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## ASBH task force develops revision to the core competencies

*Final draft to be based on survey results*

The American Society for Bioethics and Humanities voted in 2006 to create a task force to revise the core competencies expected for those who perform ethics consults and for ethics consult services. Nearly four years later, the Core Competencies Task Force — after much debate — issued a revision in November 2009, and task force members are currently reviewing the feedback received from members on the revision.

But some disagreement remains, according to the head of the task force, **Anita J. Tarzian**, PhD, RN, an ethics and research consultant in Baltimore. Tarzian is also program coordinator of the Maryland Health Care Ethics Committee Network at the University of Maryland School of Law, and adjunct faculty member of the University of Maryland School of Nursing.

“There’s controversy in the field about whether we should go the route of professionalizing, with a code of ethics, and in addition to the core competencies, [have] some way of accrediting or credentialing people,” Tarzian tells *Medical Ethics Advisor*. “There are other people who say [that] most of the people who do this are volunteers, and they do other things in hospitals and health care facilities — and that they should just be at least minimally competent.

“It’s a tall order for the document to address those types of people, in addition to the fact that there’s still that allowance for the non-professional ethicists, who are doing it as part of other duties to kind of share the burden of the competencies in a team,” she says.

Tarzian notes that this differs from the first set of core competencies, approved by the ASBH nearly 10 years ago.

In that first edition of the document, “there was actually a position taken that they didn’t want to recommend pursuing any kind of credentialing in people, because they thought that would go down the road of professionalizing and displace the ones who are involved in this kind of work and this kind of decision making — and then push



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forward a certain type of professional, let's say, who might not have a clinical background but gets a PhD in ethics, and then you squelch diversity," she says.

The current revision, which has yet to be finalized, is important because "it is more pervasive that you have ethics consult services and ethics committees in hospitals, and some state laws are relying on these groups to help avoid having to go to court for certain decisions. There's more concern being raised that people aren't fully qualified," Tarzian says.

And currently, there's no real way for these

individuals, who perform ethics consults, to be vetted, she says.

However, once the core competencies document is finalized — probably by June — the document would be the first step toward an accrediting or credentialing process, Tarzian says.

## Standing committee formed, also

In addition to the core competencies task force, a standing committee was formed to look into whether or not the ASBH should offer something akin to board certification or other accreditation for ethics consultants.

"They are exploring other models that are similar, like chaplaincy certification. It's a similar concept of a lot of the affective skills needed. You can't just give them a multiple choice test. You have to be careful about your own bias . . . so there's [also] a lot of similarities with hospice and palliative medicine for a model, because [ethics consultation] requires communications skills," Tarzian explains. "And they do other measures that are like proxy measures; for example, they have to have taken care of a certain number of patients who are dying, a certain number of practical hours, a letter attesting to their work and character. So, is that the way to go?"

The standing committee is expected to have its report ready by the next ASBH annual conference in October.

"There, we're looking at the goal of having a really exhaustive report that says, "These are all the ways we think you could do this; this is how much it would cost; this is an estimate of how many people might be interested in doing this. You know, how much revenue would you generate, would you farm it out to another organization, would the ASBH do it, and then come out with a recommendation of what we think the first steps should be," she says. "Not actually doing it, but coming out with a comprehensive report that would then give a recommendation on next steps."

Tia Powell, MD, director of the Montefiore-Einstein Center for Bioethics in Bronx, New York, said of the revision effort: "I would say that the original core competencies report was a very important document; it was a great step forward and a real innovation. Similarly, I think this update fills a real need. I do think clinical ethics consultation has gone on for too long with insufficiently articulated standards, and that it's impossible to define what, in clinical ethics

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### EDITORIAL QUESTIONS

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consultation, is excellence, or even what minimal competency is in clinical ethics consultation, without a step forward liked the revised core competencies report.”

Powell, a physician, tells *MEA* that she approaches ethics from a clinical point of view.

“Either for that reason or for others, I really feel that if you interact with patients, you need to be accountable for your work with patients,” Powell says. “When someone goes to do an EKG or to draw blood, they have to document that they’ve been through a training program, they’re supervised, and their work is reviewed for quality. I think that the same standards should apply to clinical ethics consultants.”

### Some highlights on what’s new

The core competencies revision document recommends against relying on any one kind of model for ethics consults, advising instead that the type of model used should be adapted for the particular situation being evaluated, which is a different view from that of the original core competencies document, which was developed more than 10 years ago. There are three standard models for ethics consultation: individual consultant, the ethics consult team, or the entire ethics committee itself.

“There are some people who feel pretty strongly [that one model is superior to another],” Tarzian says, although she says there is “still a range of practice out there.”

“So, we understand that say, people in a rural setting that have to do a lot of telecommuting for providing resources, or long-term care facilities that function differently, might come up with a different way of addressing ethics consultation requests. But we’re saying in general, all other things being equal, the type of [ethics] question drives whether you use one person, the team, or the whole [ethics] committee.”

Powell tends to agree with the report’s suggestion that ethics consult services not rely on one particular model for the service.

“I agree with the report that the needs of the patient and the clinical context is needed to determine what model you use. I would say, though, that I think an excellent ethics consultation service needs to be able to work in each of these models, so that they can meet the needs of their patients,” Powell explains.

Tarzian does not find it unusual that there are differences of opinion on certain recommendations

in the document.

“Whenever you get ethicists together, you get differences of opinion. And our goal is to try and represent diversity where there is diversity, but to try to come to some consensus on basic standards,” Tarzian says. “So, basically there will be variations, and it’s up to the individual [institution]. I think what we try to say is: ‘At a minimum, you should have established what your policy is at your institution and then be consistent with your policy.’”

### Case vs. non-case consultations

Another topic where there was a difference of opinion was the revised core competencies document making a distinction between “case” and “non-case” consultations, Tarzian notes.

A case consultation is one where there is an active patient case under consideration; non-case covers “every other type of question that comes to a consultant,” such as organizational ethics policy, she says.

“We talked and talked and talked about alternative ways of naming that, but the bottom line was, the situation, or the one [where] ethics consultants can do the most damage is where there’s an active patient involved. And people go in and they can, at best, do a lot of good to resolve conflict and enlighten people and provide clarification of values and other things, but there’s a lot of harm that can be done, if you don’t know what you’re doing,” Tarzian explains.

“So, the thinking was: You kind of have to know the same knowledge base for both types of questions that come to an ethics consult service, but that there will be different procedural standards in place if there’s an active patient involved,” she says. “So, for example, you [would] want to see the patient. If you’re making an opinion and sharing recommendations about what happens to an actual patient, you want to make sure that you see the patient, then you talk to other people involved in the case, that you document your recommendation and your ethical analysis — so there are certain things that should happen.”

The document also specifically defines ethics consultation as “response to a request from someone — just like you would with medical consults,” Tarzian says.

Also, anybody with standing in a case should be able to request an ethics consult, whether that’s a patient or a family member or a member

of the health care team. Tarzian, for example, believes that once a patient consult is requested, the attending physician should always be notified that a consult is set to occur. However, this was another point of disagreement among certain ASBH members.

One realization the committee members had while conducting their research and developing the core competencies was that not everyone who conducts an ethics consultation writes this in the medical chart — something most committee members thought was an understood standard, Tarzian says.

Another area of contention was whether or not ethics consult services should be required to evaluate their institution's consult services.

And while Tarzian believes that internal debate is “good,” she still maintains that ethics consult services “could benefit from more systematic procedures to ensure quality. So, this whole movement toward quality improvement is based on being able to show what you're doing . . . I mean, who can be in a health care facility and say, ‘I'm not obligated to show the value of what I'm doing’? It seems out of touch with reality.”

*[Editor's note: For the complete revised Core Competencies document, please visit the American Society of Bioethics and Humanities web site at [www.asbh.org](http://www.asbh.org).]*

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## ACP paper: Strategies to address patient caregivers

*Many patients live within web of relationships*

Acknowledging, respecting, and accommodating the role of the patient caregiver in physician-patient relationships was the impetus for a position paper published earlier this year by the American College of Physicians (ACP)

and developed by its Ethics, Professionalism and Human Rights Committee.

With trends like increasing levels of chronic illness and attempts by hospitals to reduce lengths of stay, patient caregivers in the home are playing a larger role today in overall patient care, says **Joseph J. Fins, MD, FACP**, vice chair of the ACP committee responsible for the position paper, titled “Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships.”<sup>1</sup>

Patient caregivers are “sort of the unacknowledged caregiver in the room, and taking up a tremendous amount of burden and really not being recognized,” Fins tells *Medical Ethics Advisor*.

The goal of the paper is to provide strategies for internists and other physicians to address the role and needs of the caregiver while still upholding the primacy of the physician-patient relationship.

“We felt that it was necessary to kind of systematically review the landscape and the issues that are confronted by patients and their caregivers — and to write a guide for physicians . . . to provide ethical guidance on how to negotiate that relationship,” Fins says.

“We thought it was a skill set that internists needed to have and that [is] often called upon in these roles. And it's a situation that's at home; it's not an inpatient situation. [It] may not be in a hospice. It may not be labeled as end-of-life care, so it's kind of a chronic care sort of zone, and so we wanted to . . . go through some of the scenarios that were most likely to be complicated, where [physicians] may need some guidance and clarification,” Fins explains.

And while the paper holds that the physician-patient relationship is the priority, it suggests — as does Fins — that in order to provide the best care, a physician must respect the role of the caregiver, upon whom the patient may depend for everything from nutrition to activities of daily living to complex care, which historically may have been delivered by nurses in a hospital setting.

Fins maintains that “the notions of autonomy and patient self-determination from the early days of bioethics are a little ill-fitting in the reality of everyday patient life, in that we're not atoms in isolation — we're molecules — and we're in relationships with others, so we can talk about autonomy in sort of an atomistic approach to the individual, but we really fail if they're in these relationships.”

“The caregiver's in the room. The patient may be autonomous to make choices, but it doesn't mean that the caregiver is not going to influence

the patient, or that the patient is not dependent on the caregiver. To be autonomous, they many need to be dependent upon the caregiver, which . . . demonstrates that they're not fully autonomous or independent, because they depend on each other," Fins says.

"I think what we were trying to do here is to acknowledge the complexity of the situation that the ethical theory doesn't always explain," he notes. "There's the sociologic reality of being ill with a chronic disease and being dependent on somebody else, whose own life is affected by your illness."

The patient and patient caregiver relationship is often one of reciprocity, Fins notes, which further supports the need for acknowledging and valuing the caregiver. For example, the caregiver may depend on the patient for "love, affection, or somebody to talk to."

"The dependent patient might be immobilized with a malady, but they may be cognitively intact. Maybe they do the checkbook that the other person can't do; you know, there's all kind of variations on this theme," Fins explains.

In addition to the ACP, the position paper has been endorsed by 10 medical professional societies: Society of General Internal Medicine; American Academy of Neurology; American Academy of Hospice and Palliative Medicine; American College of Chest Physicians; American College of Osteopathic Internists; the American Geriatric Society; American Medical Directors Association; American Thoracic Society; Society of Critical Care Medicine; and the Endocrine Society.

## **Patients' needs come first**

In the paper, the first ethical guideline states: "Respect for the patient's dignity, rights and values should guide all patient-physician-caregiver interactions."

In practice, "Clinical encounters should be patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making," the paper states.

"Family caregivers may view themselves as partners with the physician in the care of the patient, especially as the patient's illness progresses and the caregiver's role increases. In this situation, there is a risk that communication about care will shift prematurely to the caregiver, even though the patient is capable of making decisions. The focus should remain on the patient," the paper states.

However, the paper acknowledges that "the

health preferences of patients can evolve over time" and also that some patients "may wish to defer decisions to the caregiver."

Another practice guideline under this ethical guidance is: "The physician should routinely assess the patient's wishes regarding the nature and degree of caregiver participation in the clinical encounter and strive to provide the patient's desired level of privacy."

Still, the paper advises physicians that provisions of the Health Insurance Portability and Accountability of 1996 Act (HIPAA) "should not be viewed as a barrier to communication." However, privacy should be maintained to the extent indicated by the patient.

"These private exchanges can be especially important for addressing concerns about whether a caregiver is acting in the patient's best interests. Private exchanges may include determining whether the patient feels safe and well cared for; eliciting fears or concerns; obtaining the names of other family caregivers the patient might want the physician to contact; and determining whether the patient requires legal or social services," according to the paper.

The paper also advises physicians that patients should be evaluated for signs of all types of abuse, including neglect and physical, emotional, or financial abuse — and they should be familiar with the relevant states laws where they practice pertaining to abuse.

## **"Excellent communication [is] fundamental"**

A second ethical guidelines states; "Physician accessibility and excellent communication are fundamental to supporting the patient and family caregiver."

An associated practice guideline to this guidance is: "The physician should strive to ensure that the patient, family caregiver and other family members have a common, accurate understanding of the patient's condition and prognosis."

According to the paper, "Caregivers cite access to clear, consistent, understandable information about the patient's medical condition and treatments as the single most pressing unmet need during ICU hospitalizations."

The paper also addresses the possibility of disagreements between the patient and the caregiver. And while measures such as counseling or an ethics consult may be considered as alternatives, the first approach should be to try to understand the nature of the disagreement, Fins says.

“I think our emphasis is really on trying to understand . . . the roots of the problem and [to] attack it there,” he says.

And, the paper states that “while patients have the right to make decisions regarding their medical treatment,” if there is a disagreement between patient and caregiver, then patients “may need to consider other caregiving alternatives if the burden of those decisions is too much for the family caregiver.”

Another practice guideline is: “Physicians should encourage discussion of the patient’s health values and advance care planning so the family caregiver and physician have a clear understanding of the patient’s wishes.”

According to the paper — and Fins underscores this point — advance care planning makes it much easier for everyone to understand the patient’s values and goals of care to facilitate decision-making. It also makes disclosing patient health information to surrogates easier as it relates to HIPAA requirements, he says.

Physicians also need to be mindful of another piece of information from the paper, which is that “Patients generally wait for the physician to initiate advance care planning discussions.”

## Other ethical guidance

Emphasizing the importance of the patient caregiver role to the health care team, the paper provides this ethical guidance: “The physician should recognize the value of family caregivers as a source of continuity regarding the patient’s medical and psychosocial history and facilitate the intellectual and emotional transition to the end stage of serious chronic disease.”

Likewise, under the rubric of the reciprocal relationship, Fins notes that the caregiver and the patient have mutual responsibilities to each other.

“As my health care agent, you have an obligation to do what my wishes are as best you understand them, but I have an obligation to tell you what my wishes are before I lose capacity,” he says.

This reciprocity points to the importance of relationships in patients’ lives for those who do have family caregivers, so it is important to acknowledge that such patients do not live in isolation.

“And those other individuals influence the care milieu that is of interest to the patient’s doctor,” Fins says.

*[Editor’s note: For additional ethical and prac-*

*tical guidance on managing the patient-caregiver-physician relationship, see the entire document on the ACP Web site at [www.acponline.org](http://www.acponline.org).]*

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## SOURCE

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# EOL video studied with cancer patients

*Viewers more likely to avoid CPR*

The latest in a series of papers published by researchers led by **Angelo Volandes**, MD, MPH, instructor in medicine at Harvard Medical School and documentary filmmaker, looked at the use of a video depicting real-life cardiopulmonary resuscitation, as well as other life-sustaining treatments often faced by patients at the end of life.

An earlier study tested a similar video in dementia patients, while this most recent study looked at patients with malignant glioma and was published in the *Journal of Clinical Oncology* last year.<sup>1</sup> Volandes believes that the use of video to describe in pictures what end-of-life options truly entail may one day be a “standard of care.”

Volandes, who also completed a fellowship in medical ethics and serves on the Partners Health Care general ethics committee in Boston, tells *Medical Ethics Advisor* that during medical school, he “took a year off to do documentary filmmaking. After my third year, I realized that a lot of the discussions we were having on end-of-life were difficult to express using words. What I meant by those words and what my patient understood by those words were often two very different things.”

Physicians like Volandes and his team often realize, he says, that patients are more likely to

look at today's "Grey's Anatomy" to gather an idea about what constitutes CPR, and what their chances are of surviving, however inaccurate that idea may be.

"[Patients] would think of these very different realities, because on those programs, over 90% of people actually survive CPR, where in the advanced state of various diseases, the vast majority of people do not survive," Volandes says.

With regard to his interest in documentary filmmaking, Volandes went to film school during his fourth year of medical school to learn the art of documentary filmmaking.

"I felt like a lot of the clinical realities — the messy clinical realities in the details that clinicians see on a daily basis — are difficult to communicate solely with words," he says. "There are many studies that showed that [physicians] are poor communicators; they often don't adequately inform our patients. So, being a medical ethics type . . . I wanted to make sure that we not only guide decisions from our patients to respect their autonomy, but also make informed decisions."

With the dementia study, his team randomized elderly subjects into two groups. One group received only a physician's description of typical end-of-life care options; the other half of the subjects were randomized "to have the same verbal discussion, but to also see a 2-minute video. And then we asked them the same question: What sort of care would you want?"

"And, what we found was that in the group that saw the video, not only were they more informed about their decisions, but they also preferred more comfort-oriented measures," he explains. "And we found that in a diverse group of people in terms of race, ethnicity, level of education, and health literacy."

They also asked their elderly subjects in the dementia study if they would be interested in seeing an EOL video for cancer — and 95% of respondents said they would be interested.

In the current study, Volandes developed and filmed a 5-minute video on goals of care at EOL.

"We attempted in a short, brief video to offer a broad framework for patients to understand what their options are at the end of life when they have advanced cancer," he says, noting that his team chose brain cancer because it includes all age groups.

"You have very young people, middle-aged people, and older people, and we really wanted to get a sense of: Would there be a difference [in response] in terms of age?" Volandes tells *MEA*.

"Would the elderly, say, be less likely to be amenable to having a video be part of the patient-doctor relationship?"

The video for cancer patients went through seven different versions, and in addition to the filming, Volandes did all of the editing for the five-minute video. It took two and a half years to make, about which he jokes, "Spielberg makes five movies in two-and-a-half years!"

The reason for the long development of the video was that Volandes and his team were attempting to reach a consensus about the video's impartiality among a group of oncologists, intensivists, ethicists, decision-making experts, and geriatricians.

"We wanted to make sure that everybody in the group felt this was a fair and impartial portrayal of options at the end of life," Volandes says. "Now, you get a bunch of oncologists together and [try to] have them agree on anything, and they just don't. So, the written script for the video went through 10 iterations — that was a year, just of itself."

"It is exhausting and laborious when you have to re-film just for one word, but we wanted to make sure — we being the group of clinicians and scientists that I lead here — that we wanted to create something that oncologists would agree is impartial and unbiased and that oncologists would actually use," Volandes explains.

He notes that his team has developed and published a set of guidelines to create such videos.

"We invite others to to make similar videos and see if there's something that we did differently or that they do differently," he says.

Already, certain health care networks are conducting pilot studies using the video in their end-of-life conversations. At the moment, there are pilot studies at four locations, but the team expects to have 10 in place at academic medical centers this year.

Volandes and his team are already studying the use of video in other cancers at Memorial Sloan-Kettering in Boston.

"Just to be clear, this is not meant to usurp or replace the doctor-patient discussion and relationship; rather, this is meant to reinforce that discussion," he says. "An ideal use of this would be having a discussion with your clinician, whether it be a physician, nurse practitioner, or social worker, and then viewing the video to reinforce what's been discussed."

Even though the video is thought to be "scary to watch" — even for Volandes — he thinks

that “if patients are telling us they want this information, then this is one additional tool with which to empower [them],” he says. “And I think it’s incumbent upon the profession to equip them with those tools to make these decisions.”

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## SOURCE

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# ASRM ethics chair on posthumous gamete retrieval

*Society is revising its ethics policy*

Recent reports that a Texas woman had her son’s sperm retrieved following his unexpected death made headlines, while the American Society of Reproductive Medicine (ASRM) is in the process of updating its ethics policy on “posthumous donation” of germ cells — using either eggs or sperm.

The only similar situation that is covered by the Birmingham, AL-based organization’s current position paper revolves generally around when there is an unexpected death in a relationship, although that relationship typically is with a spouse or partner, says **Robert G. Brzyski**, MD, PhD, chair of the ASRM’s ethics committee and professor and chief, division of reproductive endocrinology and infertility, University of Texas Health Science Center at San Antonio.

In its position paper, the committee notes that while posthumous births have been recognized since antiquity, posthumous reproduction, on the other hand, “first became possible only after semen could be frozen and used for artificial insemination after the donor was deceased.”<sup>1</sup>

The paper also notes that in the United States: “The legal and social status of a child born from these origins has been ambiguous at best, even if the insemination and pregnancy occur with the wife of the dead man. Since the role of assisted

reproduction had not been well factored into common law or social and ethical judgments, a child born from conception and pregnancy after a man’s death may not always be attributed to him for purposes of inheritance and legitimacy.<sup>1</sup>

While the technology might consist of “only the commonplace cryopreservation of the sperm and insemination . . . , the social issues are complex,” the position paper states.

This request for reproduction after death sometimes occurs when his spouse or partner requests to have the man’s sperm frozen and used for conception in the event of his death. The same is true for men and their partners in the event the man has to undergo radiation or chemotherapy, and his partner or spouse requests gamete retrieval prior to the treatment for possible reproduction later.

## Some country norms exist

In Israel, for example, Brzyski points out that widows are supported legally in that country in any efforts to obtain posthumous gametes, “because the focus there is very pro-natal, pro-life” and on expanding child-bearing in that society. That contrasts with the United Kingdom, where, without written authorization provided by the person while he was alive, posthumous reproduction would be considered “unacceptable use.”

The roots of the United States, he notes, are in the UK, which tends to view individual autonomy and self-determination as more important than “social goals.”

In the United States, he says, “this scenario is imagined where there’s not written consent and there’s been a case made by the surviving partner that this is a goal of theirs, and she wishes to pursue it. And so, once a person has passed away, what exactly are their rights?”

But that is answered by the scenarios where people have wills and other arrangements “that indicate that there’s certain social conventions of respecting the wishes of individuals even after they’re gone, in terms of the legal arena,” he says.

But the situation reported more recently regarding the mother who wished to become a grandmother using her son’s sperm retrieved after his death, Brzyski says, is a different situation.

“I think most people would recognize that and be less supportive of the ethical foundation for the claims of the mother,” Brzyski says.

## The missing link

“Part of the foundation of ethical discernment

and decisions you are making rests on human experience. That's the missing link; where you don't have a human experience, it's hard to make judgments on any sound basis," Brzyski says.

Even though most people think of ethics as rooted in philosophy, he notes that ethics is also "founded on observations, and that does sort of go into the calculus."

The institution where Brzyski practices decides cases of this nature on a case-by-case basis "based on the circumstances of the situation," he says.

"I think the thing that I personally feel comfortable supporting is the collection of the gametes, because that is a very time-sensitive issue," he notes. "So, I might, in the appropriate circumstances, be supportive of collecting the gametes, but I'd be more cautious about — I would be in no hurry — to utilize those."

He says when death is involved, there is a grievance process that has to be worked through.

"You don't want to have the surviving partner make decisions rashly when they are dealing with the acute experience of their loss," he says.

Brzyski recommends referring the surviving partner to a mental health professional to help discern that person's values, goals, and objectives in life — and how loss can influence decision-making.

He also supports having such cases come before the full ethics committee.

"It's always helpful to get a disinterested group of individuals together . . . to sort of reinforce the thought processes of the individuals involved in the case," he notes.

## REFERENCE

1. American Society for Reproductive Medicine, "Posthumous reproduction." *Fertility and Sterility*, 82, Suppl 1, 2004.

## SOURCE

**Robert G. Brzyski**, MD, PhD, Chair of the American Society for Reproduction's Ethics Committee; Professor and Chief, Division of Reproductive Endocrinology and Infertility, University of Texas Health Sciences Center at San Antonio. E-mail: brzyski@uthscsa.edu. ■

# Disclosure of error taps 'very deep cultural norms'

*Clinicians have "truth-telling obligations"*

[Editor's note: This is a continuation of Medical Ethics Advisor's March coverage of disclosure of

*medical errors and apologizing for errors in the March issue.]*

There are many reasons why disclosing errors is the right thing to do within health care delivery, according to **Nancy Berlinger**, PhD, MDiv, and deputy director and research scholar at The Hastings Center in Garrison, NY.

For starters, the Code of Ethics of the American Medical Association includes language pertaining to physician obligation. "With respect to patient autonomy, with respect to honoring the patient as a person, [it] means you tell this person what is going on with their own health," Berlinger tells *Medical Ethics Advisor*.

"Embedded inside the core obligation of patient-provider communications, there's the disclosure obligation, and with the recognition that sometimes, when you're telling the patient about their health, you're telling them about harms that occurred in the process of providing care," she notes.

Furthermore, disclosing error is part of the basic human acknowledgement that you have hurt someone.

"This taps into very deep cultural norms about what good people do, what good behavior — what ethical behavior — is between people," Berlinger says. "One of the ways we don't harm people is we don't lie to them; we don't fail to tell them something that's materially important . . . and this wasn't invented by medicine; this wasn't invented by culture, but you can see how this is all braided together."

Suffering an injury within the health care environment can have serious consequences for a patient's health, because they are typically sick to begin with.

"And also because not only is there the possibility of physical injuries, but also there are economic consequences; the cost of repairing health care harm can be quite significant," she says. "And that's the issue that gets taken up when we talk about disclosure, is how will the information being disclosed be dealt with? How do we resolve what happened?"

Berlinger notes that a particular legal scholar suggests differentiating into separate issues medical error disclosure and apology by the clinician who either caused the error him- or herself — or it happened to a patient under his or her supervision — and the determination of how to address the patient harm.

That's because the person responsible for

patient care is “not necessarily the same person who has the ability to negotiate a financial settlement or to arrange the details of care,” she says.

Therein lies the organizational ethical accountability to the patient, she adds.

A person who is injured during the delivery of care is “probably the most vulnerable person in the health care system,” Berlinger says. “A patient is a vulnerable person because they’re sick, they’re hurt, they may not be conscious . . . they don’t have their own clothes. But a patient who got hurt in the health care system is doubly vulnerable.”

To that person, she notes, “we owe them rather a lot.”

Without the truth from the health care provider when an injury has happened, she says, a patient might actually blame himself or herself without knowing the facts of what actually happened.

“So, when you get at these issues of error and response to error, we’re talking about fairness questions, justice questions,” she says. “So, this is why we locate this inside of ethics, rather than just inside of law, or just inside of medicine.”

## U. of Michigan Health System example

The University of Michigan Health System in Ann Arbor is an example, Berlinger says, where the approach to medical errors goes far beyond the idea of “I’m sorry.”

“Certainly, it’s there, and they are doing rigorous analysis of what is needed institutionally to respond to injury, but also to learn from injuries to prevent other injuries,” she says.

In an article in the *Journal of Health & Life Sciences Law*, Richard C. Boothman et al. note that “Studies that have examined patients’ reasons for seeking legal help following unanticipated medical outcomes suggest that caregivers’ reluctance to disclose actually may drive patients to lawyers’ offices.”<sup>1</sup>

In the study, the authors describe a program that “responds to the identified drivers of medical malpractice” — with guidelines for how to proceed both before errors occur and “after an unanticipated outcome occurs.”

The first guideline prior to errors is this: “Create realistic expectations about the proposed treatment or surgery in both patient and caregiver via thoughtful, thorough communication. Informed consent is an opportunity to set reasonable expectations, not just a legal hurdle to be crossed. Likewise, patients’ responsibilities are acknowledged and documented.”

After an unanticipated error occurs, the system’s first plan of action is this: “Patients/families are approached, acknowledged, and engaged in the acute phase.”

The last two lines demonstrate, importantly, that actions are being taken toward the goal of preventing that mistake or injury from occurring again. For example, the program advises, “The patient’s experience is studied for improvements that later are shared with the patient and family.” Likewise, “Future clinical care is monitored via metrics established and measured to evaluate efficacy and durability of improvements.”

“With few exceptions,” the paper states, “(usually characterized by imposition of strict liability), in our society we are expected to act reasonably, not perfectly, under the circumstances. Medicine is an imperfect science, and medical care is, in most cases inherently dangerous.”

The authors note that as one of the Michigan surgeons often comments: “Clairvoyance is not the standard of care.”

In fact, Boothman, who is chief risk officer at the University of Michigan Health System, and architect of this approach to medical errors and claims management, tells *MEA*, “I don’t concern myself too much with ethics, because the complexities of these cases and these events lead me to the conclusion that I think it would be presumptuous of me to impose my own set of ethics in those situations.”

“The ethicists aren’t there rummaging around in somebody’s belly and then they have a problem. Or they’re not there when that baby’s delivered. And I’ve been through thousands of conversations with some of the most highly trained, well-meaning human beings in the world — who humble me every day — [and] who are scared to death when something bad happens,” Boothman says.

Rather than the physician trying to analyze what went wrong and apologize in the “heat of the moment,” Boothman says instead, “What we’ve done here is create a very expert, and always available, support team, and we say to our staff, ‘Don’t try to do this. Even the most socially mature of you can’t [disclose errors] in the heat of the moment. You won’t have all the facts; you’ll be struggling with complex emotions that go in every direction.’”

“What we want our staff to do is to pledge to patients that we will get to the bottom of it; we will give them the most accurate information as it comes available to us; and we want our staff to stay in the saddle with those patients — no matter how angry they are — and pay attention to the immediate

care needs,” Boothman explains.

Boothman says the “real cost” of the traditional deny-and-defend approach is that if the clinician or institution doesn’t acknowledge that an error or problem has occurred, then “you can’t move to fix it.”

“I have my own sense of ethics, but I am painfully aware that it’s not my rear-end that’s in the sling if something bad happens,” Boothman notes. “So, I don’t impose my ethics. But I did very consciously [design this approach] with this notion that if we don’t review these incidents with complete honesty, we will never improve.”

#### REFERENCE

1. Boothman, RC, Blackwell, AC, Campbell DA, Jr. et al. “A Better Approach to Medical Malpractice Claims? The University of Michigan Experience.” *J. Health & Life Sci. L.* 2:2; 125-159.

#### SOURCE

**Nancy Berlinger**, PhD, MDiv., Deputy Director and Research Scholar, The Hastings Center, Garrison, NY.  
E-mail: berlingern@thehastingscenter.org.

**Richard C. Boothman**, JD, Chief Risk Officer, University of Michigan Health System, Ann Arbor, MI. ■

## NIH to create Genetic Testing Registry

The National Institutes of Health (NIH) announced on March 18 that it is creating a public database that researchers, consumers, health care providers, and others can search for information submitted voluntarily by genetic test providers.

The goal of the Genetic Testing Registry (GTR) is to enhance access to information about the availability, validity, and usefulness of genetic tests.

Currently, more than 1,600 genetic tests are available to patients and consumers, but there is no single public resources that provides detailed information about them.

The NIH said the GTR “is intended to fill that gap.”

The overarching goal of the GTR is to advance the public health and research into the genetic basis of health and disease.

As such, the registry will have several key functions, among them:

- Encourage providers of genetic tests to enhance transparency by publicly sharing informa-

tion about the availability and utility of their tests.

- Provide an information resource for the public, including researchers, health care providers and patients, to locate laboratories that offer particular tests.

- Facilitate genomic data-sharing for research and new scientific discoveries. ■

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## CME INSTRUCTIONS

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

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

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## 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.

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## COMING IN FUTURE MONTHS

■ The ethics of neuroimaging

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## CME QUESTIONS

13. Which of the following is the primary point of division regarding the core competencies in the revision set forth by the task force of the American Society for Bioethics and Humanities?
  - A. Whether to credential ethics consultants
  - B. Whether physicians should be ethics consultants
  - C. Who is the primary decision maker in ethics consultations
  - D. Who should accept blame when there's a problem
14. In the American College of Physicians' position paper "Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships," what individual's interests should be the first consideration?
  - A. The spouse
  - B. The patient caregiver
  - C. The patient
  - D. The physician
15. What medium did Angelo Volandes, MD, MPH, use to facilitate better understanding for patients in end-of-life discussions with their physicians?
  - A. Audio conferences
  - B. Seminars
  - C. Written pamphlet
  - D. Video
16. Richard C. Boothman, chief risk officer of the University of Michigan Health System, says he considers medical ethics when evaluating medical errors first and foremost.
  - A. True
  - B. False

**Answers: 13. A; 14. C; 15. D; 16. B.**