of pain. Also, fear of addiction is prevalent among minorities.

"Physician prescribing patterns, as well as patients' own attitudes and beliefs regarding pain, and socioeconomic factors, may all contribute to racial and ethnic differences in pain management," writes study co-author **Raymond Tait**, PhD, of the St. Louis University School of Medicine. "But all of these issues related to health care delivery are yet to be adequately explored."

In fact, says Green, a review of the literature on race, ethnicity, and pain only showed the authors how much more there is to find out on this topic.

For instance, much more research is needed on how cultural beliefs, as well as patient-level decision-making and preferences, influence the pain-related behavior of patients from racial and ethnic minorities. Further studies should be done, the authors say, to correlate experimental findings on pain perception and tolerance with clinical pain, especially where there are differences among racial and ethnic groups.

Even the tools that doctors and nurses use to ask patients how severe their pain is need to be examined for cultural and linguistic sensitivity,

the study's authors suggest. Better data on disparities in various health care settings, and in different insurance and legal contexts, should be gathered.

And more studies are needed to understand how stereotypes and other sources of bias can color the interaction between health care providers and patients, and what strategies might counteract these effects.

"Clearly, local, state, federal, and private-sector initiatives, in combination with advocacy and scientific organizations, are necessary to understand racial and ethnic disparities in pain if we are to improve the quality of pain care for all," says Green. "In the meantime, it's important for patients from all backgrounds to speak up about their pain to their health providers and insist on getting the effective treatments that now exist, along with referrals to pain specialists. Don't assume that pain has to be a part of your life." ■

## Congress considers bill to aid dying children

*Two pilot programs would test the concept*

Two Ohio lawmakers want to see palliative care become the standard for dying children in the United States. A House bill was introduced in September by U.S. Rep. **Deborah Pryce**, R-OH. The bill is also co-sponsored in the Senate by Sen. **Mike DeWine**, R-OH.

The bill, introduced Sept. 18, would expand palliative care services for terminally ill children and their families through grants, research projects, and two pilot programs that would provide treatment and counseling. The palliative care initiative would cost \$40 million a year for five years and is expected to receive bipartisan support.

The two pilot programs would help lawmakers decide whether to include palliative care as a Medicare benefit and whether to require private health insurance plans to do the same.

Parents caring for an ill child must choose between continuing regular treatment and accepting hospice assistance under Medicare rules, which are mirrored by state Medicaid rules that cover children's health care services. Current regulations allow hospice care for patients with

six months or less to live, on the condition that patients forgo all curative care. This means parents of children who need palliative care must give up on the chance of recovery.

"This limits the services children can access, and it's just not right," says Pryce, whose 9-year-old daughter died of cancer in 1999. About one million children are living with life-threatening conditions, and about 55,000 die each year, according to the National Association of Children's Hospitals.

Last year, the Institute of Medicine (IOM) issued a report calling for better care of dying children, including the removal of current regulations that require parents to choose between palliative care and curative care.

The report concluded that pediatric palliative care is either missing or woefully substandard because of poor training, conflicting parental goals, cultural barriers, and insurance regulations that discourage palliative care. It also called for demonstration projects to lead the way in finding innovative ways to address the problem.

Among the hospice-specific recommendations in the IOM report are the following:

- Children's hospitals, hospices, home health agencies, and other organizations that care for seriously ill or injured children should collaborate to assign specific responsibilities for implementing clinical and administrative protocols and procedures for palliative, end-of-life, and bereavement care. In addition to supporting competent clinical services, protocols should promote the coordination and continuity of care and the timely flow of information among caregivers and within and among care sites including hospitals, family homes, residential care facilities, and injury scenes.

- Children's hospitals, hospices with established pediatric programs, and other institutions that care for children with fatal or potentially fatal medical conditions should work with professional societies and other resources to assist clinicians and families in local and outlying communities and rural areas.

- Children's hospitals and other hospitals that care for dying children should work with hospices and other relevant community organizations to develop and implement protocols and procedures for culturally sensitive bereavement services, define bereavement support roles for hospital-based and out-of-hospital personnel, and meet bereavement needs of professionals who assist dying children and their families.

- Public and private insurers should restructure hospice benefits to add pediatric hospice care to the services reimbursed by Medicaid and other public insurance programs as well as by private health plans, eliminate eligibility restrictions related to life expectancy in favor of criteria based on diagnosis and severity of illness, drop rules requiring children to forgo curative or life-prolonging care, and include outlier payments for exceptionally costly hospice patients.

- Medicaid and private insurers' policies restricting benefits for other palliative services related to a child's life-threatening medical condition should be modified to remove obstacles to care. ■



## Hospice a factor in 'best hospital list'

If a hospital wants to be considered one of the best in the country, it had better have access to hospice care.

*U.S. News and World Report* released its list of "America's Best Hospitals" in its Aug. 4 issue. The availability of hospice and palliative care services was a significant criterion in its deliberations, which included evaluations of 6,003 hospitals across the country.

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, applauded the magazine for its understanding of the importance of hospice services for patients and families coping with serious and life-limiting illness, according an NHPCO press release.

Of the 6,003 hospitals that qualified for review, 203 different medical centers were recognized for outstanding work in 17 specialty areas. Among the best medical centers in the country dealing with cancer, geriatrics, and respiratory disorders, 96% have hospice and/or palliative care services available. One hundred percent of the highest-rated heart and heart

surgery centers offer hospice and/or palliative care. Palliative care is found in 74% of rheumatology programs.

The presence of hospice and palliative care as criteria for excellence reflects a growing understanding of the need for quality end-of-life care. These services represent an investment in the patients, families, and communities these organizations serve.

"Increasing access to hospice and palliative care will enhance the quality of health care all consumers should come to expect from hospitals in this country," said **J. Donald Schumacher**, president of the NHPCO. "Here at NHPCO we are working to increase access to hospice and promote quality end-of-life care across America. This valuable report will certainly help increase awareness and understanding." ▼

## Providers gear up for new HIPAA regulations

The Centers for Medicare & Medicaid Services (CMS) won't seek out and penalize health care organizations that don't comply with the Health Insurance Portability and Accountability Act (HIPAA) transactions and code sets rule after the rule's Oct. 16 implementation deadline. Instead, CMS will focus on helping covered entities meet the new requirements. The agency does not have the resources to search for noncompliant entities and will deal with noncompliance on a case-by-case basis, according to **Leslie Norwalk**, CMS deputy administrator.

Providers who still need help meeting the requirements — which are intended to eliminate the hassle and costs of paper claims forms by requiring payers, clearinghouses, and providers to follow a standardized form for transmitting claims information — can visit a web site designed by the Workgroup for Electronic Data Interchange in Reston, VA, and the Council for Affordable Quality Healthcare in Washington, DC.

The web site contains schedules for testing and implementing electronic transactions standards, links to different organizations' best practices HIPAA companion guides, and links to other useful web sites related to transaction and code sets requirements. The web site address is: [www.wedi.org/snip/caqhimpltools](http://www.wedi.org/snip/caqhimpltools). ▼

## JCAHO revises areas for random surveys in 2004

The Joint Commission on Accreditation of Healthcare Organizations has revised the fixed and variable performance areas that will be evaluated during random unannounced surveys next year. Beginning in 2004, performance will be reviewed in selected critical focus areas — processes, systems, or structures in a health care organization that significantly affect the quality and safety of care.

The 2004 fixed performance areas are:

- staffing;
- infection control;
- medication management;
- national patient safety goals that are relevant to an organization's care and services.

A sample of 5% of organizations accredited under the ambulatory care, behavioral health care, home care, hospital, and long-term care programs are randomly selected for unannounced surveys each year. Random unannounced surveys will end in January 2006, when JCAHO will begin conducting all regular accreditation surveys on an unannounced basis. ▼

## CMS: 3.3% rise in home health payment rates

The Centers for Medicare & Medicaid Services (CMS) announced a 3.3% increase in Medicare payment rates to home health agencies (HHAs) for fiscal year 2004. The increase will provide an extra \$340 million in payments to HHAs next year. Home health payment rates are updated annually by the percentage change in the home health market basket index. CMS establishes the home health market basket index, which measures inflation in the prices of a selected mix of goods and services

included in home health services. The updated payment rates are published in the July 2 issue of the *Federal Register*.

In addition, on June 16, CMS launched "Home Health Information Resource for Medicare," a new on-line tool for HHAs. The resource center on the CMS web site provides a comprehensive database that includes information on enrollment and participation, initiatives, policies and regulations, coding and billing, Outcome Assessment and Information Set, research, education, preventive services, program integrity, and Medicare secondary payers.

The web site also gives HHAs information for staying on top of the latest developments in the home care industry, with sections on the latest news and where to find it, home care contacts, and home health highlights. The web site says CMS created the page to "incorporate all home health-specific information in one place" and will update it regularly. You can find the site at: [www.cms.hhs.gov/providers/hha](http://www.cms.hhs.gov/providers/hha). ▼

## No quick end to nursing shortage, new report says

Although health care organizations are using innovative strategies to recruit and retain nurses, and federal, state, and local government agencies are providing financial support to help alleviate shortages, the national nursing shortage will continue to be one of the greatest challenges to the health care industry for many years, according to a report issued by Fitch Ratings, an international credit rating agency in New York City.

Because health care providers will continue to experience salary inflation and increasing benefit expenses, these costs will offset any savings from increased operational efficiency in other areas.

The "Nursing Shortage Update" report can be found at [www.fitchratings.com](http://www.fitchratings.com). Click "U.S. Public Finance," then "Special Reports." ▼

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# Fear of investigation can hinder treatment

*Survey finds pain management affected*

Despite all of its successes in improving care for patients facing the end of life, Oregon still has not made headway in treating pain and suffering, according to researchers at the Center for Ethics in Healthcare at Oregon Health Sciences University in Portland.

Statewide, Oregon has made aggressive moves over the past decade to improve health care for its residents — particularly those facing serious or terminal illnesses. And initiatives aimed at improving end-of-life care planning, access to hospice care, and use of advance directives and living wills have all reported overwhelming success, says **Susan Tolle, MD**, the center's director.

"But when people die, we are not seeing progress with treatment of pain," she explains. "We are seeing progress on every other front, but not that one."

In 2000, the center published a study in the *Western Journal of Medicine* reporting that 54% of family members of dying patients in 1998 reported their loved one experienced moderate or severe pain in the last week of life.<sup>1</sup> In addition, the study said that previously gathered data showed that the percentage of dying patients who complained of pain increased to 57% from 33% in late 1997.

Although researchers could not be certain why such a dramatic increase was reported, the feeling at the time was that there was both a greater awareness about pain treatment options on the part of family members, and noticeable change in physician prescribing practices due to increased fears of regulatory sanctions, says Tolle.

## ***Pain management remains resistant to change***

Now, the Center for Ethics in Healthcare has gone back to take a second look at the number of patients and families reporting pain and suffering at the end of life, expecting to find improvement, says Tolle. They were wrong.

"What we are finding is that there is something different about the politics of changing end-of-life planning, and making that work, and changing the practice of pain management,"

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she says. "There appears to be something more vulnerable about pain management, and we have certainly found it harder to bring about profound change."

In most situations, it is not a case of a physician or nurse consciously deciding to undertreat a patient's pain, but rather there being an overall tendency to be conservative rather than aggressive when treating pain, she says.

## ***Reference***

1. Tolle SW, Tilden VP, Hickman SE, et al. Family reports of pain in dying hospitalized patients: A structured telephone survey. *West J Med* 2000; 172:374-7. ■

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