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IN THIS ISSUE

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Washington state voters approve physician-assisted suicide

On Nov. 4, 2008, Washington state voters passed a ballot initiative giving terminally ill patients with six months to live the right to have a physician prescribe lethal drugs for the patient to self-administer to bring about his or her death.

With the passage of the initiative, referred to as "I-1000," Washington became the second state, after Oregon, to approve physician-assisted suicide.

According to those *Medical Ethics Advisor* spoke with in that state, the issue was divisive and heatedly debated, with big dollars spent on both sides of the issue.

Still, the ballot initiative, the Washington Death with Dignity Act, passed by a wide margin, according to early reports from *The Seattle Times*. The act is scheduled to take effect in March 2009.

"The whole purpose is to relieve suffering of people who are dying, and I think everybody's in favor of that," says **Tom Preston**, MD, board member and medical advisor of the group Compassion & Choices of Washington, which brought the initiative to the ballot. "Some say you can do it adequately with palliative care . . . and I'm a great supporter of hospice. Nevertheless, there is 5% to 10% of the people who do suffer greatly, even in hospice."

Preston acknowledges that "there's some people whose ideology or religion is such that they feel this is absolutely wrong — and they may say that it hurts them to [have patients] do this, but you could say that about a lot of things," he says.

"So, yes, I think that furthermore, we all know . . . that most physicians do help their patients die in one way or another, but they do it to avoid the appearance of doing something . . . So there's a lot of hypocrisy, saying, 'Well, we can't do it openly,'" Preston says.

Preston believes that "autonomy should be most important, unless someone's autonomous action hurts someone else."

The Washington Death with Dignity Act requires, among many other things, that a patient be at least 18 years old and a resident of Washington.

The patient must initiate a written request for medication, which

must be witnessed by "at least two individuals who, in the presence of the patient, attest that to the best of their knowledge and belief the patient is competent, acting voluntarily, and is not being coerced to sign the request."

One of those witnesses is not permitted to be a relative of the patient "by blood, marriage, or adoption."

The attending physician, who must make the initial determination of whether a patient "has a terminal disease, is competent, and has made the request voluntarily," also must convey to the patient "the probable result" of taking such lethal medication, as well as advise him or her of alternatives to physician-assisted suicide, including palliative care and hospice care.

A consulting physician must be called in for medical confirmation of the diagnosis, and he or she also must determine that the patient is competent and acting voluntarily.

Patients are allowed under the act to rescind their decision at any time and "in any manner."

There is a 15-day waiting period between the time of the request and the time the lethal drugs are prescribed.

Medical association opposed I-1000

The Washington State Medical Association (WSMA), with offices in Seattle and Olympia, opposed I-1000, based on the testimony of most of its membership, who spoke at a meeting of that organization's reference committee, prior to it going to the WSMA's policy-making House of Delegates (HOD) meeting in 2007.

At the 2008 HOD meeting in September, that body passed a resolution that required the association to publicize its position against I-1000.

In 2007, however, the reference committee was considering a resolution to move to a neutral position on physician-assisted suicide from its earlier 1993 position totally against physician-assisted suicide.

"And that testimony really came from oncologists, hospice medical directors, and palliative care specialists, and it was pretty powerful," WSMA president, **Cindy Markus**, MD, JD, tells *MEA*.

"We were impressed by the testimony from the oncologists and hospice physicians that if people are contemplating suicide, then they're not getting the kind of care that they should get," she says. "And one of our efforts, ever since the 1993 initiative, has been to try to improve physicians' ability to treat the pain and other discomforts of terminal life care and create a situation where people don't need the option — or don't feel they need the option — to end their lives."

Among WSMA's concerns regarding I-1000 is that there is no requirement that there be a psychiatric evaluation for patients to determine whether they may be clinically depressed, Markus says.

"We worry that even if you give them the prescription at one moment in time, that they can, of course, become depressed subsequently and perhaps prematurely end their lives," she says.

The WSMA also is "pretty concerned," Markus says, that there is no requirement that the patient's family be notified of his or her plans, although there is a requirement that the patient be "counseled" to

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discuss it with his or her family.

"We as physicians know that often the anger that these patients' families may feel after such an event as this can be directed at physicians, and of course, we don't want our patients' families to be angry with us," she says.

The requirement that any measures that a physician takes to help a patient with his or her suicide under this act must be reported to the state Department of Health is another concern of the WSMA. As the initiative is scheduled to take effect in March, WSMA says this does not give the state authority sufficient time to establish a framework and tracking mechanism for this requirement.

"As I recall, there's no penalty for not reporting, so things could happen under the radar and under the table that we will never know about," Markus says.

A physician's view

J. Randall Curtis, MD, MPH, professor of medicine and adjunct professor of health services at the University of Washington, describes I-1000 and physician-assisted suicide as "a complicated issue." Curtis has done studies in end-of-life care.

"I think the medical ethics, as well as the palliative care fields, are deeply divided on this issue, and I think that very well meaning and principled individuals on both sides of the debate feel very strongly about their points of view," he says.

Aside from being difficult to resolve from a "purely normative ethical standpoint," Curtis says he thinks that until high-quality palliative care is available for all patients facing a terminal illness, physician-assisted suicide will be among the options considered.

"And I think that the majority of patients at the end of life can have symptoms managed by high-quality palliative care, making this option unnecessary," he says.

But, at the same time, it's difficult to be "absolutely dogmatic about it," Curtis says, noting that some people just like knowing they have physician-assisted suicide as an option, even if they never decide to utilize it.

"There's another reality of this dilemma — this problem," he says. "In my experience, high-quality palliative care [includes] the option of what people call palliative sedation, meaning that if symptoms become completely uncontrollable at the end of life," it is possible to have people sedated to the point that they are unaware of what is happening.

Curtis says that if you include the option of palliative sedation within high-quality palliative care, it avoids some of the risks associated with physician-assisted suicide. Those risks include "incorrect diagnoses, which happen from time to time, coercion, or having people feel like they really must exercise this option to protect others from distress or financial ruin or what have you."

SOURCES

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Will physicians participate?

According to an essay in the Dec. 11 issue of *The New England Journal of Medicine*,[1] in Oregon in 2007, 45 physicians in that state wrote the 85 prescriptions issued under that state's physician-assisted suicide, or Death with Dignity Act.

"Because of the nature of their medical practices or personal objections to involvement, most physicians in Oregon have never written a prescription for a lethal dose of medication . . .," wrote the essay's author, **Robert Steinbrook**, MD.

Curtis agrees that, while he has not seen surveys on the issue, many physicians will not participate.

"I think there are a number of physicians who feel like this really is not a role physicians ought to be playing," he tells *MEA*.

Since I-1000 was an initiative put before the public by a citizens' group — which had a former state governor, Booth Gardner, as its spokesman, this issue received widespread attention.

Markus notes that to try to prevent the initiative from taking effect would require a two-thirds majority from the House and Senate. She notes that I-1000 was a "very, very, very contentious ballot initiative within the state."

So, at this point, Markus says, the WSMA "has decided not to try to modify the initiative through

the legislative process.

"I just don't think there's much stomach in Olympia, in our capital, to try to change something that the voters so resoundingly passed," she says.

"We have made our point known, and the voters spoke, and I think we're going to leave it that way, unless, of course, we hear from members or citizens that there are problems, and then obviously, we would reconsider that position," Markus adds.

(*Editor's note: Just prior to* Medical Ethics Advisor *going to press, the* Associated Press *reported that a Montana state district judge issued a ruling that Montana residents have the right to physician-assisted suicide.* MEA *will report on this in future issues.)*

Reference

1. Steinbrook, Robert. Physician-assisted death — From Oregon to Washington state. *N Engl J Med* 2008; 359(24):2,513-2,515. ■

Brody case highlights brain-death dilemma

The recent case of a 12-year-old boy named **Motl Brody** brought attention not only to the occasional dilemmas presented by the designation of brain death, but also how to address faith traditions in determining death.

In the well-publicized case, according to published reports, the Children's National Medical Center had declared Brody brain-dead; however, his parents, of Brooklyn, NY, who are Orthodox Jews, did not want their child removed from care due to the fact that their faith indicates that death does not occur until the heart and lungs stop functioning.

Brody's situation became a court case, with reports suggesting that the hospital maintained that because young Brody had been declared brain-dead, which the District of Columbia recognizes, he should be removed from the ventilator and not allowed to occupy the ICU bed he was in at that time.

According to an *Associated Press* article, the family requested that a judge prohibit the hospital from doing further tests to determine brain activity. The *AP* report states that the hospital responded by asking a District of Columbia Superior Court judge for permission to discontinue treatment.

The hospital maintained that Brody's brain had begun to decompose, according to AP.

Ultimately, Brody died in mid-November when his organs stopped functioning.

Hospital protecting resources?

John Banja, PhD, professor, department of rehabilitation medicine; and medical ethicist at the Center for Ethics at Emory University in Atlanta, as well as director, section on ethics in research, suggests that the hospital has a right to protect scarce resources.

"Even more than a hospital saying, 'Well, gee, we might take a financial loss on this case.' Even more important than that is the fact that, oftentimes, ICU beds are very scarce in hospitals," he notes. "And the idea that a person who is legally dead is taking up such a bed and using the ventilator, using those resources might create a lot of discomfort among hospital staff."

In fact, Banja says, it could be argued that in the case of such ICU beds, "somebody else maybe deserves more or deserves better because they have a treatable condition."

Banja says his understanding from published reports was that Brody's parents "were not demanding more aggressive treatment or demanding treatment to keep him alive." Rather, they felt that they were religiously obligated to keep him alive and to keep him on the ventilator.

"So, for them, it was a religious issue — not even so much a clinical issue," Banja says, adding later that "the issue is: Should the state-funded entity that operates — and must — as required to acknowledge state law, should it make an exception in this particular case to respect and acknowledge the exercise of religion by a family?"

The Brody case, he said, was a "pretty good example of church vs. state."

Hospitals can accommodate

In New Jersey, brain-death determinations are exempted under law if they would violate religious beliefs. In New York, there is a state regulation known as a "reasonable accommodation clause."

"What that means, no one is entirely sure of; and we, over the years, have tried to clarify what the state's intent was of that regulation, but if there's a religious or moral objection to a brain-death determination, we need to make a reasonable accommodation," says **Joseph J. Fins**, MD, professor of medicine, professor of public health

and professor of medicine in psychiatry at Weill Cornell Medical College in New York, where he also is chief of the division of medical ethics and director of medical ethics at New York Weill Cornell Medical Center.

Over the years, the hospital has had "a number of cases" wherein there was an objection to the brain-death determination. Fins also has written about the issue in a number of articles.

"I can't go into specifics about individual cases, but I can say that I think that it's a difficult situation in that it creates a kind of secular vs. theological divide," he says.

However, Fins believes that the brain-death category also "serves an important legal and instrumental purpose in defining a category of defining death so as to allow organ transplantation, which was its original impetus back in 1968, after the Harvard Brain Death Criteria were established."

The state regulation requiring "reasonable accommodation," does not, however, mean that the hospital cannot declare a patient brain-dead, Fins notes. What it does mean is that the hospital has to make an accommodation for the family to be there and to "try to talk it through."

"When we've had cases over the years, we've sought [guidance from] sister and brother institutions in the state and also from regulators," he says. "And there's a vagueness to the term, I think, probably intentionally."

Fins says he finds it "helpful to look at brain death as the ultimate in medical futility; that is, anybody who is brain-dead is never going to have any recovery from that state."

Families with religious beliefs that do not recognize brain death, or have another definition of death, see it differently. He notes that it is not only one particular religious group, such as Orthodox Jews, that does not recognize brain death. Fins cites other cases involving patients from Japan, China, and the Caribbean.

"Most families who are not religiously inclined will understand and accept it," he says. "For those families that come from a faith tradition that doesn't accept brain death, I think the questions have to be reformulated within the ethical junctures of their tradition."

Ways to accommodate faith

In cases where there is an objection to the brain-death determination, Fins says he strives to understand the family's faith tradition. For example, in Judaism, "there's this notion of a 'goses,' which is someone who is imminently dying," he notes.

If the ventilator of a brain-dead patient is removed, for example, the person may have cessation of cardiopulmonary function, "because they don't have a brain stem, so they have no respiratory drive," Fins says.

With patients, Fins says he talks to the family and says, "Look, whether you accept this person as brain-dead, he or she can certainly be considered to be a goses, and Jewish law proscribes prolonging the dying process."

The challenge is that in Jewish law, there also is a requirement to seek healing, and balancing those two obligations is sometimes difficult, he says. In some instances, the hospital has brought in the family's rabbi to seek out his or her wisdom, and perhaps a resolution.

"What we try to do is, one, we reframe it in their own faith tradition without bringing up the question of brain death — frame a compromise position; and, two, make sure that what they're saying is actually part of an organized faith tradition," Fins explains.

(*Editor's note: In next month's* Medical Ethics Advisor*, the newsletter will look further at the brain-death determination.)* ■

Brain-death determination creates dilemmas

While brain death is widely accepted as a way of defining when death has occurred, this determination, or category of death, can create its own set of problems.

Typically, neurologists or other clinicians conduct tests for brain activity in cases where a patient's status is in question. According to **John Banja**, PhD, professor, department of rehabilitation medicine; medical ethicist, Center for Ethics at Emory University in Atlanta, electrical pockets of activity may remain in the body for some time after the brain-death determination.

He suggests that for brain death to be determined, it requires "not just the upper part of the brain, like you'd [see] in a vegetative state, but it requires the brain stem to be permanently dead as well," Banja explains.

But the fact that electrical pockets of activity remain — in some cases, for several hours — has "big ramifications" for purposes of organ

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transplantation, which is why such laws were established, he says.

"The problem is this contradiction in the law, because we're saying that the patient's whole brain has [to] be dead; but when they meet all the test [criteria], and then the transplant surgeons want to come in and take their organs . . . there are still some areas in these patients' brains that are still alive," Banja maintains. "That's the contradictory nature of this phenomenon that we're dealing with today.

"Always remember this: that the definition of death — defining death — is not a medical decision; it's a political or social decision," he says. "In other words, it's the society that has to have a meaning, or an understanding, of what will count as death in that society. Then, the society will authorize certain people — like in our society, physicians. In another society, it may be the witch doctor, or whoever."

Still, Banja says the brain-death determination is practically useful for many people.

"Although the brain-death model might admit certain imperfections, I do believe that it is very pragmatically useful and that its drawbacks do not morally outweigh its benefits," he says. ■

Kaldjian wins 'Defining Wisdom' grant

"Defining Wisdom," a project of The University of Chicago across multiple disciplines, awarded **Lauris Kaldjian**, MD, PhD, in 2008 a grant to develop a framework for medical decision making.

Medical Ethics Advisor talked with Kaldjian last November about what he expects to be a two-year project.

"What I'm trying to do in this large work is to do something that would actually be concrete and practically useful at the end of the day," Kaldjian says.

He expects to develop a "conceptual framework of wisdom" for clinicians that integrates three domains: medical ethical reasoning, the professional's conscientious practice, and the professional's obligation to society."

Kaldjian notes that a great deal of focus is placed in medical ethics today on the patient's autonomy. However, he says, if a physician or a clinician says, "What about me, what about my autonomy? How do you start to fit those two together?"

Kaldjian says he believes there is a struggle with how to balance the needs of the patient to the professional and against the needs of society.

An example scenario would be: duty to serve in time of epidemic.

"You know, the experience with SARS in Toronto and elsewhere in the world led to a lot of head scratching and hand-wringing about when should a physician or other clinician be willing to sacrifice their own or their family's welfare for the sake of the social good and for patients in need, etc.," Kaldjian says.

The goal, he says, would be on one hand to "first bring together what I call contrasting normative values," including a deontological principles approach, a consequentialist, and a utilitarian approach.

"How to understand these different approaches would be to say that deontological principles have to do with: What is the intrinsically right action? Consequentialism has to do with: What is the good state of affairs you are trying to accomplish by way of outcomes? But virtue ethics is about: What is the morally good person, and when you start talking about — not just what do

SOURCE

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you think, or what will you do but who should you be, you know now you're stepping onto a very different ground," Kaldjian says.

He suggests that much of the ethical debate and dialogue today and in the past has been "not necessarily to do with what are our different options, but trying to figure out how to prioritize those options," he points out.

He says one concise and helpful definition of wisdom is "the attempt to assess the value of different ends and to determine the best means to achieve those ends in particular circumstances."

"The reference to wisdom is not meant to be abstract and sophisticated," Kaldjian says. "It's really meant ultimately to try to create a framework that makes sense to clinicians and helps them understand what it is they're trying to accomplish, and to come up with a justification for it as well." ■

RNs moving into CR jobs must change their mindset

Experts say different missions can be confusing

One ethical dilemma nurses face when they move from clinical care to clinical research (CR) is the way the two fields' missions are different with regard to patients.

In fact, many argue that clinical research participants should not be called "patients," even when they are visiting a hospital or clinic partly for patient care and partly for their research visit.

The problem is training nurses to view these people differently.

"This is a very serious problem, and nothing is being written about it," says **Carlton A. Hornung**, PhD, MPH, a professor of medicine in the department of epidemiology and population health and the director of the Office of Education and Career Development in the Clinical and Translational Science Institute of the University of Louisville (KY).

"Certificate nursing schools and baccalaureate nursing schools really do not train nurses in what are the ethics for clinical trials," he says.

Since a majority of clinical trial subjects now are enrolled at nonacademic medical sites, such as private doctors' offices and outpatient medical clinics, this issue has to be more of a priority, Hornung notes.

While academic medical centers could provide training to groups of nurses and CR staff, small clinical trial sites have to handle this on a more individual basis.

But anecdotal evidence suggests CR sites are not doing an adequate job of providing ethical training to their nursing staffs, Hornung says.

"One study I saw from a student obtaining her master's degree at the University of Louisville found that 70% of nurses do not believe a patient in a clinical trial is getting the best care," he explains.

Opposing philosophies

This contradiction could be explained by the different philosophical attitudes nurses have vs. trained CR professionals.

"Nurses are trained that their first obligation is to the patient and what they see as the patient's best interest," says **Mark Rothstein**, JD, director of the Bioethics Institute at the University of Louisville (KY) School of Medicine.

"But nurses also have an ethical responsibility to respect the self-determination of their patients," Rothstein adds. "And if a patient provides informed consent to participate in a clinical trial, then the nurse should not deviate from the protocol on the grounds that he or she thinks it's not the standard therapy or that it's an undue burden on the nurse."

It's the researchers' responsibility to make sure the clinical trial staff are well educated about what they need to do and why it's important, says **Pamela Normandin**, RN, MSN, CCRC, a clinical nurse specialist in the office of research at Iowa Lutheran Hospital in Des Moines.

"It takes time up front training nurses, and I know a lot of research groups don't do it," she says.

"I work in a hospital where there are many research groups," Normandin adds. "And some do a really good job, and some do not."

The key is the upfront training, because that is what could make or break a trial, she says. **(See story about strategies for training CR nurses, p. 8.)**

The consequence of not teaching nurses about research ethics is that it's difficult for some nurses to fully grasp the importance of clinical research equipoise, Hornung says.

Research subjects often are randomized to a new drug or treatment or to standard care or a placebo, and no one on the research team knows which patient receives which treatment. Also, no one knows for certain which will be better for the patient until the data are collected, he explains.

"Nurses are committed to providing the best

possible care to their patients, and they're not always in agreement that the clinical trial protocol is the best possible care for a patient who is randomized to one arm or another," Hornung explains. "And when those nurses do not adhere to the protocol and provide instead what they think is the best care, you end up with lost data, and the research subject's rights are violated."

This problem often is subtle.

For example, a nurse may delay obtaining a CR blood draw because the time for which it's scheduled is inconvenient for the research subject. Or maybe the nurse also has other clinical staffing duties and another patient needs emergency attention at 4 p.m. when the blood draw is scheduled, and so she's delayed by two hours in getting to the research participant.

"That might render whatever readings you get from the blood draw invalid," Hornung says.

"On one hand this is an ethical dilemma for nurses under certain conditions, especially in acute care situations," he adds. "And it's a problem for floor nurses given the incredible demands put on them with the number of patients they have to handle."

Full training critical

The solution is to make certain all nurses who move into clinical trial work are fully trained.

"What I want to do is make sure that nurses working in academic medical centers where there are numerous clinical trials going on are aware of the atmosphere in which they're working," says Rothstein.

"Many of their patients are involved in clinical trials, and they need to know what the consequences of that are and what are the ethical duties of nurses who work in clinical research," he adds.

The only time nurses should question a clinical trial is if there's an unanticipated adverse event to a drug or if the nurse believes there is something unethical about the trial itself, Rothstein notes.

The solution is for academic institutions and individual research sites to provide specific ethical training to their nursing staff, focusing on how clinical trial care differs from clinical care, Rothstein and Hornung say.

"In addition, institutions need to provide backup support for nurses," Rothstein says.

For example, in the scenario of a nurse who misses a scheduled clinical trial blood draw because of having to handle a patient in crisis down the hall, it's the research site's fault for not providing that nurse with backup support, he explains. "Institutions need to have quick, easy access to the research coordinator or investigators if there are questions or emergencies," he adds. ■

Strategies for training and supporting CR nurses

Basic research ethics education needed

Clinical trial (CT) sites should be providing research nurses and other staff with the best possible foundation in clinical research ethics, as well as helping them make the transition from clinical care to research trials, experts say.

Here are some suggestions to improve their training and provide adequate support:

1. Get rid of the term "guinea pig."

Clinical trial nurses and coordinators sometimes will hear CT participants or fellow medical workers call research subjects "guinea pigs," and it's up to investigators and CT sites to dispel this myth.

"When nurses perceive clinical trial subjects as guinea pigs, then we have the stage set for a problem," says **Carlton A. Hornung**, PhD, MPH, a professor of medicine in the department of epidemiology and population health and the director of the Office of Education and Career Development in the Clinical and Translational Science Institute of the University of Louisville (KY).

"Patients and subjects in clinical trials are not guinea pigs," he contends. "We start clinical trials from the basic ethical principle of equipoise, meaning we don't really know what the best care is, and we don't really know the best way to do something." Since researchers don't know what the best treatment is, it's most ethical to randomize patients to Treatment A and Treatment B with their informed consent, he explains.

"When we obtain informed consent, we explain to them that we don't know which treatment is best and their participation in the trial will help to answer that question for future patients," Hornung says.

"When nurses don't understand this concept, we end up with situations where they think they might know better, but they don't because nobody knows the answer," he adds. "So the idea that patients in clinical trials are guinea pigs is just not true."

2. Teach research nurses about placebo-controlled trials.

New research nurses should be told about how placebo-controlled trials work, and they can be reassured that the ethics and appropriateness of such studies are thoroughly reviewed by an institutional review board (IRB), says **Mark Rothstein**, JD, director of the Bioethics Institute at the University of Louisville School of Medicine.

"I think there are many misconceptions about the role of the IRB and what kind of research is approved," Rothstein says. As part of the educational program at the University of Louisville School of Medicine, the Bioethics Institute might bring in the IRB chair of a research administrator to talk with nurses about the IRB's criteria for approval, Rothstein says.

"We would also have them discuss the criteria that are used when a study is terminated, because it's either causing adverse consequences," he adds. "Or maybe it's been so successful that it can be extended to treat people in the control group when we have findings that a treatment has extraordinariy value."

3. Explain the concept of informed consent.

"I think nurses can understand the concept that they're supposed to respect the autonomy of the patient — that's part of their code of ethics," Rothstein says.

"You shouldn't enroll people in research studies unless they have all the information that's relevant to making a decision about whether or not to participate," Rothstein says. "And participants give their knowing, informed consent to do this, so they're willing to accept certain risks of harm because there is either a possibility of benefit to them or because it's an act of altruism."

4. Train CT nurses when a new trial begins.

As soon as a clinical trial begins, the site should provide CT nursing staff and coordinators with a schedule of each protocol activity, suggests **Pamela Normandin**, RN, MSN, CCRC, a clinical nurse specialist in the office of research at Iowa Lutheran Hospital in Des Moines.

"I make schedule cards for nurses," Normandin says. "I write on these exactly when things have to happen, and I write in direct orders that the physician will sign."

A CT coordinator or investigator should take time to make tables, write orders, and provide notes about the study . . . all for the purpose of reminding nurses of their CT tasks, she says.

"I do everything I can to remind nurses," Normandin says. "I call nurses and give them a little personal attention, and if I know there's a less-experienced nurse, I'll be a little more vigilant."

Normandin also speaks with nurses about evidence-based practice, and she's provided educational sessions for continuing education unit (CEU) credit. "If you give them CEUs, nurses will come," she adds.

5. Give nurses someone to call if they have any questions.

"I encourage my nurses to always ask me questions if they have any concerns," Normandin says. "I think it's important for them to be able to call me 24/7."

Normandin answers their questions as best she can.

6. Reinforce the message that CT care is different from standard medical care.

CT investigators and administrators need to teach nurses that the main difference between CT research and clinical care is that there will be a different kind of intervention than would normally be the case, Rothstein says.

"The intervention might be more efficacious for the patient as in the case of a new drug that might be more effective with fewer side effects and lower doses," he explains. "But you never know unless you actually try it on patients, and you need controlled clinical trials to evaluate the effectiveness of the drug."

Also, they should teach nurses that before an investigational drug reaches the clinical trial stage, it has successfully gone through many other stages that research goes through, Rothstein adds.

"It's only at that point of the clinical trial where there's a reasonable knowledge of the benefits and risks," he says.

"It's easy to get that point across," Rothstein says. Plus, it's important to remind nurses that many common treatments they take for granted are, in fact, experimental as well.

"There are certain areas of medicine where if we took out research uses, we'd have nothing to offer patients," he adds. "For example, most of the drugs that are used in pediatric oncology are not approved for that use; they're approved for adults, and yet we have to use them for children."

Even many frontline therapies for adults are investigational or off-label uses of other approved drugs, Rothstein says.

"Many clinicians, nurses, and some doctors would be very surprised at the high percentage of research treatments that affect standard therapy," he adds. ■

AMA asks TJC for time on disruptive docs

The House of Delegates of the American Medical Association (AMA) in Chicago at its November 2008 meeting in Orlando voted to ask The Joint Commission for a moratorium on its disruptive physicians policy, introduced in July 2008 and scheduled to take effect Jan. 1, 2009. A decision on the matter was not reached prior to press time.

A spokeswoman for The Joint Commission, in Oak Brook Terrace, IL, confirmed that the AMA's request for a moratorium, as well as a more specific definition of what constitutes a disruptive physician, is "under review."

Other actions considered included:

• **At the HOD meeting, delegates also considered a proposal on how to best conduct activities related to "secret shoppers."** Such patients are paid to visit physician offices or institutions — even emergency departments — to provide feedback on such things as customer service and quality of care to third-party payers or to those facilities. However, it was recommended that the resolution not be adopted.

According to the Report of Reference Committee on Amendments to Constitution and Bylaws; "Though there was testimony in favor of referral back to Council on Ethical and Judicial Affairs for a report that declared the use of secret shoppers to be unethical, testimony overall asked that this report not be adopted."

• **Forced repatriation of immigrants by hospitals also was considered by the HOD.** The HOD considered a resolution that asked the AMA to oppose forced deportation of patients.

According to the reference committee report, "Testimony for this resolution was divided, but witnesses generally concurred that repatriation poses significant professional challenges for physicians. It was suggested that the overarching concern in this matter involved inappropriate discharge of patients more than immigration status specifically."

Because it was suggested that "more appropriate framing would speak to physician participation in forced deportation of medically unstable patients," the resolution was referred to the board of trustees for another report to be presented to the HOD in 2009. ■

Hospitals face difficulty in disaster preparation

A new study published Nov. 13 in the Chicago-based American Medical Association's (AMA) *Disaster Medicine and Public Health Preparedness* journal found that consistent, evidence-based performance measurements are needed to accurately evaluate hospitals' ability to manage patient care during a disaster, the AMA says.

The study was released online and was to be published in the journal's December 2008 issue.

"Although health care institutions regularly perform quality assessments of routine clinical services, few metrics are available to evaluate the quality of their emergency management initiatives," lead author **Eliot J. Lazar**, MD, MBA, vice president of medical affairs and chief medical officer at New York-Presbyterian Healthcare System, said in a news release.

"The need for universally accepted, evidence-based performance measures continues to grow, as hospitals must be able to demonstrate their progress or needs for disaster readiness," he said. ■

Yale Law professor and physician Jay Katz dies

Yale Law School professor and physician Jay Katz, MD, died Nov. 17 at age 86, according to the school's web site.

Katz, who died of heart failure, "made profound contributions in the areas of law, medicine, and ethics. He was a leader in the area of reproductive technology law and ethics," according to the school.

"As a doctor steeped in the law, Jay Katz

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illuminated better than anyone has before or since the complex of medical, legal, and ethical choices that haunt the silent world of doctor and patient," said the school's dean, **Harold Hongju Koh**, JD.

Katz was the author of several books, including *The Silent World of Doctor and Patient*. ■

NEWS FROM ABROAD

UK ethicist remarks on dementia patients

United Kingdom's Baroness Mary Warnock, considered an expert on medical ethics, created a stir in late 2008 with her suggestion that those in the UK with dementia have a duty to die, so as not to strain public health resources.

She was quoted in an article in a Church of Scotland publication as saying, "If you're demented, you're wasting people's lives — your family's lives — and you're wasting the resources of the National Health Service."

Her views created buzz on both sides of the Atlantic.

J. Vincent Guss Jr., MDiv, chaplain of Falcons Landing Air Force Retired Officers Community in Potomac Falls, VA, says, "I definitely agree with her, on a moral basis, that a person has the 'right' to choose whether or not to prolong life with antibiotics, aggressive medical treatment, etc., even if pain or terminality are not issues.

"One can make the decision for oneself and choose an advocate to carry out that decision to abate medical treatment, even in cases and reason of dementia," he adds.

Guss says it is "quite another thing to jump to the next level of proposing a person has the 'duty to die' or to say, as she is quoted, that just because she does '. . . not want to continue to be remembered in a state of dementia,' that such a state of being renders others 'useless . . . and a waste to the National Health Trust.'"

Guss adds that this thinking is "not consistent with morality or bioethical principles." ▼

UK airs patient dying on camera, reports say

At press time, the United Kingdom also was getting attention for the airing of a documentary showing a case of assisted suicide on television in that country — and the patient's dying on camera, according to an *Associated Press* report.

The AP report said the decision to air the death on television prompted headlines and even a debate in Parliament, with Prime Minister Gordon Brown asked about the appropriateness of airing the suicide on camera for public view.

The AP said the documentary previously had been shown on Canadian and Swiss television and at numerous film festivals.

The AP report stated that the documentary originally was titled "The Suicide Tourist," but was renamed "Right to Die?" for the broadcast in Britain.

Assisted suicide is illegal in Britain, and the death appearing in the documentary was filmed at a Swiss clinic, the AP reports. ■

CME instructions

Physicians participate in this continuing medical education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue. Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge.

To clarify confusion surrounding any questions answered incorrectly, please consult the source material. After completing this activity with the **June** issue, you must complete the evaluation form provided and return it in the reply envelope provided to receive a credit letter. When your evaluation is received, a credit letter will be mailed to you. ■

CME objectives

After reading each issue of *Medical Ethics Advisor*, you will be able to do the following:

- discuss new information about hospital-based approaches to bioethical issues and developments in the regulatory arena that apply to the hospital ethics committee;
- stay abreast of developments in bioethics and their implications on patient care, risk management, and liability;
- learn how bioethical issues specifically affect physicians, patients, and patients' families. ■

CME answers

1. A; 2. A; 3. A; 4. B.

CME Questions

1. Washington state voters approved I-1000 on Nov. 4, 2008, which allowed physician-assisted suicide by permitting physicians to prescribe lethal drugs that patients would then self-administer.
A. True
B. False

2. Which of the following approaches does Joseph Jack Fins, MD, suggest?
A. Framing the death according to faith-based religious law.
B. Telling families that the patient is no longer suffering.
C. Not discussing the death with the family.

3. Health care professionals in New York must abide by a "reasonable accommodation" clause in dealing with patients who may have moral or religious issues related to a patient's care.
A. True
B. False

4. There are no areas of concern among ethicists relating to the brain-death determination.
A. True
B. False