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OCTOBER 2004

VOL. 20, NO. 10 • (pages 109-120)

Patients' spirituality: Should it play a role in their care?

Provider role uncertain when patients want to discuss beliefs

A nurse checks in on a 72-year-old patient recovering from pneumonia and, after checking her vital signs, asks if there's anything the patient needs.

Instead of asking for water or a snack, the patient replies, "Will you pray with me?"

What is the appropriate answer? What if the patient is Christian and the nurse or doctor is Jewish, Islamic, or holds no spiritual beliefs?

Standard medicine is, for the most part, less in tune to patients' spiritual needs, with physicians, nurses, and therapists absorbed instead in the sometimes monumental clinical tasks necessary to stabilize or heal a patient's body.

But when a patient indicates that his or her primary need is spiritual, medical staff sometimes find themselves searching for the appropriate response.

"The physician doesn't have the training and is pressed for time," says **Lisa Lehmann**, MD, assistant professor of medical ethics, department of social medicine at Harvard Medical School and an instructor at Brigham and Women's Hospital in Boston. "It's something they probably aren't comfortable doing. A discussion of someone's spiritual beliefs takes time, and most physicians don't have the time built into their schedules."

Physicians and nurses commonly are asked to pray for a patient or to lead a patient or family in prayer. The clinicians may feel conflicted and uncertain about how to be supportive to the patient, respect professional and personal boundaries, and remain true to their own religious beliefs.

The role of spirituality — that of the patient and of the medical staff caring for the patient — in medicine is a controversial one. Opinions diverge over whether prayer and spirituality actually can help in a patient's physical recovery, and whether clinical staff should encourage, discourage, or ignore spirituality in treating patients.

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More accepted, ethicists say, are the positive effects that strong religious beliefs can have on patients' emotional health and outlook.

How to respond to patient requests

According to **Kate Kwiatkowski**, at the End-Of-Life Physician Education Resource Center, there are options that allow a physician or nurse to

support a patient's emotional needs while maintaining the integrity of his or her own beliefs.

"It is entirely appropriate for physicians to pray if they feel [comfortable doing so]," she says.

Kwiatkowski suggests that the clinician who is uncomfortable praying with or for a patient may lend support by sitting quietly and providing company to the patient while he or she prays, without actively participating and endorsing a particular belief system. This might be a good choice when the physician or nurse does not hold the same spiritual beliefs as the patient, or when the caregiver feels that to offer spiritual care is violating a professional boundary.

Simply declining the patient's request, respectfully, is another option. The physician or nurse should do so in a way that lets the patient know that he or she is not being rejected, but that the clinician does not feel comfortable lending spiritual support. Calling in a hospital chaplain, if the patient agrees, is one resource for meeting patients' spiritual needs.

What a doctor or nurse should not do is try to impose his or her own religious beliefs on a patient. If willing to lead a prayer, a health care provider should offer a nondenominational prayer, including neutral, inclusive terms such as "God" rather than Jesus, Allah, or Buddha, the End-of-Life Physician Education Resource Center advises. And asking for God's support, rather than for a particular outcome (particularly when a patient is near death), is advisable.

Prayer — a useful adjunct?

Researchers have reached vastly different conclusions about what role religion should play in patient care. Studies, including a 1999 study published in the *Archives of Internal Medicine*, show that there is a significant benefit to intercessory prayer (others praying for a patient). The 1999 study examined patients admitted to a coronary care unit and found that prayer on the patients' behalf was a "useful adjunct" to their medical care.¹

But when debating religion or alternative medicine, other studies do not reflect favorable results. A 2001 study published in *Mayo Clinic Proceedings* reports that researchers found intercessory prayer has "no significant effect on medical outcomes" in a coronary care unit.²

A 2001 report on a study in the *American Heart Journal* found that, while results were not statistically significant for any of the outcome

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

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Statement of financial disclosure: In order to reveal any potential bias in this publication, and in accordance with Accreditation Council for Continuing Medical Education guidelines, board members have reported the following relationships with companies related to the field of study covered by this CME program. Dr. Cranford, Dr. Hofmann, and Ms. Rushton report no consultant, stockholder, speaker's bureau, research, or other financial relationships with companies having ties to this field of study. Dr. Banja reports receiving grant funding from the Agency for Healthcare Research and Quality. Dr. Derse, Mr. Guss, and Mr. Miller did not provide disclosure information.

This publication does not receive commercial support.

Subscriber Information

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

Subscription rates: U.S.A., one year (12 issues), \$489. Outside U.S., add \$30 per year, total prepaid in U.S. funds. Discounts are available for multiple subscriptions. For pricing information, call Steve Vance at (404) 262-5511. **Back issues**, when available, are \$78 each. (GST registration number R128870672.)

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Editorial Questions

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comparisons employed in the study of 150 coronary care patients, “the lowest complication rates were observed in patients who received off-site intercessory prayer.”³

The evidence that many patients *believe* that there are benefits from prayer is more important than whether there are data proving that such benefits actually exist.

Findings published in the July/August 2004 issue of *Annals of Family Medicine* revealed that 83% of the 921 adults included in a study want to discuss their spiritual beliefs with their doctors. The study cites evidence that patients who describe themselves as more spiritual or religious have lower mortality rates and overall better health. In this study, the patients at five family practice offices in Ohio were asked to rate their spirituality on a scale of 1 to 5, and to describe how their beliefs play a role in their health care decisions.

Participants in the survey said they found discussion of religion most acceptable when they were dealing with a life-threatening illness or impending death of themselves or loved ones. The authors of the study cite ethical conflicts, lack of training, and reluctance to venture outside the bounds of proven medicine as some reasons physicians do not more readily engage their patients in discussions of faith.

What patients want vs. what they get

In the Ohio study, respondents indicated that they were not getting what they wanted from their doctors, in terms of spiritual discussion.

When asked what kind of discussion they wanted, 63% of the respondents said they wanted their physicians to ask about their spiritual beliefs, if the situation warranted it (serious illness, illness of a loved one, etc.). Twenty percent said they always want their physician to know about their beliefs, and slightly fewer (17%) said they never want to discuss spiritual matters with a physician. Respondents were least likely to want to discuss their beliefs during routine examinations.

Even though 83% of those who participated in the study wanted at least some kind of physician interest in their spiritual beliefs, only 9% of the respondents said that a physician has ever asked about their beliefs. However, 18% said they have initiated discussions of their spiritual beliefs with physicians.

The 83% who said they want to discuss spirituality with their doctors gave several reasons for wanting to share that information with their physicians, so that:

Models for Gathering Spiritual History

HOPE

- H:** Sources of hope, meaning, comfort, strength, peace, love, and connection
- O:** Organized religion
- P:** Personal spirituality and practices
- E:** Effects on medical care and end-of-life issues

FICA

- F:** Faith and Beliefs (What are your beliefs? Are you spiritual or religious?)
- I:** Importance and Influence (Do your beliefs play an important role in your life and decision making?)
- C:** Community (Are you part of a spiritual or religious community?)
- A:** Address (How do you want your spiritual beliefs addressed by your health care team?)

Source: Puchalski CM. Spiritual assessment tool. *J Palliat Med* 2000; 3:131.

- The doctor will understand how their beliefs help them deal with their illness or injury.
- The doctor will understand how their beliefs influence their decisions about their care.
- They think that, if their doctors know their beliefs, they will use that information to determine how to take care of the patients.
- They believe that, if their doctors know their spiritual beliefs, the physicians will be more compassionate and encourage hope.

How should clinicians respond?

Whether they find any scientific merit to prayer or spiritual discussion in the recovery of patients, researchers generally find no harm in the discussion. This leaves the question of the individual physician or nurse should handle prayer requests from patients.

Initiating prayer or a discussion of spiritual beliefs by the clinician, however, could carry ethical problems because there may be implied pressure on the patient, who may be not inclined to pray but feels it necessary because the physician responsible for his care has suggested it.

Some authors blame physicians' reluctance to deal with patients' spiritual lives on lack of training and guidance. They don't know what to do because

SOURCES

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they might never have been taught what to do.

"Part of the challenge is finding the time, but it's also getting providers comfortable with doing it," says Lehmann. "There's a lot of controversy among physicians as to how that kind of information is going to be incorporated into a patient's treatment plan, and whether it even should be incorporated into the plan."

Guidelines developed by the Association of American Medical Colleges are partially responsible for about 70% of U.S. medical schools that now offer courses relating to spirituality and health. Many also include sections on taking a spiritual history — that is, including questions about a patient's beliefs during the patient history which is completed at the initial contact (well visit or emergency intake) with that patient.

"There's increasing emphasis or awareness amongst medical educators on incorporating a spiritual history along with the usual physical history," Lehmann says. She points out that simple question formats, such as the HOPE and FICA models, are popular methods for incorporating spiritual history with physical history for a patient. The HOPE mnemonic has long been used in medical schools, and the FICA questions, which were developed by a physician, have become widely used since they were first published in 2000. (See **Models on p. 111.**)

The fact that most medical schools are adding at least one session on spirituality is a sign that the medical community is more sensitive to patients' spiritual needs, Lehmann says.

"But even though they're devoting the time to it now, it will be years before we see the effects of it," she points out. "It will take a long time to get the full effect."

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Postmortem procedures controversy unresolved

Value of training vs. consideration of family, ethics

From the time of the ancient Greeks, learning about the human body and how to manipulate and treat it has involved the use of cadavers. Western medicine still relies on the use of cadavers for teaching purposes, but one aspect of the use of dead bodies has emerged in recent years as a point of debate: Should medical personnel obtain consent from family members before practicing medical procedures on a newly deceased person?

Ethicists, medical organizations, clergy, and lawyers have weighed in on the matter, with little consensus. Most agree that having consent — either from the person before he or she died, or from his or her family upon death — is the ideal situation. However, barring easily and quickly obtained consent, opinions are split on whether medical personnel should conduct procedures on a body without the knowledge of family members.

The issues raised against requiring consent include: difficulty identifying some patients (particularly in emergency cases), fear that the family would refuse consent, concern about adding to a family's grief, and expediency. Those in favor of requiring consent say that it reduces legal liability, is more considerate of the family and the deceased, and is simply the right thing to do.

Is harm done if consent is not obtained?

The American Medical Association (AMA) conducted a poll of medical students to find out students' thoughts on performing procedures on newly dead patients. During their training, medical students are sometimes asked to practice procedures on recently deceased patients. According to the AMA, nearly 40% of critical care medical training programs in the United States employ

practicing on newly deceased patients. The procedures include endotracheal intubation, placement of central venous catheters, surgical venous cut-downs, and thoracotomies.

According to the AMA survey, 54% of the students said the practice was acceptable as long as patients were told during admission that they may be subject to postmortem procedures. Seventeen percent said the procedure is not acceptable to them because they do not believe the educational value is great enough, and an equal number said they disapprove because family members usually are not made aware of the procedures.

Mary Beth Foglia, RN, MSN, of the Veterans Health Administration National Center for Ethics in Health Care in Washington, DC, says there is conflicting evidence regarding the necessity of performing procedures on cadavers at all.

"We found no evidence to support the claim that clinical training would be severely compromised if, in fact, fewer corpses were available as a result of requiring consent," she says. "The majority of authors publishing in respected journals concluded that the training advantage of practicing on the newly dead is definable, but limited.

"Plus, we know there are many training programs that simply don't practice on the newly dead, and no one has suggested that these programs produce unqualified clinicians," added Foglia.

Consideration for the family aside, there are religious and cultural implications, ethicists point out. Practicing medical procedures on a dead body may violate that person's religious or cultural customs regarding treatment of the body after death. Some religions and cultures believe that what happens to the body immediately following death has implications for the afterlife.

Medical associations weigh in

Recognizing that while a dead body might not be harmed by procedures done postmortem, the AMA in 2001 adopted a nonbinding policy that warns against performing procedures without consent.

"[Institutional] policies should consider rights of patients and their families, benefits to trainees and society, as well as potential harm to the ethical sensitivities of trainees, and risks to staff, the institution, and the profession associated with performing procedures on the newly deceased without consent," the AMA policy states.

The AMA urges physicians to inquire about the deceased's expressed preferences concerning postmortem procedures. Physicians should

obtain consent, or, if unable to establish either the patient's preferences or consent from the family, they should avoid postmortem training practices on deceased patients.

"In the event postmortem procedures are undertaken on the newly deceased, they must be recorded in the medical record," the AMA policy states, addressing one of the major ethical issues involved in postmortem practice — evidence that physicians rarely tell patients' families that postmortem procedures were performed.

"Some health care professionals report feeling angry — not so much by the practice of training on the newly dead, but rather, that the practice of training on the newly dead is concealed from families and the public," Foglia says.

Concern that asking the families beforehand might result in refusal for the practice might be based on an incorrect assumption, she notes.

"In general, we see willingness on the part of patients and next-of-kin to allow postmortem practice so long as consent is obtained," Foglia adds.

Some teaching hospitals have adopted the position that lack of a "yes" does not mean "no." In these institutions, postmortem procedures may be performed unless there is a previous refusal from the patient or family, and teaching may proceed if the family is unavailable for consent, according to a committee report by the American College of Emergency Physicians (ACEP).

Both the ACEP and the Society for Academic Emergency Medicine (SAEM) have studied the issue, because the emergency department is the scene of most practices on the newly dead.

ACEP's Ethics Committee released a report in 2003 that spelled out some of the issues in practicing on the newly dead, and concluded that more research is needed.

In a report published in a recent issue of the SAEM journal *Annals of Emergency Medicine*, SAEM's Ethics Committee strongly recommended that families be asked for consent before procedures are done on the newly dead. The SAEM report addresses, in particular, the need to avoid an appearance that such procedures are done secretly, out of consideration for the families and to maintain public trust in the medical profession.¹

The Emergency Nurses Association endorses teaching skills and practicing on the newly dead, but only if consent is obtained, while the British Medical Association and Royal College of Nursing issued a joint statement that practicing on the newly dead should be an exceptional practice, and may only be justified if the body

has severe head, neck, or facial injuries with the expectation that consent will be obtained from the family.

Foglia says some hospitals have skirted the consent issue by performing procedures on nearly dead patients before pronouncing them dead.

"*The Wall Street Journal* reported in 2002 that at one Midwestern hospital, emergency room physicians established an unwritten policy that they would no longer practice emergency procedures on the newly deceased without obtaining consent," she states. "But they now often use nearly dead patients to train the hospital's residents, but don't inform the family or ask for consent."

Foglia contends that this practice is indefensible from an ethical standpoint, and that teaching hospitals should set policies barring such procedures.

Legal considerations

The question of who owns a dead body has been debated for hundreds of years. The general rule under British and American law is that bodies and body parts cannot be considered property.

However, tort claims resulting from postmortem procedures abound and cite such injuries as intentional infliction of emotional distress, intentional mishandling of a dead body, abuse of a dead body, negligence, and infliction of emotional or mental distress.

To recover on an action for intentional infliction of serious emotional distress, specific legal elements must be proven, including proving that the practitioner intended to cause emotional distress or knew that his or her actions would cause distress, that the conduct was "extreme" and "outrageous," and that the distress was almost unendurable. While those criteria might be difficult to reach, some legal experts say there is a legal risk to doing postmortem procedures without consent.

Gregory P. Moore, MD, JD, a physician with Kaiser Permanente in Sacramento, CA and frequent author on medico-legal issues, says some recent cases are declaring that families do have property rights to deceased loved ones, and that to obtain consent before performing postmortem procedures "is probably prudent."

Moore co-authored a 2002 article in which he speculated that trends in emotional distress lawsuits give hospitals and clinicians reason for caution.

"It is undeniable that we are in a time of

SOURCES

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increased sensitivity to personal autonomy and individual rights as reflected in both the medical and legal arenas," Moore wrote. "Traditionally, courts have not viewed any true property rights in a dead body, but recently have been willing to relabel and thus change this dogma. While the legal community has argued over the classification of the rights of families in their loved ones' cadavers, there is no doubt that some kind of a right exists. Regardless of this technical analysis of the law, damages increasingly are being awarded for the emotional distress caused by mishandling of bodies. Medical liability insurance may not cover this type of transgression, placing physicians at significant personal risk if successful litigation ensues."²

Besides possible legal ramifications, the loss of public trust might be at stake, Foglia says.

"There is a strong presumption on the part of patients and families that health care professionals will tell them the truth about what they are going to do to the patient," Foglia says. "Families expect to be asked about practicing procedures on a recently deceased family member, and are often willing to give consent when approached.

"However, the practice as currently conducted is often shrouded in secrecy, known only to the clinicians engaging in it. This violates tenets of professional ethics such as disclosure and truth-telling and can contribute to undermining public trust in the integrity of health care institutions and providers."

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Peer ethics network created in Vancouver

Program puts frontline ethicists in every unit

It is a common reaction when a judgment call has to be made in any setting: We turn to the person next to us and say, “What would you do?”

When Providence Health Care system, a network providing health care at several sites in Vancouver, BC, was formed in 1997, the ethicist for the system saw an opportunity to build on that peer-adviser idea as a way to handle day-to-day ethical dilemmas. They created ethics mentors in every unit of every hospital in the system.

The Ethics Network was launched in 1999, and now is directed by health care ethicist **Bashir Jiwani**.

“When Providence came together, my predecessor, Kevin Murphy, [determined] what the ethics services would look like,” he recalls. “He decided that every unit, every area, [and] every program would have an ethics mentor.”

These ethics mentors were volunteers from the staff in those units. They were trained in medical ethics and were available anytime they were at work to help sort out ethical dilemmas as they arose.

“That person [was] a first line of support when an ethics question arose in the clinical setting,” explains Jiwani.

“So we had our mentors, and they were trained and sent back to their units at their institutions,” he continues. “The mentors at each institution [formed] ethics teams for their institution, to do some proactive kinds of work.”

Jiwani says response to the Ethics Network has been enthusiastic — at its inception, 90 staff volunteers went through two days of training. As of this year, 400 ethics mentors — including staff, physicians, and nurses — have been trained and sent back to their units to be used as resources when ethics questions arise.

After a year, the network received rave reviews for what hospital staff described as its “collegiality” — the process of working through ethics questions with colleagues gave employees more confidence in their abilities to deal with the situations.

Hospitals are places of life and death so, for hospital staff, ethical dilemmas aren’t just theoretical — they’re a challenging, practical part of everyday work, says Jiwani. And being able to rely on the mentors who are on the floors and in the units to help solve ethical questions that arise in their areas of specialty makes sense, he adds.

Ethics Network mentors can call on Jiwani for ethical questions that are beyond their level of expertise. But when it comes to minor situations, the peer ethicists are available on all shifts and in all units, and have, in many cases, been highly successful in carrying out the goals of the program.

He says the successes of the program stem from the individuals who act as mentors, rather than the situations or units where they work.

“You can see places where it’s working and others where it’s not, and it has much more to do with the people and their sensitivity for the work than it does with what department they are working in,” Jiwani adds.

Building on success, tweaking the weaknesses

As successful as the program has been in some respects, it is time to move on to the second phase, Jiwani says. That will allow the Ethics Network to build on its strengths while correcting some weaknesses.

“I have heard stories of some mentors feeling uncertain of what to do,” he says. “They say nobody ever asks them anything, and they don’t really have the power to jump in and say, ‘There’s an ethics issue here.’”

Future training will include more material to help the mentors better understand what to do with the new knowledge they have.

“We have some other challenges, as well,” Jiwani admits. “We have recognized that the folks who attend the seminars might not have been trained well enough to do the tasks we were asking them to do.”

Training is, by far, the greatest expense associated with the peer mentor system. But as the Ethics Network grew, Jiwani and Providence administrators realized they needed to give infrastructure some attention to allow the mentors to be most effective.

“The mentors were asked to do the work, but

SOURCE

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were not given the space on their units to do the work," he says. "The key is not just sending them to the educational programs and then saying, 'Go do it.' We have to find room for them to use their expertise."

The second phase of the Ethics Network includes working with managers on all the system's units to build up the ethics resources throughout the system. "We have some wonderful energy, and quite a few people with the sensitivity for ethics work, so now we are focusing on every specific program area and working with the leaders in those areas," Jiwani explains. "For example, we have a bunch of mentors in the eating disorders clinic, so now we want to work with the leaders of the program and say, 'Can we take one or two of these people out, give them more intensive training, and then create an infrastructure so these people are given the space to raise the questions ethics trains them to raise?'"

The Ethics Network at Providence is a home-grown ethics solution created by and for the facilities that make up the Providence network, but Jiwani says it can be tailored to work in systems or

institutions in other areas and of other sizes.

In fact, Jiwani copied it himself.

"Before I came to Providence, I was working as an ethicist in one of the regions in Alberta, [structuring] a regional ethics program," Jiwani reports. "I knew Kevin [Murphy], and knew what he was doing here, [so] I drew on that a great deal.

"That's one of the nice things about this — it's eminently translatable to other settings." ■

Handle organ procurement delicately with families

OPOs educate public, assist hospitals

One of the most difficult encounters for medical staff is simultaneously informing a family of the death of a loved one and bringing up the idea of donating organs and tissues. Staff awareness of resources to coordinate organ procurement — and the staff's attitude toward organ procurement — can make a big difference in an area's organ procurement rate.

An important resource at this critical time is the area Organ Procurement Organization (OPO). OPOs are nonprofit agencies overseen by the federal government, and each OPO is assigned to a specific territory. When a donor becomes avail-

Audio conference: Including children in clinical research

Children get sick. When they do, parents and pediatricians alike expect to employ just the right therapies, which often include a regimen of drugs, to treat their conditions. But are drugs known to be safe for adults, necessarily safe for children?

It has long been known that drug safety cannot be assessed based on studies with adults. So the FDA and the NIH has encouraged over the years, and even required, that clinical trials include children. But there is a right way and a wrong way to do it. The right way has to do with understanding the ethical dynamics and ensuring that all concerned understand the risks and benefits of involvement in a clinical trial.

Thomson American Health Consultants is offering an audio conference with the information necessary to help you recognize the ethical and regulatory issues related to working with children in clinical trials.

Getting Assent/Parental Permission for

Children Involved In Clinical Research, which will be held Thursday, Oct. 21, 2004, from 3 p.m. to 4 p.m. EST, will be presented by **Robert "Skip" Nelson**, MD, PhD, and **Alan M. Sugar**, MD.

Dr. Nelson is Associate Professor of Anesthesia & Pediatrics in the Department of Anesthesiology and Critical Care Medicine at the University of Pennsylvania School of Medicine, Children's Hospital of Philadelphia. He also is founder of the IRB Forum. Dr. Sugar is chairman of the New England Institutional Review Board and professor of Medicine at Boston University School of Medicine.

This program will serve as an invaluable resource for your IRB coordinators, chairs, and members, as well as principal investigators and clinical trial coordinators. Your fee of \$249 includes presentation materials, additional reading, and free continuing education. For more information, visit us at www.ahcpub.com, or contact customer service at (800) 688-2421 or by e-mail at customerservice@ahcpub.com.

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able and the OPO in that area is notified, the OPO recovers the organs and coordinates allocation of the organs or tissues to qualified patients.

But despite being a vital link in the transplantation process, the role of OPOs is not always clear to hospital staff, some studies indicate. According to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), many health care organizations experience problems during JCAHO surveys because staff are unsure about organ procurement guidelines, such as the time frame in which the OPO needs to be notified about an "imminent death." Because organs must be recovered quickly to be transplanted successfully in another patient, the OPO must be involved in a timely fashion or the organ may no longer be useful.

OPOs provide education and procurement

The primary function of OPOs is to coordinate the procurement and allocation of organs and tissues by evaluating potential donors, discussing donation with family members, and arranging for the surgical removal of donated organs. They also serve as educational resources by providing public awareness campaigns and education to clinicians and the general public to encourage organ donation.

Educating hospital staff can mean the difference between a family agreeing to donate tissue and organs, and rejecting the idea. A study published in 2001 in the *Journal of the American Medical Association* found that the time spent with an OPO coordinator was a strong factor in families' decisions to donate. The authors of the study concluded that the role of hospital staff should be limited to involving OPO staff early in the process and working under their direction to optimize the donation request, taking advantage of the experience of the OPO staff who are better prepared to work with the family than the hospital staff might be.

Hospital staff awareness of when to notify an OPO of a potential donor is key, as well. Hospitals must notify OPOs of pending death, rather than waiting until the patient dies. The OPO determines the medical qualifications for donation, and if the initial determination is positive, sends procurement staff to the hospital to evaluate the patient and to discuss donation with the patient's family.

Even though OPO staff are responsible for direct contact with the donor's family about making a donation, the hospital staff's attitude toward donation can be a critical influence. One

Best Practices for High Organ Donation Rates

1. Orient organizational mission and goals toward increasing organ donation.
2. Do not be satisfied with the status quo; innovate and experiment continuously.
3. Strive to recruit and retain highly motivated and skilled staff.
4. Appoint members to OPO board who can help achieve organ donation goals.
5. Specialize roles to maximize performance.
6. Tailor or adapt the organ donation process to complementary strengths of OPO and individual hospitals.
7. Integrate OPO staff into the fabric of high potential hospitals.
8. Identify and support organ donation champions at various hospital levels; include leaders who are willing to be called upon to overcome barriers to organ donation in real time.
9. Secure and maintain buy-in at all levels of hospital staff and across departments/functions that affect organ donation.
10. Educate constantly; tailor and accommodate to staff needs, requests, and constraints.
11. Design, implement, and monitor public education and outreach efforts to achieve informed consent and other donation goals.
12. Anticipate; don't hesitate, and call early even when in doubt.
13. Draw on respective OPO and hospital strengths to establish an integrated consent process. One size does not fit all, but getting to an informed "yes" is paramount.
14. Use data to drive decision making.
15. Follow up in a timely and systematic manner. Don't let any issues fester.

Source: U.S. Department of Health and Human Services; 2003.

health care system surveyed its staff to gauge understanding of the donation process, and found that potentially disruptive misconceptions abounded. After implementing an inservice program to educate staff, the hospitals in the system saw a marked increase in their donation rates.

OPOs say that while facilitywide education is desired, staff in trauma and emergency departments need focused training because the likelihood of staff in those departments being involved in donor situations is highest. While legal requirements vary from state to state (some states mandate that an OPO make the

first request to families of potential donors), involving a hospital chaplain or family minister can help ease fears about the process.

Health care and organ procurement professionals agree that public education is critical because making a decision on organ donation is more easily made before the need arises. If an informed decision is reached and the future donor shares his or her wishes with family, the burden is removed from the family at a time of crisis.

Researchers from the University of Buffalo's School of Social Work recently published a study in the journal, *Death Studies*, that showed public education on organ and tissue donations, when delivered at the middle school and high school levels, promoted family discussions about donations and ensured that accurate information on organ donation and end-of-life choices was conveyed. High school participants in the study reported that they felt "very prepared" or "somewhat prepared" to make those choices after participating in a program on organ donation.

The issue of expressed consent is a critical element of organ donation that must be emphasized to anyone involved in organ procurement.

According to the U.S. Department of Health and Human Services (HHS) "The Organ Donation Breakthrough Collaborative: Best Practices Final Report," (available at www.organ-donor.gov/bestpractice.htm), potential donor families are typically thrust into these circumstances in shock and in great need. An integrated OPO and hospital approach to meeting the wide range of needs of potential donor families also is more likely to result in an informed decision to donate. (See **Best Practices, p. 117.**)

Preparing the family for imminent death contributes to informed decision making and successful organ donation, the HHS report states. Further, during the consent process, OPO staff, often have hospital staff present to help answer questions from family members about brain death and organ donation. In the event that families initially refuse to donate, OPO staff will seek to determine whether the family is denying the request to donate at all, or is denying the request at that time for another reason, which may justify approaching the family again later.

A common misconception is that a signed donor card or driver's license is all that is necessary to carry out a person's wish to be a donor. Because there is no national donor registry, individual donors must share their decision with their families, and the families must give consent. Based on

studies indicating success of school-based public education on organ donation, HHS created *Decision: Donation — A School Program That Gives the Gift of Life*, a model instructional package for high schools that emphasizes the importance of organ and tissue donation and the need for teenagers to make an informed decision about whether to be a donor and share their donation wishes with their families.

Resources

- The Organ Donation Breakthrough Collaborative, U.S. Department of Health and Human Services. www.organ-donor.gov. Information on best practices as well as regional OPO assignments and the *Decision-Donation High School Program*.
- Life and death decisions: Using school-based health education to facilitate family discussion about organ and tissue donation. *Death Studies* 2004; 28:643-657. ■



Dying patients discuss physician-assisted suicide

Researchers in Oregon, the only state where physician-assisted suicide is legal, found that about 17% of that state's residents facing death have discussed having a physician help them end their lives. But **Susan Tolle, MD**, director of the Center for Ethics in Health Care at Oregon Health and Science University (OHSU) explains that only about 2% of dying patients actually formally request physician-assisted suicide. The study did not address possible reasons why so many fewer patients actually requested assistance than considered it. OHSU researchers found that 44% of the dying patients included in the survey were in favor of physician-assisted suicide, 15% stated they are neutral about it, and 41% said they oppose letting physicians help terminally ill patients commit suicide. Tolle reports in the September *Journal of Clinical Ethics* that patients most likely to consider physician-assisted suicide are younger, white, do not report having strong religious beliefs, and suffer from cancer. The Center for Ethics in Health Care at OHSU conducts research on all end-of-life issues, and

neither supports nor opposes the option of physician-assisted suicide. The study was funded by the National Institutes of Health and a grant from the Robert Wood Johnson Foundation. ▼

Public plea spurs new liver, plus some debate

A billboard advertising a cancer-stricken Houston man's need for a liver yielded what he hoped — a liver transplant — but has raised ethical questions about how donated organs are assigned. Todd Krampitz, 32, received his new liver in August after a family that read media reports about the Internet and billboard campaign his family conducted to locate a donor organ contacted LifeGift Organ Donation Center in Houston with a specific request that the liver be given to Krampitz.

The happy ending to Krampitz' story has a tinge of controversy, however. The United Network for Organ Sharing has decided to study public solicitation for organs although federal law permits directed donations of organs from deceased individuals. The Krampitz web site (www.toddneedsaliver.com) offers information on becoming an organ donor, and supporters of the idea point to the number of calls to organ donation centers that came following publicity of the Krampitz case. ▼

Medical schools tighten conflicts-of-interest standards

A recent study by the Association of American Medical Colleges (AAMC) indicates that U.S. medical schools have made significant progress since 2001 in clarifying and strengthening their financial conflicts of interest (COI) standards in clinical research, with 95% now having a policy in place that applies to all human subjects research.

In 2001, the AAMC issued guidelines recommending researchers with a significant financial interest not be permitted to conduct research on human subjects unless the researcher could

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demonstrate compelling circumstances to proceed, and made full disclosure to research subjects and in other communications. AAMC recently conducted a survey to assess the degree to which COI policies of the nation's accredited medical schools reflected the recommendations of the task force and responded to the changed circumstances of clinical research.

Despite this substantial progress, the survey results also indicate that certain policies and procedures still need more attention from the academic medicine community.

The AAMC survey found 81% of medical schools permit a researcher with a significant financial interest to conduct human subjects research when they find that compelling circumstances exist, 40% did not require researchers to disclose significant financial interests in oral presentations of research results, 9% did not include outside representatives on standing conflict of interest committees, and 41% of schools with standing committees did not include the evaluation of significant financial interests prior to final institutional review board approval. ▼

Video: How to talk about medical errors

Suggestions for dealing head-on with bad outcomes and medical errors are presented in

COMING IN FUTURE MONTHS

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CME Questions

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 certificate of completion. When your evaluation is received, a certificate will be mailed to you.

13. According to an Ohio study, at what point in their interaction with their physicians do patients who want to discuss their spiritual beliefs prefer to have that discussion?
 - A. When faced with a serious medical condition of their own
 - B. When a loved one is faced with a serious medical condition
 - C. During an initial physical examination, when no serious health conditions exist
 - D. Both A and B
14. According to Lisa Lehmann, MD, the effects of medical school training in spirituality are likely to be seen immediately.
 - A. True
 - B. False
15. According to an American Medical Association poll of medical students, how many of those surveyed said that practicing medical procedures on newly dead patients was acceptable as long as patients were told during admission that they may be subject to postmortem procedures?
 - A. 10%
 - B. 25%
 - C. 54%
 - D. 82%
16. After six years of utilizing its Ethics Network, Providence Health Care in Vancouver has identified which of the following features of the program?
 - A. Staff have reacted positively to working on ethics questions with colleagues.
 - B. Peer ethics mentors sometimes have found their training is not adequate for the tasks presented to them.
 - C. The health care system's infrastructure needs modification to allow the system to work fully.
 - D. All of the above

Answers: 13. D; 14. B; 15. C; 16. D.

"Discussing Unanticipated Outcomes and Disclosing Medical Errors," a videotape recently completed by **John Banja, PhD**, associate professor at Emory University Center for Ethics in Atlanta. The tape has been made available to hospitals throughout Georgia. The video is one of the products of a grant that was awarded to the Georgia Hospital Association Research and Education Foundation by the Agency for Healthcare Research and Quality in 2001.

The video includes a panel discussion among a hospital risk manager and two health care attorneys who tackle three clinical vignettes involving medical error, and a series of empathic communication techniques that can be useful to health professionals when they conduct "bad news" conversations. Banja said the video should be especially useful to health professionals who must engage in uncomfortable conversations such as those that follow unanticipated outcomes or medical errors.

The video is available for free on-line viewing at the Center for Ethics' web site, www.ethics.emory.edu. The suggestions contained in the tape are not meant to serve as legal standards or guidelines, but as recommendations only. For more information about the film, contact Banja by e-mail at jbanja@emory.edu, or phone (404) 727-4954. ■