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Prenatal care for illegal immigrants divides Nebraska lawmakers

Illegal immigration and health care have been mentioned a great deal in the news recently, and the issue has Nebraska's lawmakers at odds. Some conservatives are supporting a plan to offer state aid to pregnant women in the United States illegally.

The measure being put before Nebraska lawmakers requires the state to pay for prenatal care to low-income women who have entered the United States illegally, and also extend coverage to an estimated 1,162 fetuses each year, at a cost of $650,000 in state money and $1.9 million in federal tax dollars.

The measure has made opponents of normal typical allies, with Republican Gov. Dave Heineman pushing hard against the proposal, even while noting his strong opposition to abortion. The Republican speaker of the Legislature, Mike Flood, has taken the opposite position, supporting the measure while stating that he has always been against illegal immigration.

When the measure advanced through with the required votes, Heineman singled out Flood, saying he and other lawmakers were wrong to support taxpayer-funded benefits to illegal immigrants, regardless of the reason.

"Unless you and the legislature reverse course, the legacy of this session will be one in which illegals were given preferential treatment over legal Nebraska citizens," Heineman said, reading from a letter that his staff hand-delivered to the speaker's office. "This will be a session remembered for a tax increase on legal, working Nebraskan men and women, while illegal aliens were provided taxpayer-funded benefits."

EXECUTIVE SUMMARY

A new measure is being put before Nebraska lawmakers regarding illegal immigration and health care, which has lawmakers divided.

- The measure requires the state to pay for prenatal care to low-income women who have entered the United States illegally.
- The measure extends coverage to an estimated 1,162 fetuses each year, at a cost of $650,000 in state money and $1.9 million in federal tax dollars.
- Providing quality health care to illegal immigrants who are being detained by ICE is an important and challenging task.

Flood, who has sponsored legislation banning late-term abortions, said the immigration concern is important but trumped by the health concerns for unborn children who lack access to prenatal vitamins, ultrasounds, doctors, and nurses. He said medical data do not support the notion that pregnant illegal immigrants would move to a state for prenatal care.

Abortion opponents said the vote marked an important victory to assuage their fears about the health of unborn children, and the prospect that women without access to care could seek abortions.

Supporters argue that by helping women have a healthy pregnancy, the state would reduce infant deaths and, ultimately, save money by avoiding emergency births, long hospital stays, and treatment for children who develop complications. Opponents say the bill would reward unlawful behavior with taxpayer-funded benefits, and could attract more illegal immigrants to Nebraska. Opponents said the money is needed elsewhere.

Nebraska Right to Life, the state's largest pro-life group, issued a statement calling on six pro-life senators who voted "no" on LB 599 to switch and support the bill.

Heineman and other opponents of LB 599 have said the issue is illegal immigration, not the rights of the unborn. "This is an issue of fairness," the governor said in a statement. "Hard-working Nebraskans pay their taxes and obey the laws. Illegal aliens who don't pay taxes and don't obey the laws should not be receiving taxpayer-funded benefits."

Exact counts vary on how many states now provide taxpayer-financed prenatal care. The governor, citing a check by the Nebraska Department of Health and Human Services of federal Medicaid statistics, said 14 states cover the unborn children of undocumented women through the Children's Health Insurance Program: Arkansas, California, Illinois, Louisiana, Massachusetts, Michigan, Minnesota, Oklahoma, Oregon, Rhode Island, Tennessee, Texas, Washington, and Wisconsin.

The Children's Health Insurance Program uses a combination of state and federal funds. The Kaiser Family Foundation additionally lists New York, New Jersey, and Washington, D.C., as having state-funded prenatal programs.

The National Immigration Law Center says there are 13 states and Washington, D.C. Advocates for LB 599 said the studies they are aware of discount any magnet effect, the concern noted by Heineman.

Detainees' health care

A 2000 study,[1] "Health care use among undocumented Latino immigrants," surveyed immigrants who settled in Texas and California cities. Respondents said jobs and family led them to settle in those cities. Another study, "The integration of immigrant families in the United States," released in 2001, concluded that jobs, and not generous social safety nets, prompted immigrants to settle where they did.

That study also concluded that illegal immigrant families grew four times faster in states that offered less-generous public benefits than in those offering relatively ample safety nets, because more jobs were available.

For every $1 invested in prenatal care, studies

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Senior Vice President/Group Publisher: **Donald R. Johnston**.
Managing Editor: **Leslie Hamlin** (404) 262-5416 (leslie.hamlin@ahcmedia.com)
Executive Editor: **Shelly Morrow Mark** (352) 351-2587 (shelly.mark@ahcmedia.com).

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EDITORIAL QUESTIONS

Questions or comments? Call Leslie Hamlin at (404) 262-5416.

indicate a savings of between $1.70 and $3.38 by reducing neonatal complications, according to the National Conference of State Legislatures.[2]

Providing quality health care to illegal immigrants who are being detained in Immigration and Customs Enforcement's (ICE) custody is an important and challenging task, says assistant director for ICE Health Service Corps (IHSC) **Jon Krohmer**, MD, FACEP, in a statement.

The ICE Office of Enforcement and Removal Operations (ERO) ensures the safe and humane conditions of confinement for illegal immigrants detained in ICE custody. This includes the provision of reliable, consistent, and appropriate health services.

IHSC, which falls under ERO, is comprised of more than 900 Public Health Service-commissioned officers, federal civil servants, and contract support staff. Their mission is straightforward: to serve as the medical authority for ICE on a wide range of medical issues, including the agency's comprehensive detainee health care program, according to DHS officials.

However, at this point, only estimated costs for this health care program are available, and vary between $50 million and $150 million per year.

IHSC provides direct care to approximately 15,000 detainees housed at 21 IHSC-designated facilities throughout the nation. In addition, IHSC oversees the medical care provided to an additional 17,000 detainees at non-IHSC staffed detention facilities across the country. Whenever necessary, it authorizes and pays for off-site specialty and emergency care, consultations, and case management, according to ICE.

"A detainee's health care begins the moment they walk through the facility's doors," said Dr. Krohmer. "Within the first 12 hours of their admission, all detainees undergo a preliminary health screening, which includes an evaluation of the individual's medical, dental, and mental health status, and within the next 14 days, a more detailed physical examination takes place."

Because so many of these detainees are either new arrivals in the country or haven't had access to health care in the past, Dr. Krohmer said it is not unusual for serious health problems to be diagnosed at these screenings.

"We're finding out about health issues that even they didn't even know about, and, in most cases, are able to begin treatment," he said.

However, some observers find Dr. Krohmer's findings disturbing.

"I'm more concerned with illegal aliens who may enter the U.S. carrying a serious — even deadly — disease that may be highly contagious. Why don't IHSC physicians and medical staff concentrate on screening immigrants coming from nations that may have serious health problems?" asks former NYPD police officer and emergency medical technician **Nick D'Amato**.

The continuity of care not only lasts during the individual's period of detention, but also throughout their removal to their country of origin. Before any detainee boards a plane to be removed from the United States, the detainee must first undergo an evaluation to make sure he or she is fit to fly, according to officials.

In order to continually upgrade the quality of medical services they deliver, IHSC not only actively complies with the Performance Based National Detention Standards, but is also instrumental in the standards' continuous upgrades and improvements. "My staff and I are aware that detainee health care is an ever-evolving issue, and that just like in the general population, health care priorities are constantly changing," said Dr. Krohmer. "We are working to develop a more systematic approach to our health care system within the detention facilities."

For instance, ICE recently streamlined the treatment authorization request. This application — used to formally request a specialized medical procedure that falls outside the scope of what IHSC can provide — is now typically reviewed and approved within 24 hours.

Krohmer added that plans are underway to forge a more uniform health care system among the IHSC facilities, enabling them to work together more cohesively.

"Sounds to me like illegal aliens are getting better health care than American citizens who are poor or homeless and can only receive emergency medical treatment at hospitals. It's a disgrace," said **Mike Baker**, a political strategist and attorney. ■

Program studies role of religion in practicing medicine

Is a doctor's spirituality an obstacle or a benefit in the clinic? Does religious affiliation affect medical decision making? Can a spiritual calling protect doctors against career burnout?

With a $2.5 million grant from the John Templeton Foundation, the University of Chicago School of Medicine has launched a new program to help faculty scholars study these questions and more about the role of spirituality in medical practice and education.

"We want to look at the spirituality of being a practitioner, rather than focusing completely on the spirituality of being a patient," said **Daniel Sulmasy**, MD, PhD, Kilbride-Clinton Professor of Medicine and Ethics in the

Department of Medicine and Divinity School and co-director of the Program on Medicine and Religion. "This new program will jump-start scholarship and teaching at the intersection of medicine and religion."

The Faculty Scholars program, which started last month, will train junior faculty to conduct further research on how a physician's personal beliefs inform his or her professional life.

The program will enroll four faculty scholars each year for a two-year program of learning and research on the role religion plays in a physician's practice. Participants will examine how Christianity, Judaism, Islam, and other spiritual traditions influence physicians' beliefs, decisions, and satisfaction with their profession.

"We hope this is a first step in a growing series of projects to train people who will shape the way religion is dealt with in medical education, and the profession more broadly, in the future," said **Farr Curlin**, MD, associate professor of medicine and co-director of the Program on Medicine and Religion.

According to a survey of 2000 U.S. physicians conducted by Curlin and colleagues, nine out of 10 clinicians claim a religious affiliation. More than half of responding physicians also agreed with the statement, "My religious beliefs influence my practice of medicine." Subsequent studies discovered relationships between physicians' religious affiliations and their attitudes on controversial clinical issues such as end-of-life care, abortion, and birth control.

"The big issue is whether a physician's religion should be seen as a threat to their medical practice or a resource," Curlin said. "Often religion is construed as a set of personal beliefs and ideas that threaten to prejudice a physician's practices or responses to patients, and interferes with physicians' professional obligations."

"In contrast, we want to ask how medicine can be construed as a spiritual vocation, as work that has sacred meaning," Curlin continued. "To think of medicine that way is to look for how physicians might practice medicine in ways that are congruent with, and animated by, their spiritual beliefs and practices."

The spiritual dimensions of medicine may be a useful antidote against the rising tide of dissatisfaction among physicians with their work. According to a May 2011 editorial in *Journal of the American Medical Association*,[1] 30 to 40% of U.S. physicians experience "burnout" from work-related stress — a phenomenon that could hurt patient care and drive physicians away from medical careers.

"There's a sense of alienation from the practice of medicine itself," Sulmasy said. "When it becomes seen as purely technology, as merely something that is done to persons, as objects, that winds up also in a sense making the clinician into an object. We can have spectacular, 21st century technologically advanced medicine and treat people as whole persons at the same time, but we need to move the balance back to where we're doing both and not just one."

One place where spirituality and religion could be integrated into clinical practice is at the medical school level. Following the model of the MacLean Center for Clinical Medical Ethics (where the Program on Medicine and Religion is based), the Faculty Scholars program hopes to inspire participant faculty to create curricula in religion and medicine at their home institutions.

"We are modeling this on other successful programs that have really been able to effect a change in the culture of medicine and build capacity in other fields," Sulmasy said. "In the great tradition of the University of Chicago teaching the teachers, we're trying to do the same thing here."

The first class of Faculty Scholars, announced March 1, will include John J. Hardt of Loyola University, Abraham Nussbaum of the University of Colorado, Aasim Padela of the University of Chicago School of Medicine, and Michael Balboni of the Dana-Farber Cancer Institute/Harvard University. The program will begin with a spring retreat in May 2012.

"We seek to help develop a field that really doesn't exist right now, which is the field of medicine and religion," Curlin said. "It's part of an overall hope that we can, through this work and future projects, contribute to a spiritual renewal within the practice of medicine," Curlin said. ■

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RESOURCE
• Physicians' observations and interpretations of the influence of religion and spirituality on health — http://bit.ly/HMeZYr

Can patients be given too much room to make own decisions?

Needless pressure can result

If a patient has high blood pressure, prescribing medication might seem like a "no-brainer" to the physician. However, this isn't always true for

the patient, according to **Mary Catherine Beach**, MD, MPH, core faculty at the Berman Institute of Bioethics at Johns Hopkins University in Baltimore.

"Obviously, we need to bring the patient's blood pressure down," she says. "But some patients may not want to take medication." If you give reluctant patients a prescription without asking what they think about it, they may not take the medication, says Beach.

Clarence H. Braddock III, MD, MPH, FACP, professor of medicine at Stanford (CA) University and director of clinical ethics at the Stanford Center for Biomedical Ethics, says that physicians may confuse a "shared decision-making" approach, which presents patients with various options along with the physician's recommendation, with simply asking patients what they want and giving it to them.

"The doctor may lay out options as you would with a restaurant menu, without offering any information about the relative merits of one or another," he says.

Instead of saying to a patient with high cholesterol, "You can take medication or you can work on your diet. Which would you rather do?" Braddock says that physicians should lay out the two options for the patient, and then decide together which one is best.

Using this approach, the physician might tell the patient, "Based on what I know about your situation and your risk factors, I think the best thing is to take the medication. Does that sound OK to you?"

The patient and physician can then have a conversation that leads to a decision, based on both medical considerations and the patient's values and preferences, says Braddock. "The physician is the expert on the medical stuff, and the patient is the expert on the way they want to live their life," he says.

Here are things to consider when engaging patients in medical decision making:

• The physician needs to decide how much to tell patients about risks of a particular treatment.

If the chance of an excellent outcome is 95%, but there is nevertheless a risk of death from surgery, how does the physician tell the patient there is a miniscule chance he or she might die?

"This is something that frequently troubles physicians," says **John Banja**, PhD, a medical ethicist at Emory University's Center for Ethics in Atlanta. "You don't want to scare the patient away by telling them everything that can possibly go wrong. That would take hours, which health professionals don't have."

• The physician needs to consider whether a particular treatment is likely to benefit the patient.

Some treatments might be available but are not worth the effort, says Banja. "If a treatment benefits only one patient out of 1000, is it reasonable to do?" he asks. "We sometimes meet up with these problems in what are called 'last chance therapies.' There are no good rules to guide us, because these cases are highly contextual."

What might be appropriate in one case isn't necessarily appropriate in another, but, nevertheless, health care providers may encounter angry, demanding family members who threaten to sue if everything isn't done for their dying loved one. "This can be very upsetting to the staff," Banja says.

• The provider may be putting too much pressure on the patient.

The trend of allowing patients more autonomy in making decisions is misinterpreted by some physicians, according to Beach.

"People do have the right to participate in decisions that are related to their health and well-being," she says. "Unfortunately, some doctors might feel like the patients have to make the decisions."

Patients may feel anxious about this because they feel they lack the information to make the right decision, she explains, and would rather be given a recommendation. "The notion of autonomy was never intended for patients to be given more responsibility than they want," she says.

At the same time, says Beach, even the most reluctant patient would probably like to have the doctor explain his or her reasoning, and say, "I think that under the circumstances, this is the best thing to do. How does that sound to you?"

• The provider probably won't be able to guess which patients want to be more involved.

Previous research done by Beach showed that doctors were not able to predict which patients wanted to be more involved in decision making.[1]

"We are very bad at guessing whether a patient wants to make the decision. That doesn't work very well," she says. Doctors wrongly assumed patients with lower literacy levels didn't want to be as involved in decision making, for instance, when the patient may simply have been uncomfortable using medical terminology.

If there is a decision to be made, Beach says that

EXECUTIVE SUMMARY

Physicians may confuse a shared decision-making approach, which gives patients options and a recommendation, with simply asking patients to choose from various options.

- Patients may wish to make lifestyle changes to avoid taking medications.
- Even if only one treatment option exists, physicians can ask patients if it sounds acceptable to them.
- Physicians should work with patients to come up with a care plan that doesn't put the patient or society at risk.

physicians should "lay that out for the patient. If you present options to people when those options exist, along with some guidance, I don't think that could harm anybody."

Inappropriate demands

Patients often come in demanding a particular medication before they've even been examined, says Banja, due in part to direct-to-consumer advertising. "Patients having a lot of room to make the decision implies they know a lot about what's going on," he says. "Often, they really don't know what they are asking for, because they don't know their condition all that well."

If a patient comes in asking for an antibiotic that isn't indicated, or a magnetic resonance imaging scan for knee pain, when this isn't the standard of care, says Beach, it doesn't make sense to allow the patient to make that decision.

"It's the physician's responsibility, not just to give over decision making to the patient, but, rather, to work with the patient to come up with a plan that doesn't put the patient at risk or hurt society," she says.

Always engage patients

"The patient and the physician usually have the same goal," says Beach. "They are both looking for the patient to get better, and some decisions are fairly straightforward." However, even if there is only one treatment that's appropriate, Beach says the physician should still engage the patient in decision making with "low-level participation."

"The physician could say, 'This is what I think, and this is why I think it. How does that sound?' It's just a double check that you are all on the same page," says Beach.

Patients aren't likely to have the medical expertise to make more serious medical decisions on their own, but they should still be engaged in a "substantive discussion," says Beach. "Once you know somebody understands the situation, you can engage them much more effectively."

To get relevant information from patients, physicians should ask questions such as, "What side effects are you willing to tolerate?" and "What is a good quality of life for you?" advises Beach.

"The doctor has to be willing to cross that bridge and really know who that person is and what they want out of the situation," she says. "The goal is for the doctor to get an idea of what the patient wants, and for the patient to understand what the doctor thinks." ■

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• **John Banja**, PhD, Medical Ethicist, Center for Ethics, Emory University, Atlanta. Phone: (404) 712-4804. Email: jbanja@emory.edu.
• **Mary Catherine Beach**, MD, MPH, Associate Professor, Division of General Internal Medicine, Johns Hopkins University, Baltimore, MD. Phone: (410) 614-1134. Email: mcbeach@jhmi.edu.
• **Clarence H. Braddock III**, MD, MPH, FACP, Director, Clinical Ethics, Stanford Center for Biomedical Ethics. Phone: (650) 498-5923. Email: cbrad@stanford.edu.
• **Rosa Braga-Mele**, MD, MEd, FRCSC, Associate Professor, University of Toronto. Phone: (416) 462-0393. Email: rbragamele@rogers.com.

Cataract surgery: Multiple options become ethical issue

Negotiation is best strategy

Options for a cataract patient might include a monofocal lens that will require the use of glasses, or a multifocal intraocular lens that might not, but carries the risk of side effects such as glares and halos.

Patients with cataracts may hear about premium intraocular lenses from their friends, and tell the ophthalmologist, "That's what I want. I don't ever want to wear glasses again."

"But premium intraocular lenses may not be appropriate," says **John Banja**, PhD, a medical ethicist at Emory University's Center for Ethics in Atlanta. "This is a scenario that ophthalmologists confront fairly often." According to the American Society of Cataract and Refractive Surgery, there were an estimated 3.3 million cataract surgeries completed in the United States in 2011.

"Ophthalmologists are a group of physicians who you don't think of all that often in terms of ethical dilemmas," says Banja. "They don't deal with front-burner, headline-grabbing ethical issues. But this is an interesting problem that they confront frequently."

Negotiate with patient

Rosa Braga-Mele, MD, MEd, FRCSC, an associate professor in the Department of Ophthalmology at the University of Toronto in Canada, says cataract

patients are much more aware of their options than in the past. "Particularly with the baby boomer population aging and access to the Internet, patients want to be part of the decision-making process," she says. "It is a team effort."

Braga-Mele says she informs cataract patients of their options, then indicates what she thinks is a good choice for them. "Ultimately, they make the final decision, unless I think it would be detrimental to their eye health to either proceed or not proceed," she says.

Some ophthalmologists offer just one option to the patient, while others offer multiple options and go with what the patient wants, even if the ophthalmologist has second thoughts about whether the patient's choice is truly appropriate, says Banja. "But the overwhelming number will negotiate with the patient, in the hope of identifying a choice both can live with," he says.

In addition to the patient's eye anatomy, the patient's personality may come into play. "For example, ophthalmologists are very reluctant to put a premium lens into a person who is an arch perfectionist," he says. "If there are side effects like night glares and halos, the perfectionist patient is likely to find them very disconcerting."

If ophthalmologists feel strongly that the patient won't be happy with a premium intraocular lens, they might present only the monofocal option. "This removes the choice completely from the patient," says Banja. "Of course, if the patient is unhappy with the physician's refusal to accommodate their wishes, the ophthalmologist can refer him or her to another doctor."

Patient may demand

Some patients may demand a multifocal or premium intraocular lens regardless of the physician's recommendation against it. "Suppose the patient says, 'I'm the one who is paying for this, you do what I tell you to do,'" says Banja. "A small group of physicians might give it a try."

The physician may have seen tens of thousands of patients go through the surgery and have vast prognostic experience, but he or she could still be wrong that a premium intraocular lens won't work for a particular patient. "There is always a fallibility dimension," says Banja. "The physician may have thought a certain patient would do horribly, and the patient ends up just loving it."

It's an ethical dilemma if patients demand a certain technology or procedure, such as an intraocular lens, even though it's not in their best interest, says Braga-Mele.

"The doctor needs to learn to steer the patient in the correct direction," she says. "If they feel uncomfortable, they need to let the patient know. They may need to refer them elsewhere for care." ■

Patient preferences at end of life overlooked

Treatment plans don't consider their wishes

If a nursing home resident has a urinary tract infection, he or she may want to avoid the discomfort and side effects of being transported to the hospital for intravenous antibiotics, and would rather be cared for with medications in the nursing home.

Too often, however, the patient's wishes aren't even taken into consideration in this scenario, says **John G. Carney**, MEd, president and CEO of the Center for Practical Bioethics in Kansas City, MO. Nursing home patients are not routinely asked about their preferences and values at the end of life, he explains, so these aren't considered when treatment goals are determined.

"We don't integrate any questions around the quality of life except until the very end — and then, these are usually asked only after a referral to palliative care or hospice," he says.

In fact, quality of life is more important to many patients than clinical interventions, argues Carney. "Since we don't have the mindset to even be asking those questions or addressing those issues, we leave them out of the equation," he says. "That's the biggest deficit that we have with end-of-life care."

Default is to treat

Caregivers typically don't even talk about a patient's

EXECUTIVE SUMMARY

A patient's wishes, quality of life, and functional status often aren't taken into consideration when treatment goals are being determined at the end of life.

- Quality of life may be more important to patients than clinical interventions.
- Assessment of the quality of hospital care doesn't include patients who are discharged to a nursing home or rehabilitation center, or family members of patients who die in the hospital.
- Several tools are available to evaluate patient assessments of end-of-life care.

quality of life and functional status when determining a treatment plan, according to Carney.

"In most cases, our treatment plan defaults to standard of care for an otherwise healthy patient, regardless of how sick a patient may be," he adds. "If we asked these questions and paid attention to what people said, we would not do some of the things that we currently do."

If the patient can't answer these questions for themselves, adds Carney, caregivers could ask someone who knows the person well what they would want.

Early in his career, Carney was part of a team at the National Hospice and Palliative Care Organization that identified three outcomes to assess quality end-of-life care: Safe and comfortable dying, self-determined life closure, and healthy grieving.

Even now, however, palliative care and hospice professionals lack good evaluation measures to assess end-of-life care, says Carney. "Attention to quality of life, and preferences and values, is so critically important in this part of health care," he says. "There are outcomes that the patient wants to see, that we simply don't ask about."

Many patients are far more interested in functional status than survival, adds Carney. "We know that if we sit down and talk to them about survival interventions to prolong their life, they don't value the same things that an otherwise healthy patient would," he says. *(See related story on surveying patients on end-of-life care, p. 68.)* ■

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• **John G. Carney**, MEd, President and CEO, Center for Practical Bioethics, Kansas City, MO. Phone: (816) 979-1353. Email: jcarney@practicalbioethics.org.

• **Joan M. Teno**, MD, MS, Professor of Health Services, Policy, and Practice, Warren Alpert School of Medicine, Brown University, Providence, RI. Phone: (401) 863-9627. Email: joan_teno@brown.edu.

Sickest patients aren't surveyed

Sample is "very biased"

As it stands now, only hospital patients discharged to a home setting complete the Hospital Consumer Assessment of Healthcare Providers and Systems survey —- not patients who are discharged to a nursing home or rehab, or family members of patients who died in the hospital.

"Assessment of the quality of hospital care in the U.S. is based on only live discharges to a home setting," says **Joan M. Teno,** MD, MS, professor of health services, policy, and practice at Brown University's Warren Alpert School of Medicine.

"If you only talk to patients who can be interviewed, you are going to get a very biased sample," says Teno. "It doesn't reflect the sickest patients who have the greatest needs."

This conflicts with one of the basic tenets of palliative care — the importance of including family members caring for the patient, she adds.

Teno created the Brown University Family Evaluation of Hospice Care, which is currently being used by hospices to assess the quality of hospice care, and was part of a research team which created the CARE (Consumer Assessments and Reports of End of Life Care) survey, which measures consumer assessments of end-of-life care, and was endorsed by the National Quality Forum (NQF). (To obtain the CARE survey, send an email request to cindy_williams@brown.edu.)

"We have been making the survey available to people for free, along with the documentation that we provided to the NQF about its reliability and validity," says Teno. "So that is one measure people can use to evaluate how well they are doing."

Rates "appalling"

The most important thing health care providers can do right now is develop a care plan that reflects patients' preferences and values, argues Teno. "Right now, my sense is that what gets measured is largely utilization," she says. "What is harder to measure is consumer needs and expectations regarding care."

Teno points to her own 2004 study, which surveyed family members of 1578 patients about end-of-life care. For patients whose last place of care was a nursing home, 38% of family members said their loved one wasn't always treated with respect, and 38% said the patient had an unmet need for pain management.[1]

"When you look at those rates, they are appalling," says Teno. "While the rates for hospitals were not as bad as the nursing homes, hospitals also have opportunities to improve." Only 47% of family members of a patient who died in a hospital said the care provided was excellent, compared with 71% when the patient died at home with home hospice services.

"If we don't start providing care that is patient- and family-centered, we're really going to lose some of the consumer's confidence in the quality of care we are providing," says Teno. ■

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Genetic testing "running way ahead" of ethics

Patients — and their doctors — misunderstand results

If genetic testing reveals a woman has a 60% chance of developing breast cancer in her lifetime, what good does this information do for a patient?

"To have a genetic marker does not entail that you will get a disease. Patients need to understand that clearly," says **Kenneth W. Goodman**, PhD, professor and director of the University of Miami (FL)'s Bioethics Program.

"Patients often interpret an increase in risk probability to equal 100%."

Goodman says that physicians and patients both need to understand that the information acquired in most genetic testing is probabilistic, and that "genetic disease" is actually an amalgam of heredity, environment, lifestyle, and other factors.

"The technology is running way ahead of the answers to ethical questions that are raised by the ability to get this information," says **Robert W. Marion**, MD, chief of the section of child development in the department of pediatrics at Albert Einstein College of Medicine in Bronx, NY.

The whole genome sequencing test "is moving into the limelight," says Marion, and is already giving individuals information about their susceptibility to disease.

"When the costs decrease, it can become an everyday test we do in the clinic," Marion says. "When that happens — and it will happen within a number of years — there are all kinds of ethical questions that need to be answered. But the fact is, the test is going to go primetime before we have the answers."

Patients need to know the risks, benefits, and alternatives to genetic testing, and this will require improvement in everyone's "genetic literacy," according to Goodman.

"Physicians and others have duties to safeguard personal information, to ensure that the consent process is adequate to the task, and to ensure they are adequately educated to practice in a genomic world," says Goodman. Here are some other ethical issues to consider:

• Patients may misunderstand their risk.

"Genetic information is probabilistic. Before anything is communicated, patients need to understand that important fact," says Goodman.

If a patient finds out he has a genetic predisposition to diabetes, says Marion, this information doesn't really provide him with any definitive answers. "Not only do individuals have trouble understanding this and knowing what to make of it, but doctors do as well," he says.

Some genetic testing is already being misused by physicians who don't really understand that the results are not definitive, and are based on a probability, adds Marion. He gives the example of an internist who treated an 85-year-old woman for bronchitis, and without obtaining consent, did a genetic test for susceptibility for coronary artery disease.

"During a follow-up visit, he told the patient that she had a high probability of developing coronary artery disease, and asked her if she wanted to start on a medication to prevent it," he says. "That is complete misuse of this technology."

• Patients need to give informed consent.

This means that clinicians need to understand the probabilistic nature of genomic information, and be able to communicate effectively about it, according to Goodman.

"Informed or valid consent is still the mother of all ethical issues," he says. "Consent is not a courtesy, it is a necessity. The 'informed' part of informed consent has never been more important."

Shift to prevention

To some extent, says Marion, physicians already know a lot of information about a patient's susceptibility to disease even without genetic testing, such as the need for patients with a family history of coronary artery disease to take their cholesterol levels very seriously because they're at increased risk.

"The gift of whole genome sequencing is going to be to use that information, in addition to family his-

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EXECUTIVE SUMMARY

Whole genome sequencing testing is already giving individuals information about their susceptibility to disease, but some physicians are misusing this testing, and patients often misunderstand the meaning of the results.

- Physicians and patients both need to understand that the information acquired in most genetic testing is probabilistic.
- When costs decrease, the test will become an everyday part of primary care.
- Results can be used, along with family history and other factors, to help individuals make choices to lead healthier lives.

tory and other factors, to help individuals make choices to lead healthier lives," he says.

The testing can help physicians determine whether a patient truly needs to take medications to lower cholesterol levels, adds Marion, which may have significant side effects that may alter the patient's ability to lead a healthy life.

Genetic testing reflects a sea change in the way medicine is practiced, "moving from reaction to prevention," adds Marion.

"At the present time, we wait for patients to develop symptoms of disease and react with treatment," he says. "With whole genome sequencing, we will be able to predict who is going to develop symptoms, and take steps to prevent it." (*See related story, p. 70, on ethical issues involving primary care physicians and genetic testing.)* ■

SOURCES

• **Kenneth W. Goodman**, PhD, Professor and Director, Bioethics Program, The University of Miami (FL). Phone: (305) 243-5723. Email: kgoodman@miami.edu

• **Robert W. Marion**, MD, Section of Child Development, Department of Pediatrics, Albert Einstein College of Medicine in Bronx, NY. Phone: (718) 430-8521. Email: robert.marion@einstein.yu.edu

PCPs to face ethical dilemma of genetics

Doctor/patient relationship may improve

In the near future, genomics will become an ordinary part of physician office visits, predicts **Kenneth W. Goodman**, PhD, professor and director of the University of Miami (FL)'s Bioethics Program.

"Everything is changing very quickly. The cost of genetic tests is going way down, and that means that genetic information is going to be insinuating itself with greater frequency into clinical practice," says Goodman.

This means that clinicians need to consider ethical issues and improve their understanding of the utility of the new genetic tools — what they can tell a physician, and equally important, what they can't tell the physician, says Goodman.

If a physician isn't prepared to advise patients about how to interpret the results of genetic testing, Goodman says that he or she should not "wing" it. It would be analogous to practicing beyond your capacity, which is always a bad idea. You need to learn some genetics before you talk to patients about genetics."

Goodman says that quite possibly, genetic testing will improve some aspects of the doctor/patient relationship. "In order to communicate effectively about genetic information, you need to really know your patient," he explains.

In hands of PCPs

"We are at the beginning now. The challenge is figuring out how quickly things will change," says Goodman. "If history is a guide, they will change very quickly."

Primary care physicians may soon make recommendations and customize medications based on a patient's genetic profile. "If and when the standard of care changes, then every physician is going to learn genetics," Goodman says.

Just as an internist would consult with a cardiologist about a patient with heart disease, primary care doctors need to consult with geneticists and genetic counselors, advises **Robert W. Marion,** MD, chief of the section of child development in the department of pediatrics at Albert Einstein College of Medicine in Bronx, NY.

"They need to use the experts in the field to help them interpret this information," says Marion. "That's not happening all the time, and it needs to happen." The number of geneticists and genetic counselors needs to increase, he adds, so these individuals can act as liaisons between the labs and the medical community.

"As time passes, this will be more and more in the hands of primary care doctors," adds Marion. "They will need to familiarize themselves with the ABCs of genetic testing." ■

Review board focuses on children, pregnant women

Decision to divide based on increasing research

When an institution's study portfolio gets large enough, its review board must decide: Is it time for a new board? And if so, how do you divide the work? At many institutions, that division is based on methodology — studies are assigned to either a biomedical review board or one devoted to social-behavioral studies.

At Orlando Health, Inc., in Florida, review board officials looked to the growing number of studies being generated by two of its affiliated hospitals — the Arnold Palmer Hospital for Children and the newly opened Winnie Palmer Medical Center for Women and Babies — and created a dedicated review board

for research involving children, infants, and pregnant women.

Review board manager **Jonathan Lin**, MHSE, CCRP, says the idea was to provide more comprehensive review of these studies by bringing members with different pediatric specialties to the board.

"We thought there needed to be more of a precise review from different types of expertise among the pediatric realm," Lin says. He discussed the development of this new IRB (Institutional Review Board) at PRIM&R's (Public Responsibility in Medicine & Research) recent Advancing Ethical Research Conference.

New specialists

Lin says that on the original Orlando Health review board, members included an obstetrician-gynecologist and a pediatric cardiologist, because the Arnold Palmer Hospital has a strong pediatric cardiac care program.

The newly formed Arnold Palmer Medical Center (APMC) review board has added more specialists, including a second OB-GYN, a neonatologist, a pediatric pharmacy specialist, and a pediatric emergency physician.

"They're all bringing in their backgrounds and providing their perspectives within the review," Lin says. He says the members all have extensive research experience and previous review board experience.

Adult research is now handled by the original review board, renamed the Orlando Regional Medical Center IRB. In creating the new IRB, Lin says he looked to existing IRBs at children's hospitals.

"I consulted with a few IRB managers or IRB representatives from those institutions," he says. "They definitely provided a lot of guidance. They directed me to their policies and procedures, and I'd see how those matched up with our state law and our institutional policies."

He says the process required creating new forms for the new review board, including an assent form for pediatric research written in appropriate language for children. But the biggest change was in the way studies are reviewed, Lin says.

"We provide consistent review between both IRBs, but the new IRB is very specific in addressing and documenting the reviewers' determinations with regards to the subject population," he says. "There's a lot more discussion on the APMC IRB than when the IRBs were [combined], because people are bringing their backgrounds to the table and bringing different concerns that were not previously missed, but maybe not emphasized in these [combined] IRB meetings."

He says the research conducted with pregnant women hasn't raised many new issues because it tends to consist of minimal risk studies, such as surveys and chart reviews. ■

CME INSTRUCTIONS

To earn credit for this activity, please follow these instructions.

1. Read and study the activity, using the provided references for further research.
2. Log on to www.cmecity.com to take a post-test; tests can be taken after each issue or collectively at the end of the semester. First-time users will have to register on the site using the 8-digit subscriber number printed on their mailing label, invoice, or renewal notice.
3. Pass the online tests with a score of 100%; you will be allowed to answer the questions as many times as needed to achieve a score of 100%.
4. After successfully completing the last test of the semester, your browser will be automatically directed to the activity evaluation form, which you will submit online.
5. Once the completed evaluation is received, a credit letter will be e-mailed to you instantly.

CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

COMING IN FUTURE MONTHS

- More patients are demanding specific medications
- Avoid major pitfalls with error disclosure
- Accepting gifts from patients
- Patients texting, "friending" docs

CME QUESTIONS

1. Which is recommended regarding patient involvement in medical decision making, according to **Mary Catherine Beach**, MD, MPH?
   A. Although patients likely lack the medical expertise to make serious medical decisions, they should still be engaged in a substantive discussion.
   B. In the vast majority of cases, physicians should simply ask patients what they want and give it to them, without offering a recommendation.
   C. All patients should be given the ultimate responsibility for making health care decisions, even if they appear reluctant to do so.
   D. A shared decision-making approach should be used only for patients with higher literacy levels.

2. Which is true regarding patient preferences for end-of-life care, according to **John G. Carney**, MEd?
   A. If the patient can't answer for themselves, it is not advisable for caregivers to ask someone who knows the person well what they would want.
   B. The vast majority of patients are more interested in survival at the end of life than functional status.
   C. It is a safe assumption that patients at the end of life value survival interventions to prolong life in the same way that an otherwise healthy patient would.
   D. Caregivers typically don't consider a patient's quality of life and functional status when determining a treatment plan.

3. Which is true regarding evaluation of consumer assessment of the quality of hospital care, according to **Joan M. Teno**, MD, MS?
   A. All patients, including those discharged to a nursing home, currently complete a Hospital Consumer Assessment of Healthcare Providers and Systems survey.
   B. Assessment of the quality of hospital care in the U.S. is currently based only on live discharges to a home setting.
   C. There are no tools currently available for hospitals to measure consumer assessments of end-of-life care.
   D. Family members are significantly happier with end-of-life care that took place in a nursing home, compared to home hospice services.

4. Which is ture regarding discussing genetic testing results with patients, according to **Robert W. Marion**, MD?
   A. It is not necessary for patients to understand that genetic information is probabilistic, and not definitive, before results are communicated by the physician.
   B. Some physicians are giving genetic tests without understanding that the results are not definitive, and are based on a probability.
   C. Primary care doctors generally should not consult with geneticists and genetic counselors to help them interpret this information.
   D. It is not advisable for geneticists and genetic counselors to act as liaisons between the labs and the medical community.