

# Medical Ethics Advisor™

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## It's all in the timing: Joint Commission unveils pain management standards

*Patient awareness, physician education could work in your favor*

All your ethics committee needs right now is another set of standards, right? Actually, this set might give your committee the extra muscle it needs to help your facility focus on pain assessment and management. The new standards were released in August by the Joint Commission on Accreditation of Healthcare Organizations. They couldn't have arrived at a better time to help your committee educate staff on the need for increased awareness for pain management. Fear of unrelieved pain at death has always been a major concern

**"I recommend that frustrated caregivers in the hospital turn to the ethics committee for help in bringing about change."**

among patients. Physicians, however, have been hesitant to prescribe higher doses of medications for fear of prosecution from authorities or, worse yet, hastening a patient's death. Ethics committees could serve as harbingers of change as hospitals start focusing on meeting the new standards. "Undertreatment of pain is clearly an ethical issue. I recommend that frustrated caregivers in the hospital turn to the ethics

committee for help in bringing about change," says **June L. Dahl, PhD**, professor of pharmacology at the University of Wisconsin-Madison Medical School. Dahl also serves as executive director of the Wisconsin Cancer Pain Initiative, which helped develop the standards for the Joint Commission.

"Pain is the primary reason patients seek medical attention. But when pain goes unrelieved, it has no redeeming virtue — it is soul-destroying," Dahl says. Clearly, ethics committees can be involved in helping prepare a mission statement that addresses pain management in the facility. They also can develop a patient rights or patient responsibilities handbook, she adds.

There's no doubt the tide is turning in terms of how legislators view pain management. The calls for effective pain management have reached Capitol Hill. Sen. Don Nickles (R-OK) and Rep. Henry Hyde

# CME

questions

1. June L. Dahl, PhD, professor of pharmacology at the University of Wisconsin-Madison Medical School, says undertreatment of pain is clearly an ethical issue. She recommends:
  - A. Frustrated care providers turn to the ethics committee for help in bringing about change.
  - B. Teaching patients about their disease and what kind of pain they should expect throughout the course of the disease.
  - C. Teaching staff the importance of not overmedicating patients with opioids.
  - D. All of the above.
2. The Joint Commission on Accreditation of Healthcare Organizations' new pain management standards, according to Ira M. Byock, MD, research professor at the University of Montana and principal investigator of the Missoula Demonstration Project, are necessary because:
  - A. Staff don't see the importance of measuring pain.
  - B. An oversight agency's involvement emphasizes the importance of effective pain management.
  - C. Long-term care facilities need strict enforcement in the area of pain management.
  - D. All of the above.
3. One of the reasons the Medical College of Wisconsin placed resources available through the Center for the Study of Bioethics on the Internet, according to Mark Kuczewski, PhD, associate professor of bioethics, was:
  - A. Students wanted more resources available on an instantaneous basis.
  - B. The school's network consisted of ethics committees at hospitals, medical centers, and teaching institutions in a four-state area.
  - C. It serves as an advertisement for the center.
  - D. All of the above.
4. One of the advantages to the new Richmond, VA-based United Network for Organ Sharing's (UNOS) liver allocation policy, according to Jeremiah G. Turcotte, MD, director of the Ann Arbor-based University of Michigan Medical Center's liver transplant program and immediate past chairman of the UNOS liver and intestinal organ transplantation committee, is:
  - A. A heightened awareness among staff that livers are in high demand.
  - B. A larger population base to match potential donors and recipients.
  - C. A coordinated transportation system for allocated organs.
  - D. All of the above.

(R-IL) are co-sponsoring the Pain Relief Promotion Act of 1999, which would amend the federal Controlled Substances Act in two areas. First, it would affirm that pain control is a legitimate medical treatment, even if the use of controlled substances increases the risk of death. Second, it would clarify that the use of controlled substances for assisted suicide and euthanasia is not allowed.

The medical community is recognizing the need for better pain management as well. Medical schools are teaching effective pain assessment and management techniques. **(For suggestions on institutional steps toward better pain management, see box, p. 103, top.)**

"The Joint Commission represents a new and critical participant in the area of assessing and managing pain. The accreditation and oversight community's involvement is another part of the corral that we are building around the management of pain," adds **Ira M. Byock**, MD, research professor at the University of Montana and principal investigator of the Missoula Demonstration Project. Byock also is author of the book *Dying Well*.

"It becomes evermore clear to any clinician or teacher or for a student in medical training that the assessment and management of pain is essential. It's no longer an embellishment or ancillary to the clinical encounter," he explains.

Although the standards are applicable to providers throughout the continuum of care, the standards for hospitals fall under the Patient Rights and Organization Ethics chapter of the *Comprehensive Accreditation Manual for Hospitals*.

"Unrelieved pain has enormous physiological and psychological effects on patients. The Joint Commission believes the effective management of pain is a crucial component of good care," says **Dennis S. O'Leary**, MD, president of the Joint Commission.

Introduction of the standards is the result of a two-year joint effort between the Oakbrook Terrace, IL-based Joint Commission and the University of Wisconsin-Madison Medical School. The project was funded by the Robert Wood Johnson Foundation in Princeton, NJ. **(See *Medical Ethics Advisor*, October 1997, p. 113.)**

"The new Joint Commission standards will serve as a great stimulus among providers. I've seen a great deal of interest among providers in various settings in making pain management a priority. We just completed a pilot program with home care agencies in Wisconsin and a very high

## Help focus your facility on pain management

These are the elements of an institutional commitment to the relief of pain:

- Develop an interdisciplinary work group.
- Analyze the current pain management practices in your care setting.
- Articulate and implement a standard of practice.
- Establish accountability for pain management.
- Provide information about pharmacologic and nonpharmacologic interventions to clinicians to facilitate order writing and interpretation and implementation of orders.
- Promise patients a quick response to their reports of pain.
- Provide education for staff.
- Continually evaluate and work to improve the quality of pain management.

Source: Based on the recommendations of the Agency for Health Care Policy and Research and the American Pain Society's quality improvement commitments.

## Pain management resources

### Publications

The Wisconsin Cancer Pain Initiative published a resource manual when developing the standards in conjunction with the Joint Commission on Accreditation of Healthcare Organizations. *Building an Institutional Commitment to Pain Management, the Wisconsin Resource Manual for Improvement* outlines key elements of a process for institutionalizing pain management. It contains sample tools shared by pain management groups from around the country. For details, visit the American Alliance of Cancer Pain Initiatives' Web site ([www.aacpi.org](http://www.aacpi.org)).

### World Wide Web sites

- Agency for Health Care Policy and Research: [www.ahcpr.gov](http://www.ahcpr.gov)
- American Academy of Pain Medicine: [www.painmed.org](http://www.painmed.org)
- American Pain Society: [www.ampainsoc.org](http://www.ampainsoc.org)
- American Society for Pain Relief, Research and Education: [www.cris.com/~igupta/ASPRRE.htm](http://www.cris.com/~igupta/ASPRRE.htm)
- National Foundation for the Treatment of Pain: [www.paincare.org](http://www.paincare.org)
- Ohio Cancer Pain Initiative: [www.ocpi.org](http://www.ocpi.org)
- University of Utah Center for Pain Medicine: [medstat.med.utah.edu/pain\\_center/](http://medstat.med.utah.edu/pain_center/)
- Wisconsin Cancer Pain Initiative: [www.wisc.edu/wcpi/](http://www.wisc.edu/wcpi/)

percentage of patients report experiencing pain," says Dahl. (For more suggestions on how the ethics committee can get involved in pain management, see p. 104.)

The standards have been endorsed by the American Pain Society in Glenview, IL. Hospitals, as well as long-term care facilities, outpatient clinics, and home health agencies, will be expected to:

- recognize the right of patients to appropriate assessment and management of pain;
- assess the existence, nature, and intensity of pain in all patients;
- record the results of the assessment in a way that facilitates regular reassessment and follow-up;
- determine and ensure staff competency in pain assessment and management, and address pain assessment and management in the orientation of all new staff;
- establish policies and procedures that support the appropriate prescription or ordering of effective pain medications;
- educate patients and their families about effective pain management;
- include patients' needs for symptom management in the discharge planning process;
- collect data to monitor the appropriateness and effectiveness of pain management.

### Putting the problem center stage

"These standards are putting the importance of pain management at center stage, ensuring that health care providers and professionals will take pain management in a serious way," says **Russ Portenoy**, MD, president of the American Pain Society.

The standards acknowledge that pain coexists with a number of diseases and injuries, requiring explicit attention. A breast cancer patient, for example, should be treated not only for the actual illness, but also for any associated pain under the new standards.

The new pain management standards — along with examples of compliance — are being included in 2000-2001 manuals. The standards will first be scored for compliance in 2001. Copies were sent earlier this year to accredited health care organizations, a variety of professional groups and associations, consumer groups, and purchasers. The standards received an average approval rating of 92%.

Pain experts suggest that patients themselves

## SOURCES

- **American Pain Society**, 4700 W. Lake Ave., Glenview, IL 60025. Telephone: (847) 375-4715. Fax (847) 375-4777. Web: www.ampainsoc.org. E-mail: info@ampainsoc.org.
- **Joint Commission on Accreditation of Healthcare Organizations**, One Renaissance Blvd., Oakbrook Terrace, IL 60181. Telephone: (630) 792-5000. Fax: (630) 792-5005. Web: www.jcaho.org.

could help shift the focus of providers toward more effective pain management. "It is our great hope that patients and families will demand that health care providers pay attention to pain. That's one of the reasons we proposed language in the patient education chapters in the Joint Commission manual and also in the Rights and Ethics chapter," notes Dahl. Patients and families need to understand that pain management is an important part of their treatment, she adds.

"It won't be long until it seems unnatural, and we'll remember with bemused embarrassment that we once made rounds and left the patient's bedside without asking about their discomfort. I hope that day is not long in the future," notes Byock. ■

## Here's what you can do

### *Steps your committee can take*

Your ethics committee can take the following steps to prepare your facility for the new pain management standards from the Joint Commission on Accreditation of Healthcare Organizations in Oakbrook Terrace, IL. The suggestions come from **June L. Dahl**, PhD, a professor of pharmacology at the University of Wisconsin-Madison Medical School in Madison. Dahl also serves as executive director of the Wisconsin Cancer Pain Initiative, which helped develop the standards for the Joint Commission.

- Inform patients during their initial evaluation that relief of pain is an important part of their care.
- Ask patients in the initial evaluation and as part of regular assessment about the presence, quality, and intensity of their pain.
- Work with patients and other health care providers to establish a goal for pain relief.

- Review and modify the plan of care for patients who have pain.

- Use ethics rounds to address pain and identify patients with ethical dilemmas.
- Address the myth that opioids hasten death, are addictive, and that tolerance to them develops quickly. ■

## Can you learn about ethics on the World Wide Web?

### *Wisconsin center offers on-line certification*

A teacher in a nursing school at a small university in the Southeast wants to advance her education in bioethics to give her students an ethical framework for making clinical decisions. A medical librarian at a large hospital in the West is appointed to her institution's ethics committee and needs information on ethical issues faced by health care professionals.

They are among a growing number of people benefiting from a new study program offered through the Milwaukee-based Medical College of Wisconsin's (MCW) Center for the Study of Bioethics. In an attempt to provide its educational and research resources to a wider base, the center is now offering a four-course Certificate in Clinical Bioethics through an innovative distance-learning program that allows students to take specialized "classes" on the Internet.

"When I came here two years ago, one of the first things I wanted to do was expand our ability to bring our graduate offerings to our ethics committee network," explains **Mark Kuczewski**, PhD, associate professor of bioethics at the Medical College of Wisconsin and the director of graduate studies at the center.

The school's network consisted of ethics committees at hospitals, medical centers and teaching institutions in the four-state area of Wisconsin, Minnesota, Iowa, and northern Illinois. The committees rely on the center and each other to provide educational resources and changes in existing laws that may have bioethical implications.

"We have this huge geographic region, but, basically, with the Midwestern winters, our ability to get to those hospitals and do some educational programs for them was really quite limited," Kuczewski says. "We have this marvelous

graduate program here that really was only of use to people in the greater Milwaukee area. Somehow we wanted to bring the resources of that program to serve the greater geographic region.”

The solution, Kuczewski found, was in setting up a resource on the Internet known as a listserv — a mailing list on a specific topic that allows “subscribers” to see messages from the host, or moderator, of the list and to see other subscribers’ responses as well.

Students enroll in the program and are assigned a password, which allows them access to the listserv on the Web. The professor “teaching” the class posts a lecture of about eight or nine pages and assigns a case study to read along with the lecture. Students must follow instructions and then submit an analysis or opinion in reply that is distributed to the listserv.

“For example, we have assigned readings, which come from books and journal articles, and then there is a task for them, like a case for discussion, and they send their opinion or analysis to the listserv for the whole group to read,” he explains.

### ***Four courses offered***

The four courses now offered through the distance learning program are:

- clinical topics in bioethics;
- law and bioethics;
- philosophical bioethics;
- justice in health care (a class dealing with

“resource allocation at the societal level, specifically, managed care issues,” says Kuczewski).

The graduate-level courses can be applied to completion of the master of arts in bioethics degree at MCW. Courses also can be applied to certificate levels of study, and they offer continuing medical education and nursing continuing education credit hours.

The format offers benefits not found in the traditional classroom, Kuczewski says. **(For information on other on-line programs, see box, above right.)**

“One thing, in a classroom, the discussion is limited by class time,” he says. “Here, students can compose their answers at their leisure, take the time they want, and they are not limited. If they want to say more later, they can. And for me as an instructor, I can give them individualized feedback because I can reply directly back to off of the list.”

## **Bioethics course information on the Internet**

The following institutions offer an on-line educational component to course offerings:

- Bioethics Information Center at the University of Buffalo: <http://freenet.buffalo.edu/bioethic>
- Biomedical Ethics: <http://www.uwc.edu/fonddulac/faculty/rgrigteri/biomed.htm>
- University of Minnesota’s Center for Bioethics: <http://www.med.umn.edu/bioethics/>
- Center for Bioethics and Health Law at the University of Pittsburgh: <http://www.pitt.edu/~bioethic>
- Center for Bioethics at the University of Pennsylvania: <http://www.med.upenn.edu/bioethics>
- Center for Human Bioethics at Monash University: <http://www.arts.monash.edu.au/bioethics/index.htm>
- MacLean Center for Clinical Medical Ethics: <http://ccme-mac4.bsd.uchicago.edu/CCME.html>
- University of Toronto Joint Centre for Bioethics Ethics Committee Resources: [http://www.utoronto.ca/jcb/ec\\_information.htm](http://www.utoronto.ca/jcb/ec_information.htm)

Eventually, the center plans to offer its master of arts in bioethics degree through a distance-learning program. Students could take the majority of classes over the Internet, with an intensive in-residency seminar on MCW’s campus.

“It would follow sort of the executive MBA model, the Web-based learning combined with some intensive study here,” he says.

### ***Problems with distance learning***

Some on-campus time will be essential for students to get a proper background in bioethics, says **Arthur Derse**, MD, JD, associate director for medical and legal affairs at the center. “We have been able to do some amazing things with the distance learning program, but there are some other issues that have to be addressed, and we are addressing them,” he notes.

Although case studies and the study of the philosophical foundations of ethics are important, some time at the bedside of patients and in a clinical setting is essential, Derse says. A way of incorporating the clinical experience and real

situations will have to be part of the program if it is to provide the truest benefit to the participants, he says.

In accepting students into the initial on-line offering, Kuczewski says the center was careful to include students from a variety of backgrounds.

“Most people do have some sort of clinical encounters in their professions, the perspective of a physician, nurse, social worker, health care attorney,” he explains. “Others are people such as the medical librarian appointed to an ethics committee, or a transplant coordinator at a hospital. If you keep the class limited to a small number of people, even those who haven’t had direct patient contact, they can still get that from interacting with the other clinicians.”

The on-line format also lacks another important component of the traditional program, Kuczewski says. “The Web doesn’t really teach you the same skills that you need for oral presentations. When you have to speak in front of a group or facilitate a discussion at a meeting or talk at grand rounds, you are speaking orally, there is a [podium from which] you are looking at the audience, you have body cues and all of that. People will be asking questions, you have to know how to respond.”

### ***Blending on-line and hands-on***

The center is working on how to blend on-line education with hands-on experience to serve the needs of health care professionals who do not have access to a traditional program at a major academic center.

More and more, bioethics education programs are looking for ways to provide resources to a wider audience. The Centre for the Study of Human Bioethics at Monash University in Clayton, Australia, already offers its master’s in bioethics in coursework degree through an Internet-based distance-learning format. The University of Pennsylvania offers continuing medical education credits in bioethics on-line.

The center at MCW and others will continue to search for innovative ways to bring resources for

the study of bioethics to more people working in the health care field, says Kuczewski. That includes the on-line course offerings, plus video-conferences and other materials that graduates can use to facilitate discussions and seminars in their own institutions.

“We have sort of a moral mission in this,” he says. “It has been, to some extent, the ‘scandal’ of bioethics that we have been confined to the academic health science centers, which are mostly in urban areas. But, people are born, live, and die everywhere, and we have to get out there somehow.” ■

## **Organ procurement group changes liver policy**

The United Network for Organ Sharing (UNOS), the Richmond, VA-based nonprofit organization that administers the national Organ Procurement and Transplantation Network, voted in June to change the way donor livers are made available for transplant nationwide.

Under the new policy, livers must be made available to all Status 1 patients — those in the most urgent category of need — in the wider “regional” area before being offered to less-urgent candidates in the “local” area in which the donor organ originated. The country is divided into 11 regions serving 125 liver transplant centers.

Previously, available livers were offered to all medically eligible local recipients first, then to recipients on lists in the same region, then to recipients nationally. **(For a detailed breakdown, see chart, p. 107.)**

“The problem is, donor livers become available on sort of a random basis. In one area, you might have to wait a week or two for a liver that is the right blood type, etc. Whereas, next door, they may have several,” explains **Jeremiah G. Turcotte, MD**, director of the Ann Arbor-based University of Michigan Medical Center’s liver transplant program and immediate past chairman of the UNOS liver and intestinal organ transplantation committee, which developed the new allocation policy.

“By having a larger population base to donate the liver, you take the randomness out of it. However, there will still always be fewer livers available than are needed.”

The committee originally made regionwide

### **SOURCES**

- **Arthur Derse, MD, JD; Mark Kuczewski, PhD**, Medical College of Wisconsin, Center for the Study of Bioethics, 8701 Watertown Plank Road, Milwaukee, WI 53226-0509. Telephone: (414) 456-8498.

sharing a voluntary process; it is now mandatory. “The regions that did not participate in the voluntary program will need to come up with a proposal of how they are going to share regionwide,” Turcotte adds.

“There is some variation in what the impact will be for different regions. It is much different to be in an area where you have a half-dozen similar-size hospitals with transplant programs. It is a lot different than being in a smaller program right next to a large transplant center. The policy will allow people to share but also to pose some variance that will make it feasible in their area. That variance will have to be approved by the liver testing committee.”

The new policy’s adoption comes in the wake of a report from the federal Institute of Medicine (IOM) evaluating the fairness of U.S. organ transplant policy. (See related, story, p. 108.) Addressing longstanding criticism that the system administered by UNOS favored established transplant centers instead of benefiting the largest number of critically ill patients, the U.S. Department of Health and Human Services (HHS) proposed regulations in 1998 that would have established a nationwide system of organ-sharing. (See *Medical Ethics Advisor*, April 1998, p. 37, and May 1998, p. 49.)

Many in the transplant community opposed the new regulations, and HHS instituted a moratorium on enforcement while the matter was studied by IOM.

The new UNOS policy is a step forward, but it still does not remedy inequities in the liver allocation system, says **Goran B. Klintmalm**, MD, PhD, FACS, director of the Dallas Liver Transplant Program and director of the Baylor Institute for Transplant Sciences at Baylor University Medical Center in Dallas.

“It is an improvement, but a miniscule one,” says Klintmalm, who has been critical of UNOS policy and testified before the IOM committee on organ procurement and transplantation policy, which was evaluating the system.

“It will affect only in the neighborhood of 25% of the patients. I do 50% of all liver [transplants] in this region, and we do only six of those Status 1s a year. The acute patients are taken care of, but it is those who are sick, but not as urgent, they are the ones who suffer. That is the problem, and that is why we need a patient-centered system.”

Turcotte acknowledges that changes still need to be made in the way patients are categorized

## New Liver Allocation Policy

Here is a comparison of the sequence of organ offers for available donor livers.

Old System	New System
1. Local Status 1	1. Local Status 1
2. Local Status 2a	2. Regional Status 1
3. Local Status 2b	3. Local Status 2a
4. Local Status 3	4. Local Status 2b
5. Regional Status 1	5. Local Status 3
6. Regional Status 2a	6. Regional Status 2a
7. Regional Status 2b	7. Regional Status 2b
8. Regional Status 3	8. Regional Status 3
9. Nationally in descending order of medical status	9. Nationally in descending order of medical status

Source: United Network for Organ Sharing, Richmond, VA.

and ranked for consideration for transplant. The committee now is looking at a new model: one that would rely less on the concepts of geography, waiting time, and current status as the main factors in determining a recipient’s placement for transplant.

“What we are looking at, which I think is a more ethical approach to the whole subject, is the probability of dying while on the waiting list,” says Turcotte. “If you are a patient, that is your main concern.”

### *Making it fairer for patients*

The committee is examining data and trying to arrange an allocation system that would allow all patients to have the same probability of dying on the waiting list, regardless of their initial status.

“The way liver disease works, you could be doing reasonably well enough in the hospital, and some event happens, and you die,” he says. “The statuses we have are useful but they don’t really predict how long you are going to live; they predict how urgent you are at the moment.”

The committee still needs more data to establish a new policy, but Turcotte says it will be a more ethical policy once they can allow patients who are less urgent a chance to receive a liver transplant.

“As it is now, I think many places almost never do a Status 2b because they use up all of the livers,” he says. “We should have our resources spread out a little bit, so that some people at Status 3 should be able to get a liver because they have been waiting a long time and so on. The big ethical question is, is it really fair to use up all of the livers on the people who are very sick at the top of the list and the only way you ever get a liver is to get really sick?”

### **Regulation and enforcement a problem**

Klintmalm and Turcotte agree that a much-needed overall change in transplant policy is a reliable system of enforcement of allocation regulations.

“The whole system depends on trust between the various people in the system and enforcement of those regulations,” says Turcotte. “The HHS has not been willing to enforce anything, which makes it difficult to impose regulations. If people are not confident that everybody is abiding by these regulations, they do not want to abide by them. We are going to have to have some sort of self-regulations or oversight by the government.”

Klintmalm argues that a new regulatory body, one independent of both the government and the medical transplant centers and staff, is needed to enforce a fair system.

“Right now, UNOS oversees itself and issues regulations,” he says. “One thing that the IOM report states is that there should be an independent advisory board, independent of the HHS as well as UNOS, and I think that is one of the most important points, but it has been largely overlooked.” ■

### **SOURCES**

- **Jeremiah Turcotte**, MD, University of Michigan Medical Center, Department of Surgery, Liver Transplantation Center, 2924F Taubman Center, Box 0331, Ann Arbor, MI 48109-0331. Web: <http://www.med.umich.edu/>.
- **Goran B. Klintmalm**, MD, Baylor Institute of Medical Sciences, Baylor University Medical Center, 3500 Gaston Ave., Dallas, TX 75246.
- **United Network for Organ Sharing**, 1100 Boulders Pkwy., Suite 500, Richmond, VA, 23225-8770. Telephone: (888) 894-6361.

## **IOM releases report on organ allocation**

**A**lthough the nation’s existing donor organ allocation policy functions well, distribution of available organs should be made across wider geographic areas in order to improve access for patients in most urgent need of a transplant.

That’s the recommendation based on a report from the national Institute of Medicine (IOM) committee on organ procurement and transplantation policy.

“The current system of organ procurement and allocation works reasonably well, but significant improvements in both its fairness and effectiveness could be made,” explains committee chair **Edward Penhoet**, dean of the school of public health at the University of California, Berkeley.

Over a period of two years, the committee studied data on 68,000 patients on waiting lists for livers from 1995 to 1999. The committee found that organ procurement organizations serving larger populations are associated with improved access for patients most in need of a transplant and with lower mortality rates following transplantation.

The report recommends that donor livers, for example, should be allocated over regions with no fewer than 9 million people. Currently, defined geographic regions for liver allocation range in populations of 1 million to 12 million people.

### **Geography not a factor**

In evaluating the data, the committee concluded that one key assumption held by critics of the existing organ allocation policies — that geographic variability in waiting time is an indicator of system fairness — was misleading.

“Based on a thorough review of waiting times for liver transplants, however, the committee found that those with the highest medical need actually wait for a comparable period of time at sites around the country,” the statement reads.

However, transplant rates vary significantly for patients who are not as ill, depending on the size and location of the organ procurement organization (OPO) that serves the transplant center where the patient is registered.

The committee also discovered that low-income patients, regardless of racial or ethnic backgrounds, are less likely than affluent white patients to be referred for evaluation because they often do not

## How to get the report

Copies of *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule* are available from by writing to: National Academy Press, 2101 Constitution Ave., Lockbox 235, Washington, DC 20055. Telephone: (202) 334-3313; toll-free (800) 624-6242. The cost of the report is \$34.95 (prepaid) plus shipping charges of \$4.50 for the first copy and 95 cents for each additional copy.

A copy of the UNOS response to the release of the IOM report is available on the Internet at: [http://www.unos.org/frame Default.asp?Category=Newsroom](http://www.unos.org/frame%20Default.asp?Category=Newsroom).

have access to health insurance and higher-quality health services. Once patients are referred for a transplant, however, there do not appear to be disparities in acceptance to a waiting list.

The committee was originally charged with evaluating the impact of a proposed Washington, DC-based U.S. Department of Health and Human Services (HHS) regulation that set new rules for organ procurement and allocation nationwide.

After receiving complaints from many transplant surgeons, OPOs, and transplant centers, HHS suspended implementation of the new regulations pending study of the new rules' potential impact on donation rates, equitable access to transplantation, and cost.

The study found no evidence that the regulation would reduce access by minorities, force closure of smaller transplant centers, or drive down donation rates. However, the committee did find that increasing the geographic area for distribution could result in a more expensive overall system due to increased transportation costs and higher costs associated with transplants for sicker patients.

The United Network for Organ Sharing (UNOS), the private, nonprofit umbrella organization in Richmond, VA, that administers the nation's organ transplant system, praised the committee's report in a response released after the report was made public.

The committee essentially affirmed that the UNOS system was effective and equitable, proposed a geographic basis for organ allocation that is similar to the one currently in use, and found that UNOS policies do not discriminate based on race or economic factors, according to UNOS

president **William D. Payne** in a statement released to UNOS members and posted on the organization's Web site (<http://www.unos.org>).

"The Institute of Medicine report could not be clearer. Its second recommendation is to 'discontinue use of waiting time as an allocation criterion for statuses 2b and 3,'" explains Payne. "It later adds: 'Overall median waiting time, which has dominated the policy debate, is a poor measure of differences in access to transplantation.' The report notes that the heavy emphasis placed on waiting times by the Department of Health and Human Services created the perception that the current system was unfair. The report repudiates this notion."

Because the report calls into question the "basic medical premises" of the pending federal regulations, the regulations should be withdrawn, says Payne.

"Although the Institute of Medicine's report endorses increased federal oversight, its scientific findings knock out the very foundation of the pending regulations and we will respectfully ask the Department of Health and Human Services to withdraw them," his statement reads.

Members of the transplant community must simply wait to see how the IOM report's recommendations will be incorporated into the HHS rule that is implemented, says **Goran B. Klintmalm**, MD, PhD, FACS. Klintmalm is chairman of the Baylor Institute of Transplant Sciences and Director of the Dallas Liver Transplant Program at Baylor University Medical Center in Dallas.

"I think the IOM report is a carefully crafted compromise, but the bottom line is that the IOM says the organs should be given to the patients in need and not the transplant centers, which is how it now works out," he says. "[U.S. Secretary of Health and Human Services Donna] Shalala has said that she will adjust her proposed recommendations to reflect the IOM report. But of course, both sides — UNOS, which is most of the transplant centers, and HHS — claim that the report supports their position."

## SOURCES

- **Goran B. Klintmalm**, MD, Baylor Institute of Medical Sciences, Baylor University Medical Center, 3500 Gaston Ave., Dallas, TX 75246.
- **Institute of Medicine**, Office of News and Public Information, The National Academies, 2101 Constitution Ave., N.W., Washington, DC 20418.

The report does call for the formation of an independent advisory board to oversee the nation's organ allocation system, which is an essential step in establishing a fully equitable system, says Klintmalm.

According to the IOM statement, the report calls for the formation of an independent multi-disciplinary board to provide guidance on how the system should best serve the public. The recommendations also call for HHS to establish better performance measures for determining how efficiently the system is working.

However, experts on both sides of the debate feel that congressional action is needed clarify the organ transplant system. "With as much rancor as has been part of the debate, if she [Shalala] just issues rules instead of Congress passing laws, the rule will be challenged in various states," concludes Klintmalm. ■

## NEWS BRIEFS

### Wife in right-to-die case takes on political cause

Michele Finn, widow of Hugh Finn, spoke publicly in early August on behalf of a legislative candidate who supported her decision last fall to end life support for her husband in a well-known case. (See *Medical Ethics Advisor*, November 1998, p. 124.)

Finn spoke on behalf of Democratic legislative candidate Denise Oppenhagen, who is running against legislator Robert G. Marshall (R-Prince William) in the Virginia legislature. Finn accuses Marshall of "ignoring the laws of the state for his own personal and moral righteousness, and pitted one family member against another."

Recent reports that Finn's lawyer is not satisfied with the state's payment to defray her legal costs is causing some voters to question her motives and those of her lawyer. Finn states her costs exceed \$100,000, and the state legislature approved a payment of \$48,000, which, according to Finn, covered the costs from last fall.

Finn stated at the political gathering that she came to the fundraiser to say "each of us has the right to our own opinion about end-of-life decisions." ▼

### States get voluntary fertility clinic guidelines

*Would create parity, provide accreditation tool*

The U.S. Department of Health and Human Services in Washington, DC, released a set of quality guidelines for fertility clinics in late July.

The guidelines would help establish parity among the nation's 300 unrelated fertility clinics and give states a tool to accredit the clinics. Also, some states may regulate the industry following recent high-profile examples of mix-ups. A New York woman recently gave birth to twins, for example, but one child was the genetic child of another couple.

"We know no one can ever guarantee that every couple who turns to a fertility clinic will be pleased with the results of the treatment. But using this model, the state governments can reassure those couples that the clinics they're using are living up to the highest standards of quality," says Donna Shalala, U.S. Secretary of Health.

The guidelines focus on the areas of lab procedures and equipment, record keeping, and personnel qualifications. Birmingham, AL-based American Society for Reproductive Medicine, which represents 90% of the U.S. clinics, endorses the standards. ▼

#### COMING IN FUTURE MONTHS

■ Is informed consent always necessary?

■ How to ensure genetic tests are read accurately

■ Ensuring equitable care among different races

■ What to do when parents insist on life-prolonging measures

■ Is physician unionization a good idea?

# Florida expands advance directive laws

The Florida legislature last session passed a bill changing the state's law on advance directives. Previously, the law allowed for directives withholding or withdrawing life-prolonging procedures for terminal patients or patients in a persistent vegetative state. The new provision includes patients with end-stage conditions.

Florida law defines an end-stage condition as "a condition caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and complete physical dependency and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective."

The problem with the change in the law lies in the ambiguous use of the term 'end-stage,' says **Joel Mattison, MD**, physician adviser at St. Joseph's Hospital in Tampa. "We are already using this [term] as an official adjectival modifier of such diseases as [end-stage] renal disease and [end-stage] COPD [chronic obstructive pulmonary disease]." ▼

## Programs improving care of dying receive grants

The New York City-based Project on Death in America, a division of the Open Society Institute, recently announced funding totaling 1 million dollars for eight new faculty scholars.

Winners of the grants must demonstrate innovative programs in clinical care, research, education, and advocacy to improve care of the dying. Over the last five years, Project on Death in America has appointed 58 faculty scholars in 36 medical schools, two U.S. nursing schools, and four Canadian nursing schools.

The scholars define and strengthen popular and professional understandings of what constitutes good care at the end of life and encourage a wider commitment to caring for dying people, according to **Susan Block, MD**, director of the faculty scholars program.

Project grant recipients include:

- Palo Alto, CA-based Stanford University's

continuing education programs on end-of-life care to educate African-American physicians;

- Chicago-based Loyola University Medical Center's program to improve the care of the dying in the Roman Catholic community;
- Boston-based Dana-Farber Cancer Institute's program to critically evaluate the quality of care provided to children with terminal cancer.

Grant recipients receive fellowships of up to \$150,000 for two years for projects aimed at improving end-of-life care. The next deadline for applications to Project on Death in America's faculty scholars program is January 6, 2000.

*[Editor's note: For more information regarding the faculty scholars program, contact the Project on Death in America at the Open Society Institute, 400 W. 59th St., New York, NY 10019. Telephone: (212) 548-0150. Fax: (212) 548-4613. Web: <http://www.soros.org/death.html>.] ■*

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### Editorial Questions

Questions or comments? Call **Kevin New** at (404) 262-5467.

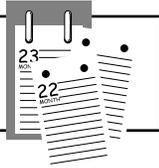
Group Publisher: **Brenda Mooney**, (404) 262-5403, ([brenda.mooney@medec.com](mailto:brenda.mooney@medec.com)).

Managing Editor: **Kevin New**, (404) 262-5467, ([kevin.new@medec.com](mailto:kevin.new@medec.com))

Contributing Writer: **Cathi Harris**.

Production Editor: **Terri McIntosh**.  
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# CALENDAR



- **National Bioethics Advisory Commission Meeting.** Sept. 16-17, 1999, Arlington, VA. Contact: National Bioethics Advisory Commission, 6100 Executive Blvd., Suite 5B01, Rockville, MD 20892-7508. Web: <http://bioethics.gov/>.
- **American Society of Law, Medicine & Ethics Annual Meeting.** Sept. 16-18, 1999, Cambridge, MA. Contact: conference director Lisa Bears. Phone: (617) 262-4990, ext. 12. E-mail: [lbears@aslme.org](mailto:lbears@aslme.org).
- **National Conference on Organization Ethics and Health Care.** Sept. 25-26, 1999, Charlottesville, VA. Sponsored by Center for Biomedical Ethics and Olsson Center for Applied Ethics at University of Virginia. Phone: (804) 982-4227. E-mail: [mvr2j@virginia.edu](mailto:mvr2j@virginia.edu). Web: <http://hsc.virginia.edu/medicine/inter-dis/bio-ethics/conf.html>.
- **Medicine's Integrity in the Face of Change: The Examination of the Provider's Role as Health Care is Reformed.** Oct. 15-17, 1999. The third annual Michigan State Medical Society Mackinac Island Conference. Sponsored by Michigan State Medical Society. Contact: David Fox at (517) 336-5731. E-mail: [dkfox@msms.org](mailto:dkfox@msms.org).
- **American Society of Bioethics and Humanities Annual Meeting.** Oct. 28-31, 1999. Philadelphia. Contact: American Society of Bioethics and Humanities (ASBH), 4700 W. Lake Ave., Glenview, IL 60025-1485. Phone: (847) 375-4745. Fax: (847) 375-3777. Web: <http://www.asbh.org>.
- **Genetics and Ethics Conference.** Oct. 29-30, 1999, St. Louis. Contact: professor Gerard Magill, PhD, center director and department chair, Saint Louis University Center for Health Care Ethics, 1402 S. Grand Blvd., St. Louis, MO 63104. Phone: (314) 577-8195. Fax: (314) 268-5150. E-mail: [magill@slu.edu](mailto:magill@slu.edu).
- **Expanding the Boundaries of Ethics: The Canadian Bioethics Society 11th Annual Conference.** Oct. 28-31, 1999, Edmonton, Alberta, Canada. Speakers will be members of the board of the International Association of Bioethics. A post-conference will be held on October 31, and attendees will have a choice of attending a workshop on "Ethics, Health Care and the Allocation of Resources at the End of Life" or a workshop on "The Ethics of Health Research Using Qualitative Methods." The research workshop will be hosted by the National Council on Ethics in Human

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• **International Conference on Applied Ethics.** Dec. 28-30, 1999, Chinese University of Hong Kong. Keynote speakers: Peter Singer, Bonnie Steinbock, and Jenny Teichman. A call for papers is being issued for the following topics:

1. The ethics of life and death, including (but not limited to): abortion, euthanasia, surrogate motherhood, human cloning, genetic engineering, and capital punishment.

2. Sexual ethics, including (but not limited to): pornography, homosexuality, premarital and extramarital sex, and sexual perversion.

3. Environmental ethics and animal rights.

Contact: Hon-Lam Li, e-mail: [honlamli@cuhk.edu.hk](mailto:honlamli@cuhk.edu.hk), or Kai-Yee Wong, e-mail: [wongg31k@cuhk.edu.hk](mailto:wongg31k@cuhk.edu.hk). Phone: (852) 2609-7144; (852) 2609-7145; or (852) 2609-7136. Fax: (852) 2603-5323. Web site for updates on the conference is: <http://www.arts.cuhk.edu.hk/~phidept/>. ■