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**AHC** Media

## Study: Residents uncomfortable with end-of-life conversations

*Simulation, real-time feedback are needed*

Internal medicine residents remained uncomfortable with end-of-life care discussions even after receiving additional training, according to a recent study.<sup>1</sup> Researchers surveyed 83 internal medicine residents at a large academic medical center about comfort with end-of-life care discussions, and compared the findings to data from a similar survey completed by residents in the same program in 2006. The 2013 group reported having more lectures about end-of-life communication and had

watched an attending have an end-of-life discussion more often than the 2006 residents. However, there were only modest improvements in their comfort level with such discussions; only about half felt strongly they were able to have open, honest discussions with patients and families.

Many practicing clinicians do not have any training in end-of-life communication. "Currently only 15 to 17 hours, on average, are spent on end-of-life and goals of care communication

### EXECUTIVE SUMMARY

Only half of internal medicine residents were comfortable discussing end-of-life care with patients even after observing such discussions and attending lectures, according to a recent study. Some recommended approaches from experts to teach residents this complex skill:

- Allow residents to practice discussions in a simulated environment with real-time feedback.
- Provide periodic booster sessions to keep skills current.
- Partner with residency program directors to craft curricula that address end-of-life discussions.

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**EDITORIAL QUESTIONS**

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in medical and nursing schools,” says  
**Salimah H. Meghani**, PhD, MBE,  
RN, FAAN, and associate professor  
at Philadelphia-based University of  
Pennsylvania’s School of Nursing.

The most important consequence  
of inadequate end-of-life training is  
that patients receive care inconsistent  
with their preferences, says Meghani.  
“Clinicians often feel unprepared  
to approach the topic in the clinical  
setting, resulting in significant  
personal and financial tolls for  
patients and families,” she says. This  
includes uncertainty about care  
options and prognosis, multiple  
burdensome care transitions, care  
fragmentation, very late referrals  
to palliative and hospice care, poor  
quality of life and symptom control.  
“These are real and consequential  
matters for patients and families,”  
says Meghani.

Important deficiencies persist  
for training in end-of-life care,  
according to the September 2014  
Institute of Medicine (IOM) report,  
“Dying in America: Honoring  
Individual Preferences Near the End  
of Life.”<sup>2</sup> “Good communication  
is fundamental to good end-of-life  
care. All clinicians who work with  
these patients need communication  
skills training,” says **James A. Tulskey**,  
MD, one of the IOM committee  
members. Tulskey is professor of  
medicine and nursing and chief of  
palliative care at Duke University  
Medical Center in Durham, NC.

Communication about end-of-  
life care is an essential skill, says  
Tulskey; like any other complex skill,  
it requires training. “Unfortunately,  
most clinicians have never received  
any training in such tasks as  
delivering serious news or discussing  
goals of care,” he says. This is not  
routinely taught in medical school,  
residency, or subspecialty fellowship  
training; the education programs that

do exist were generally created after  
most clinicians in practice received  
their training.

Simply hearing a lecture about  
how to communicate with seriously  
ill patients is unlikely to change  
clinician behavior. “To learn  
communication skills, clinicians  
must observe good communication,  
practice these skills, and then receive  
feedback on their behavior,” Tulskey  
says.

The opportunity to practice  
complex skills in a simulated  
environment, with residents  
getting real-time feedback on  
their performance, has proven  
effective for many other skills that  
residents are expected to perform  
competently. “The same is true  
for end-of-life conversations,” says  
**Eytan Szmuilowicz**, MD, assistant  
professor of medicine in the division  
of hospital medicine at Northwestern  
University’s Feinberg School of  
Medicine in Chicago. “What doesn’t  
work is just doing lectures — simply  
talking about how to have these  
conversations — because it omits the  
practice part.”

Szmuilowicz was lead author  
of a 2012 study that revealed a  
focused, multimodality curriculum  
can improve resident performance  
of simulated code status discussions;  
skill improvement lasted for at least  
two months after the intervention.<sup>3</sup>  
“If residents are uncomfortable  
engaging in these discussions, then  
at the very least, they need to ask for  
some help — in the same way we,  
hopefully, work collaboratively in  
other areas,” notes Szmuilowicz.

Since there aren’t enough  
palliative medicine specialists to help  
every patient, however, the goal is  
for all clinicians to achieve a basic  
comfort level with such discussions  
in order to engage patients and  
families earlier in advance care

planning. “To send trainees out into practice without these basic skills is unfair both to them and their patients,” says Szmuiłowicz.

Here are some approaches Szmuiłowicz has found to be particularly important involving effective training in end-of-life discussions:

- **There is a right time and place for learners to receive such training.**

Trainees need to have some clinical experience on which to frame the skills. “Without that experience, we can teach them what to say and when to say it, but I don’t know how well it sticks,” Szmuiłowicz explains. “Trainees might not be ready for some of the more complicated nuances early in their residency.”

- **Booster sessions are needed to avoid skills eroding over time.**

The challenge is to find a way to dedicate the necessary resources in light of limited resident and faculty time. “The struggle we have is there is a limited amount of time to teach a lot of things,” says Szmuiłowicz.

- **Mere observation is not enough.**

Not all senior residents and attending physicians are well-trained and comfortable with end-of-life discussions themselves. “What I sometimes encounter is that people think of communication as a ‘soft’ skill, and that people should be able to pick it up by watching their senior resident or attending,” Szmuiłowicz says. “That is not the best way to ensure competence.”

Trainees need to have somebody actively watching them and giving them feedback. “You can’t get good at this by just watching someone and then trying it yourself,” says Szmuiłowicz.

- End-of-life discussions are a

process, and need to be periodically revisited.

“These things are dynamic and they evolve over time,” says Szmuiłowicz. “It’s not a one-time conversation. It’s great if one clinician can shepherd the conversation over time, but it’s not always possible.”

This means clinicians must think of this as a “team effort.” The idea may be introduced by one clinician, picked up later by another, and then revisited by a third. “We need to feel comfortable not always having a ‘conclusion,’ and we need to be better at communicating our progress with all of our colleagues,” says Szmuiłowicz.

Szmuiłowicz suggests that bioethicists partner with residency program directors to craft curricula that address end-of-life discussions, noting that interpersonal skills and communication are one of the six core competencies required by the Accreditation Council for Graduate Medical Education (ACGME).

“For something to occur routinely, it must be a seamless part of an existing work flow. Bioethicists may serve to normalize end-of-life conversations at the institutional and community level,” says Meghani.

Bioethicists could work with their local palliative care teams as well as their hospital leadership, suggests Tulsy, to encourage the identification of patients for advance care planning discussions. “Bioethicists can proactively identify patients for whom these discussions are relevant,” he says. “This needs to be a joint effort involving palliative specialists, other specialists, IT staff, and leadership.”

Bioethicists can then create systems interventions that ensure that identified patients

have the conversation with a trained clinician. “This is a great opportunity for an electronic health records solution,” says Tulsy. “Clinicians could be flagged about appropriate patients, and perhaps receive point-of-care guidance about how to conduct the conversation.”

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# How bioethicists can encourage disclosure of medical errors

*Harm to patients has “less obvious ethical cost”*

Patients increasingly expect that medical errors and unexpected outcomes will be disclosed openly; the reality is that this practice is infrequent. “Only a very small percentage of adverse events from health care involving a significant degree of patient harm have documented evidence for institutional disclosures,” says **Edward Dunn**, MD, a palliative medicine physician and director of the Integrated Ethics Program at Lexington (KY) VA Medical Center.

The ethical obligation to disclose medical errors is rooted in the professional virtues of veracity and fidelity, according to **Andrew G. Shuman**, MD, chair of the Adult Ethics Committee and Consultation Service at University of Michigan Health System in Ann Arbor, which has pioneered a strategy of proactive disclosure of medical errors.<sup>1,2</sup> “This approach is rooted in the underlying professional obligations of clinicians and health systems, but also in the belief that patient satisfaction and trust will be maximized in an environment that fosters open, honest disclosure,” says Shuman.

To deliberately withhold clinically relevant information or deceive individuals violates the trust inherent to the doctor-patient relationship, says Shuman — “as such, in broad strokes, honest, open disclosure of medical errors is obligatory.”

Just as patients have a right to informed consent prior to medical or surgical intervention, “they also have a right to informed understanding of a medical mistake,” says **Margaret**

**R. McLean**, PhD, associate director of Markkula Center for Applied Ethics at Santa Clara (CA) University. It is well-recognized that medical errors come at a significant cost, both in terms of harm to patients and financial loss. “But there is a less obvious ethical cost as well, in the loss of patient trust in medical professionals and the health care system,” McLean says.

Dunn says it’s important to focus on poor outcomes and adverse events resulting in harm to patients. “This really isn’t about errors; humans make errors frequently, which is not particularly noteworthy,” he explains. “What matters is whether or not the patient was harmed, regardless of a mistake being made or not.”

For the majority of adverse events, it is unclear whether a medical mistake was actually made, Dunn explains. “In disclosing adverse events, we are meeting our ethical and professional responsibility to honor patient autonomy, and tell the truth about what happened during the course of their medical or surgical care,” he says.

The threshold for what constitutes an error, and what level of detail should be shared, will vary based upon the clinical circumstance and the involved protagonists, according to Shuman. “As with all clinical situations, judgment is necessary,” he says. For instance, intraoperative blood loss need not be disclosed down to the cubic centimeter. “In situations that arise within this gray zone, or in which clinicians request guidance, the involvement of

patient representatives, institutional administrators, and ethics consultants can be invaluable,” says Shuman.

The content of a disclosure meeting with a patient and/or family member should never be primarily about using the “right” words, says Dunn. “That is where most physicians become stymied and fearful of making a wrong statement,” he says. “This is about open, honest, and timely disclosure in a compassionate and empathic way.”<sup>3</sup>

University of Michigan’s ethics consultants can help the involved parties in determining the appropriate next steps, ensuring that mutual trust and respect are maintained in the face of a perceived negative outcome. “This role is distinct from hospital administration, risk management, and legal counsel, who may continue to be involved,” says Shuman.

Bioethicists should be involved in “sustaining an ethical climate” through developing policies that encourage the disclosure of medical error, says McLean. “Bioethicists should assist in the creating of ethically defensible policies and procedures for error disclosure,” she says. McLean recommends that bioethicists do the following:

- **Encourage the development of a transparent disclosure process.**

“Bioethicists can insist that, to the extent possible, both organizational and clinical decision-making and action be transparent to both professionals and patients,” says McLean.

- **Help to build clear institutional support for disclosure.**

For instance, bioethicists can involve administrators in the creation and review of medical disclosure policies and protocols and make institutional support explicit in such policies. “Institutions should provide training in error disclosure and make certain that their policies support professionals in disclosing errors to patients,” says McLean.

• **Address professionals’ concerns.**

Physicians are often uncomfortable in disclosing errors to patients, and may wonder, “What do I say?,” “How do I say it?,” and, “Do I apologize?” Bioethicists can assist in developing guidelines delineating the basic content of disclosure, and participate in disclosure training. “Bioethicists can also remind professionals of the duty to tell the truth, thereby providing an ethical impetus for disclosure,” says McLean.

Dunn was the principal investigator on a VA-funded grant to develop and implement a Disclosure Training Program workshop. “We have done 19 two-day interactive workshops over the past three years, using simulation methods to facilitate disclosure meetings conducted by workshop participants,” he says. Professional actors play the roles of patients and family members. “After each simulation, the facilitator leads a debriefing with participants to reflect on their performance and

reinforce communication techniques grounded in compassion, empathy and improvisational communication skills,” says Dunn.<sup>4</sup>

The workshops train clinicians to disclose adverse events largely through experiential learning. “All of that was informed by our operational experience doing institutional disclosures in Lexington,” says Dunn. The team uses clinical scenarios in various clinical settings, including outpatient clinics, the emergency department, mental health, and both medical and surgical hospital cases.

“Regardless of whether a tort claim is made, it’s important for patients to understand what happened to them,” says Dunn. “The clinician has a professional and ethical responsibility to disclose what happens to his or her patient 100% of the time.” In some cases involving a significant level of unanticipated patient harm, the institution also has a duty to disclose. “The clinician cannot speak for the institution; only its leadership can meet this responsibility,” says Dunn.

During the workshops, audience response technology is used to elicit feedback from attendees to administer pre- and post-tests of knowledge, and for program evaluation by participants. Through the first 14 workshops, approximately 400 participants demonstrated a 30% improvement in a test of knowledge and submitted a 95% overall

favorability rating of the workshops on several measures.<sup>4</sup>

Even with effective processes in place, clinicians find it difficult to disclose mistakes. “Our litigious society really gets in the way of that,” says Dunn. “[As a provider,] you are also worried about reputational loss in the community, and the story getting out in the news.”

Ethicists can provide much-needed support to clinicians, who often experience a crisis of confidence after a poor patient outcome, with or without evidence for a medical mistake. “It’s devastating personally when you get a suboptimal outcome. There is often nowhere, no formal place, for a clinician to go for help,” says Dunn.

Dunn recommends that ethicists take a very proactive approach to helping clinicians after a medical mistake. “This is not something you can do from a conference room or committee,” he says. “You have to be available to quickly spring into action to aid the person in need of help.”

After an adverse event occurred in the operating room which resulted in a patient’s death, a physician involved in the case was personally devastated and unable to return to work for several months. “We met with him immediately after the incident and for several months thereafter,” says Dunn. “We affirmed him as a physician and supported his emotional needs as a human being.”

The physician subsequently received help from a mental health professional. “But there is nothing more important for a clinician than to receive a timely call from a peer after his patient suffers an adverse event,” says Dunn.

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## EXECUTIVE SUMMARY

Despite patients’ growing expectations that medical errors and unexpected outcomes will be disclosed openly, the practice is infrequent. To promote disclosure, bioethics experts suggest the following:

- Provide guidance as to what level of detail should be shared.
- Encourage the development of policies and procedures for disclosure.
- Use simulation to train clinicians and administrators in the process of disclosure.

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# Disruptive behavior isn't always addressed, either in policy or practice

*"You change it with effective role models," expert says*

In 2008, The Joint Commission issued a Sentinel Event Alert on behaviors that undermine a culture of safety; its leadership standard requires all hospitals to have a process for managing disruptive and inappropriate behaviors.<sup>1</sup> Seven years later, however, disruptive behavior remains a troubling problem in health care.

"Some physicians have enormous hubris," says **William Doscher**, MD, associate chair of ethics in the Department of Surgery at Hofstra North Shore-Long Island Jewish School of Medicine in Hempstead, NY, and an attending physician in the Department of Medicine's Division of Medical Ethics. "They feel they are untouchable: 'What are you going to do, fire me? I'm the only guy who can do the total knee.'"

Disruptive behavior was experienced by 93% of 394 interns surveyed at Partners HealthCare in Boston during the 2010 and 2011 academic years; they most frequently identified nurses as the source of disruption.<sup>2</sup> Forty attending physicians were also surveyed, and reported other physicians as the most frequent source of disruption.

**Donald P. Owens, Jr.**, PhD, the James

A. Knight, MD Chair of Humanities and Ethics in Medicine at Tulane University School of Medicine, says in his experience, bullying is most often directed at medical students by residents and nurses. Owens says ethicists have an obligation to:

- help to create policies that prohibit disruptive behavior, and
  - explain the procedures for reporting disruptive behavior, and support individuals when it occurs.
- "This needs to be developed with the input of those who have been impacted by disruptive behavior," says Owens.

Almost all (96%) of 1627 physician executives surveyed in a 2004 study reported regularly encountering disruptive physician behavior; nearly 80% said disruptive physician behavior is under-reported because of victim fear of reprisal or is only reported when a serious violation occurs.<sup>3</sup>

**Gopal Kowdley**, MD, PhD, associate program director in the Department of Surgery at Baltimore-based St. Agnes Hospital, recently surveyed practicing physicians and trainees about disruptive behaviors. About half of the physicians reported observing aggressive or intimidating behavior in the workplace,

most commonly in the emergency department. "Places where a process was in place to deal with aggressive behavior tended to make physicians perceive themselves as happier," says Kowdley, adding that the most common incidents involve interactions among physicians and ancillary staff in the ER or operating room settings. "As a program director, I run into this often," he says. "Belittling, and sometimes elevation of voices, is common, especially when there is a delay in services."

Inclusion of ethicists during the process of developing policies on disruptive behavior, Kowdley says, "will allow the process itself to be inclusive of all parties and their wishes," he says. "Ethicists do a great job of having individual opinions be respected and heard."

Denial is one reason disruptive behavior continues at many organizations, even those with policies in place to address it. Recently, Doscher expressed concern to a colleague over a physician who was observed speaking rudely; the colleague's response was, "Don't worry about him, he's always like that, it's nothing to be concerned about." "But it is!" says Doscher. "Who

can argue about the fact we should try to do something about it? But it doesn't happen by magic, it really doesn't."

Doscher most often encounters disruptive behavior in surgeons; he says that ideally, physicians should resolve disruptive behavior amongst peers. "You don't want this to go to administrators. That is exactly the worst way to deal with physicians; this is a professional problem," he says. "But how do we defuse these situations before a bioethicist is called in?"

Physicians may become defensive if approached by an ethicist without a clinical background. "There is a feeling that they are just sticking their noses in and quoting from a book they read," says Doscher. "But we need input from both physicians and non-physicians. We all have to work together on this."

Doscher envisions using peer-to-peer meetings as a vehicle to address disruptive physicians. "We've talked about establishing a committee of physicians who can sit down and talk with the physician — not next week, but as soon after the incident as possible," he says. Doscher helped to rewrite the organization's bylaws addressing disruptive behavior, but acknowledges that even the best policies don't ensure such behavior is eradicated. "It's very easy to say, 'Thou shalt not be a bully.' But we are dealing with human beings who are under significant stress," he says. "We are beginning to understand this. But it's not going to happen overnight."

The problem of disruptive behavior

reflects a misalignment between organizational values and the behavior of individual clinicians, according to **William A. Nelson**, PhD, associate professor at The Dartmouth Institute for Health Policy and Clinical Practice in Hanover, NH. "As the organization establishes its values, it is really up to every person to be aligned with those values in their behaviors," he says. "When inappropriate, abusive behavior is occurring, it really is the responsibility of everyone to call it out and address it."

Despite The Joint Commission's 2008 standards, Nelson expects that many organizations still lack formal policies or guidelines to address disruptive behavior. "Part of the work of an ethics program should be to at least review, if not draft, that policy," he says. "Just as guidelines to withdrawing life-sustaining treatment are essential, so are guidelines to ensure appropriate behavior."

Ethicists need to ensure that unacceptable behaviors are identified; a structure must be in place to address incidents as they arise. "There ought to be training about this, so that people understand what is expected of them as a professional," says Nelson. "If people feel they have been treated inappropriately, they need to have a resource or mechanism to go to." This will vary depending on the organization's resources. For instance, the chair of a department can make it clear that if disruptive behavior occurs within the department, anyone can go directly to him or her to report it.

"If leaders are aware of inappropriate behavior, it needs to be called out one way or other. It cannot be ignored," says Nelson.

When disruptive behavior is tolerated, it becomes part of the organizational culture. "You change it by having effective role models," says Nelson. "If leaders don't demonstrate the values that are captured in various policies, then you have a real problem."

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## EXECUTIVE SUMMARY

Disruptive behavior remains a common occurrence in health care; organizations may lack policies to identify, prevent, and address such behavior.

- Physicians can address disruptive behavior with peer-to-peer meetings.
- Bioethicists can ensure individuals who report such behavior are supported.
- Leaders can make it clear that disruptive behavior won't be tolerated.

# Voice ethical concerns — not just during consults, but organizationwide

*Connect ethics to bottom line*

It's not enough for bioethicists to tell hospital administrators what is right and wrong morally with decisions made at the organizational level, says **James Corbett, JD**, senior vice president of community health and ethics at Centura Health in Denver. Corbett is a fellow at Harvard Medical School's Division of Medical Ethics and member of the National Institutes of Health's Nursing Research Council.

"If you're talking to executives and folks with different incentives, you need to connect ethical principles to the bottom line," he says. Corbett says what's needed is "ethics committee plus" — ethicists who are able to address both financial and ethical issues with hospital leaders. "You can advise all you want, but that's not where the decisions are made," he says. "The key is for bioethicists to be equipped to be at the table."

Generally, ethics committees function in an advisory role. This limits their scope and efficacy, says Corbett. "Additionally, the decisions made in the C-suite often do not include bioethicists, partially because they are not equipped to be at the table," he

adds. Disparate care, for instance, has both financial and ethical implications. "There are a lot of reasons to address inequities, but the financial incentives are one big driver," he says, pointing to the emerging concept of population health management.

"Health systems need to understand everything about that population in order to keep care under a certain budget," Corbett says. In the past, for example, the fact that Hispanics may have a higher sodium intake might have gone unaddressed by health systems because it didn't directly affect the bottom line; this is no longer the case.

"Hospitals are seeking to keep specific individuals under a certain budget while hitting quality metrics," says Corbett. "This is a tremendous opportunity for ethicists." Accountable care organizations give institutions an additional incentive to understand diverse communities and implement coordinated care efforts that reduce their cost of care, Corbett explains. "Some people do the right thing for the right reasons, and others need incentives," he says. "We need to do a better job of incentivizing this behavior."

Bioethicists typically don't see payment models and financial penalties in health care as part of their purview. "When I talk to bioethicists about the importance of their role, they often ask, 'Are you telling us we need to learn about health care finance?'" says Corbett. "They don't think of it as part of their role."

Corbett points to the history of bioethics, which made the transition from philosophy departments at academic institutions to medical institutions. "They learned that skill set," he says. "All I'm arguing is that the learning is not done."

Effective participation at administrative tables requires the clinical ethicist to develop another world view and to appreciate different priorities, says **Steven S. Ivy, MDiv, PhD**, senior vice president for Values, Ethics, Social responsibility, and Pastoral Services at Indiana University Health in Indianapolis.

When dialogue shifts from how an individual patient is treated to how patients are treated in general, the bioethicist's orientation must also shift. "The clinician should not lose awareness of individual well-being, but must grow in appreciation for institutional well-being as another good to be nurtured," says Ivy.

Ethics consultants too narrowly define their area of special expertise as having bioethical knowledge, says **Autumn Fiester, PhD**, director of the Penn Clinical Ethics Mediation Program and faculty in the Department of Medical Ethics & Health Policy at Perelman School of Medicine at the University of

## EXECUTIVE SUMMARY

Clinical ethicists can voice concerns not just during consults involving individual patients, but also more generally to address organizationwide issues. Bioethics experts suggest the following:

- Point out the financial costs of disparate care.
- Utilize conflict management skills to resolve patient grievances.
- Call attention to trends such as conflicts over withdrawal of ventilator support.
- Play a role in the emerging concept of population health management.

Pennsylvania in Philadelphia.

“Clinical ethics consultants have a specialized skill area, and it is in navigating conflict among parties with often diametrically opposed positions,” she notes. Ethicists who are trained in conflict resolution could help to resolve various types of conflicts within the organization, including patient grievances.

“Many physicians lament the existence of what they deem the ‘difficult’ patient,” says Fiester. “In my view, these challenging clinical encounters can often be remedied with good conflict resolution techniques.”

Some health care systems make it easier than others for ethics perspectives to be addressed throughout the organization. “For example, many religious heritage organizations, both Roman Catholic and Protestant, include executives whose primary role is to ensure that moral perspectives and ethical expertise is brought to bear on clinical, administrative, and community functions of the organization,” says Ivy.

At these institutions, there are pathways in place for clinical ethics to affect systemwide processes. Some organizations have promoted an integrated clinical-organizational ethics continuum. “The ethics committee

balances concerns for patient needs with attending to the processes which may challenge or further clinicians’ ability to act ethically,” explains Ivy.

Other organizations have not structured themselves to conduct interdisciplinary ethical discourse. “It is indeed more difficult to gain a seat at decisional tables,” says Ivy. “It happens best when clinical ethicists review their records so that they can identify repetitive or clustered issues.”

Ethicists may note, for example, that 50% of their referrals involve conflict between physicians and families over withdrawal of ventilator support at the end of life. In this case, they might develop relationships with key intensivists. Bioethicists could sit on review committees and bring this cluster of situations to the attention of leaders and begin identifying what processes can be improved.

“Or, they may note that a particular care unit has repeated calls from nurses unhappy with how physicians are managing a certain class of patients, which could be race, ethnicity, or religion,” says Ivy. In this case, ethicists could bring resources to the unit to increase diversity awareness.

During the past six months, Indiana University Health’s ethics

team has been asked to prepare white papers and sit at policy tables regarding treating Ebola patients, proposed state government legislation, and solid organ transplants for persons who are not U.S. residents.

None of these issues involved a specific patient case. “All involved potential and actual groups of patients that administrators were seeking to address with foresight and integrity,” says Ivy. “‘Tone from the top’ really does matter.”

## SOURCES

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## Parents eager for newborn genomic testing; ethical questions currently unanswered

*Too little is known to encourage widespread use*

Parents have widespread interest in genome sequencing for newborns, regardless of their demographic background, according to a recent study led by researchers at Brigham and Women’s Hospital and Boston Children’s Hospital. Researchers queried 514 parents within 48 hours

of a child’s birth.<sup>1</sup>

Parents reported being not at all (6.4%), a little (10.9%), somewhat (36.6%), very (28.0%), or extremely (18.1%) interested in genomic testing for their newborns. Surveying parents about genomic sequencing did not prompt rejection of conventional state-

mandated newborn screening.

Genetic testing of newborns “holds great promise, but too little is known now to encourage its widespread, routine or universal use,” says **Kenneth W. Goodman**, PhD, director of the Bioethics Program at University of Miami Miller School of Medicine.

The primary ethical concern is that most parents are unlikely to be aware of all that can be detected that is definitive, and all of the findings of uncertain importance that will be detected, according to **Reed E. Pyeritz**, MD, PhD, William Smilow Professor of Medicine and professor of Genetics at the University of Pennsylvania's Perelman School of Medicine in Philadelphia.

"Even if the parents are truly informed, they will then be faced with difficult decisions when a result shows that their child will develop some serious condition late in life," says Pyeritz. In addition, since many such conditions are autosomal dominant, it is likely that one of the parents actually has the same change but has not yet shown clinical signs of the condition.

There are two major ethical dilemmas if all 30,000 genes in newborns are sequenced, says **Charis Eng**, MD, PhD, FACP, chair of the Genomic Medicine Institute and director of the Center for Personalized Genetic Healthcare at Cleveland Clinic. "You will find many variants of unknown clinical significance in genes," she explains.

When new research comes along classifying these variants into pathogenic mutations or completely benign, the question arises as to whose duty is it to

find the newborn — who might now be an adult and living in a different country.

Parents should be able to opt out from knowing about mutations in genes that predispose newborns to adult-onset disorders, says Eng, until the newborn becomes an adult and can receive a genetic counseling session. This brings up the question of who should notify the child upon adulthood that there is genetic information he or she may wish to know, that their parents chose not to receive.

Ideally, says Eng, every single variant would be assigned with a clinical outcome, with patients informed how to manage the risk. "Also, the exome would need to be stored somewhere, so that new research can inform the variants in real time and somehow be able to alert their caregiver," she adds.

"Genetic screening of newborns is a great idea if they are sick and if we do not know why," says Goodman. However, the generation of large amounts of probabilistic genetic information can fuel "great and unnecessary" anxieties, he cautions.

"More data does not mean more information, and certainly not more knowledge," says Goodman. "We want to avoid running tests because we can, and then struggle with what to make of the results."

This is especially problematic when parents are not well-informed about what genetic testing reveals, or what it's really good for. "We already overtest patients," says Goodman. "Let's not add to that unhappy burden without more research on the practical utility of genome sequencing."

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# Impaired physicians have ethical obligation to self-report, experts say

*Bioethicists are "crucial"*

**D**o physicians have diminished capacity as a result of substance abuse, burnout, behavioral or psychological issues, or physical illness? Regardless of the reason for impairment, physicians have an ethical obligation to protect their

patients from harm.

"One key ethical principle that should be highlighted when discussing impaired physicians who self-report is that of nonmaleficence," says **Sigal Klipstein**, MD, chair of the

American College of Obstetricians and Gynecologists Committee on Ethics. Above all else, physicians have a responsibility to protect their patients from harm.

"When physicians suspect that they may be at risk of providing

compromised care to their patients due to any type of impairment, they should take all possible actions to prevent harm to patients,” says Klipstein, a clinical instructor of obstetrics and gynecology at University of Chicago. The first step in this prevention is for physicians to remove themselves from situations which may compromise patient care. “This may involve completely relinquishing all clinical responsibilities, or modifying their practice so that they do not place patients at risk,” says Klipstein.

Practices that may need to be modified or eliminated include providing consultation, writing prescriptions, and performing surgery. “Any actual or potential deficit in decision-making capacity or physical limitations that can affect patient care should lead physicians to remove themselves from situations of responsibility,” says Klipstein. She offers these recommendations:

- Physicians should regularly self-assess their ability to provide the highest standard of care to their patients. “Any doubt that they have should immediately prompt them to further investigate whether such doubt is founded in fact,” she adds.

- Bioethicists should provide counseling to physicians and institutions regarding the appropriate approach to situations in which it is not initially clear whether an impairment exists.

“Bioethicists are also crucial in providing consultation when there is not clear agreement among stakeholders regarding whether or not an impairment is present,” says Klipstein.

Failure of impaired physicians to self-report puts patients and the integrity of the medical profession at risk, warns **Helen M. Farrell, MD**, an instructor at Harvard Medical

School and a staff psychiatrist at Beth Israel Deaconess Medical Center in Boston. Several obstacles make self-reporting a challenge; physicians may experience emotional conflicts such as denial and fear of stigmatization. “They might also worry about the status of their position and license stability if one reveals a mental condition or substance abuse problem,” says Farrell.

Nonetheless, just as physicians are obligated to report colleagues who present with signs and symptoms of substance abuse, so, too, are they obligated to report themselves. “Physicians should be encouraged by the highest levels of institutional governance that self-reporting of impairment and removal of oneself from situations that are potentially harmful to patients is a strategy to improve patient care,” says Klipstein.

Bioethicists can be instrumental in assisting institutions in writing policies that encourage physicians to self-report when they suspect that they are impaired. “They can provide guidance to institutions and physicians in order to safeguard confidentiality while not impacting patient care,” says Klipstein.

Physicians should not be penalized for self-reporting, but rather, should be commended for their focus on patient safety.

“Rehabilitative programs should be put into place that support and assist physicians, with the aim of returning them to health and imbuing them with the ability to

resume their professional roles,” says Klipstein.

Modifications to practice could include referrals of patients to practice partners or, if needed, to physicians in other practices that can meet their needs. “Physicians need not specify the reason for their leave of absence,” says Klipstein. “They do, however, have a responsibility to not abandon patients and to provide alternative options for care.”

Institutions should make state rules for reporting physician impairment readily available to employees, advises Farrell. “Laws and regulations are similar in spirit across jurisdictions,” she adds.

Many states have “sick doctor” statutes allowing license protection and preservation for doctors who report impairment from a mental illness or substance-related condition. “Institutions can proactively help colleagues seek treatment, which is often very successful, under physicians’ health committees and treatment programs,” says Farrell.

## SOURCES

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## COMING IN FUTURE MONTHS

- Increase utilization of clinical ethics consult services
- Educate others on limitations of life-sustaining treatments
- Ensure competence of all clinicians in basic palliative care
- Informed consent and health literacy in human subjects research

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## CME QUESTIONS

**1. Which is true regarding end-of-life training, according to James A. Tulskey, MD?**

- A. Clinicians should observe good communication, practice skills, and receive feedback on their behavior.
- B. Attending physicians have received extensive training in discussing goals of care in school, residency, and fellowship training.
- C. The best way to change clinician behavior in communicating with seriously ill patients is through interactive lecture.
- D. Observation has been proven effective in ensuring competency in communication with seriously ill patients.

**2. Which is recommended regarding bioethicists' roles, according to Steven S. Ivy, MDiv, PhD?**

- A. Ethicists should not address financial costs of disparate care.
- B. Resolving patient grievances is not part of the ethicist's role.
- C. Ethicists should review their records to identify repetitive or clustered issues such as conflicts over withdrawal of ventilator support.
- D. Ethicists should focus only on the treatment of individual patients instead of how patients are treated in general.

**3. Which is true regarding newborn genomic testing, according to Charis Eng, MD, PhD, FACP?**

- A. Parents frequently reject such testing despite the known benefits.
- B. Parents are aware that many findings are of unknown clinical significance.
- C. Parents should be able to opt out from knowing about mutations that predispose newborns to adult-onset diseases.
- D. The benefits of such testing for most conditions clearly outweigh the possible harms.

**4. Which is true regarding impaired physicians, according to Sigal Klipstein, MD?**

- A. Physicians are ethically obligated to remove themselves from situations which may compromise patient care.
- B. Physicians should not regularly self-assess their ability, since they are biased observers.
- C. Bioethicists should recuse themselves when there is no clear agreement among stakeholders regarding whether impairment is present.
- D. Institutions should penalize physicians for impairment, whether self-reported or not, to prevent patient harm.