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INSIDE

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New IOM report spotlights inadequate end-of-life care

Misconceptions on palliative care "quite durable"

The American healthcare system is poorly equipped to care for patients at the end of life, according to the September 2014 Institute of Medicine (IOM) report, "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life."

"The greatest value of this report is that a non-partisan institution with the gravitas of the IOM has made clear statements about what is needed for patients living with serious illness and facing the end of life," says **James A. Tulsky**, MD, one of the IOM committee members. Tulsky is professor of medicine and nursing and chief of palliative care at Duke University Medical Center in Durham, NC.

Reasons for poor end-of-life care are many, according to the IOM report. They include a shortage of doctors proficient in palliative care, reluctance among providers to have direct and honest conversations about end-of-life issues, and inadequate financial and

EXECUTIVE SUMMARY

The U.S. healthcare system is poorly equipped to care for patients at the end of life, according to a 2014 Institute of Medicine report. Key recommendations in the report include the following:

- Providers should normalize the advance care planning process with ongoing conversations.
- All clinicians should be competent in basic palliative care.
- Medical schools, accrediting boards, and state regulatory agencies should improve end-of-life training and certification requirements.

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EXECUTIVE EDITOR: Russ Underwood (russ.underwood@ahcmedia.com).
MANAGING EDITOR: Jill Drachenberg (jill.drachenberg@ahcmedia.com)
DIRECTOR OF CONTINUING EDUCATION AND EDITORIAL: Lee Landenberger.

EDITORIAL QUESTIONS
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organizational support for the needs of dying patients.

The report recommends a "life cycle" model of advance care planning. The goal is to normalize the process by starting it early, with regular conversations with family members and care providers. "A key recommendation is that advance care planning alone — and certainly advance directives — are not enough," says Tulsky. "The focus needs to be on the quality of communication about goals of care, not just the fact that it happens."

The report recommends the following:

- All clinicians, regardless of specialty, should be competent in basic palliative care: communication skills, interprofessional collaboration, and symptom management.
- All medical schools, accrediting boards, and state regulatory agencies should bolster their end-of-life training and certification requirements.
- Payers and healthcare delivery systems must ensure access to skilled palliative care through the course of illness and across settings.
- The quality of clinician-patient communication must be measured and incentivized in reimbursement, licensing, and credentialing.
- Healthcare financing incentives must be restructured.

"Providers need to be rewarded for high-quality care that decreases the need for emergency and acute care services, coordinates care across settings and providers, and reduces the use of unnecessary medical services and those not consistent with a patient's goals of care," says Tulsky.

Perhaps the most controversial aspect of the report, says Tulsky, is that it recognizes that social determinants have more impact on the quality of life for people with serious illness than what can be done medically.

"Meeting the needs of patients living with serious illness and toward the end of life will require the integration of payment for medical and social services," he says.

Need to correct misconceptions

Some myths about palliative care "have proven quite durable," says IOM committee member **Salimah H. Meghani**, PhD, MBE, RN, FAAN. Meghani is an associate professor at Philadelphia-based University of Pennsylvania's School of Nursing.

"Most general public and health professionals alike still think of palliative care as a last resort option," she explains. However, non-hospice palliative care can be incorporated simultaneously with cure-focused treatments throughout the continuum of care — even at the time of diagnosis of a serious progressive illness.

Based on a growing body of evidence, including well-designed clinical trials, the committee found that seriously ill patients who receive both palliative care and usual medical care live longer than similarly ill patients who receive usual care only.

"In addition to living longer, palliative care is associated with improved quality of life, lower symptom burden, improved mood and well-being for patients, and greater satisfaction among families," Meghani says.

While many referrals to hospice occur too late, says Meghani, evidence suggests that patients' and families' experience of care improves considerably once they are referred and agree to hospice care.

A "hospice-palliative care" approach is important for addressing the palliative care needs of patients in the terminal phase of illness. "These patients can meaningfully benefit from social, spiritual, and emotional attention; aggressive pain and symptom management; and support for families, rather than elaborate technological interventions," Meghani says.

Bioethicists often get involved too late in the process, when care planning is in a "reactionary mode," says Meghani. Patients may no longer have the capacity to make their own decisions. She recommends that bioethicists take a proactive approach by becoming familiar with the IOM report and its recommendations, and advancing the recommendations for clinician-patient communication and advance care planning.

The IOM report found "major and concerning gaps" with health professional training in end-of-life communication. Bioethicists are ideally positioned to address this particular problem, says Meghani, given their training in mediation and addressing conflicts caused by communication breakdowns.

"They can play a very important role in the communication training of other clinicians — doctors, nurses, social workers, and physician assistants — at their institutions," Meghani says.

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- Salimah H. Meghani, PhD, MBE, RN, FAAN, Associate Professor of Nursing, Department of Biobehavioral Health Sciences, University of Pennsylvania, Philadelphia. Phone: (215) 573-7128. Fax: (215) 573-7507. Email: meghanis@nursing.upenn.edu.
- James A. Tulsky, MD, Professor of Medicine and Nursing; Chief, Duke Palliative Care, Duke University Medical Center, Durham, NC. Phone: (919) 668-7215. Fax: (919) 684-0572. Email: james.tulsky@duke.edu. ■

Ensure patients' wishes are respected through surrogate decisionmakers

Even caring surrogates can make inappropriate choices

A recent ethics consult at The Ottawa Hospital in Ontario, Canada involved a victim of domestic violence. "The challenge was that the husband, who had severely beaten the patient, was the patient's substitute decisionmaker," recalls **Thomas Foreman**, DHCE, MA, MPIA, director of the Department of Clinical and Organizational Ethics.

Ethicists grappled as to whether the individual could be legally eliminated as a decisionmaker who would determine whether life support would be withdrawn. "What ultimately happened was because the person was arrested, he no longer met the criteria to be the decisionmaker," he says.

In another case, the surrogate was an estranged wife who the patient had not seen in years, yet they were still legally married and she had decisionmaking authority. "When told that her husband was suffering, her response was 'Good, I want him to suffer.' She was clearly an inappropriate surrogate," says **Craig M. Klugman**, PhD, professor and chair of the Department of Health Sciences at DePaul University in Chicago.

Some surrogates inappropriate

Most surrogate decisionmakers care deeply about the patient, "yet often make inappropriate choices," says **Lea Brandt**, OTD, MA, OTR/L, co-director of the MU Center for Health Ethics at University of Missouri in Columbia. Family members sometimes have no idea what the patient would want, she says.

Often, the content of an advance directive does not seem to apply to the patient's current situation, or it was developed many years ago, calling its validity into question.

"If the surrogate has not ever had a discussion with the patient regarding his or her wishes, has moral beliefs divergent from the patient, or is emotionally conflicted, then the surrogate's ability to make decisions consistent with the patient's values is compromised," says Brandt.

Some surrogates make statements such as, "I know my mom wouldn't want this, but I just can't bring myself to make a decision which will cause her death."

"When surrogates become agitated and focus solely on the

medical decision instead of the process for determining what the patient would want, it is a red flag," says Brandt. He or she may not be appropriately representing the patient's wishes.

Here are some other "red flags" involving surrogates that bioethicists should be mindful of, says Klugman:

• **The long-lost relative.** "This is the person who shows up out of the blue, has not seen or spoken with the patient in five, 10, or 20 years, and suddenly tries to state what the patient would or would not have wanted," says Klugman.

• **A surrogate who seems to be making decisions that are best for him or her, not the patient.** "For example, a new spouse does not want to pursue treatment with a high likelihood of beneficence for the patient, and stands to inherit a great deal of money," says Klugman.

• **The convenient surrogate.** Some individuals are named as surrogates simply because they are available. "This person may not know the patient all that well, but is the easiest person to get ahold of," says Klugman.

If the bioethicist suspects that the surrogate does not have the patient as the central focus of deliberation, or is operating from a personal agenda, then it is essential to inform the healthcare team and attempt to have a different surrogate appointed, says Klugman. This may require an emergency hearing with a judge.

"The role of the bioethicist is to ensure that all voices are heard and represented," says Klugman. "If the surrogate is not accurately representing the patient, then another surrogate should be sought."

Providers are often unaware of regulatory requirements in their state involving surrogate decisionmakers. "You don't want to exclude people who have a legal right to participate. But you want to be careful about bringing people into that circle who don't have a right to be there," says Foreman.

In Ontario, this is less difficult. When the team believes the surrogate is not acting in the patient's best interest, the case is referred to a tribunal for an independent review. "That is great, because it takes it out of the hands of the team," says Foreman.

The board hears the medical plan and the surrogate's response, and determines which of the two is in the patient's best interest.

"In the U.S., there is more of a regulatory vacuum, so there is more difficulty resolving those cases," says Foreman.

Bioethicists and providers can advocate for good legislative direction for providers to use when patients haven't named a specific decisionmaker. "If you have excellent guidance, it doesn't solve all the problems. But it does give providers support," Foreman says.

Foreman says one of the biggest problems is that no one has ever asked the patient, 'Who would you like to function as your decisionmaker when the time comes that you can't make your own decisions?"

To some extent, advance care planning takes away the discretion of the substitute decisionmaker. "Why are we waiting until the patient is incapacitated to think about who might function in that role?" asks Foreman.

If providers suspect there may be a conflict, they can bring a nurse or social worker into the conversation. Both parties can document the patient's wishes.

On the other hand, having a private conversation with a patient with no documentation of what was said "opens yourself up to a challenge you might not be able to withstand," says Foreman. "You never want to find yourself in a situation where it's your word against someone else's."

Bioethicists should not assume that the surrogate knows what his or her responsibilities are. "The notion that you are to make the decision that the patient would have made is a foreign one to most people," says Klugman.

Instead of giving surrogates a bunch of options and asking them to choose, he adds, "we need to guide them to think about the patient and what that person values, in order to make a true substituted choice."

Before asking surrogates what they think the patient would want regarding continuation or discontinuation of a specific

EXECUTIVE SUMMARY

Surrogate decisionmakers may have a conflict of interest or unsavory intentions. Even individuals who care deeply about the patient can make inappropriate choices. The following expert tips can help avoid problems:

- Ask patients who they would like to function as their decisionmaker earlier.
- Advocate for good legislative direction for providers if no surrogate has been named.
- Ask surrogates to recount conversations regarding the patient's end-of-life choices.

treatment, the ethics consultant should first ask the following questions, says Brandt:

• Are you aware of any experiences the patient had with family or friends who became seriously ill or injured? If so, how did the patient respond?

• Do you remember any conversations you personally had with the patient regarding end-of-life choices?

• Can you describe the patient's religious, cultural, and personal beliefs?

"Then have the team speak to the likelihood of reaching clinical goals consistent with the patient's beliefs and values," says Brandt.

This approach lessens the emotional burden on surrogates because they don't feel as though they are making a decision regarding ending or sustaining the patient's life.

"Rather, they are providing useful information which allows the healthcare team to make medical decisions consistent with what the patient would have wanted," says Brandt.

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• Lea C. Brandt, OTD, MA, OTR/L, Co-Director-MU Center for Health Ethics, University of Missouri—Columbia. Email: brandtlc@health.missouri.edu.

• Thomas Foreman, DHCE, MA, MPIA, Director, Department of Clinical and Organizational Ethics, The Ottawa Hospital, Ontario, Canada. Phone: (613) 737-8899 ext. 19967. Email: tforeman@toh.on.ca.

• Craig M. Klugman, PhD, Professor and Chair, Department of Health Sciences, DePaul University, Chicago, IL. Phone: (773) 325-4876. Fax: (773) 325-8430. Email: Cklugman@depaul.edu. ■

Innovative program effectively educates nurses on clinical ethics

Nurses experienced less moral distress

A Clinical Ethics Residency for Nurses has been developed at two large northeastern academic medical centers. One goal is to teach nurses how to be effective advocates for patients whose circumstances, problems, and treatments are ethically complex.

The program is funded by the Health Resources and Services Administration, and serves nurses at Massachusetts General Hospital and Brigham and Women's Hospital, both in Boston.

"The ethical aspects of nursing practice are weighty. Nurses see some of the saddest, most tragic kinds of circumstances," says **Ellen Robinson**, PhD, RN, the program director and nurse ethicist at Massachusetts General.

In addition to classroom lectures on ethics, the program incorporates the opportunity to explore one's personal bias and its impact in highly emotional, complex ethical situations, communication techniques, role-play and simulation, and clinical mentorship.

"Big and little ethical questions arise daily for nurses," says **Susan M. Lee**, PhD, RN, a senior nurse scientist at Brigham & Women's Hospital's Center for Nursing Excellence. Nurses often remain silent; if they do speak up, sometimes they do so in ways that are not effective.

"Sometimes, speaking up causes a backlash that may lead to silence in the future," says Lee. "Nurses are often without forums for reflection, support, and mentorship."

The program succeeded in reducing nurses' levels of moral distress and increasing their self-confidence in handling emerging ethical situations, according to a 2014 report, which included feedback from 67 participants over three years of the program.[1]

"Nurses were given many opportunities to debrief with peers and mentors, while gaining support, new perspectives, and more effective language," says Lee.

The group used the American Society for Bioethics and Humanities' "Improving Competencies in Clinical Ethics Consultation: An Education Guide" as the foundation for the program, along with nursing's professional code of ethics and other discipline-specific resources.

Ethics work is often interdisciplinary; different disciplines bring different strengths to ethical reflections, says **Rev. Angelika A. Zollfrank**, coordinator of pastoral education at Yale New Haven (CT) Hospital. "It is key to draw on the resources and skills of several professions, and create interdisciplinary programs that intentionally take advantage of these skills and strengths," she says.

Nurses' moral distress

Nurses are often in the best position to intervene and prevent emerging ethical dilemmas. "There are times when even prevention or early detection are not sufficient," adds Robinson. "Nurses must take up the task of stepping into the ethical difficulty."

In difficult cases, nurses may need to initiate ethics consultations. Not all are comfortable doing so. "Nurses need the tools to do this work," says Robinson. "Cases that are fraught with controversy and indecision require more skills than knowledge alone."

Historically, hierarchical structures in hospitals typically meant that physicians' decisions reigned. "Today, we do see much greater collaboration," says Robinson. "But at times, when there is nurse-physician conflict, it surely helps for nurses to have good communication tools to work with." According to Robinson, "a more frequent ethical problem in patient care today is family members' difficulty in accepting that their loved one is dying."

Utilizing the techniques of role play and taped simulation allowed nurses to take on roles of other healthcare professionals and various family members, while applying newly acquired communication strategies. "They were able to see how they responded and communicated in real time, and allowed a space for debriefing about how they could then respond differently," says Robinson.

Moral distress over end-of-life care

Nurses are often the ones who notice that the patient is suffering, that life-sustaining treatments are no longer conferring benefit and may be harming the patient, that conflict exists in the family structure/dynamics, or that healthcare teams are not in agreement. "Advances in medicine, surgery, and technology have brought us to uncharted waters, particularly in academic medical centers, where aggressive treatments are the norm," says Lee.

Nurses witness a lot of what Lee calls "misalignment." They see physicians giving prognoses that are not aligned with the patient's declining condition, and care that is not aligned with the patient's wishes, she says.

For example, it is not unusual that families request that pain medication be withheld so that their loved one is not sedated. "However, nurses cannot withhold medication in the face of suffering beyond what the patient is willing to tolerate," says Lee. "Pain relief is a patient's right, not a family decision."

Organizations need to re-think their approach to ongoing education of nurses, says Lee, and address their moral and professional development in addition to skills and technology. "Ethics education is not a one-shot deal," she says.

Nurses became more confident

Nurses are often first to notice emerging ethical dilemmas, but may not know how to articulate the problem. Many simply don't feel comfortable speaking up.

"Many, though not all, dilemmas could probably be headed off with consistently good communication between and among the team, family members, and the patient," says **Pamela J. Grace**, RN PhD, FAAN, associate professor of nursing and ethics at Boston College's William F. Connell School of Nursing in Chestnut Hill, MA.

At times, nurses are discounted by others as not having important things to say. "We have long realized that nurses could be powerful forces in fortifying the ethical climate in an institution," says Grace.

"Before and after" narratives completed by the participants were in sharp contrast. Initially, nurses often expressed powerlessness in trying to get what was needed for patients accomplished. Several months later, after the clinical ethics program was completed, nurses were more confident.

"They were much more willing to engage the team in discussion, or to put into place preventive initiatives such as ethics rounds or unit education offerings," says Grace.

The program's results demonstrated that a comprehensive approach is necessary. "It is a mistake

EXECUTIVE SUMMARY

A clinical ethics residency for nurses at two academic medical centers reduced nurses' levels of moral distress and increased their self-confidence in handling emerging ethical dilemmas.

- The program includes classroom lectures, role-play and simulation, and clinical mentorship.
- Nurses are often in the best position to identify emerging ethical problems.
- Often, nurses don't feel comfortable expressing ethical concerns.

to think that one can teach bioethics in a purely didactic fashion," says Grace. "Healthcare professionals need to understand the ethical nature of all of their professional actions."

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- Susan M. Lee, PhD, RN, Senior Nurse Scientist, Center for Nursing Excellence, Brigham & Women's Hospital, Boston. Phone: (617) 525-9564. Fax: (617) 277-0383. Email: slee40@partners.org.
- Ellen Robinson, PhD, RN, Massachusetts General Hospital, Boston. Email: erobinson1@mgh.harvard.edu.
- Rev. Angelika A. Zollfrank, Coordinator, Pastoral Education, Yale New Haven (CT) Hospital. Phone: (203) 688-7036. Email: Angelika.Zollfrank@ynhh.org. ■

Surprising data on FDA committee members' financial ties

"More sophisticated" approach is needed

Food & Drug Administration (FDA) advisory committee meetings have, on average, 13% of members with financial conflicts of interest, according to a recent study. Researchers analyzed financial conflicts of 1,400 advisory committee members over a 15-year period.[1]

One set of findings in particular surprised the researcher. "We typically think that, if one financial tie is bad, then more financial ties must be worse," says **Genevieve Pham-Kanter**, PhD, assistant professor in the Department of Health Management and Policy at Drexel University School of Public Health in Philadelphia.

What she found instead was that those FDA advisors with multiple financial ties were less likely to vote in favor of firms with whom they have ties than advisors with single ties. In fact, the scientists with multiple financial relationships didn't vote any differently from those with no financial ties.

"This could be because they were less dependent on any single firm, or because these people with multiple ties are different than those who have exclusive ties," says Pham-Kanter. It is possible they had more expertise, or were more skeptical than those with exclusive financial ties to firms.

Regarding specific types of financial ties and how they were associated with voting behaviors, the findings were fairly predictable, she says. The types of financial ties that were most strongly associated with voting bias were being on an advisory board for a firm and holding some ownership or equity stake in the firm — "in other words, ties where people who had greatest potential for financial gain," says Pham-Kanter.

L. Lewis Wall, MD, DPhil, MBioeth, professor of obstetrics and gynecology at Washington University School of Medicine in St. Louis, would have expected the number of conflicted FDA advisors to be substantially higher.

"This was somewhat surprising, given how the pharmaceutical industry targets 'thought leaders' in the medical world," he says. "This is actually a huge problem."

Physicians generally are in denial that financial relationships with pharmaceutical companies influence their decisions, adds Wall. Evidence suggests that even small gifts to doctors influence prescribing habits.[2,3,4]

It is not so much that a doctor

EXECUTIVE SUMMARY

The Food and Drug Administration (FDA) advisory committee meetings have, on average, 13% of members with financial conflicts of interest, according to a recent study.

- Some argue the FDA should require panel members with financial ties to recuse themselves from decisions.
- It is difficult for regulators to detect financial conflicts of interest.
- Some doctors may seek out more financial ties as a means to hide biases.

can be "bought" for a packet of candy, he explains. Rather, gifting and other financial relationships sets up a mental predisposition to favor the one who has previously favored you.

"And it works — or the pharmaceutical industry would not spend so much money doing it," says Wall.

Pham-Kanter says the study's findings raise the following ethical concerns:

• It is difficult for policymakers and regulators to detect financial conflicts of interest that may be detrimental to the public interest.

• It is possible that some doctors will now seek out more financial ties as a means to hide their own biases.

If a doctor with an exclusive tie is worried about scrutiny or perhaps even knows that he or she has some bias, says Pham-Kanter, "he or she might attempt to limit scrutiny and/or cloak the bias by seeking out ties from other firms in an attempt to look like the unbiased and high-expertise scientists with multiple ties."

Institutions that employ doctors who serve in research advisory capacities should be vigilant about this, says Pham-Kanter. "For starters, they could do more than a cursory review of their advisors' financial ties," she says. "A simple numeric count won't be sufficient to distinguish potentially problematic ties from those that are not."

Institutions could also focus on the nature of the tie, she says. For example, ownership and advisory board ties should be bigger red flags than other kinds of financial ties.

The FDA should require panel members with financial ties to recuse themselves from decisions where financial relationships exist with industry, says Wall. "The public expects no less," says Wall. "There will be increasing pressure to eliminate such conflicts of interest in FDA decisions — and that is the right thing to do."

Pham-Kanter hopes that the research will encourage a more sophisticated approach toward the regulation of physician-industry relationships. "Not all ties are alike," she says. "We will lose some good along with the bad, if we just do a simple tally of financial ties as a measure of badness."

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• Genevieve Pham-Kanter, PhD, Assistant Professor, Department of Health Management and Policy, Drexel University School of Public Health, Philadelphia, PA. Phone: (267) 359-6163. Fax: (267) 359-6001. E-mail gpkanter@drexel.edu.

• L. Lewis Wall, MD, DPhil, MBioeth, Professor of Obstetrics and Gynecology, Washington University School of Medicine, St. Louis, MO. Phone: (314) 362-4511. Fax: (314) 362-3328 Email: walll@wudosis.wustl.edu. ■

Study validity may be compromised if patients drop out

Use informed consent process to educate participants

Occasionally, individuals who agreed to participate in a research study withdraw for various reasons; some simply stop participating without communicating with investigators.

"We have a real problem in clinical trials when people decide they just don't want to participate after they've enrolled," says **Jonathan L. Halperin**, MD, professor of medicine at the Icahn School of Medicine at Mount Sinai and associate director of the Zena and Michael A. Wiener Cardiovascular Institute at The Mount Sinai Medical Center in New York City.

If some research participants discontinue treatment due to side effects they are experiencing or for other medical reasons, this doesn't necessarily compromise the study's findings. The same would presumably be true of actual patients, who are sometimes non-compliant. "In the real world, people interrupt therapy for all kinds of reasons," says Halperin. "The problem comes when people disappear from view and don't allow the investigators to know how

they are doing."

While study participants have the right to withdraw consent, "it's very important for them to realize how damaging that is to the results," says Halperin. Investigators are unable to determine the participant's outcome. "In that case, we must consider all of the possible outcomes. Did they die, or is it that they just weren't in the mood to continue follow-up?" he asks.

Due to this uncertainty, the validity of the study is compromised. This leaves investigators unable to conclude whether the randomized treatment being studied is harmful or helpful. "This is costly — not just in terms of money, but in terms of confidence in the trial results — and we don't spend that lightly," says Halperin.

If a study requires 500 participants and 10 stop participating without contacting the investigators, that means that the 490 other participants put themselves at risk for a study with an invalid outcome, he says.

"We may no longer be able to draw a conclusion, because we no longer have the statistical power to prove whether the treatment works not," says Halperin. "So in a way, 10 people have put 490 others in harm's way."

There is no ethical justification to interfere with a participant's decision to opt out of a study, says **Tomas Jose Silber**, MD, MASS, director of the Pediatric Ethics Program and research subject advocate at Children's National Health System in Washington, DC. Nor should there be penalties such as refusing to give an agreed-upon payment, he says.

"Since Nuremberg, the voluntariness in research participation has been enshrined as the essential component of any investigation," Silber says. "It stands to reason that if enrollment is voluntary, so is opting out." Thus, some studies may have to be discontinued if the number of participants withdrawing makes it scientifically untenable.

Educate prospective participants

Halperin recommends educating potential participants. Researchers can say, for instance, "If you don't think you can allow us to follow you until the study is done, it's better you don't do this. Think carefully, because you are making a commitment. You have the right to withdraw, but please do so for good reason."

> "THE PROBLEM COMES WHEN PEOPLE DISAPPEAR FROM VIEW AND DON'T ALLOW THE INVESTIGATORS TO KNOW HOW THEY ARE DOING."

Silber recommends the following practices:

- Make it very clear in the informed consent, and during the process of obtaining consent, whether the study holds a prospect of direct benefit to the subject. If it does, and there are study medications that need to be continued or gradually withdrawn, place a clear warning in the research protocol.
- Emphasize this requirement during the process of obtaining consent, or permission if the participant is a minor.

"If, in spite of this warning, the subject wants to end participation, the researcher should ask for permission to inform the participant's primary doctor about the interruption of the regimen and further recommendations," says Silber.

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- Jonathan L. Halperin, M.D., Director of Clinical Cardiology Services, The Zena and Michael A. Wiener Cardiovascular Institute at The Mount Sinai Medical Center, New York City. Phone: (212) 241-7243. Fax: (212) 831-2195. Email: jonathan.halperin@mssm.edu.
- Tomas Jose Silber, MD, MASS, Director, Pediatric Ethics Program, Children's National Health System, Washington, DC. Phone: (202) 476-3066. Fax: (202) 476-3630. Email: tsilber@childrensnational.org. ■

EXECUTIVE SUMMARY

When research participants who committed to a study withdraw or simply stop participating without communicating with the researchers, the study's validity may be harmed.

- Noncompliance doesn't necessarily compromise the study's findings since this mirrors real world experience.
- Studies may have to be discontinued if the number of participants withdrawing makes it scientifically untenable.
- Emphasize the commitment participants are making during the informed consent process, one expert recommends.

Evidence of economic burden of disparate care for minorities continues to grow

Healthcare reform alone won't solve problem

A recent tragic case involving informed consent obtained from parents with limited English proficiency led to a successful lawsuit against the hospital. The parents were told the risks of surgery for their child included kidney damage, but there was no interpreter in the room.

"The child ended up on dialysis for the rest of his life. The parents sued, and the hospital settled for $12 million in a matter of weeks," says **Thomas A. LaVeist**, PhD, director of the Johns Hopkins Bloomberg School of Public Health's Hopkins Center for Health Disparities Solutions.

"This is a tragedy on so many levels — not only for the family, but also for the hospital, the surgeon, and the people served by the hospital," says LaVeist.

From an ethicist's perspective, social justice is an obvious reason to care about health and inequalities. "But that's not the only reason why this matters. There is a utilitarian argument as well," LaVeist says. "It is expensive to pay out claims of that type, or to have people be sicker than they should be."

Eliminating health disparities for minorities would have reduced direct medical care expenditures by $229.4 billion for the years 2003-2006, according to a 2011 study.[1] "If we don't get a handle on health disparities, the implications are far bigger than social justice," says LaVeist, the study's lead author.

Clearly, more is being done now to address disparities than five or 10 years ago, says **Augustus A. White**, III, MD, PhD, director of the Culturally Competent Care Education Program at Harvard Medical School in Boston. White is author of *Seeing Patients: Unconscious Bias in Health Care* (Harvard University Press, 2011). "So in that sense, there's progress — but not in the sense of epidemiological studies that show disparities that were once noted are gone," he says.

Under the Affordable Care Act (ACA), adds White, "more people are insured. That's an important issue, because it means people are likely to have some kind of care."

Also, the National Center on Minority Health and Health Disparities, created in 2000, was re-designated as the National Institute on Minority Health and Health Disparities under the ACA. "So it has more clout, and hopefully will be more effective in diminishing disparities," says White.

However, **Cynthia Jones**, PhD, associate professor of philosophy and director of the Pan American Collaboration for Ethics in the Professions at The University of Texas–Pan American in Edinburg, has little confidence that the ACA will lead to a decrease in health disparities.

Conditions need to be ameliorated earlier, she says, to prevent diseases like Type 2 diabetes from reaching the point where they are critical. "Health disparities are the result of a complex tangle of factors, and despite decades of attention and research, we have yet to see movement in these disparities," says Jones. "Dumping more money into high-cost care is unlikely to affect change."

Problem is multifactorial

Reducing disparities is "an extremely complex issue," says White. "Healthcare itself is so complex, with many variables — policies, politics, human behavior and technology. All of those things are very formidable problems."

Bioethicists have an obligation to do whatever they can to diminish healthcare disparities, says White. This includes approaching hospital leaders.

"Ask CEOs and chiefs of services if there is a place for some specific institutional engagement on disparities," he says. When such matters are discussed, says White, "the ethicist needs to be at the table. The issue is it's not ethical to penalize people for being in some particular

EXECUTIVE SUMMARY

Health disparities for minorities are continuing due to multiple complex factors. In addition to social justice, the economic cost of disparate care is an ethical concern. According to experts, bioethicists can:

- Approach hospital leaders to lobby for organizationwide changes.
- Educate providers on providing culturally competent care.
- Raise the issue of disparate care during ethics consults.

group by providing care that is less good."

To address healthcare disparities at their institutions, bioethicists can do the following, according to experts:

• Train healthcare providers in communication methods that increase trust and lead to increased health literacy of the patients.

"Historical inequities have resulted in lack of trust, which can impact health outcomes," says Jones. "Providers can attempt to mitigate trust issues through stressing culturally competent care."

• Raise the issue of disparate care during ethics consults.

The bioethicist can point out that a particular condition tends to be managed in a disparate fashion. "Ask, 'What can we do to ensure that this patient is receiving good and appropriate care, and not disparate care?'" says White.

• Include disparities in patient satisfaction surveys.

"People are trying to explore ways to provide feedback to physicians, so they can learn if they are thought to be culturally competent," says White, adding that physicians with poor feedback can obtain training to improve their cultural competence.

• Help clinicians to be aware of their own biases.

Disparate care often occurs unintentionally. "Everyone has biases. The bias is only a problem if it impacts behavior," says LaVeist. "Awareness might help people to check themselves."

• Raise the issue of disparate care during committee meetings.

Committees can unknowingly make decisions that have a differential impact on patients based on their race, ethnicity, or income status. "Someone needs to be in a position to say, 'What is the impact of this on the vulnerable populations that we serve?'" says LaVeist. "Often, there is no one making that observation."

• Bring financial costs to the attention of hospital leaders.

If hospitals are viewed as unfriendly to minorities, this will affect their market share negatively. "With the expansion of Medicaid comes a whole new market of paying customers who previously didn't get care or got uncompensated care," says LaVeist. "Why wouldn't you want to get their business?"

Such decisionmaking usually occurs at the board level, says LaVeist, "and it trickles down to the operational level of people running departments. But I never see bioethicists involved."

Bioethicists need a good understanding of the financial cost of disparate care in order to call attention to the problem at the institutional level.

"Bioethicists tend to be more comfortable with a social justice framework, but utility is quite important," says LaVeist. "It is the language that administrators are going to understand."

REFERENCE

1. LaVeist TA, Gaskin D, Richard P. Estimating the economic burden of racial health inequalities in the United States. *Int J Health Serv* 2011; 41(2):231-8.

SOURCES

• Cynthia Jones, PhD, Associate Professor of Philosophy/Director, Pan American Collaboration for Ethics in the Professions, The University of Texas–Pan American, Edinburg. Phone: (956) 665-8081. Email: jonesc@utpa.edu.

• Thomas A. LaVeist, PhD, Director, Hopkins Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD. Phone: (410) 955-3774. Fax: (410) 614-8964. Email: tlaveist@jhsph.edu.

• Augustus A. White, III, MD, PhD, Director, Culturally Competent Care Education Program, Harvard Medical School, Boston, MA. Phone: (617) 998-8802. Fax: (617) 998-8808. Email: augustus_white@hms.harvard.edu. ■

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CME QUESTIONS

1. Which is a recommendation of a September 2014 IOM report on end-of-life care?

A. Competency in basic palliative care should be limited to palliative care specialists.
B. All medical schools, accrediting boards, and state regulatory agencies should bolster their end-of-life training and certification requirements.
C. The quality of clinician-patient communication should not be tied to reimbursement.
D. Non-hospice palliative care can be incorporated successfully simultaneously with cure-focused treatments.

2. Which is recommended to avoid conflicts with surrogate decisionmakers?

A. Ask about conversations surrogates personally had with the patient about the patient's end-of-life choices.
B. To preserve confidentiality, do not involve nurses when asking the patient to identify a surrogate decisionmaker.
C. Do not document private conversations about patients' end-of-life wishes, since this information was not witnessed.
D. Avoid sensitive topics, such as asking surrogates to describe the patient's religious, cultural, and personal beliefs.

3. Which is true regarding financial conflicts of FDA advisory committee members, according to a recent study?

A. No committee members had any financial interest in any drug company whose product was up for review.
B. No types of financial ties were associated with voting bias.
C. The types of financial ties that were most strongly associated with voting bias were membership on an advisory board for a firm and holding some ownership or equity stake in the firm.
D. Scientists with multiple financial relationships were more strongly associated with voting bias than those with no financial ties.

4. Which is recommended by experts regarding informed consent and research participants' right to withdraw from a study?

A. Noncompliance always compromises a study's validity.
B. Particpants should carefully consider the commitment they're making.
C. Once begun, participants may not withdraw from a study.
D. Researchers may not reveal whether the study holds the prospect of direct benefit to the subject.