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Ethics during epidemics: Old lessons get new look

Balancing personal protection with professional duty

Last year's worldwide outbreak of a deadly new virus, severe acute respiratory syndrome (SARS), made health systems around the world re-examine their preparedness to deal with a sudden epidemic of infectious disease.

But in addition to designing new methods for detecting outbreaks and improving measures to prevent spread, health care providers again must look at the complex ethical issues that epidemics pose to society, experts say.

Prior to the emergence of HIV and AIDS in the late 1980s, many in the health care community assumed that large outbreaks of infectious disease were no longer a problem for the developed world, says **Matthew Wynia**, MD, MPH, director of the Institute of Ethics of the American Medical Association (AMA) in Chicago.

As a consequence, they never expected to face many of the ethical dilemmas of their older counterparts, he says. Questions such as when and how patients with a communicable illness should be quarantined, and whether health care providers have a duty to provide care, even at risk to their own safety, must be re-examined.

"It has sort of been forgotten now that it has been dangerous in the past to be a doctor, or a nurse, or a health care professional of any type," Wynia says. "In the early part of the 20th century, it was [a] well-known and well-accepted part of what it meant to be a doctor. More than 20% of each year's medical class would get active tuberculosis [and], some people would die. It was very common in the 1940s and 1950s, before the age of antibiotics, for health care workers to become ill because of the work they did."

In 1847, when the AMA was formed, part of the group's code of professional conduct stated that physicians would continue to care for patients "when pestilence prevails," Wynia says. But by the 1970s and 1980s, some medical leaders were talking about removing that statement because epidemics were thought to be on their way out.

Many of today's physicians were trained in an age when infectious

disease was not thought to be a major concern.

"When the HIV epidemic came along, there was a great deal of controversy about the role and rights of health care providers — there were a lot of doctors who wanted to debate whether it was an ethical obligation to take care of patients with HIV infection," Wynia says. "It took four or five years for us to finally resolve it and say that, in fact, it was an ethical obligation."

The recent federal plan to prepare for a possible bioterrorist attack with weaponized smallpox, the anthrax attacks two years ago, and the SARS outbreak, have all refocused attention to these concerns, he adds.

Wynia and other experts in medicine and ethics recently participated in a conference at Union College in Schenectady, NY, titled "Ethics and Epidemics: An International Conference on the Ethical Dimensions of Epidemic Control."

"We talked quite a lot about the fundamental ethical issue in terms of being prepared for bioterrorism or epidemic disease. What if there is an epidemic and health care professionals don't show up?" Wynia says. "In every hospital that dealt with SARS, they had problems with this — every single one. And the applications to medical school and nursing programs in Toronto are way down this year."

As part of their bioterrorism and epidemic preparedness activities, hospitals should consider some amount of education about ethical responsibilities to care for patients during epidemics.

The September issue of the journal *Health Affairs* contains a report of a survey of physician willingness to treat patients with infectious illnesses. "Approximately 80% said they would [continue to care for patients in the event of an unknown, potentially deadly illness], and 20% said they would not. As the estimates of risk to the health care providers increased, the number of physicians who would agree to continue treating patients decreased," Wynia explains.

Only about half of the respondents said there was a professionwide duty to treat patients during epidemics.

Access to care

Participants at the conference also discussed the possibility of improving access to primary care as a function of national bioterrorism preparedness efforts, Wynia says.

"People who don't have ready access to care now, [such as] undocumented immigrants or the uninsured, could prove to be vectors for a new epidemic — either natural or man-made," he explains. "There are lots of reports of multidrug-resistant tuberculosis spreading in uninsured populations, and then eventually spreading and infecting others in the community."

Because people without insurance and those who are in the country illegally might avoid

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seeking treatment, the emergence of a new epidemic could go undetected for some time.

"Using some of the money dedicated to bioterrorism preparedness to improve access to basic primary care would not only improve the health of the community, but it would also improve the success of the current surveillance and detection systems," Wynia says. "There have been moves on the part of some states to compel physicians and nurses to turn in their patients who are here illegally. First of all, it is abhorrent to fundamental principles of medical ethics. It also seems really dumb in terms of preventing future epidemics."

Distributional justice

Hospitals also will have to consider how to allocate scarce resources, both in terms of personnel, equipment, and medicine, says **Michael Olesen**, an infection control specialist with St. Cloud (MN) Hospital.

Many health systems already are struggling to take care of the patients they currently see, with their current levels of resources. If a large-scale disaster were to occur, many fear they wouldn't have the "surge capacity" (extra personnel, equipment and funds) to cope.

Last year's influenza season for example, notably strained emergency medicine resources in a number of cities, with many hospitals reporting shortages in medicine attributable to the outbreaks and increased incidences of ambulance diversions due to overwhelmed emergency departments.

Working with a regional planning group on epidemic and bioterrorism planning issues, Olesen also decided to investigate whether the area would have enough ventilators if a large outbreak of SARS or another severe respiratory ailment occurred.

"While I was doing education on SARS in our facility, I did a ventilator national surge-capacity assessment," Olesen explains. "Given that an estimated 10%-20% of patients with SARS will require ventilators, I calculated that we would hit national capacity to deal with SARS once we had 40,000-80,000 concurrent cases. This represents just about 0.001%-0.003% of the U.S. population."

By comparison, he notes, on any given day, an estimated 0.4%-0.8% of the population has influenza.

"This was rather shocking to me, and I realized that SARS could easily overwhelm our ICUs if it were to become established," Olesen notes. "I spoke with our ethics committee about beginning a discussion on distributional justice around medical devices. Who gets ventilators when we run out? Do we remove it from someone with a low chance of recovery to give it to someone with better chances?"

The committee still is examining the issue and, at this point, has a lot of questions and few answers, he says.

They also realize that ventilators won't be their only concern.

In doing bioterrorism preparedness planning at his facility, Olesen bases calculations on the assumption that, as Wynia indicated, many health care workers will refuse to come to work.

"Even if we did have enough ventilators, would we have the staff to operate them?" he says. "If you look back, historically, when there have been large outbreaks at hospitals, you really can count on a range of from 30%-80% of people disappearing from your staff if things are really ugly. I kind of steer doing planning around the assumption that 50% of the staff is gone either because they are scared or because they are sick. If you loose that many staff, getting more [ventilators] isn't going to help." ■

SOURCES

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- **Matthew Wynia**, MD, MPH, Institute for Ethics, American Medical Association, 515 N. State St., Chicago, IL 60610.

Federal ethics council releases report on ART

Revision of embryo use regulations recommended

The current lack of oversight for assisted reproductive technology (ART) and human embryo research is compromising the future of children created using ART as well as hindering the progress of research into new and innovative treatments for diseases and conditions, a new report from the President's Council on Bioethics indicates.

The April 1 report, "Reproduction and

Responsibility: The Regulation of New Biotechnologies," urges the federal government to 1) fund more studies of the impact of ART on the families and children already affected by it; 2) encourage oversight mechanisms to monitor the progress of research involving human gametes (sperm and eggs), embryos, and reproductive processes; and 3) update current federal legislation to ban certain extreme procedures before they are performed.

"The intersection of assisted reproductive technologies and genomic knowledge is an increasingly busy intersection and one that raises a daunting array of opportunities and dilemmas for patients suffering with infertility and for doctors and researchers," the council's chair **Leon R. Kass**, MD, PhD, said in a statement announcing the release of the report. "It raises the prospect, but also certain kinds of risks, of new life for children born with these procedures. And it has certain social implications important for regulators and policy-makers and indeed for the American public as a whole."

Need for guidance

Because there is no "uniform, comprehensive and enforceable system of data collection, monitoring, or oversight" of ART technologies and private human embryo research, there is little information to guide the development of laws and policies, council members stated.

The result is that existing federal regulations are out of date and unworkable and, at the same time, private research and activities continue unguided and unmonitored by society.

A good example is the current controversy over stem cell research, says **Michael Sandel**, D.Phil., professor of government at Harvard University in Cambridge, MA, and a council member.

"A great merit of the [recommendations] in the report is that they point to a possible solution to the vexed issues of cloning and stem cell research that could overcome the current impasse in the United States Senate," Sandel noted in the council's open session to discuss the report's findings.

Despite widespread opposition to reproductive cloning, a federal ban has been impossible due to disagreements about such a law's impact on biomedical research. Yet biomedical research has been impeded by fears that research into therapeutic cloning could lead to a slippery slope of unfettered experimentation with human embryos.

"Recent scientific developments illustrate the need to adjust federal funding policy," Sandel continued. "Only 17 [stem] cell lines are currently available on the National Institute of Health's registry for federally funded research."

In March, Harvard biologist Douglas Melton, PhD, announced the creation of 17 new embryonic stem cell lines that he intends to make available, free of charge, to scientists for noncommercial research purposes, Sandel said. The cell lines were derived using private funds from blastocysts left over from in vitro fertilization clinics, and meet all of the same ethical requirements as the existing lines eligible for federally supported research.

Under current federal policy, research on these cell lines is ineligible for federal funding simply because they were derived after 9 p.m. on Aug. 9, 2001. "Now, the Aug. 9 cutoff may have been a reasonable compromise 2½ years ago when it was thought that some 60 or 70 cell lines would be available," Sandel says. "But in the light of what we know now, that cutoff looks less and less sustainable."

The United States needs to be able to move forward in this area with well-considered, thoughtful policies that take into account the values and opinions of the society as a whole, instead of interim stopgap measures, he says. The council's report represents an important first step.

"The proposed regulations taken together also point toward a possible compromise on federal funding of stem cell research," Sandel says. "They do so by addressing at least one of the main worries people have about stem cell research, which is the slippery slope worry. This is the worry that without clear limits, embryo research could lead down a slippery slope of exploitation and abuse."

The fear is that if our society allows stem cell research today, tomorrow some people might try to transfer embryos into a woman's uterus, or an animal's uterus or to grow organs for transplant, creating the nightmare prospect of embryo farms, fetuses exploited for spare parts, and the commercialization of human life, he explains.

"The regulations contained in this report address that slippery slope argument. They do so by assuring that such research is done responsibly, within carefully prescribed limits," Sandel says. "No embryos used for research could be used or preserved beyond a 10- or 14-day limit, or transferred into a woman's uterus or into an animal's body to grow organs for harvest, nor could embryos be bought and sold. By assuring that stem cell research is conducted within these limits, these regulations address the slippery

slope objection, the worry about exploitation and abuse."

Diagnosing the situation

Although the report examined a range of potential regulatory and policy approaches, it made only a few specific recommendations, the council noted.

Its review of the field determined that data were lacking in a number of crucial areas and the council was not prepared to recommend sweeping institutional reforms or innovations without sufficient evidence, the executive summary indicated.

"This report is fundamentally a diagnostic document," the summary stated. "Even most of the recommendations with which it concludes aim largely at improving the nation's capacity for future diagnosis of the state of this field."

Nevertheless, the council still contended that immediate action was needed in some areas to "alleviate some clear and significant present problems, especially including the lack of information on certain key practices and their consequences."

The recommendations fall into three major categories: studies and data collection, oversight and self-regulation by professional societies, and targeted legislative measures. Key recommendations include:

- A federally funded longitudinal study of the impact of assisted reproductive technologies on the health and development of children born with their aid
- Federally funded studies on the impact of ART on the health and well-being of women
- Undertake federally funded comprehensive studies on the uses of reproductive genetic technologies, and on their effects on children born with their aid
- Prohibition of the transfer, for any purpose, of any human embryo into the body of any member of a nonhuman species
- Prohibition of the production of a hybrid human-animal embryo by fertilization of human egg by animal sperm or of animal egg by human sperm
- Prohibition of attempts to conceive a child by any means other than the union of egg and sperm
- Prohibition of attempts to conceive a child by using gametes obtained from a human fetus or derived from human embryonic stem cells
- Prohibition of attempts to conceive a child by fusing blastomeres from two or more embryos
- Prohibition of the use of human embryos in research beyond a designated state in their development (between 10 and 14 days after fertilization)
- Prohibition against the buying and selling of human embryos
- Prohibition on the issuing of patents on claims directed to or encompassing human embryos or fetuses at any stage of development

SOURCES

- **Marian Damewood**, MD, and **Eric Surrey**, MD, American Society of Reproductive Medicine and The Society for Assisted Reproductive Technology, 1209 Montgomery Highway, Birmingham, AL 35216-2809.
- **Leon R. Kass**, MD, PhD, and **Michael Sandel**, D. Phil., President's Council on Bioethics, 1801 Pennsylvania Ave., N.W., Suite 700, Washington, DC 20006.

Reaction from professional societies

Representatives from professional societies of specialists in infertility and reproductive medicine expressed support for the report, with some reservations about recommendations that the societies improve their strategies to monitor and compel compliance with ethical standards.

Eric Surrey, MD, president-elect of the Society of Assisted Reproductive Technology (SART) says, "SART has always been proud of the role we have played in self-regulation. We began collecting ART outcomes data several years before the federal government got involved and have a long history of setting guidelines for our members. While we have always approached this in an educational rather than punitive manner, we look forward to examining the suggestions from the council to see if the process can be improved to benefit our patients and their physicians."

An earlier draft of the council's report released last year drew fire from some patient groups and fertility experts for appearing to advocate involuntary government monitoring of reproductive choices and proposals to ban already common practices such as selling human gametes. The final draft dropped those recommendations and altered some language that critics contended seemed to equate human embryos with children.

"This report is the result of a comprehensive well-researched review and evaluation of current reproductive technology with much thoughtful consideration by members of the council," says

Marian Damewood, MD, president of the American Society of Reproductive Medicine. "We may not have consensus on every conclusion presented; however, the council was very willing to listen to our comments and concerns. We are looking forward to continue to work with the council and have invited Dr. Kass to meet with our board of directors in a few weeks."

The council's report is available in electronic form on the web site of the President's Council on Bioethics (www.bioethics.gov). ■

Research reveals pain problems in ED

Inconsistent pain treatment by clinicians

More education for physicians and research into pain management strategies appropriate to the emergency setting are needed to ensure appropriate care in the emergency department (ED), new research indicates.

Two upcoming studies published in the April issue of the *Annals of Emergency Medicine* reveal that ED physicians' prescribing practices vary widely — even when the clinical scenarios are the same.

Researchers at Case Western Reserve University in Cleveland presented different hypothetical clinical scenarios to a group of ED physicians practicing nationwide.[1] The study found that ED physicians' responses to individual pieces of clinical information, such as patients requesting "something strong" for the pain, were highly variable, with at least 10% saying they would be positively influenced by this request and at least 10% of physicians saying they would be negatively influenced by it.

"Pain is the most common reason patients seek emergency department care, and emergency physicians are increasingly viewed as pivotal to improving pain treatment," says **Knox H. Todd**, MD, MPH, director of the Pain and Emergency Medicine Initiative in Atlanta, which is tasked with building a knowledge base for emergency medicine and creating a forum where medical, legal, and ethical issues related to pain and emergency medicine may be discussed. The initiative is supported by The Mayday Fund, a leading foundation supporting pain treatment efforts.

"It is apparent that pain management practices in emergency medicine are evolving rapidly," Knox adds. "From 1997 to 2001, there has been an impressive 18% increase in analgesic use in U.S. emergency departments, with marked increases in both nonsteroidal anti-inflammatory agents and opioid analgesics. Pain research, such as the articles highlighted here, will help us make improvements in this area more rapidly."

Researchers from the University of Texas Southwestern Medical Center at Dallas report in their review article[2] that ED pain management practices need to become more consistent across all demographic groups. The article identifies several areas where improvements could be made, such as intensifying the educational emphasis on pain management in nursing and medical schools, reducing biases held by clinicians in utilizing pain medications, and increasing the number of rigorous studies of populations with special needs that could improve pain management in the ED.

"Going forward, emergency medicine as a specialty should begin by defining its own standards for excellence in pain management and promote quality improvement initiatives to achieve these goals," says Todd. "Although we will find many allies in efforts to relieve pain and suffering, the duty to provide superior emergency department pain management remains our own."

Setting presents unique challenges

Pain management in the ED is difficult because the department presents clinical situations that force physicians to make many treatment decisions without complete information, says **Joshua H. Tamayo-Sarver**, PhD, a researcher in the Department of Epidemiology and Biostatistics at Case Western Reserve University in Cleveland, OH, and lead author on the first *Annals of Emergency Medicine* study.

"Much of the information must come from a patient with whom the physician is unfamiliar," he explains. "For painful conditions, where there is little objective evidence of the severity of the pain, the physician must establish sufficient rapport with the patient to determine the severity of the pain, select the most appropriate treatment, and discern the likelihood that opioids are desired for secondary gain."

To evaluate prescribing practices, Tamayo-Sarver and colleagues developed three separate clinical scenarios (a patient with a broken ankle, one with a migraine, and one suffering from back pain), each scenario containing a basic vignette with specific supporting clinical information.

The researchers were trying to select clinical characteristics that might influence a physician to prescribe an opioid analgesic as well as those that could influence a physician to decide against prescribing one.

"We hypothesized that contextual factors would be less important where there were objective clinical findings [an ankle fracture], more important when there were ambiguous indications [migraine], and most important where there are no objective findings [back pain]," he explains. "Second, we also conducted a large secondary data analysis of these conditions in a national data set and our results were consistent with our hypotheses."

But the overall likelihood of the physicians to prescribe an opioid in the situations given showed marked variability with at least 10% of physicians saying they were likely to prescribe, and 10% saying they were unlikely to prescribe for each situation. Physician responses to individual pieces of clinical information, such as the patient requesting "something strong" for the pain, were likely to produce opposite reactions in different physicians, with at least 10% indicating the information would influence them to prescribe and 10% indicating the same piece of information might influence them to decide against it, Tamayo-Sarver notes.

"I think this study demonstrates that ED physicians learn opioid pain prescribing idiosyncratically — there is no uniform approach to pain management," he says. "There was even a good chunk of physicians who used a simple heuristic ['I don't prescribe opioids.'] and none of the information influenced anything. Of note, however, whatever learning process the physicians had varied greatly between physicians, but each individual physician appeared to use the same approach to all three different conditions — despite our hypothesis to the contrary. This suggests to me that physicians informally learn a general approach to pain management at some point in their development, and then apply it to multiple presentations."

Emergency medicine on the 'front lines'

The study results are disturbing because ED physicians are on the front lines of treating patients in pain, notes Todd.

"The vast majority of patients come to us because of pain problems, and they have very severe pain problems," he says. "People in the primary care setting are often surprised at the level of pain these patients are actually in."

The initiative has done large-scale surveys of patients presenting to EDs and found that more than half present in very severe pain.

"We know ways to measure pain that are reproducible and pretty reliable, and it turns out that fully 50% of patients that come to the ED in pain do so in severe pain," Todd reports. "This includes all patients — the sore throats and very minor sprained ankles, etc. — but 50% feel that they are in severe pain on the order of postoperative pain in terms of severity. These findings are underappreciated by the public and by emergency medicine providers alike."

As in other specialties, emergency medicine physicians are not well trained in managing patients' pain, Todd says. Medical schools in this country put little effort toward educating their students about appropriate pain management.

"Pain management and analgesic use is almost an afterthought at most medical schools," he says.

That's not to say good work is not being done, Todd adds. Many ED physicians are willing to aggressively treat pain if they are aware their patients are suffering, and improvements in care are being made.

But, as Tamayo-Sarver indicates, they often are faced with treating patients they don't know in difficult circumstances. More work needs to be done helping ED physicians determine consistent approaches to pain treatment.

To that end, the initiative is sponsoring research into pain in emergency medicine patients.

"We have already done a few studies, and right now we are embarking on a multicenter study in the United States and Canada that is enrolling patients at anywhere from 20-30 sites in both countries to look at patient pain experience," Todd says. "We want to look at their experience, when they arrive at the ED, how they are treated, [and] how they feel about their experience. Then, we want to follow them up for three months if they still have

SOURCES

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- **Knox H. Todd**, MD, MPH, Emory University, Rollins School of Public Health, Mail Stop: 1518/002/1AA, Atlanta, GA 30322.

pain problems, and to see what happened to them."

The Initiative and the American College of Emergency Physicians have entered into dialogues with other specialties and advocates for chronic pain patients to work to improve treatment of pain across the spectrum of care.

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Communicate with surrogate decision makers

Shifting focus to patient's wishes alleviates burden

Recent studies in intensive care units[1] (ICU) have found that critical care specialists often try to base decisions about withdrawal of advanced life support measures based on their perception of the patient's wishes and the likelihood of survival in the ICU. **(See *Medical Ethics Advisor,* February 2004, p. 16.*)***

But making accurate decisions about a patient's wishes in such situations often requires clinicians to communicate effectively with surrogate decision makers — members of the patient's family or others empowered to make decisions should the person become incapacitated.

Unfortunately, this is one of the most difficult tasks faced by physicians caring for patients at the end of life, says **Paul Hofmann**, DrPH, FACHE, a consultant on clinical and health care organizational ethics and vice president of Provenance Health Partners in Moraga, CA.

"In trying to come to a decision, physicians frequently ask family members, 'What do you want me to do?' instead of, 'What would your family member want under these circumstances?'" he says. "Asking the question this way can put an unnecessary burden on the surrogate decision maker."

Physicians and family members may understandably have their own values and wishes to consider, and this often leads both groups of people to make decisions that frequently don't reflect the true wishes of the patient, he says.

Several statistics seem to bear this out.

Numerous studies performed over the years have indicated that most terminally ill Americans hope to die at home in the care of their families, as opposed to a health care setting. Yet, as a recent study published in *Critical Care Medicine*[2] finds, most Americans still die in hospitals — with the largest percentage receiving care in ICUs.

"In that study, based on discharge data received about more than 500,000 deaths nationwide in 1999, 38% of deaths occurred inside a hospital, and 22% of those in the ICU," he says. "Extrapolated nationally, more than half a million patients die annually in ICUs. This is all the more reason to emphasize the need find better ways to honor the patient's wishes at the end of life."

According to Hofmann, patients and family members can be better served if physicians phrase their question as, 'What would your family member want under these circumstances?'

One doctor, he explains, puts the question another way.

"He asks the family members, 'If I could give your family member a magic potion that could make him or her conscious for five minutes, what would your family member say [he or she] wanted under these circumstances,'" Hofmann says. "It is another way of lifting the burden from the family member and saying, 'This is the opportunity to honor and respect what your family member would want.'"

Physicians also should be careful when talking to family members about the patient's condition.

Too often, he says, physicians go into extensive descriptions of the patient's condition or prognosis without first determining what level of knowledge and understanding the family members already have.

"If the physician were to begin by asking the surrogate decision makers and other family members to describe what they understand the patient's condition to be, then the physician can be better positioned to explain and describe the circumstances within the context the family understands," he explains. "This can be very helpful in terms of minimizing misunderstanding and listening to the family."

Family members may have misconceptions or concerns about their loved one's condition that they do not reveal unless asked, or, conversely, they may understand more than the patient's physicians realize.

"There may be a high degree of understanding or a low degree of understanding, and there may be complete consensus among the family, or as is

SOURCE

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often the case, there maybe disagreement among family members about what they understand the prognosis and the patient's wishes to be," he says. "I encourage physicians to think about the whole communication process and how it can be enhanced to best serve the needs of the patient as well as the family members."

Hospitals also need to periodically evaluate and re-evaluate any policies they have on caring for patients at the end of life, especially those that concern substituted judgements — someone other than the patient making decision about the patient's care.

For example, Hofmann says, hospitals are required by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to have a policy on do-not-resuscitate (DNR) orders.

Although JCAHO does not stipulate what the policy should contain, they do require each accredited hospital to have one. Consequently, many institutions have policies that are out of date and not useful in many areas of common practice.

"For example, many do not stipulate what should happen in the event that a patient with a DNR should return to the operating room for surgery," he notes. "Many clinicians feel that, in some circumstances, it is appropriate to suspend a DNR when a patient is undergoing surgery for a procedure that is expected to improve their condition." But a suspension may not be appropriate for all circumstances. An up-to-date DNR policy should indicate when, if ever, the DNR would be suspended if the patient is scheduled to undergo surgery.

Other institutions Hofmann has worked with have developed their own policies regarding difficult issues at the end of life. One has a specific policy on incapacitated patients who do not have surrogate decision makers available, he says. Another has developed a policy on administration of nonbeneficial treatments.

"These are policies that were developed and reviewed by all of the hospital committees and approved by the board of directors," he says. "So, both were very long, thoughtful processes that allowed the hospital to develop policies that honored its institutional values."

Many hospitals are reluctant to have such specific policies because they believe in the value of having an ethics committee make an individual decision about cases in which a conflict or question arises, Hofmann says.

However, it is important to develop such policies because it allows for a more relaxed, thoughtful discussion of the issue by different groups of health care professionals at the institution, rather than a last-minute, pressured decision by an ethics committee on each case.

"With regard to patients at the end of life, a hospital should not only develop appropriate policies, but they should also make sure their existing policies are reviewed," he concludes.

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Health 'illiteracy' may cause disparities in care

Many adults do not understand health information

Nearly half of all American adults — 90 million — have difficulty understanding and using health information, and there is a higher rate of hospitalization and use of emergency services among patients with such limited health literacy, states a new report from the Institute of Medicine (IOM).

Released on April 8, *Health Literacy: A Prescription to End Confusion* represents almost two years of work by an 11-member panel of experts in public health, primary medical care, health communication, sociology, anthropology, adult literacy education, and elementary and secondary education.

The group was formed in October 2002 and charged with determining the scope of the problem of health literacy in the United States. They conducted extensive reviews of the published studies on literacy issues related to health care, interviewed experts researching the impact of literacy on health care access and outcomes, and convened public workshops to get input from a variety of sources about how easily Americans are able to understand the health information

provided to them and participate as decision-makers in guiding the care the receive.

"Health literacy is fundamental to quality care," says **David A. Kindig**, MD, PhD, professor emeritus of population health sciences, University of Wisconsin-Madison and chair of the committee that developed the report. "The public's ability to understand and make informed decisions about their health is a frequently ignored problem that can have a profound impact on individuals' health and the health care system. Most professionals and policy-makers have little understanding of the extent and effects of this problem."

The IOM report defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health."

More than a measurement of reading skills, health literacy also includes writing, listening, speaking, arithmetic, and conceptual knowledge, the report indicates.

At some point, most individuals will encounter health information they cannot understand. Even well-educated people with strong reading and writing skills may have trouble comprehending a medical form or doctor's instructions regarding a drug or procedure, it states.

Health information is particularly difficult to understand for people with limited overall literacy skills, Kindig notes. Attempts to improve health education in grades K-12 have met with substantial barriers over the years and, as a result, many people lack the ideas and concepts they need to be health-literate.

But that's not the only problem, he adds.

"Another reason is that health professionals often lack education and training about how to communicate with patients, and how to help improve the health literacy of their patients," he says. "During the evidence-gathering phase of this project, our committee heard from individuals who have been ill-served by the health care system as a result of limited health literacy — which means limited reading or writing ability — but also a limited capacity to navigate a complex health care system and to advocate for themselves within it."

For instance, the committee heard testimony from a woman who signed a consent form to undergo surgery without understanding that she was going to have a hysterectomy.

"It isn't [the woman's] fault that she did not know she had a hysterectomy," Kindig says. " Problems with limited health literacy such as [hers] arise from a confluence of factors and failures in the health care system, the educational system, and culture and society. For instance, an individual may have a different idea of what being healthy means than his or her doctor does, may have trouble understanding the medical jargon that we in the health professional sometimes use without thinking, or may speak a different language. These are all common problems that are related to health literacy."

Literacy and bias may coexist

Communication problems may be particularly harmful for members of racial and ethnic minorities and immigrants, many of whom have limited access to care and are further disadvantaged by cultural and systemic biases.

A 2002 IOM report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, concluded that minorities experienced disparities in quality of care and access to care that were not able to be attributed to socioeconomic status and severity of their medical condition.

That report demonstrated that health care providers often have biases and preconceptions about certain groups of patients that they may not even be aware of, says **Alan Nelson**, MD, MACP, former chair of the IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in

Health Care, which issued the report.

Compound that with the problems of low literacy and a complex health system and you have a recipe for disaster.

"We also need to have a better understanding of the communication problems that may lead the minority patient to have difficulty communicating with the providers and making wise choices about their treatment," Nelson said in an April 5 teleconference on racial and ethnic disparities in health sponsored by the Kaiser Family Foundation. "And, on the other hand, we found that bias and stereotypical behavior on the part of the physicians and other clinicians may very well be a factor."

The medical community needs to do a better job of understanding why biases exist and do a better job of teaching cultural competence, Nelson said.

Recommendations for change

The American Medical Association (AMA) recognized in 1998 that limited health literacy was a problem and has since taken several steps to begin to address it, AMA president-elect **John C. Nelson**, MD, said in a statement accompanying the release of the IOM report.

And low health literacy presents problems for the entire population, not just the individual patients who don't get the care they need, he said. "Excess hospital stays, multiple doctors' visits, expenses incurred by misunderstanding and miscommunication — all of these create costs borne by everyone through higher premiums, higher taxes, and the higher inefficiencies low health literacy brings to the process."

The AMA and the AMA Foundation have sponsored a multiyear effort to study how physicians and others are experiencing low health literacy and develop tools to help turn the tide, he said.

They have developed a health literacy kit, "Health Literacy: Help Your Patients Understand," which is available at www.amafoundation.org on the web. The kit contains a 48-page manual for health care professionals, a video and patient information.

The IOM report details ways in which low health literacy affects the delivery of health care and makes several recommendations about how the situation might be improved.

A concerted effort by the public health and health care systems, the education system, the media, and health care consumers is needed to improve the nation's health literacy, the report says. If patients cannot comprehend needed health information, attempts to improve the quality of care and reduce health care costs and disparities may fail.

The report recommends also that health care systems should develop and support programs to reduce the negative effects of limited health literacy and that health knowledge and skills be incorporated into the existing curricula of kindergarten through 12th grade classes, as well as into adult education and community programs.

Furthermore, programs to promote health literacy, health education, and health promotion programs should be developed with involvement from the people who will use them. And all such efforts must be sensitive to cultural and language preferences, the report states.

Copies of *Health Literacy: A Prescription to End Confusion* are available from the National Academies Press. Visit www.nap.edu on the Internet or phone (202) 334-3313 or (800) 624-6242. The cost of the report is $47.95 (prepaid), plus shipping charges of $4.50 for the first copy and 95 cents for each additional copy. ■

SOURCES

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CME Questions

17. During an epidemic, hospitals may face which of the following challenges?
A. Health care workers unwilling to treat infected patients
B. Shortages of medicine or equipment
C. Staff shortages due to ill personnel
D. All of the above

18. The President's Council on Bioethics recommended which of the following regarding human embryo research?
A. Federal law stipulate a developmental stage limit for embryos used in research
B. Federal law prohibit all research using human embryonic stem cells
C. A federal oversight body be established for approving new ART procedures
D. None of the above

19. According to research published in the *Annals of Emergency Medicine:*
A. Emergency physician practices with regard to prescribing opioid analgesics vary widely from provider to provider.
B. Emergency physicians infrequently prescribe pain medication.
C. Emergency physicians overprescribe medication for pain.
D. None of the above

20. Clinicians discussing a patient's condition with a surrogate decision maker should:
A. Ask the person what he or she believes the patient would want, given the circumstances
B. Ask the person and other family members, if they are present, what they understand the patient's condition to be
C. Attempt to focus the decision making process on honoring the needs and wishes of the patient
D. All of the above

Answers: 17-D; 18-A; 19-A; 20-D.