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IN THIS ISSUE

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Texas medical center on verge of ending cancer treatment for illegal immigrants

Ethicist: Problem is an ethics crisis for the nation, not just one state

The University of Texas Medical Branch (UTMB) in Galveston has long been the hospital where indigent patients — including illegal immigrants — sought care. But the strain placed on the hospital's cancer treatment resources for the indigent has led the university hospital to propose refusing cancer treatment to patients who cannot document that they are legal U.S. residents.

The decision on whether to deny care based on documented status was pending at press time, but a University of Texas ethicist told *Medical Ethics Advisor* the time when state-funded hospitals had to choose who to turn away has been looming for a long time.

"What happened was we had a crunch a couple of years ago, and there was actually a period of time when the cancer program ran out of money before the end of the year, and all [indigent] patients were being turned away [from the cancer program] by the end of the year," recalls **Howard Brody,** MD, PhD, director of the Institute for the Medical Humanities at UTMB and chair of the medical branch's ethics committee.

Political debate quickly ensued, comparing the merits of denying care to certain segments of a population based on immigrant status in order to preserve resources vs. denying care to taxpaying, legal U.S. residents because resources are expended on illegal aliens.

Brody says the question is not whether the hospital is forced to deny care, but rather, "Who do you say no to?"

The issue being faced by UTMB and other hospitals in the United States — particularly in the 24 border counties that run along the U.S.-Mexico border — is not over denial of emergency care. The Emergency Medical Treatment and Active Labor Act (EMTALA) requires hospitals to treat and stabilize patients seeking emergency care. Furthermore, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 — commonly referred to as "Medicare Section 1011" — provides reimbursement to hospitals, physicians, and ambulance providers for unreimbursed costs of services required

under EMTALA and furnished to undocumented aliens, aliens paroled into the United States, and Mexican citizens permitted temporary entry to the United States.

Section 1011 provides $250 million per year for fiscal years 2005-2008 for payments to eligible providers for emergency health services provided to undocumented aliens and other specified aliens, and Texas is slated to receive $44 million of those funds in 2008. A 2004 Texas attorney general's opinion leaves it up to hospitals in the state to decide individually whether to use state funds for providing preventive or nonemergency care to people who do not have legal status in the United States.

But for nonemergency treatments, such as cancer therapy, hospitals are being forced to get lean and creative to serve as many patients as possible on set budgets.

$12 million stretched for indigent cancer care

The UTMB set aside about $12 million in the $1.4 billion annual budget for 2007 to treat indigent cancer patients, but that isn't enough to meet demand, says **Karen Sexton**, RN, PhD, vice president and CEO of hospitals and clinics at the medical branch.

And the cancer program is running lean, the hospital and Brody report. The medical branch laid off 381 employees in 2006 to counter rising costs, state funding cuts, and a growing constituency of uninsured patients.

After several years of running out of money and cutting off care to all indigent patients when the money ran out of the cancer budget, Brody says, the medical branch tried to come up with a better plan.

"In trying to do something in the interim, they tried the best they could to document where people were from — not to identify immigrants vs. U.S. citizens, but just to document where they were coming to us from, because some counties [in Texas] have more generous funding and some have deals with our system and some don't," he explains. "It's a crazy patchwork for funding cancer care, and if someone who had funding [in their home county] could go back home for care there, then the money we had would stretch farther."

At no time, Brody repeats, was an emergency patient turned away, but nonemergency patients who could be steered back to their home counties for care were rerouted when possible. And patients already under care at the branch were not denied care, nor would they be if they were already under care at UTMB if and when the hospital was to decide to halt care to undocumented immigrants.

"While this was going on, the chemotherapy group really looked hard at all their costs, and cut their costs significantly," says Brody. "They took steps for efficiency anywhere they could, to become a lean machine for providing care, because they believe sincerely in the money going to the care of patients."

Ethics in an unethical situation

Brody told *MEA* in December that UTMB was planning a forum on rationing care in January, but as of press time the cancer program had not requested a formal consult with the ethics center.

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"They may feel that they have to make a decision quickly, that it's an institutional decision that will come through institutional channels," says Brody.

He says even under a bad system, there are ethical and unethical ways to make decisions.

Deciding who gets care

"Do you want to categorize patients broadly, or decide patient by patient?" he asks. "The argument for patient-by-patient selection is that you can stretch your dollars and maximize your outcomes by selecting patients who will benefit most from your resources.

"The danger is, is the patient you like going to get treatment, and the patient you don't like going to be denied treatment? Is someone with a different lifestyle going to be labeled as noncompliant? Are you opening the door to too much of a personal judgment when it's left up to such individual decisions? Individual choices can be very suspect."

Making selection choices based on broad categories carries its own ethical risks, he continues.

"I would warn that it's not ethically defensible that immigrant status be used to turn people away," he says, referencing California's passage of Proposition 187 in the mid-1990s. Proposition 187 sought to bar illegal immigrants from social programs, public schools, and free health care, but was ruled unconstitutional and declared dead in 1999.

"I think of the concerns raised by the legislation in California that would have denied care to undocumented immigrants — if they don't have papers, are they illegal? And is it racial stereotyping if you ask your Hispanic patients for papers, but not patients who appear Anglo?"

Brody says the problems faced by the cancer program at UTMB don't start and end with the U.S.-Mexico border states.

"Obviously, some hard choices have to be made, starting with the failure of the United States to have some comprehensive plan of care," he suggests. "Historically, if hospitals couldn't provide a service, people didn't expect them to provide it. But today, there's a disconnect between us being an affluent country but being unable to provide care to people who can't afford it."

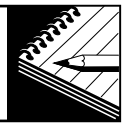
Sexton issued a statement saying hospital staff are keenly aware of the impact any decision is going to have on patients.

"We're trying to do the best we can to help our physicians and others with a decision by making it not so subjective," she said. "It doesn't feel right to us, either."

Nor should it, says ethicist Brody.

"I don't think we should try to stop it from being upsetting — we want it to be upsetting," he points out. "When we have to turn people away today, we should be thinking about what we can do to change the system so we don't have to turn people away tomorrow." ■

GUEST COLUMN



Rationing of care to undocumented immigrants

By **Marc D. Hiller**, DrPH
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Is it antithetical to Hippocratic oath?

There is little doubt that the budget problems and added demand on limited resources that undocumented immigrants contribute to health care institutions is real, and that institutions located closest to the border bear the greatest bur-

den. Yet, in wrestling with such issues, hospitals ought not to shun their ethical responsibility to treat, if not seek to heal, the sick without unfairly rationing care as a means to an end.

Fiscal vs. charitable concerns

Health care institutions that turn to rationing health care as a means to improve their fiscal condition need risk shifting from dominant patient care and charitable values, or what Cunningham has described as its healing mission, to a business ethic and a loss of public confidence.[1,2] And, doing so with the knowledge and intent that those who will experience the most negative impact of such a move are among the neediest, having little voice and even less power, suggests a failure to respect the long historic humanistic and charitable foundation of nonprofit health care in the United States.[3]

One needs to ask whether adopting a decision to refuse treatment of one particular group of individuals, i.e., those who are unable to document their status as legal U.S. residents, is consistent with the organization's character as defined by its mission, vision, and core values. While I am unable to speak specifically about the character of University of Texas Medical Branch (UTMB) in Galveston, it is hard to believe that any reputable health care institution would find such a practice within its character.

Violation of Declaration of Geneva

Furthermore, should it be, one could argue that making such a decision seriously risks its violating the internationally respected Declaration of Geneva (adopted in 1948 and amended in 1983) that proclaims that health care providers should not permit considerations of religion, nationality, race, party politics, or social standing to intervene with their duty to serve their patients.[4]

While it appears that UTMB in Galveston has in the past not shied away from the historic Hippocratic tradition and its long-held commitment toward providing needed cancer treatment to indigent patients, it appears that growing financial pressures are forcing a reconsideration of its values and its practices. Yielding to such pressures, rather than finding or having to make some alternative decision, risks sacrificing its core ethical principles by opting to explicitly ration (or deny) a set of lifesaving services to those who are among the most in need regardless of their unpopular — at least politically — status. While these patients may be unable to document their legal status as U.S. residents, they are human beings in need of the care that UTMB can provide. And, while denying them care may pose the simplest fiscal solution, it does not appear to be a morally justifiable one.

In adhering to the historic Hippocratic tradition, health care organizations must not allow themselves to be blinded to the fundamental ethical duties:

- **Nonmaleficence.** This dictim rests at the core of the Hippocratic tradition, "primum non nocere" (or first, do no harm). Knowingly refusing lifesaving care to any population group will result in its being harmed.
- **Beneficence.** This duty requires that health care providers benefit, i.e., give meaningful and beneficial treatment, to those in need of those providers' care. Not doing that which is known to benefit a particular population group, such as cancer victims, is wrong.
- **Justice.** This duty commands that all people be treated in a fair and just manner as a basic human right, and not unjustly refusing care to any population based on a particular characteristic that deems them less valuable or more expendable than others. This principle is at greatest risk of being violated in imposing any rationing schema that targets or most negatively impacts a single population group, particularly one that is highly disenfranchised, unpopular, and viewed negatively, or otherwise unable to voice an effective opposition.
- **Respect for Persons (Autonomy).** This fourth, highly cherished ethical obligation (though in more recent times having been viewed contradictory to the Hippocratic tradition) is extraordinarily embedded in the value structure of this nation (as reflected in the 14th Amendment to the U.S. Constitution) as well as in health care. It serves as a foundation for many of health care's priorities, such as informed consent, confidentiality, veracity, compassion, and possibly above all, respect and trust. Obviously, ignoring the needed treatment of a group of people, deemed less worthy due to their legal status, reflects a lack of respect for them as individuals as well as a population group.

Finally, while rationing is being realized increasingly as a method to control expenditures (or, as some may argue, an alternative to adopting a more just and compassionate health care system that assures universal access), it should

never be imposed without serious attention being afforded certain essential ethical criteria.

Dougherty has asserted that "rationing should: be done in the context of universal coverage for basic care, serve the common good, protect those who are most vulnerable, guard such important intangibles as caring and trust, set priorities openly and avoid insidious discrimination, and observe the Golden Rule, meaning those who ration must themselves be subject to rationing."[5]

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Five people you need to know during a pandemic

Groups represent essential public health, clinical roles

A recent bestselling novel centers around five pivotal people the main character meets in the afterlife. But ethics researchers at The Hastings Center say there are five pivotal people that public health leaders are going to want to meet now, to prepare and protect them before an influenza pandemic.

International public health experts agree that a new flu pandemic is inevitable, and in response to this threat and to a federal mandate, all states in 2007 submitted pandemic influenza preparedness plans to the Centers for Disease Control and Prevention (CDC). But while all plans note that rationing of supplies, devices, and manpower is inevitable in a pandemic, few address how they would make ethical decisions on rationing. **(*Medical Ethics Advisor* reported on state pandemic plans and their lack of attention to ethics in "Pandemic plans address vaccines but not ethics," June 2007, p. 68.)**

Nancy Berlinger, PhD, deputy director and research associate at New York's The Hastings Center bioethics research center, is co-author of an ethics backgrounder, "The Five People You Meet in a Pandemic — and What They Need from You Today," published in December 2007.[1] In the report, Berlinger and co-author Jacob Moses describe five key people — actually, five groups of people — who community and health leaders should identify and prepare in order to make fair decisions under the pressure of a sustained public health crisis.

A recent survey of states' pandemic influenza preparedness plans revealed that ethical decisions that must be made in preparing for and dealing with a pandemic were mostly left out of plans, or given only cursory mention.[2]

"Ethical challenges — how a community will make fair decisions about using scarce resources, protecting public health, and keeping basic services running — must be discussed before pandemic hits," the authors write. Berlinger says in meetings on pandemic preparedness, it became evident to her that pushback to rationing plans on the clinical level was the result of health care workers not perceiving the guides as based on ethically sound plans.

"We realized the level to discuss this was really the interface between clinical medicine and public health," Berlinger says. Thus, the five key groups of first responders to see a community through a public health crisis posed by a flu pandemic include clinicians, non-clinical service providers, and individuals who straddle the clinical and public health boundaries.

Where public, clinical ethics meet

Preparation for a pandemic includes making sure everyone involved in planning understands ethics the same way, Berlinger says.

"When public health officials talk to clinical ethicists and ask how to get ethics into the plan, if the ethicist hasn't had a lot of public health exposure, they quickly see that clinical ethics and public health ethics aren't the same thing," says Berlinger.

Specifically, whereas clinical ethics emphasizes the values and preferences of the individual patient, "in a public health crisis, you can't ask each individual about their values and preferences," she says.

To devise a tool that public health officers can use to bring together clinicians, administrators, business, media, clergy, and elected officials to speak in the same language about ethical decisions

in a pandemic, the Providence Center for Health Care Ethics and The Hastings Center partnered to convene a meeting of public health officials, experts on public health ethics and clinical ethics, and clinicians to discuss the challenge of building pandemic plans on an ethically sound framework. From that meeting, the "Five People" model was developed.

"The plan has anticipated five groups — some in health care, some outside, some rules makers, some rules followers," Berlinger continues. "No matter the size of the community, you will have all these people in your community. This is a way of working through and saying, 'What does [our plan] look like through the eyes of the person with the least power?'"

The five groups of people, as identified by the authors, are:

- The **truck driver**: Represents community members responsible for essential non-medical tasks in a public health emergency;
- The **gatekeeper**, the **triage officer**, and the **janitor**: Represent groups working inside hospitals, responsible for a variety of essential tasks and decisions;
- The **public health official**: Represents local, state, and federal authorities responsible for making or carrying out the rules — laws, regulations, emergency triggers, policies — that communities will follow during an emergency and that will help them recover after an emergency.

Besides identifying the five groups, community public health leaders must then make sure those five are trained to act under emergency conditions in ways that might not come naturally. Hand in hand with that is making sure the groups know they are prepared and that they will be protected; the essential nature of their roles makes them high priority groups for receiving vaccine in the event of rationing.

"The temptation is there to say, 'They'll know what to do; they're trained for triage.' But we're going to be asking them to think and act differently. We can't also be asking them to think on the spot how to do it ethically," Berlinger explains. "That's where the planner comes in — to create the rules that say, 'If you follow these rules, you're acting ethically even though you're acting differently than you normally would, you're doing things differently, and the hospital is different."

Five groups to train and protect

Truck Driver. The truck driver represents the first responders who produce, deliver, or ensure delivery of essential supplies that cannot be stockpiled or that have run out. This includes those who ensure supplies of food, medical supplies, fuel, and clean water, as well as essential personnel who unload and load the trucks; public safety officers who make sure the truck drivers can get through; and factory workers who meet demands for vaccines.

The Gatekeeper. The gatekeeper's role is to ration access to public health facilities. Hospital emergency department personnel will be overrun with influenza patients, on top of the regular emergencies that come to the hospital under normal conditions. Berlinger says the gatekeeper's role can be played by clinical personnel; chaplains, administrators, and social workers who help turn people away if they're not ill enough to be admitted under the emergency rules triggered by the pandemic; and security staff, who will be charged with protecting hospital staff and patients.

The Triage Officer. In an influenza pandemic, intensive care for the most severely ill will be in high demand, and hospitals with inadequate staffing or beds may have to restrict access to only the sickest patients. In those cases, the authors suggest, pandemic plans have to anticipate a shortage of ventilators — some ventilators will already be in use, and influenza is a respiratory illness. Berlinger says planning in concrete, actionable, ethically sound terms will give gatekeepers the tools to say who gets access to available ventilators and under what conditions.

The triage officer is a gatekeeper with very specific duties, focused on ventilators. The triage officer should be supported by clinical ethicists who can apply clear, consistent rules that acknowledge the rights of individual patients

SOURCE/RESOURCES

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1. Berlinger N, Moses J. *Bioethics Backgrounder.* The Five People You Meet in a Pandemic — and What They Need from You Today. November 2007. Available for free download at www.providence.org/resources/Oregon/PDFs/Ethics/pandemicbackgrounder1107.pdf.
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while also acknowledging that, for the duration of the emergency, the need to be fair to all patients may trump individual claims, the authors state.

The Janitor. Though non-clinical, the janitor — like the truck driver — is an essential component to a pandemic preparedness plan. Because the janitor — which includes housekeeping, laundry services, orderlies, food service staff — works in the hospital, the risk of exposure to infection is high. Planners for this group must determine the priority to assign the janitor when it comes to rationing vaccine, weighing supply against the effects of not having the janitors at their posts during and after the pandemic.

The Public Health Official. Public health officials include not only those in traditional public health roles, but government officials who can make good decisions — or, as Berlinger says, "bone-headed decisions" — that affect public health during an emergency.

"People are already talking about who will show up at work, and who is ready to do things that need to be done," she says. "The unilateral decisions, however — like closing routes that prevent doctors from getting from their homes in the suburbs to their hospitals in the city — need to be thought through, to be sure that they're good decisions."

Planning for public health officials also needs to clearly address secondary effects of a pandemic, including disruption of hospitals' cash flow from Medicare and insurance, and fears of negligence liability on the part of clinicians (as seen following Hurricane Katrina), the authors point out.

Plan, then make plan transparent

Berlinger says that the effectiveness and success of any pandemic preparedness plan hinges on the public being able to understand it and have questions about it answered.

"Planners need to encourage the media to be a vector of public information and education, and not incite panic," she says. "Putting things on a factual basis helps people understand the reasoning behind ethical rationing decisions."

Even though the idea of scarcity is an unfamiliar one to most Americans — true unavailability of vaccine or access to care is something few Americans have had to face, Berlinger says — to assume that the public won't follow rules or adhere to rationing rules would be to "break faith" with the public interest before a plan even has a chance to be tested.

"In Toronto [during the SARS outbreaks], 25,000 citizens were quarantined, so it is possible in major North American cities to do this," she points out. One way to help accomplish a greater level of compliance is to create a system that can't be "worked."

"You don't want to set up a system that people can work around. You don't want people to think they won't have to worry about rules, because that makes thing very hard," says Berlinger. ■

Veterans allege religious discrimination in chapel

VA says neutral space for worship respects all faiths

A Veterans Health Administration (VA) hospital's move to make its chapel religiously neutral by removing Christian symbols except during Christian services is under fire by two veterans who are considering legal action over what they say is suppression of Christians' freedom of religion.

Until late September 2007, the chapel at Fayetteville (NC) Veterans Affairs Medical Center had a cross and Bible on permanent display except during services conducted by other religious faiths. However, the Veterans Health Administration's National Chaplain Center stepped in when it was notified that the hospital's chapel was being used as an exclusively Protestant Christian chapel, with Christian religious articles and symbols continuously present.

The National Chaplain Center directed the chaplain at the Fayetteville hospital to bring the chapel into compliance with VA policy by removing symbols of a denominational nature immediately after Christian services and returning the chapel to its "religiously neutral state" for the use of patients or family for private devotions, says

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Ev Chasen, VHA chief communications officer.

It was the removal of the cross and Bible from permanent display that led two veterans, both of whom volunteer at the hospital, to lodge a complaint with the hospital, write editorials in local newspapers, and finally, threaten legal action.

Chapel for Christians, separate space for others?

John Whitehead, JD, president of the Rutherford Institute, a nonprofit, conservative legal group that litigates for religious causes, says his group has taken up the veterans' complaint against the VA hospital because there is more at stake than the presence of a Bible and cross in the hospital chapel.

"The general issue is the secularizing of the hospital," says Whitehead. As of early December, Whitehead said there had been no legal action taken, but that the hospital had been mailed a letter asking that the chapel be restored to a place of Christian worship.

"Our suggestion is to mollify concerns by letting Christian symbols remain in the Christian chapel, then creating [a separate] interfaith chapel that all other religions could use," says Whitehead. The veterans who have enlisted Whitehead's help maintain that most of the veterans using the VA chapel are Christian, and should be afforded a chapel with permanent Christian symbols on display.

Asked if permitting Christians to have a unique chapel while grouping all other religions into one neutral interfaith chapel is not also discriminatory, Whitehead said it is not.

"[The VA has] gone into a Christian chapel and wiped out Christian references," he says. "Secularizing in that way isn't neutral, it's hostile. They've put up curtains over the stained glass windows to block the Christian images — why not just knock out the stained glass windows?"

Chasen, however, says the chapel was never "a Christian chapel."

"VHA policy going back to the 1950s has addressed the proper use of VA chapels," Chasen explains. "Most VA medical center chapels, including the Fayetteville chapel, were built as what might be called 'all faith' chapels and were to be utilized for religious services for all faith groups."

Chasen says VA policy requires that its chapels be kept open and available for meditation and prayer by veterans and their families of all faiths, and VA chaplains are responsible for setting the chapels up with appropriate religious symbols, pictures, and other items that will permit people of particular faiths to pray or conduct worship services. When worship services are complete, Chasen says, the religious items particular to a religious group are expected to be removed, stored, and the chapel returned to a neutral state appropriate for anyone to use.

"VA believes that meeting the spiritual and pastoral care needs of veteran patients is an important part of the healing process," Chasen says. "Our care of the veteran and his or her family begins with respect for who they are and what they believe. The changes made in the Fayetteville chapel reflect our commitment to respect and care for all our honored veterans." ■

Role of direct-to-consumer ads for genetic tests

Do tests hold emotional appeal for patients?

Many genetic tests advertised directly to consumers are "home brews" that are neither regulated by the U.S. Food and Drug Administration (FDA), nor clinically valid, according to findings by a Boston obstetrics/gynecology specialist.

Erin Tracy, MD, MPH, a physician with Massachusetts General Hospital's OB/GYN Service, says direct-to-consumer advertising for commercial genetic testing is on the rise and may be problematic, because it's poorly regulated and may present potential pitfalls for patients and physicians.

"Some of the tests that are being offered have no proven clinical validity whatsoever and are quite costly," says Tracy, who published her findings in December 2007.[1] "So patients spend money trying to identify a particular gene to figure out if their child is prone to addictive behavior, for example.

"If the test comes back positive, parents are often not adequately counseled as to what those results might mean, whether these tests have any proven value, or what resources are available for follow up."

While the FDA might need more funding to regulate genetic testing, Tracy says, it also is limited in its ability to regulate services based in other countries. According to a 2002 study in *Genetics in Medicine,* 24 of 105 web sites offering genetic testing directed potential clients to international mailing addresses, she says, and many web sites listed professional societies or accredit-

SOURCE/RESOURCE

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1. Tracy EE. Are doctors prepared for direct-to-consumer advertising of genetics tests? *Obstet Gynecol* 2007;110:1389-1391

ing organizations on their pages, implying sponsorship or approval of their activities that may not be accurate.

Like other direct-to-consumer ads, these materials do not need to be reviewed by the FDA before they are published, Tracy says. Many involve emotional appeals — such as placing an ad for a cancer-associated gene test in the program of a play about a woman dying from ovarian cancer — instead of clear discussion of the rationale for screening. Results of genetic tests have the potential to cause excessive alarm or to falsely assure consumers that they will not develop cancer or disease, she says, and direct-to-consumer advertising for genetic tests may also give the erroneous impression that a certain test is mandatory preventive medicine.

"Some patients with no risk factors for breast cancer come in and request the test for BRCA-1 and BRCA-2 mutations," says Tracy — requests sparked by a recent advertising campaign. "The ads are compelling and they're emotionally driven. I end up spending time discussing why a particular test being advertised is not appropriate when I should be addressing important issues such as eating a healthy diet or smoking cessation."

At the same time, she notes, without proper counseling a patient who does not have the BRCA-1 or BRCA-2 mutations might assume she has no risk for breast cancer and forgo recommended mammograms and clinical breast examinations.

Patients who inquire about genetic testing should be engaged by their physicians in conversations about their particular risk for cancer or other diseases, Tracy suggests.

"Before any test is ordered, there should be a thought process about whether that particular test is appropriate and what we'll do with [the results]," she adds. "And physicians need to stay current about what's out there so we can best advise our patients." ■

Pioneering bioethics group disbands after 22 years

Bioethics Resource Group concludes its goals are met

The Bioethics Resource Group (BRG), a medical ethics education organization in Charlotte, NC, voted to shut itself down in December after 22 years in which it fostered hospital ethics committees and educated clinicians on advance directives and do-not-resuscitate orders.

According to **D. Scott Lindsay**, DMin, director of pastoral care at Presbyterian Healthcare in Charlotte, when the BRG first convened in 1985, fewer than 10% of hospitals in the Southeast had ethics committees, advance directives and living wills were not routinely sought out when patients were admitted, and programming in medical ethics was not easy to come by.

Lindsay, one of the original board members of the BRG, credits the commitment of the founding members to the success the organization enjoyed in bringing medical ethics education to the Charlotte area.

"Once the group was pulled together, there was agreement that there were issues that many of us had been thinking about, and they agreed these [individual health care systems] would pull together on them," Lindsay adds.

The BRG's goals were to:

- Heighten community awareness of bioethical issues by inviting scholars, researchers, and other qualified individuals to present public programs, and by making speakers and relevant materials available to the general public;
- Assist health care providers in recognizing bioethical issues and keeping them abreast of developments that relate to bioethical issues;
- Encourage the establishment of ethics committees in hospitals and other health care institutions, and to offer them support and guidance on policies and decisions that are bioethical in nature.

Lindsay says that key to the group's decision to disband is the sense that it has accomplished its goals — ethics committees flourish at Charlotte area hospitals, and medical groups and medical schools provide ongoing opportunities for public and clinical education on bioethics issues.

"The danger could have been we could have continued to meet as a board and have wonderful programs, but where would the true contribution to the larger community be?" he asks.

"We know that the pioneering work done by the BRG in the field of medical ethics will continue through ethics education at the fine colleges and universities in the region and through the ethics committees at health care facilities," says BRG President **Mark Stephens**, PAHM, CMR, senior account manager for Pfizer Inc.

Over the years, the work of the BRG has included working with North Carolina hospitals as they created internal ethics committees; educating clinicians and the public about advance directives; and providing speakers and resource materials on enduring ethical issues as well as the ethics surrounding stem cell research, genetics, HIV/AIDS, health care access and reform, organ transplantation, and pharmaceuticals.

The membership of the organization reflects the wide net cast by health care ethical issues: Doctors, nurses, hospital administrators, chaplains, ethicists, lawyers, journalists, pharmacists, educators, and pharmaceutical professionals have been involved in the BRG's efforts throughout its life, Lindsay points out.

One of the catalysts in the birth of the BRG was the rise in the early 1980s of diagnosis-related groups (DRGs) and the push to classify patients based on the resources they consumed. Charlotte radiologist George Barrett, concerned that the Medicare regulations for cost-containment could have a negative impact on patient care, wanted to find a way to get the region's three acute care hospitals to work together to address the changes brought on by DRGs, and he concluded the way to get them talking was to get them talking about bioethics, Lindsay recalls.

Recognizing a mission accomplished

"For 22 years, this [organization] really met a need; at one time, we were told that there was none other like it in the country, and certainly it made it possible for hospitals in North Carolina and South Carolina to get good, solid medical ethics programs going," he says. By serving as a resource for education on developments in bioethics, the BRG put Charlotte health care providers in the position of being well-equipped to integrate changes such as the 1989 federal mandate that made advance directives the rule, rather than an oddity.

"We were able to get committees going, programs going in North and South Carolina, provide resourcing and educational events, so we were in a good position to do something with advance directives when the legislation came down," Lindsay explains. "And this was all happening before The Joint Commission started asking hospitals what provisions they were making for medical ethics.

Not that the BRG made for easy answers on developing ethical policy.

"It helped these health care systems have more conversations than they might have had, but yet, when we tried to develop a community-wide policy for [do not resuscitate] orders, a committee from the BRG and representatives from the two hospitals worked for 22 months and never could produce one," Lindsay says.

About two years ago, Lindsay says, some BRG directors began asking the hard question: Had the group served out its useful life?

A planning committee met for six months in early 2007, and in December made its recommendation that "the time had come to celebrate we've done and all the remarkable things being done at University of North Carolina at Charlotte and Davidson College [schools actively involved in BRG efforts], and to recognize that hospitals are taking care of themselves to a greater degree when it comes to bioethics and ethics resources," says Lindsay. "We did what we set out to do, and now ending it is a bold thing to do, but it's the right thing to do." ■

Look for clues that patient comprehends information

Take time to ensure capacity for understanding

Physicians pressed for time need to note whether their patients truly comprehend what they're being told and what they read about their medications; deficient health literacy is being counted as one contributor to health care disparities in some populations.

"Health literacy" is defined by the Institute of Medicine and the U.S. Department of Health and Human Services *Healthy People 2010* as the degree to which a person has the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

A 2003 study by the National Center for Education Statistics indicates that more than one-

CME answers

5. D; 6. E; 7. B; 8. D.

third of adult Americans have levels of health literacy that are below what is required for them to understand typical medical information.[1]

But health literacy shouldn't be equated with the ability to read or even educational level, says **Michael Mackert,** PhD, a University of Texas at Austin assistant professor of advertising who has conducted extensive research into health communications and health literacy.

"A lot of [research] has looked at the reading level of the text included in the body of advertising, and there are a lot of things that work their way into ads that someone with lower health literacy might not comprehend," he says. "Health literacy includes the science behind the literature, so you might have someone who is literate, but might not understand what a randomized, blinded trial is."

Mackert says a class he taught recently researched health literacy as it applies to pharmacist-customer communications, and he says the students came up with several tools that can help different patients better understand their medications, the reasons for the drugs, and the effects the drugs might have.

"The students created a checklist for pharmacists that included skills that are effective in providing information — like drawing pictures, for example — and also clues that can help the pharmacist identify people who were potentially health illiterate," he says.

For example, a patient might nod in the affirmative when asked if she understands her medication and the science behind it. But then, when asked what medications she takes, must look at the pills because she identifies them as "the purple one" or "the little [or big] pills."

The average informed consent document is written at a college reading level, but numerous studies have shown that half of American adults can only comprehend material written at the 8 th-grade level or below.

In cases where pharmacists or physicians might suspect a lack of comprehension, follow-up phone calls can be effective in reinforcing or clari-

SOURCE/RESOURCE

For more information, contact:

- **Michael Mackert,** PhD, assistant professor, department of marketing, University of Texas at Austin. E-mail: mackert@mail.utexas.edu.
- **National Center for Education Statistics.** The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. Available on-line at http://nces.ed.gov/Pubsearch/pubsinfo.asp?pubid=2006483.

CME instructions

Physicians participate in this continuing medical education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue. Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge.

To clarify confusion surrounding any questions answered incorrectly, please consult the source material. After completing this activity, you must complete the evaluation form provided at the end of each semester and return it in the reply envelope provided to receive a credit letter. When your evaluation is received, a credit letter will be mailed to you. ■

CME objectives

After reading each issue of *Medical Ethics Advisor*, you will be able to do the following:

- discuss new information about hospital-based approaches to bioethical issues and developments in the regulatory arena that apply to the hospital ethics committee;
- stay abreast of developments in bioethics and their implications on patient care, risk management, and liability;
- learn how bioethical issues specifically affect physicians, patients, and patients' families. ■

COMING IN FUTURE MONTHS

■ Doctors' professional ethics slipping?

■ Lawmakers want pharmas to register gifts to doctors

■ Quality of prisoners' health care

■ CA stem cell funding cut for conflict of interest

fying information the patient might not have grasped fully during the first office or pharmacy visit.

"Doctors, nurses, and pharmacists are always pressed for time, and nobody has the time to deal with a lot of new questions, but the extra two minutes could save a lot of time in follow-up questions by phone, or a deteriorated condition because they didn't understand the instructions," Mackert adds. "If you build up their knowledge once, you don't have to constantly go back over the same questions." ■

CME Questions

5. The University of Texas Medical Branch in Galveston is considering denying non-emergency cancer treatment to undocumented aliens because:
A. of political pressure on the hospital to not spend taxpayer dollars on illegal immigrants.
B. the Texas attorney general has ordered hospitals to deny care to illegal immigrants.
C. other counties in Texas can better afford to provide care to indigent patients.
D. the center's $12 million annual budget for cancer care for indigent patients ran out and refusing treatment to undocumented immigrants would stretch the budget farther.

6. The Declaration of Geneva proclaims that health care providers should not permit which of the following considerations to intervene in service to patients?
A. Religion
B. Nationality
C. Race
D. Social Standing
E. All of the above

7. According to a pandemic influenza preparedness backgrounder created by The Hastings Center, the five people public health planners should identify and plan for — the truck driver, gatekeeper, triage officer, janitor, and public health official — represent groups of clinical and non-clinical professionals whose regular job duties will adequately prepare them for making ethical decisions during an emergency without additional public health guidance.
A. True
B. False

8. "Health literacy," as defined by the Institute of Medicine and the U.S. Department of Health and Human Services *Healthy People 2010,* is:
A. the ability to read at an 8th grade level.
B. the ability to read at college level.
C. the ability to identify medications by name, rather than by color.
D. the degree to which a person has the capacity to obtain, process, and understand basic health information to make appropriate health decisions.