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**AHC** Media

## Coverage of brain-dead patient on life support: "Profound lack of understanding about the concept of death"

*High-tech care contributes to misunderstandings*

The widely publicized case of Jahi McMath, a California teenager who remains on life support after being declared brain dead, has generated a great deal of discussion on end-of-life issues, "but not in a positive way," says **Craig M. Klugman**, PhD, professor and chair of the Department of Health Sciences at DePaul University in Chicago, IL.

The girl's family claims that doctors

have found signs of brain function, and is seeking an unprecedented court order declaring her alive. "This is a story about refusing to accept death and using large amounts of resources in a futile quest," says Klugman. There is no known case of brain death being reversed.

"The sad case of Jahi McMath has been making headlines again, this time with the claim that the original tests that confirmed

### EXECUTIVE SUMMARY

The widely publicized case of a California teenager declared braindead who remains on life support illustrates how contemporary intensive care unit medicine complicates the determination of death.

- Terms such as "life support" can be misleading.
- Families may think the term "brain death" means their loved one is still alive.
- Brain death causes confusion for patients and even providers, as such patients do not appear dead.

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**EDITORIAL QUESTIONS**

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(404) 262-5416.

total brain failure were wrong,” says  
**Leslie M. Whetstine**, PhD, associate  
professor of philosophy at Walsh  
University in North Canton, OH.

Unfortunately, says Whetstine,  
much of the media coverage  
surrounding the case reflects “a  
profound lack of understanding about  
the concept of death determined on  
neurologic criteria.”

This disconnect points to a need  
for a broader discussion about societal  
values, according to Whetstine. “Until  
this occurs, we will likely continue to  
see challenges and misunderstandings at  
the bedside,” she predicts.

Public discussion needs to center  
on accepting death as a natural part of  
life, argues Klugman. “Families that  
want to believe their loved [one] is alive  
are going to grab onto this story, and  
interpret it as hopeful and applying to  
them,” he says.

There is a potentially positive side to  
the attention generated by the case, says  
**Amber Barnato**, MD, MPH, associate  
professor of medicine at University  
of Pittsburgh School of Medicine.  
“Anytime there is public discourse  
prompted by a case, it’s meaningful,” she  
says. “It provides us an opportunity to  
talk about these issues, and for people to  
reflect on their own values and wishes.”

The McMath case is “a [classic] case  
of how contemporary ICU [intensive  
care unit] medicine has complicated  
dying,” says Barnato.

Technology used in the ICU  
challenges longstanding assumptions  
about life and death. “It is entirely  
possible that ICUs can maintain a  
body despite the loss of the individual,”  
explains Whetstine.

Brain death causes confusion for  
patients, and even providers, because  
such patients do not look dead. “When  
families see a loved one who is pink  
and warm, who is breathing and has a  
spontaneous heartbeat, it may be quite  
difficult for them to accept that they are

looking at a corpse,” says Whetstine.

## End-of-life terms misleading

Regarding the McMath case, says  
Klugman, “people are going to believe  
what they want to believe. It’s possible  
that all of the facts in the world will not  
change their mind.”

The language used by providers  
contributes to misunderstandings, as  
does the patient’s appearance. “A family  
walks into an ICU and sees a body  
with good color,” says Klugman. “The  
chest moves up and down, the eyes  
may be open, the eyelids may flutter.  
There may even be some spontaneous  
movement.”

The family is then told that the  
patient is “brain dead” and that the  
medical team is recommending removal  
of “life support.” “The family ends up  
thinking, ‘How can this body that looks  
very much alive not be alive?’” says  
Klugman. “There is a confusion between  
what they see and what they hear.”

Families may think the term  
“brain death” means their loved one is  
still alive. “The use of life support to  
maintain a body brings up the idea of:  
Why would it be ‘life’ support if there’s  
no life?” says Klugman. “All of this gives  
a strong message that the person is still  
alive.”

Here are some ways in which  
bioethicists can help to avoid situations  
that give families unrealistic hope:

- **Carefully consider the language used.**

“Instead of ‘brain death,’ we  
should say ‘dead’ or ‘dead by  
neurologic criteria,’” advises Klugman.  
“I think it’s important to use the  
term ‘dead’ first, and then explain the  
circumstances.”

He suggests providers use the terms  
“artificial corpus support,” or “replacing  
natural function” instead of “life  
support.”

“The word ‘life’ is what brings on the confusion,” says Klugman. “It suggests to the family that we are sustaining life, when, in fact, with brain death we are simply keeping a biological unit functioning.”

• **Make sure medical information is understood.**

“I’ve turned to a family member after a physician speaks and said, ‘I didn’t understand that, did you?’” says Klugman. The bioethicist can then turn to the doctor and ask them to explain more simply. “Families need to have information in easy-to-understand terms. And you have to repeat the concepts often,” he says.

• **Explain what various diagnostic tests for death measure, what the scale means, and where their loved one falls on it.**

Sharing these criteria and the data can lead a family to form their own conclusion that their loved one is dead. “These are complex and subtle concepts, and we have to explain them clearly,” says Klugman. “This takes time and patience.”

## Acknowledge strong emotion

When families pray for a miracle, “it often causes providers to throw up their hands,” says Barnato. “But it’s actually an open wedge for you to get in.”

Providers can respond, “I deeply wish we could have that miracle, because it would take a miracle.”

“It honors the family’s belief that miracles exist, and helps you get on the same page,” she says. “There is an opportunity for some shared understanding.”

Providers sometimes persist with an educational approach, with the mindset “if only we could get you to understand this information,” says Barnato, instead of acknowledging the family’s strong emotion.

“It’s really hard to explain the concept of brain death to anyone,” says Barnato. “The concept of death in a more spiritual space isn’t constrained by that definition. So I can see where there would be conflict.”

Klugman was recently told that due to a family’s religious beliefs, they would never accept that their loved one was brain dead as a result of trauma.

“As we talked, I started using their language about faith and will,” he says. After a lengthy, difficult meeting, a shared understanding was achieved. “After a few more hours and one more test, they came to accept the death, and began the next step of their mourning,” says Klugman. ■

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# Too often, patients not given culturally competent care

*Providers lack training, time, and resources*

When the family of an elderly Chinese patient insisted she not be told about her diagnosis of metastatic cancer, her physician felt he had an obligation to inform the patient.

“As the result of an ethics consultation, the physician agreed to ask the patient if all diagnostic information and treatment options should be shared not with the patient, but with her eldest son,” says **Paul Hofmann**, DrPH, FACHE, president of Hofmann Healthcare Group, a Moraga, CA-based consulting firm

specializing in health care ethics, and a former hospital CEO. The patient concurred — an outcome which respected the values of the physician, patient, and her family, says Hofmann. Here are some obstacles to patients receiving culturally competent care:

• **Providers may believe that ethical obligations are met as long as there is competent language translation.**

“But cultural competence is not achieved solely through having a translator in the room, with the

goal of the patient agreeing to the proposed treatment plan,” says **Margaret R. McLean**, PhD, director of bioethics at Markkula Center for Applied Ethics at Santa Clara (CA) University. Culture is far more than language, she explains — it shapes how patients think about illness and death, and how they perceive and describe pain and other symptoms.

“For the most part, hospitals provide competent language translation,” says McLean. “But they need to support provider cultural competence by encouraging that

culture brokers be part of the care team.”

Providers’ ethical obligation stretches beyond providing language interpretation, says **Karen Peterson-Iyer**, PhD, a lecturer in the Department of Religious Studies at Santa Clara (CA) University. “Patients need to be understood and empowered within their own specific cultural contexts,” she underscores.

If a patient embraces a culturally based belief that direct conversation about death is considered taboo, for instance, it is incumbent upon providers to respect those cultural leanings.

“This might involve, for example, uncovering whether a patient would like to have those sorts of conversations directly or through the intermediary of a designated close family member,” says Peterson-Iyer.

**• Some physicians, nurses, and other healthcare professionals have not received adequate education on culturally competent care during their academic training.**

“It is not enough to have knowledge of different cultural beliefs and practices,” says **Rosalind Ekman Ladd**, PhD, a visiting scholar in philosophy at Brown University in Providence, RI. “One must be able to assess one’s own unconscious biases, cultivate a sensitive attitude, and develop a communication style that elicits trust.”

**• In many cases, there is a wide gap between the ethnic and socioeconomic status of physicians and patients.**

“The experience of medical students with people unlike themselves is limited,” says Ladd. “Thus, without some deliberate effort and education, they do not know how patients of diverse backgrounds approach medical decisions.”

**• Hospitals fail to make culturally competent care a higher priority.**

Hofmann criticizes hospitals for failing to recruit and appoint staff members as culturally diverse as the communities they serve. “Unless and until these problems are addressed, significant progress will not be made,” he says. Time constraints and inadequate resources are common barriers or obstacles, but they are also “convenient rationalizations for the failure to make improvements,” Hofmann says.

## Bioethicists can teach and support

Hofmann says bioethicists “can and should perform a pivotal role by using actual cases to teach and to support providers in giving more culturally competent care.”

Cultural context should be brought up in the discussion of every case, urges Ladd, whether

hypothetical ones or actual cases referred to the ethics committee.

Providers must adhere both to accepted ethical practices in Western medicine, and the equally important moral mandate to honor and respect a patient in the context of his or her specific cultural beliefs and practices, says Peterson-Iyer.

“It is a mistake for a provider unquestioningly to assume that U.S. practices of delivering information or discussing sensitive topics are always the ‘right’ way to do so,” she underscores.

Simple awareness on the part of a provider that an individual patient may not share these Western assumptions goes a long way toward attaining a higher level of cultural competency, adds Peterson-Iyer.

“As the United States increasingly becomes a diverse land, our health care system will need to come to grips with, and fund, these needs, if it is to avoid a dangerous — not to mention unethical — level of health stratification,” says Peterson-Iyer. ■

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## EXECUTIVE SUMMARY

Providers may fail to give culturally competent care due to time constraints, inadequate resources, and lack of education. Some solutions:

- Hospitals can recruit and appoint staff members as culturally diverse as the communities they serve.
- Providers can communicate with patients with cultural context in mind.
- Bioethicists can bring up cultural context when discussing actual or hypothetical cases.

# Nurses have much to offer with end-of-life care — but are often left out of discussions

Nurses are often the health care providers who know the most about a patient's wishes for end-of-life care, but are sometimes left out of such discussions.

"Often, the medical focus is on cure. Many nurses and physicians have difficulties being truthful with patients facing end of life," says **Sharon Valente**, PhD, APRN, BC, FAAN. Valente is associate chief nurse for research and education at the Greater Los Angeles Veterans Affairs Healthcare System

In one such case, nurses were upset because a physician wasn't informing a woman's family that she was near death. "The physician was too close to the patient to, in his words, 'abandon hope,' and give the bad news. But he was willing to have me do that," says Valente. She informed the family that time was short, and encouraged the husband to bring the family and rabbi to see his wife very quickly.

"That afternoon, the patient's IV pain management was increased and she was in a coma," says Valente. "However, the family did gather to say goodbye before it was too late."

## Move toward team-based care

Some physicians are unwilling to delegate any aspect of end-of-life care discussions to nurses. "But that fear may be displaced," says **Daniel P. Sulmasy**, MD, PhD, Kilbride-Clinton Professor of Medicine & Ethics at the University of Chicago's MacLean Center for Clinical Medical Ethics.

Research suggests that nurses are, in fact, more comfortable about their ability to discuss do-not-resuscitate

orders with patients and surrogates than the in-house medical officers to whom attending physicians often delegate this task.<sup>1</sup>

"Nurses are often wonderful resources in these discussions," says Sulmasy, the study's lead author. "Physicians who don't make use of the nurse's professional expertise in this setting might be missing an opportunity to provide the best possible care."

Nurses sometimes have knowledge physicians lack about family dynamics or a patient's wishes before he or she lost decision-making capacity.

"In an era in which we are moving toward more team-based care, there is something problematic when this kind of conversation isn't part and parcel of the care given by the team," says Sulmasy. Here are common scenarios:

- **Nurses may feel as though they aren't getting the full story about a patient's prognosis.**

"I have heard, for instance, of nurses being fearful to talk about the discontinuation of left ventricular assistive devices, in a unit run by a thoracic surgeon who continues to paint a rosy picture," says Sulmasy.

- **Nurses may experience moral distress due to what they perceive as unethical end-of-life care.**

"When they feel that, they need an avenue to reach out," says Sulmasy.

Nurses may feel they are

contradicting their own professional ethics by treating aggressively when they know the patient wants palliative care, for example. In one such instance, a competent patient who was dying wanted to forgo food and fluids.

"The nursing home agreed to this plan, but acted differently," says Valente. "The nurses brought food and fluids in frequently and the provider ordered [megestrol acetate] to encourage appetite."

Management did not meet with the nurses to discuss the patient's wishes. "Autonomy is a major issue," says Valente. "The nurse often knows the patient's wishes for dignified death, but may not be able to advocate for this with the providers."

- **Nurses may administer a high dose of pain medication without realizing that the physician intended to hasten death.**

"The nurse may feel guilty afterward that he or she gave a medication that hastened death, but was not informed whether this was the patient's wish or the physician's intention," Valente explains.

If patients want to talk about hastening death, nurses may feel unskilled or uncomfortable with this discussion. "Many nurses have no available consultation or counseling to help them sort out these dilemmas," says Valente.

## EXECUTIVE SUMMARY

Nurses are often excluded from discussions involving a patient's end-of-life care, to the patient's detriment. Bioethicists can:

- Encourage nurses to initiate ethics consults if necessary.
- Ask nurses for input during rounding.
- Post signs reminding physicians to include nurses.

## Facilitate nursing involvement

Lack of nursing involvement is one of the main barriers to oncology patients arriving at an understanding of their diagnosis and making the transition from aggressive life-sustaining therapy to end-of-life therapy, says **Paul Helft**, MD, director of the Indiana University Health's Fairbanks Center for Medical Ethics in Indianapolis.

"Clearly, nurses have a lot to offer," says Helft. "They are highly committed to advocating on behalf of patients, and are generally good at 'translating' the things that doctors say." Here are some approaches to encourage nursing involvement in end-of-life care:

- **Post signs reminding providers to ask a nurse to come into the patient's room during discussions of end-of-life care.**

"There have been efforts to try to do this better," says Helft. Indiana University Health's "Call a Nurse" program posts signs on exam room doors reminding medical staff on the oncology inpatient unit to pull a bedside nurse into the room if there

is going to be a significant discussion about any aspect of care. While some physicians already did so routinely, the practice has become more widespread and consistent. "Everybody has seen the benefits, and it's become a priority," says Helft.

Nurses provide "an extra set of eyes and ears" to help patients absorb information, says Helft. Patients sometimes need prompting to ask questions they've forgotten, such as side effects of treatment.

"I've seen skilled and experienced nurses head off conflict, when medical teams are not communicating effectively with a patient or their family," says Helft.

- **Ask nurses directly for their opinion.**

When rounding on the intensive care unit, bioethicists can routinely ask nurses, "What do you think?" suggests Sulmasy.

- **Empower nurses to call consults.**

At Indiana University Health, about half of ethics consults are initiated by bedside nurses; in some cases, this is due to a conflict between nursing staff and the attending physician.

"Nurses need to be aware that they

can initiate an ethics consult if they see something that is troubling," says Sulmasy. "This needs to be made known by the ethics committee." ■

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# Patients' right not to know genetic screening results presents ethical challenges

*Ethics are "still evolving"*

**P**roviders and researchers are increasingly faced with a difficult decision: Should they inform patients of genetic screening results, when patients did not specifically request such results?

"What is 'ethical' in genomic research is still evolving," says **Reed E. Pyeritz**, MD, PhD, director of the Center for the Integration of Genetic Healthcare Technologies and professor of medicine and genetics

at the University of Pennsylvania in Philadelphia.

Patients can be asked prior to any testing what information they would like to know. "However, their expression of preferences in the abstract or hypothetical context may not be what they really want when the information is available," says **Lisa S. Parker**, PhD, associate professor of human genetics and director of graduate education at

the University of Pittsburgh's Center for Bioethics and Health Law.

The principle of informed consent still applies, says **Wylie Burke**, MD, PhD, professor and chair of the Department of Bioethics and Humanities at University of Washington in Seattle, but "genomics raises some complexities." She recommends these practices:

- Patients who undergo this testing

should be informed ahead of time about how extensively the genome will be analyzed and what types of results they can therefore anticipate.

- Patients should have the opportunity to consent to genomic analysis, and to provide separate consent to the analysis that addresses their clinical question and to any additional screening.

- If patients do not consent to screening, analysis that is unrelated to their clinical question should not be done.

Burke says this same principle applies to research participants. The analysis planned in the study should be specified in the informed consent process, so that an individual can decide whether or not to participate. “In research, there is the additional question of what research findings will be returned to the participant,” notes Burke.

Researchers do not have a legal obligation to return research results to individual participants, and the degree to which they should do so is debated. “There is a growing consensus in the bioethics community that researchers should return results that are clinically significant and relevant for the participant’s health care,” says Burke.

## Patients can opt out

In 2013, the American College of Medical Genetics (ACMG) recommended that laboratories conducting whole genome or whole exome sequencing on a patient assess the presence or absence of 56 genes associated with 24 diseases, and return the results whether the patient wants the information or not.

“After criticism from many bioethicists, the ACMG revised its recommendations to allow patients to be given the possibility of ‘opting out,’” says **Robert Klitzman**, MD,

professor of psychiatry and director of the Bioethics Masters, online course, and certificate programs at Columbia University in New York City. Klitzman is author of *Am I My Genes? Confronting Fate and Family Secrets in the Age of Genetic Testing* (Oxford University Press).

However, physicians and researchers “may not all be as aware as they should be of these issues,” Klitzman adds. “What they will do is thus unknown.”

Additionally, some institutional review boards may require incidental findings associated with immediately treatable or preventable conditions be reported regardless of the patient’s wishes.

“Informing patients about particular tests that might be run, and allowing them to decide if they want these tests performed, will involve many complexities concerning risks and benefits and uncertainty,” says Klitzman.

When physicians and researchers explain the possibility of “opting-out” to patients, he says, genetic counseling can help patients think through these decisions. “Yet such consent processes require resources that providers and researchers may feel they lack,” Klitzman adds. “This poses challenges.”

## Incidental findings

Incidental findings — information of potential health or reproductive significance that is beyond the aims of a research study or not directly relevant to a health condition for which clinical testing was undertaken — may arise whenever a gene panel test or exome or genome sequencing is performed.

Even single gene tests can reveal results suggesting unexpected family relationships, such as misattributed parentage. “Depending on the clinic’s policy, these findings may be returned along with the results being sought,” says Parker. Parker says the most ethical approach is to ask patients what information they would want to receive if it was discovered in the course of looking for something else. “The right not to know is grounded in rights of self-determination and privacy,” she underscores.

Researchers and providers sometimes want to pass along information to avoid being inappropriately blamed for withholding something that only in retrospect can be reasonably deemed valuable, to avoid being sued, or to avoid the discomfort of possessing information about someone that the person himself doesn’t know.

## EXECUTIVE SUMMARY

Providers and researchers face ethical challenges involving whether to inform patients of genetic screening results if the patient didn’t specifically request these. The American College of Medical Genetics now recommends giving patients the option of declining such information.

- Some institutional review boards require incidental findings associated with immediately treatable or preventable conditions be reported regardless of the patient’s wishes.
- Researchers and providers may fear being blamed for withholding information.
- Clinicians and researchers should disclose their plan for managing incidental findings to patients or research subjects.

“Sometimes these professionals discover information about a potentially serious health risk about which a person could take action to mitigate that risk,” says Parker. “It is very uncomfortable not to help prevent a harm to an identifiable person.”

The threshold of seriousness of the condition and the probability that the condition will manifest should be high, says Parker, in order to justify seeking out a person to impart unexpected, unsought information.

“Clinicians and researchers should practice preventive ethics, and plan how they will manage incidental findings,” advises Parker. She recommends these practices:

- **Clinicians and researchers should disclose their plan for management of incidental findings to potential research subjects or patients seeking genetic testing, and seek their consent.**

The plan may include options regarding what type of information they would want to have offered to them. “The plan should be focused on offering to return such findings if they are discovered in the future, rather than insisting that they be returned,” says Parker.

- **If incidental findings are going to be recorded in the patient’s medical record, then patients should be informed that they will not have a choice about whether and what to receive.**

- **Findings of research should be returned only if they are generated in, or confirmed in, a lab that is certified under provisions of the Clinical Laboratories Improvement Amendments.**

- **Only valid results should be offered for return.**

“It is generally accepted that incidental findings that are the strongest candidates to be offered for return are those concerning a substantial risk for a serious health-related condition for which some preventive action is possible,” says Parker.

ACMG’s list contains only highly predictive, medically actionable tests, notes Klitzman. However, other tests could be conducted — such as that for Huntington’s disease, which is highly predictive, but for which there is no treatment; or Alzheimer’s disease, for which tests are less predictive, though also not clinically actionable.

“Dilemmas thus arise of what results should be offered — of where to draw the line between what genes are sufficiently predictive and actionable versus not,” says Klitzman.

Increasingly, the lines between research and clinical service in genetic and genomic testing are blurring, says Pyeritz.

Researchers may lack the expertise, funding, or clinical staff to follow up with research subjects when potentially clinically relevant findings emerge. “The informed consent document should clearly state what will and will not be

reported, and if a potentially actionable genetic variation is identified, what the research subject’s options are,” says Pyeritz.

Many health care practitioners are not well-versed in genetics. “This has been shown in many surveys,” says Pyeritz. “When any health care practitioner orders a genetic test without the ability to perform adequate pre- and post-test counseling, then the patient is under-served.” ■

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# Incorporate ethics in all stages of neuroscience research: Avoid damaging ethical lapses

*Recommended approach is “proactive instead of reactive”*

Institutions that fund or conduct neuroscience research should incorporate ethical considerations into all stages of the process, according to the

Presidential Commission for the Study of Bioethical Issues’ April 2014 report, Gray Matters, Integrative Approaches for Neuroscience, Ethics, and Society.

“It recommends identifying ethical issues as studies are designed, all the way through to the end stages of research, including publication and dissemination

of results,” says **Nada Gligorov**, PhD, assistant professor of medical education at Icahn School of Medicine at Mount Sinai in New York, NY.

Institutions must fund the integration of ethics into neuroscience research, she argues. “These important and reasonable recommendations imply that ethicists will participate in research design, and will make efforts to identify research ethics issues before they arise,” says Gligorov.

This can be done by hiring individuals with expertise in ethics for particular research projects, and by supporting research ethics consultation services. These could be utilized by anyone doing research at a particular academic center.

“Incorporating ethics early on in a budding researcher’s education promotes the idea that ethics is an integral part of science,” Gligorov adds.

## Bioethicists have role to play

With appropriate sub-specialty expertise, bioethicists “can be useful throughout the process,” says **Paul J. Ford**, PhD, director of the NeuroEthics Program and director of education in the Cleveland Clinic’s Department of Bioethics.

“The educated bioethicist can help provide guidance concerning ethical implications of early research,” says Ford. Similarly, clinical ethicists can provide input into the implementation of clinical research protocols. Researchers in ethics, such as Ethical, Legal, and Social Implications (ELSI) researchers, can provide helpful insights into choices that guide larger policy issues.

“Conceptualizing ethical issues as intrinsic to scientific research and inquiry, as recommended in the report, is beneficial for a number of reasons,” says Gligorov.

This could help prevent ethical problems from arising in the first place. “It might also change how research ethics is conceived — moving it away from oversight and punishment to foresight and prevention,” says Gligorov.

## Lapses negatively impact research

Lack of trust in researchers and research institutions is one of the factors contributing to the underrepresentation of minority groups in research, notes Gligorov. “History teaches us that each additional research ethics scandal undermines scientific progress,” she says.

Gligorov says one issue to consider is whether research in neuroscience is different in ethically relevant ways from other areas of research.

The commission acknowledges that the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) initiative raises ethical issues, including consciousness, personal identity, and privacy. “But it is yet to be established that any of those are concerns raised in a unique way by research in neuroscience,” says Gligorov.

Ford recommends that institutions use these approaches to address the unique ethical considerations involving neuroscience research:

- **Ensure that ethics play a prominent role when setting research agendas.**

“From the earliest stages, we need explicit value choices about the benefits and risks that are downstream from the research,” Ford says.

- **Explicitly require a section on grant applications outlining reasonably expected ethical implications of the science.**

“Earmarking money for ethics components, as was done in the area of genetics, would assure work is being done on these issues that is

proactive rather than reactive,” says Ford.

- **Incorporate stakeholders in discussions about research goals in the early stages of clinical neuroscience research.**

- **Consider the tendency for media coverage to promote unrealistic expectations.**

Currently, there is a tendency to highlight the abnormally good individual outcomes rather than attempting to show the average outcomes, argues Ford. “While celebrating the amazing advancements in the neurosciences, we should continue to acknowledge the limitations of the science,” he says.

- **Find ways to improve ethical analysis to determine when animal models are not similar enough to human disease.**

“In designing trials, there are a number of ethical choices about the level of knowledge that is acceptable — in particular, whether the double blind placebo-controlled trial really is a necessity for how sure we need to be,” Ford adds.

- **Address the mortality risk posed by research involving serious diseases, such as major depression.**

“Although we need to protect subjects from unnecessary harm, we also need to recognize whether the harm of the research is more or less than the risk they are at from the disease,” says Ford.

There will always be competing interests between individual goals and societal interests, acknowledges Ford. Individual researchers may hesitate to put aspects of their field under scrutiny, for fear of losing support.

“We need to be careful that ethical considerations do not stop us from moving forward with helpful research,” says Ford. “We do not want to create bureaucratic steps that unreasonably slow down progress.” ■

## SOURCES

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# VA scandal may do harm to patient-physician relationships

*Trust is potentially eroded*

The Veterans Affairs (VA) Hospitals scandal, which involved unduly long delays in getting doctors' appointments that jeopardized veterans' health, "inevitably erodes trust by patients in individual providers as well as our system of health care," says **Charity Scott**, JD, MSCM, Catherine C. Henson Professor of Law at Georgia State University College of Law in Atlanta, GA.

The same is true of other recent news stories on fraud and abuse committed by physicians and exorbitant pricing at hospitals, she argues.

"Media coverage is replete with stories in recent years of other breaches of trust — unconscionably high numbers of medical errors causing harm and death to patients, financial conflicts of interest in research as well as in the provision of health care services — the list goes on and on," Scott says.

## Not about rationing

The VA is often seen as among the best of the many separate U.S. health care systems — small market private insurance, large market private insurance, Medicare, Medicaid, and others — according to **I. Glenn Cohen**, JD, director of Harvard Law School's The Petrie-Flom Center for Health Law Policy, Biotechnology & Bioethics in Cambridge, MA

"These revelations were unfortunate, then. But this is not about the problems

with government-provided health care per se," says Cohen, noting that such problems are not endemic to other government-run health care systems such as Canada's.

"This is not about rationing or death panels," says Cohen. "All attempts to connect this scandal to those claims are more political than real, I think."

Pay-for-performance systems have many benefits, says Cohen, "but they require careful auditing or monitoring to reduce bad behavior such as that seen here. Secondly, transparency is key to maintaining the trust of the public and patients, and that was sorely lacking here."

It is important to draw distinctions between access versus quality, asserts Cohen. "No one disputes that the quality of care from the VA, especially the quality per dollar spent on the system, is excellent," he says. "The real problem here was with access."

There is significant ethical literature questioning the moral fairness of waiting lists and "first come, first served," notes Cohen. "These tend to favor richer and more sophisticated users over poorer ones."<sup>1,2,3</sup>

## Putting self-interest over patients' interests

As an ethical and legal proposition, physicians stand in a fiduciary relationship with their patients, which

is fundamentally one of trust and confidence, underscores Scott. "A fiduciary relationship applies to physicians because they — and other professionals like lawyers — are, by virtue of their superior knowledge and skills, potentially able to take unfair advantage of a layperson seeking their services," she says.

Law and ethics temper this power imbalance by imposing both a duty of care and a duty of loyalty on physicians. This requires the physician to put a patient's interests ahead of his or her own interests.

"Trust is thus breached by putting one's own self-interest above the other person's interest, when the parties stand in a fiduciary relationship to each other," says Scott. "Examples of this abound."

Conflicts of interest are one way in which doctors can put their own self-interests above their patients' welfare. The practice of defensive medicine is another, if doctors are ordering tests and procedures that serve no purpose other than to try to prevent litigation against the doctor.

"Physicians today are feeling inordinate pressures on their time and their finances — from fear of lawsuits to administrative and payment headaches to technology glitches to overwhelming workloads," says Scott. These and other stresses strain their abilities to do the right thing by patients.

The physician who blew the whistle on the VA scandal said "it was

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unethical to put us in that position” of being understaffed and with too little infrastructure support to adequately care for veterans.<sup>4</sup>

“Most doctors deserve and want to earn the trust of patients,” says Scott. “Yet they find themselves in systems of care that impair their ability to foster such trust.” ■

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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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## CME QUESTIONS

- 1. Which is true regarding culturally competent care, according to Paul Hofmann, DrPH, FACHE?**
  - A. Providers should not share diagnostic information and treatment options with a family member instead of the patient, even if the patient is competent and requests this.
  - B. Providers' ethical obligations are met as long as there is competent language translation.
  - C. Bioethicists should use actual cases to teach and to support providers in giving more culturally competent care.
  - D. Bioethicists should not routinely bring up cultural context in the discussion of cases.
- 2. Which is true regarding nursing involvement in discussions involving a patient's end-of-life care, according to Paul Helft, MD?**
  - A. Hospital policies should specify that only physicians can initiate ethics consults.
  - B. It is unethical for physicians to delegate any aspect of end-of life care discussions to nurses.
  - C. Physicians should assume that nurses are not comfortable discussing end-of-life care with patients.
  - D. It is beneficial to post signs reminding medical staff to pull a bedside nurse into the room when discussing end-of-life care.
- 3. Which is recommended regarding ethics and neuroscience research, according to Nada Gligorov, PhD?**
  - A. Institutions should hire individuals with expertise in ethics for particular research projects.
  - B. Grant applicants should not be required to specify expected ethical implications.
  - C. Since ethicists have no expertise on implementation of clinical research protocols, their input need not be sought.