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INSIDE

Inserted in this issue:

■ Holistic care gains acceptance

■ Physician order form for life-sustaining treatment

NOVEMBER 1998

VOL. 14, NO. 11 (pages 121-132)

American Health Consultants® is A Medical Economics Company

Patient fear of managed care grows; who'll lead the way to harmony?

Committees need to redefine roles to become managed care maestros

(Editor's note: This is the last in a three-part series on ethics and managed care. Last month, Medical Ethics Advisor *examined building truthful and open relationships with managed care organizations. This month, we will focus on reaching contract agreements between hospitals and managed care organizations that benefit patients most.)*

Denied coverage. Physician deselection. Nondisclosure agreements. It seems the headline-grabbing cases involving patients who were denied treatment or — worse yet — died as a result of battles with managed care organizations (MCOs) are mounting these days. And because November is an election month, chances are that winners of local and federal races will report to their offices in January with renewed vigor to remedy current patient dissatisfaction with managed care.

Generally, Americans seem satisfied with their managed care plans. The dissatisfied minorities' horror stories, however, give most health care consumers cause to call on tougher government regulation of MCOs, including the power to sue a health care provider. An ABC News / *Washington Post* poll conducted last summer, for example, found 80% of MCO members satisfied with the quality of care provided through the MCO.

Executive Summary

Generally, Americans seem satisfied with their managed care plans, but headline-grabbing horror stories from a minority of patients are causing health care consumers to seek tougher government regulation of managed care organizations (MCOs).

- There is disagreement about who — providers, payers, or physicians — will take the lead in fixing the problem.
- Ethics committees should redefine their role within the hospital to accommodate a changing environment.
- One component to negotiating MCO contracts, experts suggest, is viewing patients as consumers.

CME questions

1. According to Steve O'Dell, vice president of Long Beach, CA-based First Consulting Group and chairman of the board of the Denver-based Rocky Mountain Center for Healthcare Ethics, physicians should be able to go to the hospital ethics committee to discuss:
   - **A.** Whether nurses should initiate advance directive conversations with patients.
   - **B.** Elements of managed care contracts they are considering signing.
   - **C.** Concerns over physician outcomes data and confidentiality.
   - **D.** All of the above.

2. According to John D. Banja, PhD, associate professor in the department of rehabilitation medicine at Emory University in Atlanta, informed consumers help hold managed care organizations accountable by:
   - **A.** Requesting annual financial audits.
   - **B.** Involving legislators in round-table discussions.
   - **C.** Asking for disclosures for agreements.
   - **D.** Creating self-regulatory boards.

3. To avoid high-profile attention to private medical decisions, ethics committees have a responsibility, according to John M. Stanley, professor of religious studies and the Edward F. Mielke professor of ethics in medicine, science, and society at Lawrence University in Appleton, WI, to do the following:
   - **A.** Consult with risk managers to determine the best possible course of action.
   - **B.** Work with patients and families to attempt to help resolve such disputes before they reach crisis proportions.
   - **C.** Hold a press conference with the media.
   - **D.** All of the above.

4. A recent study incorporating use of a form indicating life-sustaining treatment options is gaining favor among Oregon health care providers, according to Susan Tolle, MD. Results included:
   - **A.** Hospice staff recommended changes to the form.
   - **B.** More education was needed among hospital staff.
   - **C.** The form was being followed by emergency personnel, hospital staff, physicians, long-term care staff, and hospice staff.
   - **D.** All of the above.

There's no doubt that physician and patient advocacy groups alike are turning up the heat for legislators to enact stricter laws on what MCOs can and cannot do for plan members. But what happened to the health care delivery system in the United States to arrive at such a critical mass in the first place? Consider the following instances resulting in increased frustration with today's health care delivery system:

• A majority (53%) of Americans think veterinarians spend more time with animals than MCO physicians do with patients, according to a survey conducted by Washington, DC-based Luntz Research Companies.

• Of the 850 people polled, 60% expressed little or no confidence that their MCO would provide the best medical care available for them or a family member.

• Only 28% said legislation would improve the health care system, while 60% said personal initiative by patients was more effective.

Perhaps more important, say experts on both sides of the debate, is whether or not anything can be done to remedy the situation.

"Absolutely," says **Steve O'Dell**, vice president of Long Beach, CA-based First Consulting Group. O'Dell also is chairman of the board of the Rocky Mountain Center for Healthcare Ethics in Denver. He previously worked for MCOs, including as chief executive officer of PacifiCare's Colorado region. **(For information on the Rocky Mountain Center's Code of Ethics, see *Medical Ethics Advisor*, October 1998, p. 112.)**

Lots of followers, but no leaders

There still is disagreement, however, on who — providers, payers, or physicians — will take the lead in fixing the problem. "There will be a radical change in the health care system within the next two to five years," O'Dell predicts. "I think [members of] hospital ethics committees will have to look at themselves differently as a result of the changes and determine how broadly it defines itself."

For a more effective ethics committee, he suggests, hospitals should allow the committee to deal with issues such as a physician who is unhappy with an MCO contract he is considering signing. "The physician should be able to go to the group and ask if there is an ethical problem with the contract. The group should then tell the physician that it's not appropriate to complain or 'vent' to the patients about the contract.

Individual patients shouldn't be subjected to the limits of his or her contract. The patient should be encouraged to go directly to the ethics committee with any concerns. I think a committee would be stunned if that were to happen now," he adds.

To reach a point where that occurs, O'Dell says, might require an ethics committee to revise its charter. "This hasn't been the typical definition of the role of the ethics committee, but if hospitals are involved in MCO contracts, then the ethics committee should be authorized to deal with issues that concern the MCO." **(For more suggestions for ethics committees, see story, below right.)**

Current system won't last

The current managed care system — while inevitable — will not last, agrees **Arnold Relman**, MD, professor of medicine and social medicine at Harvard Medical School in Cambridge, MA. During a recent summit on health care reform sponsored by the Illinois Ad Hoc Committee to Defend Health Care in Chicago, Relman asked who will do the managing and who ultimately will benefit from changes.

One thing Relman is certain of, however, is that physicians will be a critical component of creating change. Relman supports a plan involving the public and private sector working together to create a not-for-profit system. Caregivers would receive support, he says, through local, nonprofit medical institutions and state and federal government assistance.

One component of negotiating MCO contracts that benefit patients optimally is viewing patients as consumers, experts say. "The question for ethics committees is, 'How do we, in every component of health care delivery, build the confidence and trust back for the patients?' And that shouldn't be done through a procedural mentality, but [by looking] at how to address the patient's problems. Give consumers the belief that they have made a difference in the way health care is delivered," notes O'Dell.

"As health care continues to evolve into a marketplace where consumers are the driving force, it only makes sense for them to be informed," adds **John D. Banja**, PhD, associate professor in the department of rehabilitation medicine at Emory University in Atlanta. Plus, informed consumers help hold MCOs accountable by asking for disclosures, such as what prescriptions are included in the drug formulary, he adds.

Changing the health care delivery system doesn't completely fall in the lap of the hospital, either, O'Dell says. "The hospital doesn't have to smooth over the problems patients have with their MCO. Instead, give the patient the information to solve the problem. Refer them to the MCO ethics committee. Tell them to inquire about the MCO's grievance procedure."

"The ethics committee needs to help patients take on the role of consumer. They don't know how to do that in health care because we haven't given them the information to be empowered consumers," he explains.

The ethics committee should expand its scope, advises O'Dell. "Traditionally, the ethics committee has dealt with individual patient problems, but that should be expanded. The committee needs to move from being a compliance-based, tradition driven function to an integrity-based, consumer driven group."

Ultimately, how a hospital responds to the challenges and changes from managed care depends on whether the ethics committee is prepared, says O'Dell. "It all depends on which scenario the ethics committee would rather be in: responding when patients come pounding the door down or waiting for them with an open door." ■

Jump out of the box

Steps to success for your committee

Public perception about managed care plans is changing, and ethics committees can either sit on the sidelines and wait to see what develops or play an expanded role in helping shape the future of health care delivery.

That's how **Steve O'Dell** views the public's criticism of managed care organizations (MCOs) and the role hospital ethics committees can play in the changing field of health care. O'Dell is vice president of Long Beach, CA-based First Consulting Group's Denver office and serves as chairman of the board of Denver's Rocky Mountain Center for Healthcare Ethics.

He suggests ethics committees follow these steps to expand their roles with managed care organizations:

1. **Review the organization's code of ethics.**

O'Dell recommends that hospital committees obtain a copy of the Rocky Mountain Center's

Colorado Code of Ethics for Healthcare and conduct a comprehensive discussion. **(For information on the ethics code and how to order a copy, see *Medical Ethics Advisor,* October 1998, p. 112.)** "The committee needs to look at the document's seven principles and ask, 'Are we going to take this on?' A fruitful discussion should occur, even if the committee decides not to do anything."

2. Determine if charter should be revised.

The ethics committee then should determine whether its charter should be expanded to accommodate a wider role in the health care delivery system, he suggests. "That needs to be put on the table as the central question. The committee then needs to determine if it does expand the charter, what should it include, or why it shouldn't expand the charter," O'Dell advises.

The committee should not be limited by risk management and compliance issues, either, he warns. "The hospital's attorney will say that changing the charter opens the hospital up to more liability, but that's the mentality that's kept health care locked in for the last 25 years," he explains.

"We're attempting to change health care delivery in Colorado and make it a consumer process. Part of that is bringing the issue of ethics out of the darkened back room and having open discussions with all concerned parties. It's ironic that health care is driven by other professionals, such as attorneys, and not consumers," O'Dell says.

3. Redefine what ethics is.

The issue of ethics is not easy to talk about within an organization, and that's especially true in the field of health care, O'Dell says. "Once you start talking about what you consider unethical and ethical, the leadership or administration starts to worry that they may be held to those standards, and that's not always a comfortable feeling," he adds.

The old definition of ethics relating to just one patient and one physician no longer works, he says.

"Maybe we haven't quite reached what the new definition is yet, but getting the discussion started is the first step," O'Dell explains. "The demands from consumers and managed care require that resources be allocated and delivered to groups rather than individuals." ■

Family, caregiver support needed to end treatment

Tough decisions devastate everyone involved

Few instances are more heartbreaking than the decision to halt medical treatment for a family member whose chances of recovery have been deemed slim or nonexistent. And when there is disagreement among the patient's relatives about when to stop the life-sustaining care, the results are especially devastating for everyone involved, including the ethics committee that has to recommend a solution to the perplexing problem.

Last month, Virginia resident Michele Finn fought a legal battle with her family over her decision (supported by state law) to remove the feeding tube from her husband, Hugh Finn, who had been left in a persistent vegetative state following a car accident 3½ years ago.

Declared her husband's legal guardian, she stated that he had once told her he would never want to live in such a condition. Virginia law allows a guardian to end life-sustaining treatment if they make a good-faith effort to determine the patient's medical needs. Finn's doctors had said he had little to no chance of recovery.

However, by the time a judge finally ruled in her favor on Oct. 1, the governor, a state lawmaker, and local, state, and national media had inserted themselves into what is normally an extremely personal and private decision.

So how can ethics committees learn from such a high-profile scenario as this? It might be a good idea to review existing policies and procedures. Additionally, educate staff and family members about clinical definitions, say sources who spoke with *Medical Ethics Advisor*.

The caretaker's role

Health care providers who work with patients and families in such situations have a responsibility to attempt to help resolve such disputes before they reach a crisis of these proportions, says **John M. Stanley,** professor of religious studies and the Edward F. Mielke professor of ethics in medicine, science, and society at Lawrence University in Appleton, WI.

Since 1987, Stanley has convened three meetings of the Appleton Consensus Project, an international conference of leading doctors and ethicists

from 15 countries working to establish guidelines for the ethical removal of life-sustaining treatment in near-death patients. Their guidelines were published in 1992 in the *Journal of Medical Ethics.*

"How this got to the governor, I can't even imagine," Stanley says. "What should happen [in situations like this] is that the caretakers should put the intervening family together with the wife in a situation where they supported some kind of open discussion — often the best site is an ethics committee, but it can be as simple as a case conference with just the family, doctors, and a social worker. Put them together and give them a chance to say all the things that, if they don't get a chance to say, will come out in some kind of public or official statement where they try to intervene."

Additionally, caretakers always should side with the relative who is closest to the patient and most likely to be aware of the patient's wishes, Stanley adds.

"Especially if the person had a conversation with the patient about how he or she would want to die. That person should be listened to, whoever they are," he says, noting that, in the Finn case, that would have been his wife.

Dennis Brodeur, PhD, senior vice president of Stewardship for SSM Health Care System in St. Louis and an internationally recognized health care ethics consultant, agrees. "I would look to those relationships — here, his wife — who are very clearly speaking for his interests," he says. "I believe we have obligations to the patient and whatever known patient wishes are there, regardless of what legal instrumentation is in effect, one way or the other."

Providing support crucial

While the primary physician is mostly concerned with treating the patient and giving information to the immediate family, other providers at the hospital or treatment facility, such as nurses, pastoral counselors, and social workers, can provide a network of support for these families in crisis.

"The fact is, we have a lot of available resources to deal with these issues," Brodeur contends. "I think it is incumbent on the hospital or other institution to find some group of people that come out of either pastoral services, behavioral medicine, social work, case managers, or perhaps a clergy person that is closely aligned with the faith experience of that family. Whoever that is, the institution needs to find some resources to begin to mediate the conflicts."

At his institution, the clinicians treating the patient might notice a crisis developing among family members, he explains. That information can be given to professionals in the social work, pastoral care, or behavioral medicine section. "If I were the case manager in that setting, I'd have a call into the social service department or the pastoral care department and say, 'We've got a family in crisis here. Can we begin some sort of intervention to help them work through these issues?'"

The support needs to go beyond recommending the resources to the family, he says. "You need to actually have someone go down to talk to them. The case manager could say, 'They tend to gather Saturday afternoons at two o'clock; that would be a good time to go down and meet them all. Or, 'The conflict is felt most strongly by the patient's wife; she's here every night from six to eight.'"

The consultant should make the first contact, allowing the family to accept or reject his or her efforts, Brodeur says. "They can rebuff us, but at least we have made the attempt."

Educate families on medical condition

The medical community at large needs to do more to correct misconceptions about patients in persistent vegetative states, comas, and those who have been declared "brain dead," say both Stanley and Brodeur.

Each of those terms has a specific clinical definition, but each often is misused by some health care professionals and the public. "There are very clear, clinical definitions out there, but they are not always used by people very clearly," Brodeur says. "When I hear someone say 'persistent vegetative state,' I assume they are talking about this [condition] as it has been neurologically defined and published, but that is not always the case."

The clinical definition of persistent vegetative state involves set levels of brain function that are measured with EEG, he adds.

The established standard of care for a patient diagnosed as being in persistent vegetative state allows for the removal of life-sustaining treatment after three months in most cases, Stanley notes. This published standard has been incorporated into the Appleton project guidelines and is the accepted standard of care around the world.

Certainly after 3½ years, a neurologist would be able to make a reasonable determination that

the patient's condition was irreversible, Stanley says. "That is not esoteric information; it is available to doctors in every state," he says emphatically. "I would think that if someone had gotten that information to the governor, even if he had been asked to intervene, he would have refused to."

Selected reading

• The Appleton International Conference. Developing guidelines for decisions to forgo life-prolonging medical treatment. *J Med Ethics* 1992; 18:Supp,3-22.

• GRUIC (Guidelines for the Responsible Utilization of Intensive Care) Project. *Guidelines for the Responsible Utilization of Intensive Care: How Long is Long Enough? Neonatal, Adult, Long-Term*. Lawrence University, Appleton, WI; 1998.

Sources

For more information on withdrawing life support, contact:

- **Dennis Brodeur**, PhD, Senior Vice President-Stewardship, SSM Health Care System, 477 N. Lindbergh Blvd., St. Louis, MO 63141.
- **John M. Stanley**, Lawrence University, Office of Public Affairs, P.O. Box 599, Appleton, WI 54912-0599.

• Stanley JM. Medical ethics — when to stop treatment. *J Med Ethics* 1995; 238:551-558.

• Cranford RE. The vegetative and minimally conscious states: ethical implications. *Geriatrics* 1998; 53:S70-73.

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Hyde-Nickles bill poses threat to pain relief

Groups mobilize against it

Federal anti-assisted suicide legislation, described by pain management advocates as "dangerously misguided" for the chilling effect it would have on the prescribing of controlled substances for terminally ill patients' pain, it was on a fast track in Congress this year, but it was withdrawn during the last week of the session.

Don't breathe a sigh of relief just yet, though. Sen. Don Nickles (R-OK), a cosponsor of the bill, has promised constituents that he'll revive the legislation again next year.

The Lethal Drug Abuse and Prevention Act, H.R. 4006/S. 2151, was introduced in Congress this summer by Rep. Henry Hyde (R-IL) and Nickles. It would create a medical review board within the federal Drug Enforcement Agency (DEA), authorized to investigate, prosecute, and revoke the DEA registrations of any physician or pharmacist who "intentionally dispensed or distributed a controlled substance with a purpose of causing or assisting in causing" a suicide.

Oregon is the only state where assisted suicide is legal, but the issue has surfaced in legislative and ballot initiatives elsewhere, including Michigan and Hawaii. Voters in Michigan, for example, will decide whether to allow assisted suicide on the November ballot through a referendum.

The bill "was definitely on a fast track. We knew it would go to the House floor in [early fall], having passed out of the House Judiciary Committee on a vote reflecting party lines," says **John Giglio**, director of public policy and general counsel for the National Hospice Organization (NHO) in Arlington, VA. The NHO sent urgent fax memos to its members, urging them to "respond in force" by contacting their congressional representatives regarding the dangers of this bill.

While the bill enjoys powerful supporters in Congress, as well as the full lobbying force of the National Right-to-Life Committee of Washington, DC, it is opposed by a long list of health- and pain-related organizations. Some of these opponents, such as the NHO and the American Medical Association (AMA) in Chicago, have a long history of opposition to assisted suicide.

Other opponents include the American Academy of Hospice and Palliative Medicine in Alexandria, VA, the Hospice and Palliative Nurses Association in Pittsburgh, the Hospice Association of America in Washington, DC, and other national advocacy groups. The NHO organized a coalition of groups opposing the bill and held an informational luncheon for legislative aides in August.

The AMA, the largest of these groups, reiterated its staunch opposition to assisted suicide, while opposing this particular method of blocking its legalization. "We'd do anything to avoid the intrusion of the federal government into physicians' offices," says AMA chairman **Thomas Reardon**, MD. "If the issue for Congress is physician-assisted suicide, why not just be clear with it? Why create this new oversight by the Justice

Department, second-guessing physicians." But when asked if the AMA plans a concerted, all-out effort to defeat the Hyde-Nickles bill, Reardon replies, "We've made our feelings known. It's an important issue for us. It does put us in an awkward situation, to oppose assisted suicide and this bill, but we think the bill is wrong."

Pain management advocates, such as **June Dahl**, PhD, professor of pharmacology at the University of Wisconsin in Madison, complain that members of Congress appear to have little interest in advocates' fears about the bill's threat to pain management. "It's very difficult for others to appreciate the level of paranoia doctors have about state medical boards and the DEA. These fears are not based in reality, but that doesn't make their fears any less persuasive," Dahl says. "Ironically, the drugs likely to be used for physician-assisted suicide wouldn't be controlled under this ill-conceived legislation."

"The kinds of ways it risks delaying improvements in end-of-life pain control are likely to be much more subtle than just DEA investigations of doctors," says **Joanne Lynn**, MD, director of

> **"It's very difficult for others to appreciate the level of paranoia doctors have about state medical boards and the DEA."**

Americans for Better Care of the Dying (ABCD) and the Center to Improve Care of the Dying in Washington, DC. However, being targets of such an investigation will change physicians' prescribing forever after — even if they are exonerated, Lynn adds. Although the issue may be settled by the time this newsletter is published, Lynn urges ethics committees to watch ABCD's Web site for updated information (www.abcd-caring.com).

Thanks in part to the attention to end-of-life issues generated by the assisted suicide debate in Oregon, that state now has the highest per capita rate of prescribing morphine for pain management. However, asserts **Ann Jackson**, executive director of the Portland-based Oregon Hospice Association, "If things are so good here regarding pain management, then the rest of the country is truly in trouble. We aren't doing anywhere close to what we should be doing in this area," she says.

"We have struggled with the issue of physicians who just plain don't want to prescribe [opioid] pain medications for their patients. I have attended pain and symptom management task force meetings, and a number of public hearings have underscored the barriers in this area. It is the fear of the medical board and of DEA scrutiny that keeps physicians from prescribing adequately. The effects of the Hyde-Nickles bill on physicians would be devastating, even if they are inadvertent," Jackson says. **(For more information on what's happening in Oregon, see story, below.)**

Medical Ethics Advisor will continue to follow the legislation in the next session of Congress. ■

Put it in pink if you want it to be followed

Form helps patients avoid unwanted treatments

In Oregon, a specially designed bright pink form has proven effective in ensuring the communication of and health care professionals' adherence to dying patients' wishes regarding medical treatment.

First conceived as a device that would enable emergency medical service (EMS) first responders to accommodate a patient's desire to avoid resuscitative efforts, the Physician Orders for Life-Sustaining Treatment (POLST) has become a document that enables patients and their physicians to dictate specifically the care the patient will receive — for example, allowing comfort measures but not life-prolonging ones.

"POLST has become not just about what the patient does not want done, but has become more focused on comfort issues, ensuring that the patient's needs in that area are addressed and we don't just leave them hanging," says **Susan Tolle,** MD**,** director of the Center for Ethics in Health Care at Oregon Health Sciences University in Portland, which administers the POLST program.

The form, signed by a physician and indicating what types of medical interventions are allowed and disallowed, is placed in the patient's chart. This form is recognized by EMS providers, physicians, hospitals, and hospice workers in every region of the state, Tolle says.

A recent study of the POLST document's effectiveness, published in September's *Journal of the American Geriatrics Society*, found that of 180 nursing home patients who had marked "Do Not Resuscitate" or "Transfer for Comfort Measures

Only" on the form, none received cardiopulmonary resuscitation, intensive care unit admission, or ventilator support.[1]

"That shows that the form was not lost, overlooked, or ignored," Tolle explains. "That was what we were hoping to find."

The document had its genesis in 1990 at a statewide meeting of health care professionals gathered to address ethical concerns in medicine, says **Patrick M. Dunn**, MD, senior scholar at the Center for Ethics in Health Care and chairman of the POLST task force.

"At one of the meetings here in Portland, individuals from long-term care facilities presented the case of a man who was transferred from long-term care to a hospital for medical interventions that ended up, in retrospect, to be against the patient's wishes," he explains. "This happened even though the patient had an advance directive."

The case resonated with many of the providers at the meeting, Dunn adds. "They were saying, 'Yeah, yeah, this is a problem for us. We receive these patients that have wishes that aren't written down accurately.'"

Form isn't just for directives

The coalition formed a task force of five working groups in Oregon to develop a form for documentation of a patient's wishes that would be recognized and honored across different treatment settings. The distinction between the form it developed and an advance directive is an important one, Dunn says. "Advance directives are a method by which the patient can express their values and write them down for all to see. The POLST form is a set of physician orders that take the patient values and match them with medical indications for specific life-sustaining treatments. They kind of merge those indications and treatments together to embody the patient's wishes."

EMS, for example, cannot act on an advance directive, Dunn says. In many cases in the past, EMS providers would respond to a call and begin the intervention called for in the protocol. At the same time, they would try to contact the patient's attending physician or the physician supervisor for their cachement area of EMS for instructions on how to implement the advance directive, he explains. "The POLST gives that in advance."

The current POLST form is two-sided and hot pink. On the front, there are five sections labeled A, B, C, D, and E. **(See form, inserted in this issue.)** The first four sections cover different treatment categories: resuscitation, medical interventions, antibiotics, and artificially administered fluids and nutrition.

In each category, the medical indications for each treatment and which treatments are allowed are detailed. The last section, E, lists who the physician obtained the directive from (such as the patient, a health care representative, court-appointed guardian, spouse) and what the basis

What's happening with Oregon law?

As the assisted-suicide debate reached a boiling point in Washington, DC, tentative information began to emerge in Oregon about the realities of assisted suicide under that state's 1994 Death with Dignity Act, which finally went into effect last November.

In mid-August, officials of the Oregon Department of Human Resources in Portland announced that the deaths of 10 terminally ill patients who obtained prescriptions for lethal medications under the provisions of the act had been reported to the state by their physicians.

Eight of the 10 died after taking the lethal medication, while two didn't take the medication and died from complications of their illness, reports state medical epidemiologist **Katrina Hedberg**, MD. All 10 cases showed full compliance with the law, including obtaining a second medical opinion, obeying a 15-day waiting period, seeking a determination of their terminal illness, and demonstrating competence to make the decision.

The small reporting sample showed an average age of 71 years, and all but one of the patients had cancer. The length of time between obtaining the lethal prescription and death ranged from the same day to 16 days, with an average of two days. While concerns have been raised about the effectiveness of medications used for assisted suicide, in the eight reported cases, patients died within seven hours of taking the medication, on the average within 40 minutes.

The state plans to conduct in-depth interviews with the physicians of all patients who obtain lethal medications under the Death with Dignity Act, for inclusion in a report on the act, to be issued in early 1999. Meanwhile, Oregon's U.S. Sen. Ron Wyden has issued a call to create a bipartisan working group of health professionals and key legislators to determine what federal policy should be concerning end-of-life care and how options for those nearing the end of life might be improved. ■

for the orders is. The back of the form, sections F and G, outlines procedures for changing the form and directs providers to any sources of additional information such as an advance directive or court-appointed guardian.

The form has undergone several changes, Dunn says. "Initially, it was called the Medical Treatment Cover Sheet. At first, it initially contained standards regarding cardiopulmonary resuscitation. As we learned from our EMS colleagues, the issues are really more complicated than that. . . . a simple DNR order, as clean as it may be, doesn't address the majority of circumstances they respond to."

Since the form has expanded to cover many different treatment options and situations, its benefits have extended beyond what its developers had envisioned. "If I am covering for one of my colleagues, and I get called to a nursing home about a patient who has a POLST form indicating their wishes with respect to different kinds of treatment, then that can be very helpful to me," Dunn explains.

Supportive environment necessary

The POLST form is designed to function in Oregon's "climate," Tolle adds. "I don't think that you can just take this form and drop it into any situation in any state."

As the task force developed the form, it conducted a coordinated education effort, particularly among emergency medical providers, she emphasizes. "We wanted them to know what the form was, what it looked like. We didn't want to have the form, then have them see it later and wonder, 'What is this?'"

Oregon also is unique in that its citizens have ready access to well-coordinated hospice care, and state laws are conducive to allowing patients to refuse medical treatment, she says. "This is one of the few places where, if someone needs a hospital bed in the home, I can make a call and get it there by sundown," Tolle says.

This support for medical care, particularly end-of-life care, outside the hospital setting, enables POLST to work so well, she adds.

That's not to say that some far-reaching changes did not have to be made in the process of implementing the program, Dunn says. "We had to go to the board of medical examiners who make the administrative rules of practice for first responders," he explains. "We had to work with them to adjust the scope of practice regulations, to ensure that EMS would be obliged to honor valid orders, either on a POLST or like document."

At the Center for Ethics, they refer to the POLST "program" rather than the POLST "form" because the document is in a continual evaluation process. Designated resource consultants who have been specially trained are located at medical centers across the state. Over the course of about six months, they collect information on the use of the document in their area.

That information is sent to the Center for Ethics and then presented to the task force, which continues to meet on a semi-annual basis. "Key issues are collected, and when we meet, we take up those issues," Dunn says. "We have this constant feedback regarding the form."

For example, providers in the southern part of the state expressed a desire to develop a brochure for the layperson explaining what the form was. "Of course, the form is directed toward the health care professional, specifically physicians, but there are now laypeople in the state who know about the form and have specific wishes that they want to ensure," he says.

The brochure will provide information but direct the patient back to their physicians and indicate how those physicians can obtain the POLST document, he explains.

The group also has become aware of the need for a similar document for pediatric patients. "There is a need in schools and other facilities to have a similar type of form for kids who are particularly ill and have a terminal condition," Dunn says. "There is a group that has been working independently, and as part of a collaborative effort we have invited them to sit down with the task force to see how to use some of our experience to develop a similar instrument for that population."

Although they emphasize that the form is designed for use only in Oregon, the center is

Sources

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- **Patrick M. Dunn**, MD, Legacy Good Samaritan Hospital, 1040 NW 22nd Ave., Portland, OR 97210.
- **Susan Tolle**, MD, Center for Ethics in Health Care at Oregon Health Sciences University. 3181 W. Sam Jackson Park Road, L101, Portland, OR 97201-3098. Phone: (503) 494-4466. Or call Terri Schmidt, MD, assistant director, at (503) 494-7500.

making copies and supporting information available to other health care providers who are interested in designing their own program.

Reference

1. Tolle SW, Tilden VP, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Ger Soc* 1998; 46:1,097-1,102.

Selected reading

• Dunn PM, Schmidt TA, Carley MM, et al. A method to communicate patient preferences about medically indicated life-sustaining treatment in the out-of-hospital setting. *J Am Ger Soc* 1996; 44:785-791. ■

Feds finish human genetics map early

Imagine a federally funded project actually being completed ahead of schedule. That's exactly what officials of the Human Genome Project announced in mid September. A joint effort of the National Human Genome Research Institute and the National Institutes of Health in Bethesda, MD, and the U.S. Department of Energy in Washington, DC, the project was started in 1990.

Scientists mapping the 3 billion units of DNA that make up the human body's genome say the project will be completed by the end of 2003, two years early. What's more, they plan to have a third of the genome sequenced — a process to determine the order of units of genetic information that make up the body's genetic plan — by 2001. A "working draft" of most of the remaining genome, researchers say, will be completed by 2001 as well.

A competitor, however, promises to map the entire genome first. J. Craig Venter, MD, co-founder and director of Rockville, MD-based Celera Genomics announced recently the private firm would complete the job by 2001. Celera is using a different sequencing technique than that of the National Human Genome Research Institute. ▼

Group says shared-risk agreements are ethical

The ethics committee of the Birmingham, AL-based American Society for Reproductive Medicine (ASRM) concluded in September that shared-risk programs are ethical for some patients undergoing in vitro fertilization (IVF).

The group endorses the agreements provided certain conditions are met. In shared-risk agreements, patients initially pay higher fees for IVF. If a pregnancy or delivery is achieved, the physician keeps the entire fee. If the attempt at IVF is unsuccessful, however, the patient receives a monetary refund ranging from 90% to 100%.

Shared-risk is criticized as being potentially exploitative and misleading by some physician organizations, including the American Medical Association (AMA) in Chicago. The AMA Code of Ethics has a statement against the plans because they are contrary to the tradition in medicine against paying contingency fees. Plus, critics say, the plans are offered to a vulnerable patient group at a higher cost than normal IVF services.

The agreements, the ASRM committee suggests, are ethical options for patients who might not have health insurance that covers infertility treatments, provided that practitioners fully inform patients of expenses not covered in the shared-risk program, such as pre-treatment testing, consultation fees, and ovulation drugs.

COMING IN FUTURE MONTHS

- The ins and outs of autopsy ethics
- What to do when DNR patients change their minds
- Is genetic therapy on fetuses ethical?
- Improving physician compliance with DNR guidelines
- Legislative recap of medical ethics issues

ASRM's committee also warned against shared-risk programs involving actions that might harm patients and any resulting fetuses. Patients and fetuses might be adversely affected, for example, from implanting multiple embryos to increase the chance for success. Patients should be informed about the potential conflict of interest, the committee stated. ▼

Many fear no privacy after genetic testing

Advances in genetic testing sound like a good idea for most consumers, but the availability of such tests is creating an overwhelming sense of anxiety. A recent survey of New York state residents found that 90% worry that genetic test results could be divulged to outside parties, such as employers and health insurance companies.

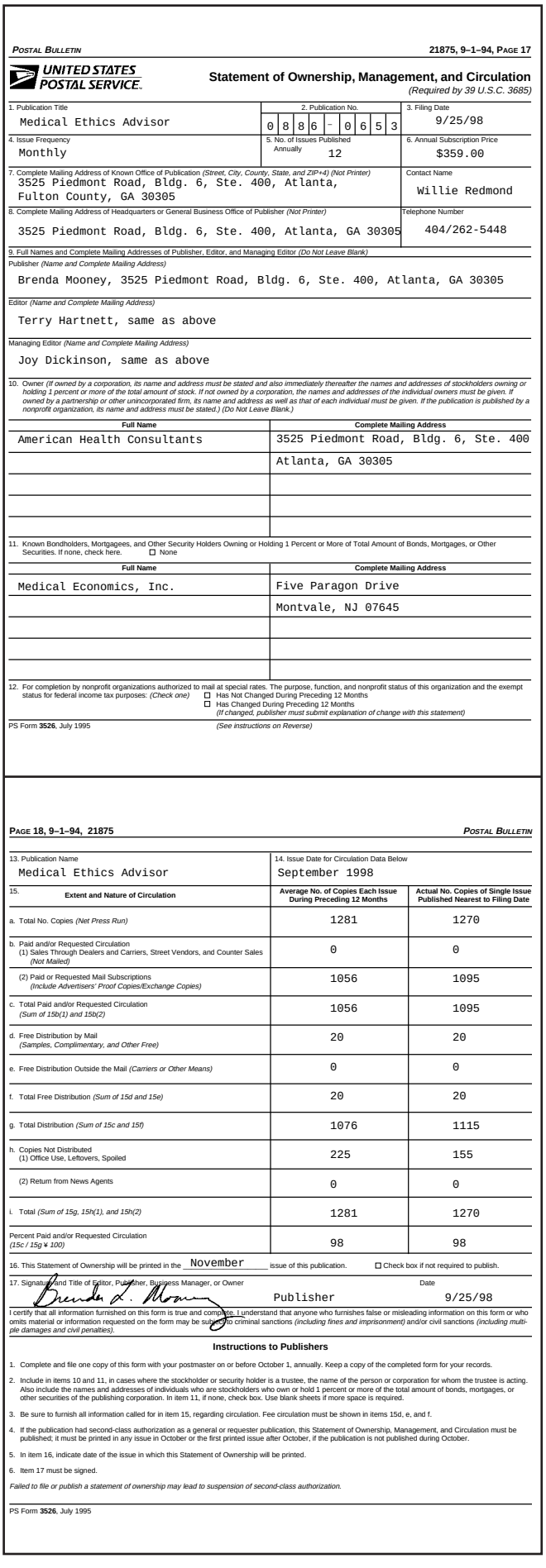
A vast majority, however, said they would undergo tests to determine their risk of disease. For example, 69% reported they would take a test to determine their risk of treatable diseases such as cancer and heart disease. A smaller group (59% of those surveyed) said they would undergo a test for diseases with no effective treatment, such as Alzheimer's disease.

A loss of medical insurance based on the results of genetic testing still is a possibility for some people, says **Francis Collins**, MD, director for the Human Genome Project in Bethesda, MD. While announcing the early completion of the Human Genome Project, Collins called for the need for federal legislation to prevent such scenarios from happening. ▼

Congress fails to create patients' bill of rights

Congress failed to pass new laws to relieve frustrations with health plans despite growing sentiment from American consumers.

Democrats helped push President Clinton's Patient Bill of Rights to the floor for debate, while the Republicans crafted and passed a counterproposal earlier this summer. The Senate could not reach a compromise on the rival versions of the bill, and neither party had the necessary votes to



POSTAL BULLETIN 21875, 9–1–94, PAGE 17

UNITED STATES POSTAL SERVICE

Statement of Ownership, Management, and Circulation
(Required by 39 U.S.C. 3685)

1. Publication Title	2. Publication No.	3. Filing Date
Medical Ethics Advisor	0886-0653	9/25/98
4. Issue Frequency	5. No. of Issues Published Annually	6. Annual Subscription Price
Monthly	12	$359.00

7. Complete Mailing Address of Known Office of Publication *(Street, City, County, State, and ZIP+4) (Not Printer)*: 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, Fulton County, GA 30305 — Contact Name: Willie Redmond

8. Complete Mailing Address of Headquarters or General Business Office of Publisher *(Not Printer)*: 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305 — Telephone Number: 404/262-5448

9. Full Names and Complete Mailing Addresses of Publisher, Editor, and Managing Editor *(Do Not Leave Blank)*

Publisher *(Name and Complete Mailing Address)*: Brenda Mooney, 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305

Editor *(Name and Complete Mailing Address)*: Terry Hartnett, same as above

Managing Editor *(Name and Complete Mailing Address)*: Joy Dickinson, same as above

10. Owner *(If owned by a corporation, its name and address must be stated and also immediately thereafter the names and addresses of stockholders owning or holding 1 percent or more of the total amount of stock. If not owned by a corporation, the names and addresses of the individual owners must be given. If owned by a partnership or other unincorporated firm, its name and address as well as that of each individual must be given. If the publication is published by a nonprofit organization, its name and address must be stated.) (Do Not Leave Blank.)*

Full Name	Complete Mailing Address
American Health Consultants	3525 Piedmont Road, Bldg. 6, Ste. 400
	Atlanta, GA 30305

11. Known Bondholders, Mortgagees, and Other Security Holders Owning or Holding 1 Percent or More of Total Amount of Bonds, Mortgages, or Other Securities. If none, check here. ☐ None

Full Name	Complete Mailing Address
Medical Economics, Inc.	Five Paragon Drive
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12. For completion by nonprofit organizations authorized to mail at special rates. The purpose, function, and nonprofit status of this organization and the exempt status for federal income tax purposes: *(Check one)* ☐ Has Not Changed During Preceding 12 Months ☐ Has Changed During Preceding 12 Months *(If changed, publisher must submit explanation of change with this statement)*

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PAGE 18, 9–1–94, 21875 POSTAL BULLETIN

13. Publication Name	14. Issue Date for Circulation Data Below
Medical Ethics Advisor	September 1998

15. Extent and Nature of Circulation	Average No. of Copies Each Issue During Preceding 12 Months	Actual No. Copies of Single Issue Published Nearest to Filing Date
a. Total No. Copies *(Net Press Run)*	1281	1270
b. Paid and/or Requested Circulation (1) Sales Through Dealers and Carriers, Street Vendors, and Counter Sales *(Not Mailed)*	0	0
(2) Paid or Requested Mail Subscriptions *(Include Advertisers' Proof Copies/Exchange Copies)*	1056	1095
c. Total Paid and/or Requested Circulation *(Sum of 15b(1) and 15b(2)*	1056	1095
d. Free Distribution by Mail *(Samples, Complimentary, and Other Free)*	20	20
e. Free Distribution Outside the Mail *(Carriers or Other Means)*	0	0
f. Total Free Distribution *(Sum of 15d and 15e)*	20	20
g. Total Distribution *(Sum of 15c and 15f)*	1076	1115
h. Copies Not Distributed (1) Office Use, Leftovers, Spoiled	225	155
(2) Return from News Agents	0	0
i. Total *(Sum of 15g, 15h(1), and 15h(2)*	1281	1270
Percent Paid and/or Requested Circulation *(15c / 15g ¥ 100)*	98	98

16. This Statement of Ownership will be printed in the November issue of this publication. ☐ Check box if not required to publish.

17. Signature and Title of Editor, Publisher, Business Manager, or Owner: Brenda L. Mooney, Publisher — Date: 9/25/98

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force the legislation to the floor for a vote.

As a result, no action was taken. The Health Benefits Coalition, a group of insurance companies and employers, know the victory is only temporary until the issue is likely reintroduced next session. The coalition argues that consumer protections will drive up insurance costs. ▼

Judge delays start of new organ donor policy

The controversial organ allocation policy creating a national waiting list for available organs did not go into effect as planned on Oct. 1.

A federal judge blocked the new system from taking effect until completion of a lawsuit filed by the state of Louisiana is heard. **(For a history of the organ allocation debate, see *Medical Ethics Advisor*, April 1998, pp. 37-40, and May 1998, pp. 49-52.)**

Louisiana legislators earlier this year passed a law requiring all organs donated in the state to be used by patients within the state, if possible. The proposed federal policy would supersede the state law. ▼

AMA launches end-of-life program

The American Medical Association, in conjunction with several other medical organizations, is offering physicians a new end-of-life resource for patients. The program is aimed at educating the medical profession, patients, and their families, as well as supporting legislation that improves end-of-life care.

The program's goals are to promote physician-patient relationships that include the following:

❑ the opportunity to talk and plan for end-of-life care;

❑ assurance that physical and mental suffering will be attended to and comfort measures used;

❑ respect for the patient's preferences when it comes to withholding or withdrawing life-sustaining interventions;

❑ attention to the goals of the dying patient. ■

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.)

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