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Before evaluating its performance, measure ethics committee's standing

Does your institution understand and support its ethics committee?

Before an ethics committee takes the time and effort to evaluate its performance, the members might want to step back and examine its standing within the institution. How well integrated is it? Does it have support at all levels of administration? Even in large institutions, ethics teams might be surprised by how they are regarded.

Take, for instance, a major university-affiliated medical center where a large department developed and put into effect an end-of-life care policy completely without the knowledge of or input from the ethics committee.

"That says to me, 'Stop ... Think ... Why?'" says **Ann Mills**, Msc, MBA, co-director of the Program for Ethics and Policy in Health Care at the University of Virginia Center for Biomedical Ethics and Humanities. "The head of the ethics committee should have gone to the department head and asked, 'Why were we not asked for input? Are we not communicating effectively?'"

Mills, co-author of two books on health care organization ethics and an assistant professor of medical education at the University of Virginia, says an annual "how are we doing" evaluation is really the second part of revealing the effectiveness of an ethics committee. The first step is to find out the ethics committee's place in its institution, both from the committee's perspective and from the viewpoint of the rest of the institution.

A committee on paper only?

"You have to determine if your ethics committee has support at all levels of your institution's administration, and to have that they have to understand why the ethics committee is there, what it does, and how it is of significant benefit to the organization. Otherwise, it's there on paper only, just so that when The Joint Commission comes in, they can say, 'Yes, we have an ethics committee,'" says **Edward M. Spencer**, MD, director of developing health care ethics programs at the University of Virginia.

Ethics committees began springing up as fixtures in U.S. hospitals in the 1970s following the high-profile *Quinlan* and *Cruzan* end-of-life

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cases and stepped-up requirements by the federal government over institutions that conducted research involving patients or research subjects. In the early 1990s, the Joint Commission on Accreditation of Healthcare Organizations (now The Joint Commission) issued a standard requiring accredited hospitals to establish a “mechanism” by which ethical issues in patient care and professional education would be handled.

This vague standard was defined as a requirement to establish ethics committees, but created no guidelines for satisfying what an ethics “mechanism” should do.

“When ethics committees got started, they were created as a basic care entity and were there to protect the rights of patients and educate all levels of their institutions to the rights of patients,” Spencer

explains. “But now, patient rights are understood by every level of an institution, so the job of an ethics committee is no longer just that. What they have to do now is consider policy issues, and support from higher levels of the institution in asking them to do these things is extremely important.”

In its 2001 report on institutional ethics committees, the American Academy of Pediatrics (AAP) Committee on Ethics noted the increased scope of ethics committees at some institutions.

“Recent trends in the financing and provision of health care have raised concerns about the impact of institutional commitments such as managed-care contracts, integrated systems, and performance incentives on the care of patients,” the AAP committee wrote. “[Institutional ethics committees] are being looked to in some institutions as a venue within which these concerns might be addressed.”¹

Some ethics committees left out

Determining how your ethics committee is viewed by the institution is fairly easily determined, Mills says.

“If an ethics committee doesn’t have a budget, it can ask itself why,” she says. “If the reason is because the administration doesn’t take the ethics committee seriously, then that’s the real question that needs to be addressed.”

Likewise, the committee can look at who it reports to — if it’s a low-level hospital official that might be an indication of the importance the administration accords the ethics committee.

“Look around and look at who the senior, well-respected members of the organization are. Are any of them on the ethics committee?” Mills adds. “If you haven’t been able to attract to the committee the senior and well-respected members of the organization, you have to ask why you haven’t.”

Spencer says ethics committees are no longer strictly patient care bodies, and shouldn’t consider themselves as such. Ethics committee members should reflect the institution as a whole.

“Get someone from administration, someone from nursing administration — not just a nurse manager,” he suggests. “Anyone with an interest in ethics, no matter where they might be in the organization.”

While he says he is not prone to advocate for the use of consultants, Spencer says a consultant with experience in the organization of ethics committees can be extremely valuable in determining what role an ethics committee has in an organization, and what role it could have.

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"These preliminary issues have to be addressed first," Mills adds. "If those things are not in place, and if the ethics committee is not able to get them in place, I don't see how anyone will be interested in having an ethics committee developing policy."

Do administrators know what you do?

Traditionally, one of the duties of an ethics committee has been to educate the institution's employees on ethical issues. But Spencer says committees shouldn't neglect educating their hospitals on what the committee does, and its value to the organization.

"Ask senior administration officers how well they understand what the ethics committee does. Often, they don't understand at all," he says.

Spencer insists that ongoing education programs that involve all levels of the institution, from the board of directors down, are critical for both familiarizing the institution with the ethics committee and instilling the idea that the committee has an important role to play outside of patient care.

"Set up a one- to two-page checklist of things that an ethics committee should be involved in, and ask yourselves whether or not these things are being done, and if they aren't why they aren't being done," he says. "You may say, 'For our institution, maybe we don't need that aspect, but we should understand and pay attention to it, because maybe we would want to consider it for the future, or not.'"

That initial evaluation of what the ethics committee is doing and what it should be doing "will tell you a lot, and from there you establish the benchmarks for success," says Mills.

From there, the ethics committee and administration will be able to clearly see whether ethics have been treated as separate from the adminis-

tration of the health care organization — a division Mills says is "a myth."

"If the hospital is determining what kinds of large capital expenditures to do this year, shouldn't it also focus and be informed on the mission and values of the organization?" she asks.

Turnover can be good

Ethics committees should experience some degree of turnover, Spencer says, to include the insights of people who are interested in ethics and willing to contribute.

"Some committees do better with little turnover, but I think there needs to be some," he explains. "The ones that are more structured tend to be in bigger, more academic institutions, and there may need to be some specific turnover rate."

On the other hand, he says some committees may find that a specific turnover time or rate may not be the best practice.

"If someone is involved in doing some important work and they are turned over, you might never get that work back, so you have to have some flexibility when you're talking about turnover," he says.

Turnover should never involve an automatic rotation, where names are drawn arbitrarily for placement on an ethics committee.

"There has to be a biding interest in ethics, because it's a committee that does a lot of work," he cautions. "They have to be willing to do the work and to get a lot of education on their own, because sometimes there aren't enough resources for them to get the education they need as new members of an ethics committee."

Mills says those who study organizational ethics have recognized a growing difficulty in recruiting physicians to ethics committees, a trend that she says is disturbing.

"Because of the pressure that physicians are under now, they just don't have time to breathe. But without physicians on your ethics committee, you have a lack of credibility," she points out. "So I do think it behooves an ethics committee to think about the future generation of ethicists, and in making calculations about turnover to think about recruitment."

Mills says once an ethics committee and its institution know what the committee's role is and how best it can serve as many levels of the organization as possible, then a process of evaluating performance and effectiveness can be created.

"Often the people we teach [at the Center for

Suggested Reading

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Biomedical Ethics] are concerned with how to evaluate themselves and their committees, without standing back to see what the committee is really trying to do or not do," she points out. "Ethics programs need to be a part of the culture of a health care organization, not an isolated [entity]." (See "Suggested Reading," below.)

For evaluations to be meaningful, Spencer adds, "it's important for ethics committee members to buy into this idea that it's necessary for them to evaluate themselves, and to understand where they fit into the administration and into medical activities, and to formally decide they need to have an evaluation every year, two years, three years."

Evaluations should include some of the same questions time after time, so data and results can be compared from year to year, Spencer says.

"This process has to be more than just going to a meeting. It's having a half-day or several workshops to see where we are and where we're going."

Reference

1. American Academy of Pediatrics, Committee on Bioethics. Institutional ethics committees. *Pediatrics* 2001;107;205-209. ■

Is TV promoting fears about organ and tissue donation?

Donor advocates taking on Hollywood 'myths'

Families who balk at organ donation when faced with the death of a loved one may have been influenced by inaccurate portrayals of organ donation in television programs, Purdue University researchers suggest.

"Organ donation appeared as a primary storyline

on entertainment television in more than 80 television episodes of medical dramas, police shows, comedies, and daytime soap operas" in 2004 and 2005, according to **Susan Morgan**, PhD, associate professor of health communication at Purdue. "We found that none of these appearances presented organ donation in an accurate or positive light."

Morgan says the Purdue study is the most comprehensive look at how organ donation is portrayed on television, and demonstrates that TV gives an inaccurate picture of organ and tissue donation and collection. Morgan says that might be costing lives.

Organ donation stories promote fear

The most commonly portrayed inaccuracies are black markets for organs, doctors not saving a potential donor's life, organs being stolen from patients, and people with money receiving higher priority on waiting lists – all of which can create fear among those who view the programs, Morgan says.

Morgan's study, *The Power of Narratives*, suggests that inaccurate storylines about organ and tissue donation stop people from registering as organ donors. Organ donation advocates are taking Morgan's findings to Hollywood to encourage more truthful depictions of the procedures surrounding organ and tissue donations and transplants.

"Professor Morgan's research has encouraged us to put Hollywood on alert," according to **Tenaya Wallace**, director of Donate Life Hollywood, a campaign to eliminate the "stolen kidney" storyline and other inaccuracies from television and film. "The organ and tissue donation and transplant community has been upset by inaccuracies in the past, but we have not taken action. Now we have hard evidence that what viewers think about donation is directly related to what they see in television storylines."

Wallace says the issue is not just about creative license in writing television storylines.

"We want Hollywood writers, producers, and executives to consider the public health impact of their donation storylines," she says.

Morgan reports that television viewers, especially those who had not decided if they would register as donors, were highly influenced by what they saw on TV. She adds that viewers are sometimes ill-equipped to differentiate between reality and storylines about organ donation because they don't always have information or knowledge to counter information they glean from TV.

Donation storylines have appeared in medical and crime dramas including *CSI: NY*, *Numb3rs*,

Common myths about organ, tissue donation and transplantation

- People with money can unfairly move up on organ transplant lists.
- Doctors are able to “find” organs for patients.
- Organs are stolen from people and sold on the black market (the “stolen kidney” urban legend).
- People waiting for an organ hope that other people die so that they might live.
- Doctors waiting for an organ to transplant hope patients die.
- If a person is dying and someone else needs an organ, doctors will not make efforts to save that person’s life.
- Only “good” people deserve organ transplants
- Someone is a good person simply because he or she is an organ donor.
- Organ recipients take on the characteristics of their donor (transmutation).
- People won’t want a person’s “damaged” organs.

House, and *Grey’s Anatomy*, as well as in comedies such as *Scrubs* and the *George Lopez Show*. In early 2007, the first television drama centered primarily around the donation and transplantation process, *Heartland*, debuted.

“Hollywood is looking for drama and inspiration,” Wallace points out. “We understand that is why shows are increasingly turning to donation and transplantation as storylines.”

To help portray donation and transplantation accurately, Donate Life Hollywood will provide writers, producers, and network executives with

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- Morgan SE, Movius L, Cody M. The power of narratives: The effect of organ donation storylines on the attitudes, knowledge, and behaviors of donors and non-donors. Presentation to the annual meeting of the International Communication Association, San Francisco, CA, May 2007. Text available at www.purdue.edu/dp/rche/donatelife/Power_of_Narratives.pdf.

real-life stories of donation and a top 10 list of storylines that are most harmful to the public’s perception of the donation process. If television shows, movies, or commercials contain any of the top 10, Donate Life Hollywood will mobilize groups and individuals touched by donation to write letters. They also praise shows that are accurate and inspirational. (See “Common myths about organ and tissue donation and transplantation,” this page.)

“Similar efforts made a difference for how HIV and AIDS were treated in film and television in the 1980s, and breast cancer before that,” Morgan says. “Today, it also can make a difference in how organ donation is depicted.” ■

New hope for minimally conscious patients

Test case may change standard of care

The outlook for patients in a minimally conscious state (MCS) may have new potential, according to a team of physicians, scientists, and ethicists who used deep brain stimulation (DBS) to improve function in a man’s still-responsive brain networks.

The 38-year-old man had been unable to communicate or eat by mouth for more than six years, since sustaining severe brain damage from an assault. According to the findings of the New York-Presbyterian/Weill Cornell team that conducted the experimental procedure, the man now eats by mouth and can communicate with words and gestures. The use of thalamic stimulation has not been applied to this patient population before, the authors state.

Writing in a recent issue of *Nature*¹, lead author **Nicholas D. Schiff**, MD, says that if the results can be replicated in other patients, it might change the standard of care for under-responsive MCS patients. Most patients in MCS are in long-term nursing facilities and don’t receive rehabilitative therapy because of their lack of responsiveness and poor prognosis. Schiff, a neurologist and neuroscientist at New York-Presbyterian/Weill Cornell, developed the concept of DBS more than 10 years ago, and teamed with experts from JFK Johnson Rehabilitation Institute Center for Head Injuries in Edison, NJ, and the Cleveland Clinic Center for Neurological Restoration.

The patient who underwent the unique therapy has asked that he not be identified. However,

his mother released a statement in which she says that because of the DBS surgery and rehabilitation, her son “can eat, express himself, and let us know if he is in pain. He enjoys a quality of life we never thought possible.”

Prior to the use of DBS, researchers write, the patient demonstrated inconsistent communication, including only slight eye or finger movements. He also was fed through a tube. Now, he uses words and gestures, responds to questions quickly, chews and swallows food, and can perform some complex movements — including those required for drinking from a cup or brushing hair — that he was unable to accomplish before.

The DBS was accomplished by surgical implanting of electrodes into the brain to deliver electrical impulses. The procedure has been used to relieve the symptoms of conditions such as Parkinson’s disease, dystonia, obsessive-compulsive disorder, and depression. This first DBS procedure is part of a pilot study approved by the FDA that will include 12 patients in post-traumatic MCS.

“The work challenges the existing practice of early treatment discontinuation for this patient population and also changes the approach to assessment and evaluation of the MCS patient,” says Schiff.

Joseph Fins, MD, professor of medicine and director of medical ethics for New York-Presbyterian/Weill Cornell, says the results of this experimental treatment give hope that patients may “recapture a lost personhood as they regain an ability to communicate. This clearly speaks to an ethical mandate to further such clinical trials designed to improve function in these patients.”

MCS – Glimpses of consciousness

MCS, unlike persistent vegetative state (PVS) or coma, is distinct in that patients show intermittent signs of awareness and may even attempt to communicate using simple words or signals. However, these glimpses of consciousness are usually rare and fleeting.

The authors of the New York study say estimates are that 100,000 to 300,000 patients with traumatic brain injury are now diagnosed as MCS. Under the current standard of care, most do not receive active rehabilitation.

“We knew that some patients in MCS, including our subject, retain functioning brain networks above the brainstem,” explains Schiff. “Activity within these integrated neural networks is supported by cells in the central thalamus, which is

SOURCE

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thought to be one key to adjusting brain activity as it responds to cognitive demands.”

Schiff says while the outcome thus far in this study is encouraging, more study is necessary to know if other patients will benefit, and what the ultimate outcome for the study patient might be.

“Without further study, we have no means of knowing for sure that the functional improvements we have observed will be seen in other subjects, yet we expect that we will find other patients who will respond,” Schiff says. “We can say that this patient’s recovery of oral feeding and communication abilities was strongly linked to the DBS. But even more encouraging is the fact that the patient’s functional gains continued even during the off-phase [periods after the electrodes were implanted when DBS was not actively used], suggesting a carryover effect from treatment.”

Fins says that if the treatment continues to result in positive effects, “it will force us to take a second look at each case and — for appropriate patients — move away from the therapeutic nihilism that has so plagued this population, most of whom are ignored, receiving what is euphemistically described as ‘custodial care.’”

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1. Schiff ND, Giacino JT, Kalmar K, et al. Behavioral improvements with thalamic stimulation after severe traumatic brain injury. *Nature* 2007;448:600-603. ■

Telling pediatric patients when they are obese

Experts: MDs should be direct

Tip-toeing around the issue of childhood obesity does more harm than good, an expert panel of pediatric health professionals has decided, so doctors should stop using terms like “at risk of overweight” and instead tell parents clearly when their

children are overweight or obese.

The Expert Committee on the Assessment, Prevention and Treatment of Child and Adolescent Overweight and Obesity — convened by the American Medical Association (AMA), Department of Health and Human Services, and Centers for Disease Control and Prevention (CDC) — spent nearly two years debating and drafting a list of recommendations aimed at helping pediatricians and other health providers address the growing problem of childhood obesity.

The recommendations (see box, this page) cover the management of overweight and obese children, and include a directive that physicians should stop calling obese children “overweight” and overweight children “at risk of overweight.”

Benjamin H. Levi, MD, PhD, FAAP, a practicing pediatrician and associate professor of humanities and pediatrics at Penn State College of Medicine, says he hasn’t seen any data on how prevalent the practice of “sugarcoating” obesity language might be, but says it’s not difficult to see why doctors might choose euphemisms rather than direct — perhaps harsher — language.

“My guess is that there’s a big difference between talking to the parent alone, and talking while the child is in the room,” says Levi. “What this is is risk communication.”

‘Softening the blow’ to keep conversation going

While some physicians might skirt the issue of obesity by using euphemisms because they want to avoid having an uncomfortable conversation, Levi suggests that the more likely reason is that they don’t want to lose the opportunity for real progress in working with obese and overweight patients.

“Do I close down my opportunity if I tell mom that her kid is obese?” Levi asks.

Kelly Meade, MD, co-director of the Healthy Eating, Active Living (HEAL) program at Children’s

Hospital and Research Center in Oakland, CA, says physicians are also sensitive to the fact that there is a social stigma attached to being overweight.

“And having an overweight child can have an effect on the parents’ self-esteem, as well,” says Meade. “If you tell a parent that their child is obese and could suffer chronic health problems as a result, the parents can perceive that they are being told they are not good parents.”

Meade says a statewide survey conducted in California of 240 health care providers revealed that almost all — more than 90% — said they need training in strategies and skills for communicating with parents about children’s weight problems.

Doctors did not come up with the descriptions of overweight and “at risk of overweight” on their own — the terms come from CDC guidelines that may be outdated. The CDC is considering the expert panel’s recommendations and will decide whether to adopt them.

Levi says honesty is the best approach, but most physicians want to have the discussion in confidence with the parents, and that’s not always possible with a child in the examining room with the parent.

“However, many schools are doing these BMI [body mass index] report cards, and they don’t mess around,” Levi adds. “They send home a number and a score, and the parent comes in [to the pediatrician’s office], and says, ‘This says my child is obese,’ and then what the pediatrician has to do is figure out whether that’s true or not.”

Health risks demand direct approach

The expert panel’s recommendations come as the United States is experiencing dramatic rates of child obesity. According to a study by the National Survey of Children’s Health (www.cdc.gov/nchs/about/major/slaits/nsch.htm), the rate of childhood obesity more than tripled from 1980 to 2004.

Recommendations of Expert Committee on Childhood Obesity

- Physicians and allied health care providers should perform, at a minimum, a yearly assessment of weight status in all children, to include calculation of height, weight (measured appropriately), and body mass index (BMI) for age.
- Children ages 2 to 18 years, with a BMI of 95th percentile or greater for age and sex, or BMI exceeding 30 (whichever is smaller), should be considered obese. This term replaces “overweight.”
- Children with BMI 85th percentile or greater, but less than 95th percentile for age and sex, should be considered overweight. This term replaces “at risk of overweight.”
- Physicians and health care providers should address weight management and lifestyle issues with all patients, regardless of presenting weight, each year.

Source: Expert Committee on the Assessment, Prevention and Treatment of Child and Adolescent Overweight and Obesity.

SOURCES/RESOURCES

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- **Trust for America's Health**, 1707 H Street, NW, 7th Floor, Washington, DC 20006. Phone: (202) 223-9870. Obesity report, *F as in Fat: How Obesity Policies are Failing in America, 2007*, is available at www.healthymamericans.org/reports/obesity/2007.
- **Expert Committee on the Assessment, Prevention and Treatment of Child and Adolescent Overweight and Obesity**. Recommendations on the Assessment, Prevention, and Treatment of Child and Adolescent Overweight and Obesity, June 6, 2007. Available at the American Medical Association web site, www.ama-assn.org/ama1/pub/upload/mm/433/ped_obesity_recs.pdf.

About 17% of American children are obese, and one-third are overweight, using the committee's recommended definitions. Health risks related to overweight and obesity include diabetes, high blood pressure, cholesterol problems, musculoskeletal injury, and other ailments more commonly found in adults.

Besides recommending changes in terminology, the expert panel urges assessing weight and body mass index at least yearly, and evaluating eating habits and activity levels at all well-child visits.

The recommendations are posted on the AMA's web site, and have been endorsed by the American Academy of Pediatrics, the American Dietetic Association, the American Academy of Child and Adolescent Psychiatry, and the American College of Preventive Medicine. ■

No-consent study raises concern over patient rights

Studies resurrect PolyHeme worries

Health care providers are watching cautiously as the federal government undertakes an ambitious \$50 million, five-year research project that will employ a controversial arrangement that avoids the traditional informed consent process.

Supporters of the study say the approach is necessary and carefully structured to protect patient rights, but detractors say it goes against hard-fought protections against conducting medical treatment on people without their knowledge.

The project will involve more than 20,000 patients in the United States and Canada. It is designed to improve treatment after car accidents, shootings, cardiac arrest, and other emergencies. The studies, organizers say, are the best way to improve treatment of trauma patients — specifically, in resuscitating of patients whose hearts stop, stabilizing patients in shock, and minimizing damage from head injuries.

In the studies, providers would randomly infuse some head trauma patients with hypertonic saline solutions, with or without dextran; emergency medicine providers would randomly try cardiopulmonary resuscitation in some cardiac arrest patients, and use electrical defibrillators in others.

Myron Weisfeldt, MD, chair of the department of medicine at the Johns Hopkins University School of Medicine in Baltimore, who is overseeing the project, says he believes in informed consent as strongly as any other health professional, but explains that this research could not be done if the researchers first had to obtain consent. And, he explains, the research is not being done without consent of any kind. It is important, he says, to understand that the researchers first must obtain approval from the community and from the local health care provider's institutional review board (IRB).

Weisfeldt says researchers complete a "community consultation" process before beginning. Local organizers try to notify the public about the study and gauge the reaction through public meetings, telephone surveys, Internet postings and advertisements, and stories in local media. Anyone who objects can get a special bracelet to alert medical workers that they refuse to participate.

"Federal regulations allow this to happen only in very specific circumstances, so there is no need to worry that this is going to be the way researchers conduct all medical research," Weisfeldt says. "I don't believe this research poses any threat."

Reason for concern

"Studies like the recently suspended PolyHeme [blood substitute] protocol put pressure on the key fault lines in research ethics," commented **Kenneth Richman**, associate professor of philosophy and health care ethics at Massachusetts College of Pharmacy and Health

Sciences. "We desperately want data on how to help trauma patients, but we also believe that patients should not be enrolled in studies without their explicit permission."

Richman says ethicists call this a conflict between beneficence and respect for persons, and says most medical research involves this conflict to some degree.

"Each study has to be examined in the context of available data and applicable guidelines, and people are concerned that scientists and review committees got it wrong in the case of the PolyHeme study," he says.

The study of PolyHeme, manufactured by Northfield Laboratories in Evanston, IL, was criticized for putting trauma patients at risk without consent. As in the current research, controversy arose from the fact that the participants in the PolyHeme study were incapable of giving their consent due to the nature of their injuries.

The only way to opt out from the PolyHeme study was by wearing a special bracelet prior to needing emergency care. After criticism from patients' rights advocates, the FDA launched a review of the entire program that permits experiments to be done without consent in emergency situations but sanctioned the current project under similar terms.

There is good reason for concern with such projects, says **Fay Rozovsky**, JD, MPH, DFSHRM, president of the Rozovsky Group, a risk management firm in Bloomfield, CT. She says the protections for patient rights built into the proposed trauma treatment studies are ineffective.

For starters, she expresses great concern over the idea that patients are protected by having the researchers inform the community as a whole.

SOURCES

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"That's a fallacy. We are a very mobile society, and when you're talking about testing treatments in an emergent situation, there is no way to know if that individual received the information," she says.

Consent difficult to obtain

The researchers say the work will help them find better treatment methods, but that informed consent cannot be obtained because these patients often are unconscious and families, if they are available, are too upset to give true informed consent.

"Can you imagine trying to get informed consent from a spouse who was also in the car accident and may or may not be injured herself? We could give her some papers and explain what we're doing, but would that really be informed consent?" Weisfeldt says.

"It's taking us down a slippery slope," Rozovsky counters. "It is trodding on the very autonomy of the individual. Some people may not want to be the recipient of a test article when they are in extremis, and we are taking away a liberty." ■

Fears of stigma keep HIV patients from getting care

It's not what you feel, but what you show

The mere perception that a physician is stigmatizing patients for carrying the AIDS virus can discourage HIV-infected people from seeking proper medical care, according to researchers at the University of California at Los Angeles.

At issue, says **Janni J. Kinsler**, PhD, the study leader and a researcher in general medicine at UCLA, is not what physicians' personal feelings and biases are, but rather how they behave outwardly to their patients.

According to Kinsler, up to one-fourth of patients she and her colleagues surveyed in the Los Angeles area reported feeling stigmatized by their health care providers, and this perception was also linked to low access to care among these patients, a large proportion of whom are low-income and minorities.

"Whether or not it is actual stigmatization is hard to measure, because it's coming from the patients that we interviewed," Kinsler explains. "The point is that these people feel that way, and that's bad enough, because they're less likely to seek the care they need."

HIV-positive people in Los Angeles County were surveyed for the study, with initial baseline interviews taking place between May 2004 and June 2005 and follow-up interviews conducted six months later. Of the 223 respondents, 80% were male, 46% were African-American, and 40% were Latino. Nearly three-quarters had a high school education or less; half had annual incomes below \$8,000; and 46% did not have insurance. In addition, 54% of the patients reported that they became infected through homosexual contact, 30% through heterosexual contact, and 16% through intravenous drug use.

Kinsler explains that there are two types of stigma: external or public stigma, and personal or perceived stigma. The latter refers to individuals' anticipated fears of societal attitudes or discrimination because of their HIV infection.

Researchers questioned patients during the baseline interviews and follow-up, asking:

Since you contracted HIV, has any health care provider:

- been uncomfortable with you?
- treated you as inferior or in an inferior manner?
- preferred to avoid you?
- refused to serve you?

Patients were also asked about their access to health care: whether they had gone without medical care due to expense, if medical care was conveniently located, whether they could obtain medical care whenever they needed it, if they had easy access to medical specialists, if emergency care was easily obtainable, and if they could be admitted to hospitals with no trouble.

The researchers found that at baseline, 26% of the patients reported at least one of the four types of perceived stigma from a health care provider, and 19% reported the same at follow-up. Also, 58% claimed low access to care on at least one of the six relevant questions at baseline, as did 57% at follow-up.

"Most importantly, we found that those who

SOURCE

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perceived stigma from a health care provider had more than twice the odds of reporting low access to care, even after examining the effect prospectively and adjusting for a host of sociodemographic and clinical characteristics," the researchers reported.¹

Perceived stigma "could greatly affect [patients'] use of needed medical services, including antiretroviral therapy." Because of this, patients may seek medical care only when their illness has progressed to a more severe stage, leading to more intensive medical interventions, hospitalization, and earlier death.

The next step is to investigate whether physicians are in fact stigmatizing these patients, Kinsler said.

"It may be easier to reduce stigmatizing behavior than prejudiced attitudes, and to reduce overt acts of stigma such as refusing to provide care, than to change subtle behaviors, such as those that convey discomfort with HIV-infected patients," Kinsler and her fellow researchers write. "Research is needed to improve our understanding of how health care providers' behaviors can negatively affect patients' experiences, and effective strategies must be developed to reduce perceived and public stigma in health care."

Reference

1. Kinsler JJ, Wong MD, Sayles JN, et al. The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care and STDs* 2007;21:584-592. ■

Religion a factor in referring to psychiatrist

Religion can interfere with 'connecting' to patient

Religion — or lack of religious beliefs — is a factor in the choice of psychiatry as a profession and in whether some physicians refer their patients to psychiatrists, according to a physician who has undertaken research on medicine and religious beliefs.

"Something about psychiatry, perhaps its his-

CME answers

13. C; 14. A; 15. B; 16. C.

SOURCE

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torical ties to psychoanalysis and the anti-religious views of the early analysts such as Sigmund Freud, seems to dissuade religious medical students from choosing to specialize in this field," according to **Farr Curlin**, MD, assistant professor of medicine at the University of Chicago.

Curlin's survey of the religious beliefs and practices of American physicians has found that psychiatry is the "least religious" of all medical specialties. Among psychiatrists who have a religion, more than twice as many are Jewish and far fewer are Protestant or Catholic — the two most common religions among physicians overall — he says. Curlin's findings are published in the September 2007 issue of *Psychiatric Services*.

The survey revealed that religious physicians, especially Protestants, are less likely to refer patients to psychiatrists, and more likely to send them to members of the clergy or to a religious counselor.

"Previous surveys have documented the unusual religious profile of psychiatry," Curlin explains. "But this is the first study to suggest that that profile leads many physicians to look away from psychiatrists for help in responding to patients' psychological and spiritual suffering."

And because psychiatrists see patients struggling with emotional, personal, and relationship problems, he continues, "the gap between the religiousness of the average psychiatrist and her average patient may make it difficult for them to connect on a human level."

Curlin and colleagues surveyed 1,820 practicing physicians from all specialties in 2003, including an augmented number of psychiatrists; 1,144

(63%) physicians responded, including 100 psychiatrists. (To read more about Curlin's findings on the role of religion in medicine, see "Controversial treatments: Where does religion fit?" *Medical Ethics Advisor*, April 2007.)

Survey responses showed that while 61% of all American physicians were either Protestant (39%) or Catholic (22%), only 37% of psychiatrists were Protestant (27%) or Catholic (10%). Twenty-nine percent were Jewish, compared to 13% of all physicians. Seventeen percent of psychiatrists listed their religion as "none," compared to only 10% of all doctors.

Curlin's survey also included an anecdote designed to present "ambiguous symptoms of psy-

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. ■

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CME Questions

13. Regarding turnover on an ethics committee, what does Edward Spencer, director of developing health care ethics at the University of Virginia's Center for Bioethics, suggest?
 - A. Appoint a turnover schedule and adhere to it.
 - B. Resist change on an ethics committee, and let an established team work uninterrupted.
 - C. Incorporate some degree of turnover to allow fresh energy and viewpoints to contribute.
 - D. Appoint new members to the committee by random selection.
14. According to Purdue University researchers, more than 80 television episodes of medical dramas, police shows, comedies, and daytime soap operas in 2004 and 2005 depicted storylines involving organ donation and transplantation. How many episodes did researchers find depicted organ donation in an accurate light?
 - A. none
 - B. one-third
 - C. half
 - D. all
15. An expert committee convened to make recommendations regarding the management of overweight and obese children suggests eliminating "at risk of overweight" when referring to children who have a BMI for their age of 85th percentile or greater.
 - A. True
 - B. False
16. According to a survey of U.S. physicians on how religion factors into their practice of medicine, how many physicians said they would refer a grieving patient to a psychologist vs. a clergy member or other religious counselor?
 - A. 25% to a psychiatrist or psychologist, 50% to a clergy member
 - B. 12% to a psychiatrist, 25% to clergy
 - C. 56% to a psychiatrist, 25% to clergy
 - D. 50% to a psychiatrist, 50% to clergy

chological distress" as a way to measure the willingness of physicians to refer patients to psychiatrists.

"A patient presents to you with continued deep grieving two months after the death of his wife. If you were to refer the patient, to which of the following would you prefer to refer first? A psychiatrist or psychologist, a clergy member or religious counselor, a health care chaplain, or other."

Overall, 56% of physicians indicated they would refer such a patient to a psychiatrist or psychologist, 25% to a clergy member or other

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religious counselor, 7% to a health care chaplain, and 12% to someone else.

Although Protestant physicians were only half as likely to send the patient to a psychiatrist, Jewish physicians were more likely to do so. Least likely were highly religious Protestants who attended church at least twice a month and responded to the survey that they looked to God for guidance "a great deal" or "quite a lot." ■