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Hospital: Growth attenuation in disabled child illegal, not unethical

Ethics committee urged court review, but was ignored

The Seattle hospital that performed growth attenuation treatments and surgery on the severely disabled child known as "Ashley" took place in violation of Washington state law, but the hospital stands behind the ethics and best-interest issues that resulted in the treatment.

Hormone treatments, hysterectomy, and removal of breast buds were performed after her parents and her physician petitioned Children's Hospital and Regional Medical Center in Seattle to permit the procedures. The family said that by keeping Ashley physically small they would be able to care for her at home, rather than eventually having to move her into an institution, and that by removing her uterus and breast buds, she would be spared the physical discomfort of menstruation and breasts that interfered with harnesses and lift devices.

The treatment was performed in 2004, but the report of it that appeared in the October 2006 issue of *Archives of Pediatrics and Adolescent Medicine* ignited national debate over the ethics of sterilization, growth attenuation, and the rights of the disabled.¹ An investigation by the Washington Protection and Advocacy System, a nonprofit group that advocates for the rights of the disabled, followed the release of the report, and the results disclosed in early May showed that the hospital broke state law by not obtaining a court order and disregarded the ethics committee's recommendation that a court should review the treatment before it was initiated.

The hospital has acknowledged the breach, apologized, and outlined steps it would take to prevent future violations of the law and promised to appoint to its ethics committee someone with a "disability rights perspective."

Ashley's best interests debated

One of the authors of the report, **Douglas Diekema, MD, MPH**, is education director at the Treuman Katz Center for Pediatric Bioethics

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at Children's and served on the ethics committee that reviewed Ashley's case before treatment was initiated.

Ashley is now 9 years old and cared for by her parents at home, where she is "an integral and much loved member of the family," Diekema writes. However, static encephalopathy with marked global developmental deficits caused her development never to progress beyond infancy. She cannot sit up, walk, or talk; she is fed via gastrostomy tube, and the specialists treating her say there will be no significant improvement in her cognitive and neurologic state.

When she started showing signs of puberty at age 6 (breast buds, pubic hair), her parents became concerned about the effects of growth and maturation on their ability to care for her and keep her

comfortable. Lifting an immobile adult at home would prove very difficult. Fully developed breasts would interfere with Ashley's ability to comfortably wear the harness that allows her to sit up, and menses would make hygiene additionally difficult for her caregivers and uncomfortable for Ashley.

For those reasons, the family asked that Ashley undergo the three procedures that have come to be described jointly as "the Ashley treatment."

Individually, these procedures are not unheard of and are even common in very developmentally disabled people, Diekema told *Medical Ethics Advisor* early in 2007. What made this case unusual, he said, was the family's and physician's choice to have the multiple procedures vetted by the hospital.

"What made it unique is that it came to the ethics committee [at Children's Hospital] without there being a disagreement between the parents and physicians," said Diekema. The ethics committee reached consensus that the parents were acting in the best interest of the child, and approved the treatment, with the advice that it would need to be reviewed by a court before proceeding further.

Ethics approved, but law broken

That's where the hospital veered off the legal course, according to Children's Hospital Medical Director **David Fisher, MD**, who released a statement about the investigation in May 2007.

"Ashley's doctors and ethicists here at Children's Hospital have worked hard to act in Ashley's best interests," said Fisher. "There were many difficult issues and our actions were not taken lightly. Unfortunately, we failed to assure we had a court order authorizing us to proceed with a hysterectomy or removal of Ashley's uterus, as we should have.

"This was an internal miscommunication, which resulted in a violation of the law, and for that we take full responsibility."

Fisher admits that the ethics committee reported that a court review would be necessary before the hysterectomy took place, but the hospital instead relied on the parents' attorney, who conveyed a legal opinion that the treatment could go forward without a court order.

"This is where our system broke down — our medical staff and administration misinterpreted this guidance from the family's lawyer as adequate 'court review,'" Fisher explained. "However, the law is clear that a court order should have been obtained before proceeding

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Editorial Questions

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with the hysterectomy.”

Children’s is introducing safeguards that will prevent repeats of the mistake when growth attenuation or hysterectomy in a disabled child is again requested at the hospital. A court order will be required for the three procedures that make up the “Ashley treatment,” and the hospital’s legal counsel will review and obtain a court order before any future growth attenuation procedures are scheduled.

Finally, Fisher said Children’s plans to appoint an ethics committee member who has a “disability rights perspective.”

Regardless of the violation of state law, Fisher insists that Ashley’s best interests were at the heart of all decisions by her parents and by Children’s.

“The decisions in this case were achieved only after long deliberation and discussion,” he said. “We understand that there is disagreement over the conclusions we reached. That disagreement should have been brought before an impartial decision maker — a judge, in a court review — to assure all points of view were considered before undertaking the procedure.”

Motives don’t necessarily justify means

Ethicist **John D. Banja**, PhD, assistant director for health sciences and ethics at Emory University Center for Ethics in Atlanta, told *Medical Ethics Advisor* earlier this year that the true benefit or detriment to Ashley from the procedures performed on her likely won’t emerge until years have passed.

But regardless of the benefits or drawbacks to the procedures, Banja finds the violation of law unsettling.

“There ought to be no unethical laws. All laws should speak to our considered moral sensibilities,” Banja suggests. “So, the issue would be whether good arguments could be made, such that a reasonable person, acting in a patient-centered way, would knowingly or unknowingly violate the law.”

In that sense, he said, the Ashley case troubles him — and raises more questions.

“Usually, one can detect very compelling reasons why laws are in place — especially laws governing end of life — because they have resulted from very careful deliberation over the difficult, conflicting circumstances that commonly arise in these situations,” he explains. “So to knowingly violate one of these laws sounds peculiar to me. What reasons would the violator have? What don’t we know

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about his or her thinking or intentions when they occurred? What do we know that would lead us to think he or she did the right (or the wrong) thing?”

Children’s disclosure of the error and plans to prevent future violations of the law don’t fully address the concerns of disability rights advocates, who want an end to treatments such as Ashley’s altogether, says **Curt Decker**, JD, executive director of the National Disability Rights Network, based in Washington, DC.

“We hope that the agreement between [the Washington Protection and Advocacy System] and Children’s Hospital will be the first step in resolving this issue and that the long-term result will be an end to the use of the ‘Ashley treatment,’” he said. “I know the entire disability community will be carefully watching the implementation of this agreement.”

Reference

1. Gunther DF, Diekema DS. Attenuating growth in children with profound developmental disability: A new approach to an old dilemma. *Arch Pediatr Adolesc Med* 2006; 160:1,013-1,017. ■

Teen’s fight for medical autonomy leads to new law

Law says refusal of care does not always equal neglect

Virginia has enacted a new law that will allow mature teenagers, their physicians, and parents to more freely consider alternative — even

risky and controversial — therapies and reject traditional treatment without fear that doing so will trigger neglect and abuse charges.

“Abraham’s law” is named after a 16-year-old Chincoteague, VA, boy, Abraham Cherrix, who won a court battle in 2006 to seek alternative therapy for a recurrence of Hodgkin’s lymphoma, but only after the state Department of Social Services had charged his parents with neglect, threatened them with jail, and attempted to remove Cherrix from their custody. (See **“When minors choose risky, alternative therapy,”** *Medical Ethics Advisor*, August 2006.)

While months of legal wrangling resulted in a compromise that permits Cherrix to pursue alternative treatments for his cancer (he also has since opted to add radiation treatments), it left his family in shambles. His parents have separated and lost their home and business.

“I believe that this law being passed has opened the door for physicians and patients to discuss more,” says **Rose Cherrix**, Abraham’s mother, who lives with her six children in Floyd, VA. “I believe that if parents are afraid of being dragged into court because they disagree with a physician, then more parents will stop taking their children to a doctor and one time it will be too late for the child.”

Abraham’s law is not so much an endorsement of young people’s right to seek out alternative therapies as it is a relaxing of laws that made it difficult — if not illegal — for parents to refuse medical treatment for their children.

Under the new law, parents would be allowed to refuse a medical treatment for their child and not face charges of neglect if four conditions are met:

- the parents and child have made the decision jointly (if the child is at least 14 years old);
- the child is sufficiently mature to have an opinion on his or her treatment;
- the family has explored and considered other treatment options; and
- the parents believe in good faith that the decision is in the child’s best interest.

Abraham’s journey

Cherrix was diagnosed in 2005 with Hodgkin’s lymphoma after he found a suspicious lump in his neck. He underwent three months of chemotherapy at Children’s Hospital of the King’s Daughters in Norfolk, VA, and says the treatment made him deathly ill.

“It poisoned me,” he told *Medical Ethics Advisor*. So when follow-up tests in early 2006 showed cancer was still present and doctors at Children’s recommended another round of chemotherapy, Cherrix said “no.”

He and his father, who had been helping his son research alternative, diet-based therapies, traveled to Mexico to explore a treatment called the Hoxsley method, offered by a clinic in Tijuana. Based on an organic diet and herbal supplements, some of which are ingested and some of which are applied topically, the Hoxsley method is illegal in the United States under FDA safety rules.

At that point, someone reported his case to child abuse investigators in the county where he lives, and the Department of Social Services asked a court to order Cherrix to continue conventional treatment and obtained a temporary order saying the Cherrixes had neglected or refused to provide necessary treatment for their son. Cherrix was placed in joint custody of his parents and social services, an action the family said was devastating to them. Cherrix refused the chemotherapy, and went to court to argue his right to choose or reject therapy options.

At the time, **Michael Gillette**, MD, an associate professor of family medicine at the University of Virginia and president of Bioethical Services of Virginia Inc., said Cherrix was charting new territory in Virginia health law.

Virginia did not — and still does not — have a mature minor statute, which in some states recognizes older minors’ right to consent to or refuse medical treatment, so Cherrix had no precedent to back him up. But in late 2006, a judge, impressed by Abraham’s maturity and grasp of the issues and risks and convinced that his parents were acting in what they believed to be his best interest, brokered a compromise that permits Cherrix to be treated by a physician in Mississippi — a board-certified oncologist who specializes in blending traditional and alternative treatments for cancer.

Rose Cherrix says her son currently is in remission and being monitored by his local doctor in Virginia.

Law doesn’t change health law

Abraham’s law — an amendment to the state law on abuse and neglect, not a change to any health care law — “is an interesting law, in part because I don’t think it really changes any-

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thing," says Gillette.

"This is not a law that creates a presumption of capacity on the part of a mature minor. It's a revision to the abuse and neglect statute that removes an assumption that refusal of health care is, by itself, abuse and neglect."

Virginia Gov. Timothy Kaine, at the bill's signing, said the statute strikes a balance between the rights of the parents and mature children to make health care decisions and the responsibility of the state to protect children.

In exchange for relieving the burden of concern about care choices being deemed neglectful, Gillette suggests, the law brings with it new questions that will probably land families in court anyway.

"The statute says you have to be 14 and capable of giving informed consent, but it doesn't spell out what that means," he points out. "So there could still be any number of situations where an individual can question a child's maturity, or whether or not other means of treatment have been investigated.

"But what it will change is that if [the Department of Social Services] believes that those [conditions] are met, they won't have to act on the refusal of treatment as if it were neglect."

Rose Cherrix says that even though Abraham's law doesn't create a mature minor provision or even change existing health care law, she believes it will serve an important purpose by opening lines of communication by removing the barrier of abuse and neglect charges.

"When his doctor from Virginia Beach called me [in 2006, when Abraham's cancer reoccurred] to ask when I was going to schedule him to start preparing for the chemo, I told her that we had decided to try something else and asked her to

monitor him while we did it to make sure he wasn't getting worse. She refused," Abraham's mother explains. "When I asked her why, she said that she did not agree with us. She never asked me what we were thinking about doing or if we were getting a second opinion. She just called social services and called it medical neglect."

She says that she wonders what might have happened had his original doctor not accused her and her son's father with neglect, but opted instead to monitor his condition while helping the family explore alternatives to the chemotherapy that Cherrix refused.

"Those answers we will never know, but her decision to not communicate or help keep an eye on him affected our whole life," Rose Cherrix insists. "The power she held in her hands was incredible. Now, with Abraham's law, maybe a physician who otherwise would not discuss other options ... will continue with them instead of [assuming that the child's welfare is being neglected]."

Gillette says that while the law has some vague points, he doesn't believe it's a bad law.

"I don't think it creates any problems, and it may eliminate some," he says. "It won't radically change the questions a physician has to ask before granting alternative care, but it simply puts on paper the questions physicians have to ask before calling social services, and gives social services more leeway in determining whether a patient's and family's decision is neglect."

Douglas Diekema, MD, MPH, director of education for the Treuman Katz Center for Pediatric Bioethics at Seattle's Children's Hospital and Regional Medical Center, says laws such as Abraham's law reflect how medicine's attitude toward patient autonomy in children is evolving.

"If you're faced with a 16- or 17-year-old who really doesn't want to [undergo chemotherapy], if it's a second relapse and they're looking at, say, a second bone marrow transplant, we'd let an adult make that decision [to forego treatment], and not necessarily think they were making a terrible choice," says Diekema. "So there can be strong cases to make for accepting an adolescent's choice."

(Abraham Cherrix has created a web site to document his treatment and pursuit of medical autonomy for minors — www.abrahamsjourney.com/Abraham.) ■

Texas works to defuse hostility over futility law

Baby Emilio's death doesn't end debate

A 19-month-old toddler with no hope for recovery became the center for the most recent debate over laws on futility, but now that little Emilio Gonzales has died (May 19, 2007), the state of Texas continues to wrestle with what to do with its advance directives act. (See **"Is care ever futile? Texas MDs, advocates square off,"** *Medical Ethics Advisor*, June 2007, p. 63.)

Texas' futile care law, originally passed in 1999, was tested most recently when Children's Hospital of Austin declared that its medical efforts on behalf of Emilio, who was believed to suffer from Leigh's Disease — a degenerative brain disease — were futile and that he was suffering as a result. Under the provisions of the act, and with the concurring opinions of physicians and the hospital ethics committee, the hospital notified Emilio's 23-year-old mother earlier this year that after the statutory 10 days, his ventilator would be removed. If she disagreed, she had 10 days to find another hospital willing to admit and care for her son. She was unable to find a hospital to accept transfer, so Emilio's mother and Texas Right to Life went to court seeking an order to continue treatment for her son.

The court barred the hospital from withdrawing the ventilator pending further review; in the meantime, Emilio died.

Following heated debate over various bills that would do anything from change the waiting period to completely gut the futility law, in early May the various parties to the issues — right-to-life, right-to-die, church-based, activists for the disabled, and medical associations — reached a compromise on a bill that would require hospitals provide life-sustaining care to patients deemed medically futile for at least 28 days after the determination of futility.

That compromise bill died in the legislature in late May, leaving the advance directives act in place, unchanged. However, physicians groups (which predominantly supported leaving the act unchanged) as well as hospitals and proponents of change to the law issued statements agreeing to work together to ensure patients and their fam-

ilies are treated as humanely as possible whenever the issue of futility arises.

Many hospitals said they are already implementing in-house policies around futility that go far beyond what the law requires, and closely resemble the compromise reform that failed to pass legislative muster. Most say they are informally and significantly extending the timetable for a family member or designated surrogate to contest a doctor's decision to stop care.

The Texas Medical Association and Texas Hospital Association indicated they would support hospital policies that would implement many aspects of the failed compromise bill, including more than doubling the amount of time families would have to find alternative care once a determination of futility is reached. Under the existing law, families have two days' notice of ethics committee meetings, plus 10 days after determination of futility, for a statutory total of 12 days.

Another change hospitals say they'll implement as a result of the debate over the futility bill will give family members or other patient surrogates easier access to medical records and resources such as right-to-life advocates. ■

SUNY medical school drafts updated 'Physician's Oath'

Draws on Hippocrates, Maimonides, Blackwell

The last medical school in the nation to use what was considered the most archaic version of the Hippocratic Oath has created a new version of a physician's oath that was pledged by graduates during commencement in May.

State University of New York (SUNY) Upstate Medical University in Syracuse was believed to be the only medical school in the country that was still using the classical Hippocratic Oath, in which graduating medical students swore to avoid performing abortions or assisting in suicides.

The new version unveiled this year borrows from the writings of Elizabeth Blackwell, the first woman to graduate from medical school in America, as well as from the Prayer of Maimonides, a 12th century Jewish physician. The new oath also retains elements of the classical Hippocratic Oath, which was

The Physician's Oath

- I solemnly commit my life to serving humanity. I will give to my teachers the respect and gratitude that is their due, and share my knowledge with those who follow me.
- I will practice my profession with conscience and dignity.
- The health of my patient will be my first consideration; may I never see in the patient anything but a fellow human in need.
- I will treat all patients with compassion, no matter how much they differ from me.
- I will respect the secrets patients confide in me.
- I will remember that the physician's duty is both to prevent disease and to treat it.
- I will work together with my colleagues as brothers and sisters in service of our patients.
- I will maintain the honor and the noble traditions of the profession.
- I make these promises solemnly, freely, and upon my honor. May I keep this oath and, in so doing, experience the joy of healing those who seek my help.

Source: SUNY Upstate Medical University.

written around the 5th century BC, as well as parts of a modern revision written in the 1960s. (See "The Physician's Oath," this page.)

The decision to change the oath came about when students in 2006 asked for changes to the white coat ceremony marking the beginning of their medical education. That served as a jumping off point to review medical education traditions, including the oath recited at commencement, according to the university.

Kathy Faber-Langendoen, MD, chair of the Center for Bioethics and Humanities and Medical Alumni Endowed Professor of Bioethics, said that she and other faculty members found the oath's archaic and often ambiguous language hindered students' ability to understand its meaning.

Faber-Langendoen conducted an informal poll of students, and found that many were not certain what some of the phrases meant.

"If the 120 or so students reciting this oath aren't sure of its meaning, then it was time to put it to rest," she explains.

A committee of faculty members and medical students drafted a new oath — one with greater clarity of message that would be more meaningful to today's students. But Faber-Langendoen

said that as they attempted to modernize the oath, they relied on the teachings of past medical luminaries, including Blackwell.

Concepts in the new oath that derive from Blackwell's writings include the importance of preventive medicine and the need for collaboration between women and men in the medical profession.

"The new oath in very simple prose codifies the core ethics of our profession," Faber-Langendoen said. "I think it will be helpful to our graduating physicians if, after a few years in practice, they come back to this oath to remind themselves of their fundamental commitments as physicians."

While most medical schools administer an oath upon graduation, and while most are based in part on the classical version of Hippocrates' Oath, there are wide variations and none are endorsed or required by medical societies (including the American Medical Association) or state licensing boards. Medical colleges in the United States did not even start using the Hippocratic Oath at graduations until the 1800s. ■

NC nurses examining policy on assisting in executions

Some nurses want license penalties for participation

Physician groups' opposition to doctors participating in death penalty executions has put a moratorium on prisoner executions in North Carolina for nearly a year, and now a group of nurses are following the lead of their state's physician licensing board. The nurses are asking their own licensing board to adopt an ethics policy that would prevent nurses from participating in carrying out death penalties.

"It is clearly against our code of ethics," Raleigh nurse **Cynthia Gallion** told the Associated Press (AP). Gallion has started a petition urging the nursing board to act along the lines of the North Carolina Medical Board, which in January issued a position statement that says doctors can lose their licenses to practice if they take any action that would:

- directly cause the death of a condemned person;
- assist, supervise, or contribute to the ability of another individual to directly cause the death of

the condemned; or

- automatically cause an execution to be carried out on a condemned prisoner.

The North Carolina Nurses Association (NCNA) has not come out in favor or opposition to the nurses' efforts to spur a position statement from the licensing board, but the president of the NCNA acknowledges that participation in executions is in opposition to the ethics of nursing.

"For the past five years, the CNN/*USA Today*/Gallup poll has ranked nursing as the most honest and ethical of all professions," says **Dennis Sherrod**, EdD, RN, president of NCNA. "The American Nurses Association, of which the North Carolina Nurses Association is a constituent member, has a long history of opposing nurse participation in executions."

Additionally, Sherrod says, the NCNA "is a strong advocate for quality workplaces and quality patient care, and opposes any public or private entity mandating that nurses participate in executions as a requirement for employment."

Sherrod refers to prisons requiring that nurses participate in executions as part of their jobs. The NCNA, which does not license nor discipline

nurses, once forbid nurse participation in executions, but eliminated that restriction several years ago, leaving the decision up to the individual nurse.

Solution lies in legislation, board says

The North Carolina Board of Nursing, however, has stated that it cannot discipline a nurse for participating in an execution unless the state legislature amends the Nursing Practice Act to prohibit nurse participation.

The state medical board, on the other hand, is authorized under state law to discipline physician members who violate its ethics policies, so no legislation was necessary for it to issue its policy statement.

The medical board's declaration in January that any doctor who participates in an execution violates medical ethics and could face sanction effectively shut down the state's capital punishment system; no executions have been carried out since then (as of the time *Medical Ethics Advisor* went to press). The issue has arisen again and been referred to the commission on standards and practices, which thus far has taken no action on it, according to Tina Gordon, the association's

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executive director.

State law does not require that a nurse attend an execution. However, court records and depositions from prison officials indicate that at least two nurses have been present at the past several executions.

"We are still exploring the situation and looking into our options," says **Gail Pruett**, RN, director of nursing education and practice for the NCNA. "I don't think we'll have anything [along the lines of a public policy] for a while."

[For more information, contact the North Carolina Nurses Association, 103 Enterprise St., Raleigh, NC 24607. Phone: (919) 821-4250.] ■

ED patients unsure about waiving consent

Few knew about PolyHeme study

A recent study suggests that emergency medicine patients may not have a high level of acceptance of the practice of providing an exemption to informed consent for research involving emergency medical settings.¹

"We looked at nearly 500 patients who presented to the emergency room and who were not critically injured, and we queried them on their attitudes and beliefs about having an exception to informed consent," says **Wayne Triner**, DO, MPH, FACEP, an associate professor in the department of emergency medicine at Albany Medical College and a senior fellow at the Alden March Bioethics Institute in Albany, NY.

"We found that, by and large, patients agreed with the notion that research of this nature, with a waiver for informed consent, was important to do, but they had issues with such research transpiring among themselves or family members," Triner says.

About one-third of those surveyed said they would be willing to have themselves or family members participate in such a study, and one-third strongly disagreed, while about 80% of participants agreed that such studies need to be done, he explains.

Investigators intentionally did not survey people who were involved in a research project.

The study took place after there were some general media reports about concerns over the

enrollment and disclosure practices of the PolyHeme clinical trial, which was sponsored by Northfield Laboratories Inc. in Evanston.

PolyHeme is an oxygen-carrying resuscitative fluid designed for use in urgent blood loss when blood isn't immediately available. During clinical trials, some patients receiving the product died of heart attacks, which raised questions about the waiver of informed consent.

The trial was conducted with informed consent waivers because of its use in emergency, life-threatening situations. Community education was conducted prior to the trial's initiation, and the public was offered a way to opt out of inclusion.

"We specifically did this after the PolyHeme study," Triner says. "We thought the emergency department patients were the best surrogate for actual patients to be enrolled from this population."

Researchers asked participants about the PolyHeme study, and found that awareness of the study was very low prior to the media scrutiny, he notes.

About half of the participants were surveyed after widespread media reports involving PolyHeme and participant awareness remained low — about 8%, he adds.

"Many previous studies that investigate community acceptance of waivers of informed consent in studies have all been done at community meetings, and there's a selection bias of who goes to these meetings," Triner says. "There are several articles showing nearly unanimous acceptance of waivers of informed consent among people who attend these meetings."

The survey's results raise questions about the use of opting out in such waiver cases.

"Intrinsic to the regulations surrounding those studies, people had to sign up if they didn't want to be enrolled in the emergency research," Triner says. "If only 4% of the population affected by the study is even aware the study exists, then how do the majority of people know to opt out?"

Alternately, opt-in registries would be impractical for researchers, he says.

"What happens is you're not going to reach a significant proportion of the population eligible for enrollment, and if you did reach them, they'd have to exercise the intent and actively enroll themselves on that registry for that particular study," Triner explains. "So from an investigator's standpoint, you would not enroll anybody, and you'd have very limited opportunity to

enroll patients.”

In the big picture, it’s important that resuscitation research continue so medical providers will have evidence on which to base emergency medical decisions, Triner says.

“I think we need to clarify social benefits vs. individual rights and risks, and there may be situations or conditions where it’s more important to do the study,” he says.

Reference

1. Triner W, Jacoby L, Shelton W, et al. Exception from informed consent enrollment in emergency medical research: Attitudes and awareness. *Acad Emerg Med* 2007; 14:187-191. ■

Survey reveals U.S. still split over right-to-die, PAS

More support right to die than support MDs helping

In the 10 years since Oregon passed its physician-assisted suicide (PAS) law, Americans have become more familiar with the idea of doctors assisting patients who wish to be allowed — or helped — to die. But though they’re familiar with it, the population is divided over whether PAS should be legal.

Just days before **Jack Kevorkian**, a former physician, was released from prison in Michigan after serving eight years for murder for providing an amyotrophic lateral sclerosis patient with the drugs he used to kill himself, the Associated Press (AP) released a survey report indicating that two-thirds of those surveyed believe there are times when patients should be allowed to die, but far fewer agree that doctors should help them die.

The AP/Ipsos survey also touched on the public’s opinion of Kevorkian’s conviction. Just over half (53%) said he should not have been jailed.

Other questions posed by the survey were:

- Whether it should be legal for doctors to prescribe lethal drugs to help dying patients end their own lives (the practice that is legal under Oregon’s PAS law) — 48% said it should be legal, and 44% said it should not be legal;
- If there are circumstances when a patient should be permitted to die, rather than kept alive by extraordinary means — 68% said there are

times when a patient should be allowed to die;

- Whether health care providers should do everything possible to prolong life in all circumstances — 30% said they should; and
- Whether respondents themselves would consider ending their own lives if they were terminally ill — 55% said they would not, and 35% said they would consider it.

PAS legislation has been proposed and defeated in the legislatures of Washington, Vermont, Wisconsin, and Hawaii. California has a bill moving through its legislature (as of May 2007), but Gov. Arnold Schwarzenegger has indicated his preference would be to put the measure to a ballot vote. Voters have turned down such legislation before in California, as well as in Michigan, Maine, and Washington.

The AP/Ipsos survey polled 1,000 randomly chosen adults who answered the questions by phone. The survey questions and results are available at www.ap-ipsosresults.com. ■



‘Lights... camera:’ Bill calls for videotaped surgeries

A bill under consideration in Massachusetts would require hospitals grant patients who request it the right to have their surgeries videotaped — a move that critics say would be expensive, difficult to implement, a violation of patients’ privacy, and distracting to surgical teams.

“Leona’s law” was introduced in January by state Rep. Martin Walsh (D-MA), who said he was spurred to act by the experience of a family friend whose mother, for whom the bill is named, died during hip surgery.

Hospitals and surgeons worry that it will create unnecessary expense and distraction for hospitals, another layer of privacy concerns, and

CE/CME answers

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

potentially a new tool for malpractice plaintiffs. Surgeons have pointed out that surgical errors constitute only a small percentage of medical errors, and furthermore, that most surgical errors happen within a patient's body, and a video camera set up in the surgical suite would be unlikely to capture such events.

Walsh, in comments to Boston media, acknowledged that the bill faces stiff opposition from the medical community. The bill originally called for all surgeries in all licensed hospitals in Massachusetts to be videotaped; Walsh modified the bill to require surgeries to be taped only upon a patient's request. At the time *Medical Ethics Advisor* went to print, the bill had not yet been heard in legislative committee.

The Massachusetts Hospital Association released a statement that the bill posed a "Big Brother-style intrusion into the surgical suite" and would prompt a "gotcha impulse" in people interested in filing lawsuits.

Videotape of surgeries — for which releases are obtained from patients beforehand — are often used in teaching hospitals and medical schools. However, the tapes are not available for patient use. ▼

Medical researchers not as unbiased as they think

Medical research scientists routinely make ethical value judgments that they aren't even aware of, according to a Weill Cornell Medical College research study reported in May's *European Journal of Epidemiology*. But the authors of the study say the ethical judgments don't always create bias, and they can result in better research.

The study finds that the framing of the research question, identification of the problem, as well as the design and methodology of the study are all subject to conscious or unconscious value judgments by investigators — for example, when research is conducted into racial health disparities.

"Epidemiologists must endorse particular public policy aims of their research in order to make methodological decisions throughout the research process," reports **Inmaculada de Melo-Martín**, PhD, MS, one of the authors of the study and an associate professor of medical ethics at Weill Cornell. "In the case of research into racial disparities, the researcher decides how to define race — whether by genetic markers or by census data. Both definitions are valid on their own, but in deciding which one to use, the scientist makes value assumptions about which would best promote the social aims of the research, such as elim-

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, you must complete the evaluation form provided at the end of each semester 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. ■

COMING IN FUTURE MONTHS

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■ Trials of emergency treatments without consent

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■ Should lifestyle bar blood donors?

■ Hospitals adopting conduct codes for doctors

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inating racial disparities.”

De Melo-Martín said many scientists “make these value judgments without being aware of it — while at the same time wrongly believing any such value-laden decisions automatically lead to bias.” To counteract that misconception, she suggests that training in epidemiology and other research fields include instruction relating to the ethical dimensions of research. (De Melo-Martín I, Intemann KK. Can ethical reasoning contribute to better epidemiology? A case study in research on racial health disparities. *Eur J Epidemiol* 2007; 22:215-221.) ■

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CME Questions

1. As the result of an investigation into growth attenuation treatments performed on a disabled child that revealed it violated state law in not seeking a court order, Children's Hospital and Regional Medical Center of Seattle is introducing safeguards to prevent future violations. The safeguards include which of the following?
 - A. A court order will be required for the three procedures (hysterectomy, surgical removal of breast buds, and hormone therapy) that make up the “Ashley treatment.”
 - B. The hospital's legal counsel will review and obtain a court order before any future growth attenuation procedures are scheduled.
 - C. The hospital will appoint an ethics committee member who has a “disability rights perspective.”
 - D. All of the above
2. Which of the following is NOT one of the four conditions that must be met for parents to refuse a medical treatment for their child and not face charges of neglect under Virginia's newly enacted “Abraham's law”?
 - A. The parents and child have made the decision jointly, and the child is at least 16 years old.
 - B. The child is sufficiently mature to have an opinion on his or her treatment.
 - C. The family has explored and considered other treatment options.
 - D. The parents believe in good faith that the decision is in the child's best interest.
3. In light of months of debate over Texas' futile care law, many hospitals say they are implementing in-house policies for proceeding on cases deemed to be futile that exceed what the current law requires.
 - A. True
 - B. False
4. In a recent survey of 1,000 Americans on their views on the right to die and physician-assisted suicide, how many respondents said they WOULD consider ending their own lives if they were terminally ill?
 - A. 25%
 - B. 35%
 - C. 45%
 - D. 55%