

Medical Ethics Advisor™

Your practical guide to ethics
decision making

INSIDE

■ **The earlier the better:**

Discussing end-of-life issues with pulmonary patients is all in the timing 136

■ **Sorry, Henry:** Controversial drug abuse bill gets last-minute boot from budget bill 138

■ **Relief is coming:** California helps dying patients by easing prescription laws 140

■ **Getting started:** Advocacy group gaining momentum in end-of-life community . . . 140

■ **News briefs** 141

Seniors talk back about end-of-life care

Bed rate decides where people die

Researchers isolate stem cells in lab

Poor and African American patients treated differently

Noted researcher calls for surgery moratorium

In this issue:

1998 MEA Index

Legal Briefings

**DECEMBER
1998**

**VOL. 14, NO. 12
(pages 133-144)**

American Health Consultants[®] is
A Medical Economics Company

Ethicists walk fine line between the bottom line and admitting homeless

Study shows homeless cost health care system thousands per patient

While the problem of caring for homeless patients might not be equally pressing in rural areas, ethics committees still must come to grips with the challenges these patients pose to the hospitals' overall bottom line, experts say.

The bottom line, according to new data published in the *New England Journal of Medicine*,¹ is that homeless patients stay longer and cost hospitals more than indigent patients with homes. But more important to ethics committees is whether these facts should interfere with the plan of care for the patient — regardless of the patient's personal situation. A recent study by the New York City Health and Hospitals Corporation of nearly 19,000 homeless patients admitted to New York-area hospitals between 1992 and 1993 compared hospital charges and expenses for those patients with 384,000 low-income patients with homes.¹

The findings were not promising for the plight of homeless patients: Homeless patients stayed an average of 36% longer than indigent

Executive Summary

New research shows that homeless patients have longer lengths of stay and cost hospitals more than indigent patients with homes. More important for ethics committees, however, is creating a balance between the cold facts of hospital finances and providing the best care possible for the patient.

- Homeless patients stay an average of 36% longer than indigent patients with homes, and the extra length of stay alone costs hospital systems an average of \$2,414 per homeless patient, according to data from New York City Health and Hospitals Corporation.
- Parkland Health System in Dallas began an effort to improve access for homeless patients through the Homeless Outreach Medical Services, which provides primary and preventive care in community-oriented primary care clinics throughout the city.
- The Health Care Center for the Homeless in Orlando, FL, operates a primary health care clinic, dental clinic, vision clinic, and tuberculosis shelter on an annual budget of about \$500,000.

patients with homes. What's more, the extra length of stay (LOS) alone cost the hospital system an average of \$2,414 per homeless patient.

Add this to the already heavy burden of absorbing the cost of indigent care, and the amount is much larger. Major reasons for the extended length of stay, according to the researchers, are legal mandates that require homeless patients suffering from mental illness to be discharged into a supportive environment.

A shortage of available supportive housing and psychiatric beds could make the wait months long. Severe overcrowding in city shelters and lack of low-income housing means that many other homeless patients are kept in a hospital bed until shelter space becomes available, the report states.

Writing in an editorial accompanying the article, **Paul Starr**, PhD, of Princeton (NJ) University, offers several solutions, but reaching these solutions would require the participation and leadership of state and federal organizations — a task much larger than the abilities of the hospital ethics committee. Starr suggests increasing the minimum wage and relaxing government regulations on the construction of low-cost housing.

"As it is now," he writes. "We continue paying to put the homeless in hospital beds while not providing them with ordinary beds of their own."

Obligation includes unbiased access

While federal regulations create bureaucratic bed nightmares that seem hopeless, there are actions ethics committees can take to curb the problem. Several public hospital systems, for example, are taking a proactive approach to the problem.

Public hospitals face more challenges than their private counterparts. These hospitals and health systems are charged with providing health care to the community at large and are overburdened with the costs of caring for the homeless. But by taking the step of developing health outreach programs, an attempt is made to head off illnesses that land these patients in a hospital bed in the first place.

In addition to the financial concerns of extended inpatient stays, many caregivers also feel that public institutions have an ethical obligation to ensure unbiased access to basic health care. What's more, the access should be early, instead of waiting until homeless patients are

in need of hospitalization before they begin treatment.

"As the public hospital for the county, we are charged with ensuring access to health care to the community as a whole," says **Susan Spaulding**, MD, director of the Homeless Outreach Medical Services program (HOMES) at the Parkland Health and Hospital System in Dallas.

A few years ago, Parkland began an effort to improve access to primary care and preventive medicine by opening several small 'community-oriented primary care clinics' (COPCs) throughout the city. The HOMES program and COPCs are funded jointly by Parkland and the City of Dallas.

Catching problems early

The concept is that by bringing primary care into the neighborhoods where people live, it enables the public to easily access the health system and enables providers to treat health problems before they become so severe they require hospitalization or other, more intensive health care resources, according to Spaulding.

The HOMES program is, in essence, the COPC for the homeless population of Dallas, she says. "It is basically the same thing, it is just that this one is mobile."

Staffed with a full-time internist and a full-time pediatrician, a clinical psychologist, registered dietitian, three nurse practitioners, three RNs, four social workers, an administrative coordinator, and three health care assistants, the HOMES program operates as a six-site health clinic and has two 40-foot mobile medical vans.

HOMES holds 30 clinics a week at 18 different locations throughout Dallas. The clinics consist of three-hour sessions on Monday afternoons; Tuesday, Wednesday, and Thursday evenings; and Friday mornings, says Spaulding.

Services include well-child checkups, immunizations, acute care, referrals to other programs and social services, adult health maintenance evaluations, sexually transmitted disease and HIV screening, acute and chronic disease clinics, and a diabetes education program.

The city originally started a health program for the homeless about 11 years ago, Spaulding says. Originally, the program involved a nurse practitioner going to the city's shelters to provide basic medical care and making referrals to the hospital.

Seven years ago, Parkland took over administration of the program, expanding it to its current

level. It is now one of the system's COPCs, although it is the only mobile one, Spaulding says.

Physicians in the HOMES program now can do lab work, such as blood testing, for homeless patients. They have a class D pharmacy on both vans, and the physicians can make referrals to specialists at Parkland's hospital.

"As the county hospital for the Dallas area, they are charged with providing care to the community at large," says Spaulding. "With the move to the COPCs, this was another effort at getting out into the community."

The hospital system doesn't keep data on which patients are homeless, so there is no accurate way to gauge the financial impact the program has had on the hospital system. Spaulding says, however, the efforts the HOMES staff make at preventive care result in fewer primary care visits to the hospital's emergency department (ED). "The cost of a visit to the HOMES site is much less than the cost of an average ED visit," she says.

Currently, the project has a budget of \$1.5 million, split between city funds and Parkland's operating funds, she notes.

She admits the hospital system absorbs most of the cost of care, but the system's overall health is shown by the fact that the hospital has been able to lessen its dependence on the Dallas tax base in the past few years, becoming largely self-sufficient. "That is always a challenge for any public hospital system."

Cooperative agreements are an option

Some hospital systems, however, have developed arrangements with existing homeless health programs, which takes a slightly different approach to solving the problem of providing care to the homeless. In cooperative agreements, a hospital system provides funds and administrative and clinical support to an organization already familiar with the homeless population and set up to handle its specific needs.

The Health Care Center for the Homeless (HCCH) in Orlando, FL, runs a primary health care clinic, dental clinic, vision clinic, wilderness outreach, and tuberculosis shelter on an annual budget of about \$500,000. HCCH receives about \$750,000 in financial support and in-kind services from three area hospitals: Florida Hospital, Orlando Regional Health Care System, and Central Florida Health Care System.

"We also have specialists throughout the

community who give us two procedures a year, and we make referrals to them," says **Paul McGlone**, president of HCCH.

When patients need surgery or hospital admission, the hospitals take the case on a rotating basis. The center has more than 9,300 patient visits per year to its primary care clinic at a cost of about \$361,000 or \$38.00 per patient.

By helping homeless people enter the health care system at a primary health care level, the center has been able to treat acute medical problems before they require a hospital admission, says McGlone.

Most treated as outpatients

A good example is pneumonia. Although in its initial stages, the illness can be treated on an outpatient basis. If left untreated, however, pneumonia can be life-threatening and often leads to hospitalization.

According to HCCH data for 1995, the latest available, the primary care clinic treated 1,379 cases of pneumonia, cellulitis, unhealed wounds, spider bites, and venereal diseases — all on an outpatient basis.

By helping homeless patients manage chronic conditions, such as diabetes and hypertension, the center also has helped reduce visits to area EDs. Many diabetes patients who present at the center are close to requiring hospitalization, with nearly 60% showing blood glucose levels of 300 or greater (normal is 100), according to center data.

In 1995, HCCH treated 247 diabetic patients, with only four patients needing a referral for treatment in the ED.

The center has a full-time clinical staff of one physician, one nurse practitioner, and a paid dental hygienist to manage the cases in the dental clinic. It is heavily dependent on the specialists and other health professionals who volunteer their services regularly, says McGlone.

The primary care clinic volunteers include 43 primary care physicians, five advanced registered nurse practitioners, 22 nurses, and seven front desk (intake) personnel. In addition, there are 77 volunteer physicians who provide specialty secondary care.

"We have one retired physician who comes in and works evenings in our primary care clinic two and a half days a week," notes McGlone.

A retired dentist also comes in and spends one evening a week seeing patients in the dental

Sources

For more information about establishing programs for homeless patients, contact:

- **Paul McGlone**, Health Care Center for the Homeless, 11 North Parramore Ave., Orlando, FL 32801.
- **Susan Spaulding**, MD, Parkland Health and Hospital System, 5201 Harry Hines Blvd., Dallas, TX 75235.

clinic, he adds. "I think that this is evidence of what can happen when you have everyone working together," he says. "You hear a lot about medical centers and hospitals and how competitive they are, but this is an example of [different systems] coming together to work toward a solution."

References

1. Salit SA, Kuhn EM, Hartz AJ, et al. Hospitalization costs associated with homelessness in New York City. *N Engl J Med* 1998; 338:1,734-1,740. ■

'The earlier, the better' with pulmonary patients

Discuss end-of-life care before disease progresses

Patients with chronic obstructive pulmonary disease (COPD) have a condition that is progressive, often severely debilitating, and, in most cases, requires intensive care unit (ICU) admission at some point in the disease process.

Yet an analysis of the medical literature shows little or no difference in the percentage of COPD patients who have discussed end-of-life treatment options with their physicians, compared to the general population.¹

"In fact, the most common situation is that, when the time comes, these decisions are left to the family because this discussion has never taken place," says **Mark P. Pfeifer**, MD, FACP, associate professor of medicine at the University of Louisville in Kentucky and author of a recent paper analyzing medical data on end-of-life care of COPD patients.¹ "It comes down to, 'What do you want to do about Dad?'"

Ideally, family members will try to act according to what they believe to be the patient's wishes, but often it's from their own perspective in relation to that person, Pfeifer continues.

In these instances, physicians are left with a limited role: advising the family on the clinical issues involved and making predictions about the outcome of treatment.

Several studies also indicate that the accuracy of predictions made by both physicians and family members regarding patient desires do not exceed those expected by chance alone, says Pfeifer.²⁻⁵

Even if the patient has communicated specific wishes about medical treatment at the outset of his or her illness, these decisions should not be considered static, he adds.

"Physicians caring for COPD patients commonly report that patients who earlier had indicated a desire to avoid mechanical ventilation request it as dyspnea and air hunger worsens and death appears imminent," Pfeifer writes in his review.

This information highlights the need for the following three actions:

- early discussion of end-of-life issues with patients with chronic conditions such as COPD;
- discussion of these issues with the patient's family members;
- a periodic re-evaluation of the patient's directives as the disease progresses.

When should initial discussion take place?

Knowing when to discuss the issues surrounding end-of-life care is not a textbook scenario. There is no magic number or definite time to indicate when a physician and patient should begin discussing end-of-life care, Pfeifer says.

"I have seen patients with very poor numbers on pulmonary function tests, who did very well in terms of the quality of life they were leading," explains Pfeifer. "I have also seen patients with good pulmonary function scores who could barely get out of bed."

It would be a mistake for ethics committees developing a policy or procedure to designate some definitive clinical parameter linked to a discussion of these issues, he adds.

Often, the best time to discuss these issues with patients is when they are "well," possibly during a physical exam before advanced complications of the condition manifest, suggests **Andrew G. Villanueva**, MD, director of the medical intensive

care unit at the Lahey Clinic in Burlington, MA. Villanueva also is a pulmonologist and specialist in critical care medicine.

“When you try to have these discussions when the patient is already very ill, it’s very stressful for them, and the patients tend to react more emotionally,” explains Villanueva.

Early on, he says, the patients are more able to consider their wishes objectively in terms of maintaining quality of life and in which circumstances they would — and would not — want advanced medical intervention.

While acknowledging that broaching the subject of end-of-life care is difficult, Villanueva stresses that he makes it a policy to discuss these issues with all patients.

Mechanical ventilation issues

One of the most difficult decisions facing COPD patients as their disease progresses is whether they want to be placed on a ventilator. There is a misconception among many physicians that once patients receive mechanical ventilation, their lungs become dependent upon it and they are never able to live without use of the machine again, says Villanueva.

This is a concern, but in many cases a COPD patient can be placed on a ventilator to get over an acute illness or complication and then be able to have the ventilator removed, he says.

Villanueva recommends that the physician and patient discuss specifically what the patient’s wishes are in terms of quality of life and then decide on parameters for the use of mechanical ventilation. “We have some patients who say, ‘I want you to do everything you can no matter what,’ but that’s rare,” Villanueva says.

“We also have patients who say they never want to be intubated, and they are also the minority, but there are more of them. Most people say something like, ‘If you think I can pull through it, then go ahead, but if there is almost no chance, then no.’ We can do that for them.”

Because it is easier to withdraw care in terminally ill patients, physicians now can adhere to specific patient’s wishes more accurately, he adds. “Even if we put you on a ventilator, believing that you will do well, and you don’t, and it looks as though the outcome will be bad, then, in keeping with previous discussions, we can take you off,” he says when discussing the issue with patients.

The standard of care previously implied that, if a medical intervention was begun, then it had to be “followed through to the end,” he adds. “Now, we can withdraw care if we believe it to be against the patient’s wishes. It is legally accepted, medically accepted, and ethically accepted.”

Implementing a patient’s wishes

After the initial discussion, Villanueva advises his patients to discuss their decision and instructions with other family members.

He prefers to include the patient’s closest family member in the discussion about the patient’s wishes, but if the patient or family member is uncomfortable, or there is no clear family member that would be the medical decision maker, he leaves the decision up to the patient.

“So there is no ambiguity when that time comes, I ask them to tell the people that they think should know,” he says.

Both Pfeifer and Villanueva say they document the patient’s wishes in the medical chart, so they will be available to all medical personnel.

Villanueva says he also makes a note about the subject and writes it on the inside flap of the folder holding the medical record to ensure the advance directives are not missed.

“In Massachusetts, an advance directive or living will is not a legal document, but it is respected by the medical community and the courts because it is the expression of the patient’s wishes,” Villanueva says.

References

1. Pfeifer MP. End-of-life decision-making: Special considerations in the COPD patient. *Medscape Respiratory Care* 1998;2(5) [on-line publication]. <http://MedicalPractice.medscape.com>.
2. Druley JA, Ditto PH, Moore KA, et al. Physicians’ predictions of elderly outpatients’ preferences for life-sustaining treatment. *J Fam Pract* 1993; 37:469-475.

Sources

For more information on end-of-life care issues for patients with chronic pulmonary diseases, contact:

- **Mark P. Pfeifer**, MD, FACP, University of Louisville, Division of General Internal Medicine, Ambulatory Care Building, A3K00, Louisville, KY 40292.
- **Andrew G. Villanueva**, MD, Lahey Clinic 41 Mall Road, Burlington, MA 01805.

3. Hare J, Pratt C, Nelson C. Agreement between patients and their self-selected surrogates on difficult medical decisions. *Arch Intern Med* 1992; 152:1,049-1,054.

4. Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol* 1988; 43:115-121.

5. Suhl J, Simons P, Reedy T, et al. Myth of substituted judgment: Surrogate decision-making regarding life-support is unreliable. *Arch Intern Med* 1994; 154:90-96. ■

Hyde-Nickles bill defeated in Congress

Co-sponsor vows to try again

End-of-life and pain management advocates are celebrating — at least this year — the defeat of a bill that would have harnessed the enforcement power of the U.S. Drug Enforcement Administration to investigate and punish physicians and pharmacists suspected of participating in legalized physician-assisted suicide.

On Oct. 14, Senate sponsor Don Nickles (R-OK) abandoned his effort to attach the Lethal Drug Abuse Prevention Act to the omnibus spending bill, which was approved by Congress the following week. Sen. Ron Wyden (D-OR) had announced on the floor his intention to filibuster the entire spending bill, if necessary, to prevent a backdoor enactment of Nickles' bill.

House sponsor Rep. Henry Hyde (R-IL) previously had withdrawn the House version of the bill before it could come up for a floor vote. Nickles vowed to "pursue the matter next year," while opponents of the bill, including the National Hospice Organization (NHO) in Arlington, VA, and the American Medical Association in Chicago, pledged to seek alternative measures that better address the real needs and suffering of dying patients.

Right-to-life advocates had pushed the Hyde-Nickles bill as a litmus test for the conservative agenda and a way to overturn the twice-passed Oregon Measure 16, which legalizes physician-assisted suicide. End-of-life care and pain specialists, including many who long have been opposed to assisted suicide, argued that the bill would have an unintended chilling effect on the prescribing of controlled substances for legitimate pain management, mainly because of doctors' well established fears of government scrutiny.

A coalition of 52 health care organizations, led by NHO, rallied the end-of-life community's opposition to the bill.

"I was heartened by the response by the hospice community in educating the members of Congress on this issue," says **John Giglio**, NHO's director of public policy and general counsel. "This helped elevate the debate on the underlying causes of assisted suicide, including the undertreatment of pain and the inability of many Americans to access appropriate end-of-life care. As a result, the palliative care community has a tremendous opportunity to advance the dialogue with Congress on how to improve care of the dying," Giglio explains.

NHO is examining its next steps and hopes to work with other end-of-life groups to define legislative proposals. "If they have bipartisan support, there's a good chance Congress will consider them," he adds.

Leaders call for action

Joanne Lynn, MD, founder of Washington, DC-based Americans for Better Care of the Dying and another leader in the fight against Hyde-Nickles, urges health care providers to "let us and NHO have their input on what kind of Congressional action they would like to see to improve end-of-life care. A lot of people on the Hill are interested in what they could do for the plight of dying patients, such as research studies or demonstration projects," Lynn says, although creation of new end-of-life medical benefits is less likely in the short run. "At least we've got to have some goals in mind."

In the wake of Hyde-Nickles defeat, some palliative care leaders have wondered whether the vehemence with which the end-of-life movement pushed suggests the danger of partnering with that movement. One of the concerned leaders is **Ira Byock**, MD, past president of the Reston, VA-based American Association of Hospice and Palliative Medicine and author of *Dying Well: The Prospect for Growth at the End of Life*, (published in 1997 by Riverhead Books, New York).

In a Sept. 30 editorial in the Portland *Oregonian* newspaper, Byock accused Hyde-Nickles boosters of trying to incite a new civil war similar to the abortion debate by escalating the assisted suicide debate "to a dangerous new level of conflict, while doing nothing to alleviate the suffering of dying patients. At a time when consensus building and constructive legislation is urgently

needed — and would likely succeed — the bill's backers have chosen instead to wag a moral finger at America," he writes.

In a subsequent interview with *Medical Ethics Advisor*, Byock labels the Hyde-Nickles effort "disgraceful" and adds, "We have learned that a small but powerful faction within the right-to-live movement is really more interested in moralizing than in alleviating suffering."

If right-to-lifers were truly interested in relieving suffering and reducing patient demand for assisted suicide, he says, they would "use the power of the congregations and parishes to declare a social right to die in comfort in a clean, dry bed. Instead, some right-to-life zealots seem willing to work with those of us in the caring community only to the extent that it advances their own, self-righteous political agenda."

Strange bedfellows

Lynn, who was a target of attack by Hyde-Nickles advocates, says "the things that separate us are still pretty small. Just like politics makes strange bedfellows, sometimes it makes strange opponents." The battle over the Hyde-Nickles bill, she suggests, "was just an honest difference of opinion over whether something would work or whether it was important to do for symbolic reasons."

NHO's Giglio adds that advocates for the Hyde-Nickles bill "were not people who normally work on health issues. They literally didn't understand or believe our objections. But I don't think it reflects a larger trend of whether or not we should be working with right-to-lifers," he observes. "I will bet that by this time next year, Congress will be considering a bill that the health community will be able to support."

According to the Oct. 20, 1998, *Hospice News Network* electronic newsletter, Oklahoma State Hospice Association (OSHA) president **Steven Edwards** says he hopes "we can work together with Senator Nickles next year to accomplish common goals that also won't hurt cancer patients and the terminally ill."

Meanwhile, an attempt to shift the assisted-suicide debate to Michigan with a proposal called Proposal B failed in the Nov. 3 election. Placed on the ballot by a group called Merian's Friends, the initiative was defeated nearly 3-1, but neither side says the issue is over.

The group is named for Merian Frederick, a Michigan amyotrophic lateral sclerosis (ALS)

patient who committed suicide in 1993 with the assistance of Jack Kevorkian. Many in Merian's Friends want to bring the issue back, perhaps in another four years, says **Bob Moreillion**, former campaign manager for the group.

The proposal resembles Oregon Measure 16, the first state law to legalize assisted suicide, and it includes such safeguards as psychiatric determination, seven-day waiting period, and certification from two physicians that the person has less than six months to live before a patient could receive assisted suicide.

Merian's Friends gathered 250,000 signatures to get the proposal on the ballot but had few resources left to purchase political advertising. Opponents spent between \$5 million and \$6 million on television ads to defeat Proposal B.

Ironically, Kevorkian, who claims to have helped more than 120 suffering patients end their lives, urged voters to defeat Proposal B because of its "stifling bureaucratic red tape."

Kevorkian's flamboyant attorney, Geoffrey Fieger, was the Democratic nominee for Governor of Michigan on this year's ballot. He lost to incumbent John Engler, a staunch opponent of assisted suicide. Earlier this year Engler signed a new law, effective Aug. 1, outlawing assisted suicide and targeting Kevorkian's activities.

Could have been easier

Background on the story of Merian Frederick is contained in an article by her daughter Carol Poenish of Northville, MI, in the Oct. 1 *New England Journal of Medicine*. Frederick received hospice care during her final months of life, but the hospice did not know that she also was receiving visits from Kevorkian, Poenish writes.

"It had to be done in secret — in a back alley. I realized after Mom's death that many of the hardest aspects would have been eliminated if the choice she made had been legal. We wouldn't have had to be so secretive; we might have had help in coming together sooner as a family, and we wouldn't have had to go to Jack Kevorkian."

Against this backdrop, a number of health associations such as the Michigan Health and Hospitals Association, the Michigan Hospice Organization, and the Michigan State Medical Society, all based in Lansing, have joined with the state's Department of Community Health in East Lansing in a program called the Circle of Light.

The first step for this group, which advocates palliative or comfort care as a positive alternative

California gives dying patients pain relief

New law takes effect Jan. 1

Calif. Gov. Pete Wilson has signed a new law, A.B. 2693, exempting terminally ill patients from the state's triplicate prescribing system for Schedule II controlled substances such as opioids for pain relief.

The law, which takes effect Jan. 1, was sponsored by the California State Hospice Association (CSHA) in Sacramento and hailed as an important step in ongoing efforts to improve the undertreatment of pain. However, pain advocates now are challenged to get the word out about the new law to the state's medical community, CSHA reports.

Intent and effect differ

Triplicates are state-issued, serially numbered prescription forms to licensed physicians. One copy of each prescription is sent to the state Department of Justice in Sacramento. Although the intent of triplicates is to discourage inappropriate prescribing and diversion of controlled substances, they also have the effect of discouraging the legitimate use of narcotics for treating pain from serious illnesses such as cancer. Surveys have shown repeatedly that many physicians avoid prescribing triplicate-controlled drugs, often substituting less effective, nontriplicate drugs because of their concerns about regulatory scrutiny.

Terminal illness in the California law is defined in terms of suffering from an incurable, irreversible illness that, in the reasonable judgment of the prescribing physician, will bring about the patient's death within one year, if the illness takes its normal course.

In a related development, New Jersey's prescribing law was changed recently to permit doctors to call in orders for an emergency supply of pain medications for terminally ill patients, to prevent them from waiting for pain relief. ■

for the critically ill, is to educate health professionals about new developments in palliative medicine. The project also is distributing state-wide ads with information about advance planning, a toll-free number for the Michigan Circle of Life Information Center, material on hospice and related issues, and a CD-ROM with patient information on cancer pain management.

In a related development, a new survey published in the Oct. 1 *New England Journal Medicine*¹ indicates that slightly more than half of patients with Frederick's disease, ALS, agreed with this statement: "Under some circumstances, I would consider taking a prescription for a medicine whose sole purpose was to end my life." In fact, 44% said they would request such a prescription from their doctor if it were legal.

Reference

1. Ganzini L, Johnson WS, et al. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998; 339:967-73. ■

News From the End of Life

Advocacy group seeks consumers, organizations

Considerable interest in the end-of-life care community has been generated recently by the planned creation of a new consumer-based advocacy group, to be called Partnership for Caring. Under the leadership of Ira Byock, MD, founder of the Missoula, MT-based Demonstration Project and project director of the Princeton, NJ-based Robert Wood Johnson Foundation's Promoting Excellence in End of Life Care, and **Karen Kaplan**, executive director of Washington, DC-based Choice in Dying, this embryonic group is seeking other collaborating organizations and individual members.

A public launching of Partnership for Caring is expected sometime this fall. "Our goals are to bring about a consumer revolution, to raise consumer expectations, and to wage major educational, political, petition, and advertising campaigns to bring pressure to bear on the system to raise the amount and quality of end-of-life care," Kaplan explains. A

number of health-related national organizations already have expressed interest in collaborating, says Kaplan, adding that she hopes to attract several hundred thousand individual members.

An organization with a similar mission, Americans for Better Care of the Dying (ABCD), was created last December by **Joanne Lynn, MD**, founder of the Center to Improve Care of the Dying at George Washington University in Washington, DC. Although it publishes an in-depth newsletter and has been a focal point for key policy initiatives and advocacy, it hasn't made much of a splash as a consumer-driven organization.

Lynn says ABCD has signed up more than 400 individual members, significantly less than the target she set in announcing ABCD. "I'm not worried about only 400 members," she says. "That's 400 more than last year, and it's always very hard to build a membership organization or recruit a large public membership base."

What will make the partnership different from ABCD? "This is going to be a very powerful organization. Our goal is to be utterly inclusive," Kaplan responds. "We'll ask the members of our collaborating organizations to join up. It will be very high-visibility and inexpensive to join.

"People like to do things that make a difference, and I think there are a lot of people out there looking for an alternative to physician-assisted suicide."

Kaplan says she doesn't believe the partnership will need to take a position on the controversial physician-assisted suicide debate, since its efforts will be targeted at improving end-of-life care, thereby reducing the demand for assisted suicide.

She urges providers to watch out for this new organization, to join when it is launched this fall, and to call her [(202) 338-9790], if they have additional questions. ■



Seniors talk back about end-of-life care

Starting last month, seniors and others interested in end-of-life issues had the opportunity to participate in electronic, Internet-based democracy on a Solutions Forum on end-of-life care, hosted by SeniorNet in San Francisco.

SeniorNet, a 24,000-member nonprofit organization, also offers computer classes to help seniors become Internet-savvy in 140 learning centers across the country. Its Solutions Forum includes interactive on-line polls and discussion forums, which change weekly. Topics for the forums include an introduction to end-of-life care, physician-assisted suicide, quality of life, and prescriptions.

In the forum, Internet visitors can read the comments of others, respond to them, and post their own comments, says **Shawn Taylor Zelman**, account supervisor for the Vienna, VA, public relations firm Barksdale Ballard. "We're targeting any organization of seniors or end-of-life care. I'd also

urge your readers to participate, to get every aspect of the end of life into the discussion — what's out there, what's available, the challenges, how it plays out in different states."

For additional information on the end-of-life forum, contact Zelman at (703) 827-8771 or through e-mail at the following address: szelman@bballard.com. SeniorNet's Solutions Forum is sponsored by MetLife, and its Web address is: www.seniornet.org/solutions. ▼

Hospital bed rate decides where people die

By far, the number of hospital beds in a community is the strongest determinant in whether a terminally ill patient dies in the hospital or at home, according to a new study published in the October issue of the *Journal of the American Geriatrics Society*.

Analysis of the wide geographic disparities in end-of-life care challenges current assumptions about the choices patients might make if they were armed with better information. The assumptions are based on data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT),

a multisite study funded by the Robert Wood Johnson Foundation in Princeton, NJ, and the Dartmouth Atlas of Health Care, produced at the Dartmouth Medical School in Hanover, NH.

The study indicates that unless local health care resources and practice styles are adjusted to meet the needs of dying patients, their wishes likely will not prevail. More than 80% of SUPPORT patients said they would prefer to die at home, but 55% of them died in a hospital. Nationally, 39% of all deaths in 1992 and 1993 were in a hospital; but this rate varied from 22% in Portland, OR, and Ogden, UT, to 54% in Newark, NJ.

Medicare data suggest that a decrease of just one hospital bed per thousand population decreases the in-hospital death rate by 3.8%, while increased spending on hospice also corresponds with a lower rate of in-hospital deaths. ▼

Researchers isolate stem cells in lab

Organ transplantation, genetic therapies, and even the treatment of diabetes, paralysis, and AIDS could receive major advances in the future thanks to recent breakthroughs in research studies.

Human stem cells, the blank cells that can develop into virtually any kind of cell within the human body, have been successfully grown in the laboratory. Stem cells differ from other cells in that they have not yet gone through the differentiation process that makes them specific to certain functions, such as liver cells, skin cells, and brain cells.

Using stem cells for any purpose, however, is at least a decade in the future. That's because scientists still don't know how to customize the 'blank' stem cells and give them a specific function.

CME questions

1. Parkland Health System in Dallas, the public health system for the city, provides unbiased access to health care for the homeless community, according to Susan Spaulding, MD, by:
 - A. Creating the Homeless Outreach Medical Services program.
 - B. Opening small community-oriented primary care clinics.
 - C. Focusing on reducing hospital admissions.
 - D. All of the above.
2. The creation of the Health Care Center for the Homeless in Orlando, FL, through a cooperative agreement among three area hospitals, has helped homeless people, according to Paul McGlone, by:
 - A. Creating a primary care network for homeless patients.
 - B. Treating medical problems before they require a hospital admission.
 - C. Accepting hospital admissions when necessary on a rotating basis among the three participants.
 - D. All of the above.
3. The most common situation regarding discussion of end-of-life care among chronic obstructive pulmonary disease patients, according to Mark P. Pfeifer, MD, FACP, is:
 - A. At the time of hospital admission.
 - B. Discussions are left to the family because it wasn't discussed with the patient earlier.
 - C. When the patient is diagnosed.
 - D. Following the first acute exacerbation.
4. The best time to discuss end-of-life care issues with chronic obstructive pulmonary disease patients, according to Andrew G. Villanueva, MD, is:
 - A. When the patient is diagnosed.
 - B. During the first hospital inpatient stay.
 - C. When they are 'well,' possibly during a physical exam.
 - D. After the family is notified of the disease.

COMING IN FUTURE MONTHS

■ Do e-mail and Web pages maintain patient confidentiality?

■ The ins and outs of autopsy ethics

■ The ethical dilemmas of genetic testing for cancer

■ What to do when patients insist on being discharged

■ Biotech advances and commercialization of body tissue

Lead researchers James Thomson of the University of Wisconsin in Madison and John Gearhart of Johns Hopkins University in Baltimore say stem cells could be used in scenarios including the following:

- growing nerve cells to repair spinal injuries and restore function to paralyzed limbs;
- growing heart muscle cells to replace useless scar tissue following a heart attack;
- making brain cells that would secrete dopamine for the treatment and control of Parkinson's disease. ▼

Poor, African Americans treated differently

More research into treatment and survival differences between higher- and lower-income patients and nonminority and minority patients is needed.

That's the conclusion researchers recently announced after comparing medical records of more than 5,000 patients diagnosed with non-small-cell lung cancer between 1980 and 1982. Poor and African American patients with the diagnosis were less likely to receive aggressive treatment and more likely to die from the disease, compared with affluent or Caucasian patients.

The research was conducted by Howard P. Greenwald, MD, at the University of Southern California in Sacramento. Results were published in the November 1998 issue of the *American Journal of Public Health*.

Patients with incomes in the highest 10% were 45% more likely to have surgery and twice as likely to live another five years as those with incomes in the lowest 10%, researchers found. ▼

Noted researcher calls for surgery moratorium

The time has come to instate a general moratorium on genital surgeries and sex reassignments performed on intersex children — those who are born with ambiguous genitalia — without their consent.

That's what sex researcher **Milton Diamond** told members of the Elk Grove Village, IL-based

American Academy of Pediatrics at its annual meeting in San Francisco this past October.

A researcher at the University of Hawaii in Honolulu, Diamond told the physicians at the meeting that no studies have shown that "normalizing surgery" does more harm than good.

Lack of data a concern

He maintains that while the surgeries have been performed for more than 40 years, they remain experimental, and without data, it is impossible for parents to give informed consent on their children's behalf.

There also should be a concerted effort to undo the effects of past physician deception, Diamond says. Deception undermines relations of trust and confidence between patient and provider and conveys the clear message that intersexuality is "unspeakably shameful in the minds of parents and physicians," he adds. ■

Medical Ethics Advisor (ISSN 0886-0653) is published monthly by American Health Consultants[®], 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodical postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **Medical Ethics Advisor**, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

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

Subscription rates: U.S.A., one year (12 issues), \$379. Outside U.S., add \$30 per year, total prepaid in U.S. funds. One to nine additional copies, \$190 per year; 10 or more additional copies, \$114 per year. Call for more details. **Back issues**, when available, are \$33 each. (GST registration number R128870672.)

Photocopying: No part of this newsletter may be reproduced in any form or incorporated into any information retrieval system without the written permission of the copyright owner. For reprint permission, please contact Karen Wehye at American Health Consultants[®]. Address: P.O. Box 740056, Atlanta, GA 30374. Telephone: (404) 262-5491. World Wide Web: <http://www.ahcpub.com>.

American Health Consultants is accredited by the Accreditation Council for Continuing Medical Education to sponsor CME for physicians. American Health Consultants designates this continuing medical education activity for 15 credit hours in Category 1 of the Physicians Recognition Award of the American Medical Association.

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

Editorial Questions

Questions or comments? Call **Kevin New** at (404) 262-5467.

Publisher: **Brenda Mooney**, (404) 262-5403, (brenda.mooney@medec.com).

Managing Editor: **Kevin New**, (404) 262-5467, (kevin.new@medec.com)

Production Editor: **Terri McIntosh**.

Copyright © 1998 by American Health Consultants[®]. **Medical Ethics Advisor** is a trademark of American Health Consultants[®]. The trademark **Medical Ethics Advisor** is used herein under license. All rights reserved.



• **The Evolving Science of Bone Marrow Transplantation.** Jan. 25-27, 1999, Naples FL. Sponsored by United Resource Networks. Contact: United Resource Networks, a specialty care company affiliated with United HealthCare Corporation, MN010-S269, 6300 Olson Memorial Hwy., Minneapolis, MN 55427-4981. Telephone: (800) 847-2050.

• **Eighth Annual Meeting. Association for Practical and Professional Ethics.** Feb. 25-27, 1999, Washington, DC. Keynote address will be delivered by E.J. Dionne, a senior fellow at the Brookings Institute and a *Washington Post* columnist. The Fifth Intercollegiate Ethics Bowl will be held on Thursday, Feb. 25. Contact: Association for Practical and Professional Ethics, Indiana University, 618 E. Third St., Bloomington, IN 47405. Telephone: (812) 855-6450; Fax: (812) 855-3315.

E-mail: appe@indiana.edu. World Wide Web: <http://php.ucs.indiana.edu/~appe/home.html>.

• **Bioethics in the New Millennium.** Feb. 26-27, 1999. This first-ever international undergraduate bioethics conference is sponsored by the Bioethics Forum of Princeton (NJ) University. Sessions on Friday, Feb. 26 will be devoted to the topic "Genetic Engineering and Cloning"; Saturday, Feb. 27 will focus on "Bioethics and International Health." Contact: Bioethics Forum of Princeton University, Dod Hall, Princeton University, Princeton, NJ 08544. Telephone: (609) 258-8333.

E-mail: Kevin Scher at ksscher@princeton.edu. World Wide Web: www.princeton.edu/~bioethic.

• **Kennedy Institute of Ethics Advanced Bioethics Course "Issues in Ethics Committees."** March 5-7, 1999. Contact: Conference coordinator, Kennedy Institute of Ethics, Box 571212, Georgetown University, Washington, DC 20057. Telephone: (202) 687-5477. Fax: (202) 687-8089. E-mail: KICOURSE@gunet.georgetown.edu. World Wide Web: <http://guweb.georgetown.edu/kennedy>. ■

EDITORIAL ADVISORY BOARD

Consulting Editor: **Cindy Hylton Rushton**
DNSc, RN, FAAN
Clinical Nurse Specialist in Ethics
Johns Hopkins Childrens Center, Baltimore

John D. Banja, PhD
Associate Professor
Department of Rehabilitation
Medicine, Emory University
Atlanta

Ira M. Byock, MD
Research Professor
University of Montana
Principal Investigator
Missoula Demonstration
Project
Missoula, MT

Ronald E. Cranford, MD
Member
Hastings Center Advisory
Panel on Termination of
Life-Sustaining Treatment
and Care for the Dying
Associate Physician
in Neurology
Hennepin County
Medical Center
Minneapolis

Arthur R. Derse, MD, JD
Associate Director
Medical and Legal Affairs
Center for the Study
of Bioethics
Medical College of Wisconsin
Milwaukee

J. Vincent Guss Jr., MDiv
Chairman
Bioethics Committee
Association for
Professional Chaplains
Inova Alexandria Hospital
Alexandria, VA

Tracy E. Miller, JD
Visiting Scholar
Department of Health Policy
Mount Sinai School of
Medicine
New York City

Catherine P. Murphy
RN, EdD, MS
Associate Professor
Graduate Program in Nursing
Boston College
Consultant in Nursing Ethics
Boston

AHC On-line

Your One-Stop Resource on the Web

More than 60 titles available.
Visit our Web site for a complete listing.

1. Point your Web browser to:
<http://www.ahcpub.com/on-line.html>
2. Select the link for "AHC Online's Home page."
3. Click on "Sign On" at the bottom of the page.
4. Click on "Register now." (It costs nothing to register!)
5. Create your own user name and password.
6. Sign on.
7. Click on "Search" at the bottom of the page.
8. Perform a search and view the results.

If you had a subscription to a product, the price next to the search results for that product would say "FREE." Otherwise, the pay-per-view cost per article is displayed. To take a look at a sample article, click on "Content" at the bottom of the screen. Select Clinical Cardiology Alert, Archives, 1997, January 1, and the first article, "More Good News About Beta Blockers." We've made this article free so you can see some sample content. You can read it on-line or print it out on your laser printer.

Test Drive AHC On-line Today!