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July 2014: Vol. 30, No. 7  
Pages 73-84

## IN THIS ISSUE

Update on national standard for  
credentialing ethics consults  
..... cover

New recommendations on  
palliative care for stroke patients  
..... 75

Time constraints on physicians  
could decrease patients' trust  
..... 76

Ethics of patients accessing  
electronic medical records ..... 78

New recommendations on ethics  
of neuroscience research..... 79

Why documentation of advance  
care directive isn't enough ..... 81

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## Is individual qualified to perform clinical ethics consults? National standard is coming

*“Monumental step forward” for bioethics*

An American Society for Bioethics and Humanities (ASBH) task force is currently developing a two-step quality attestation process that will result in a national standard to assess clinical ethics consultants. This will identify individuals who are qualified to perform this important role.<sup>1</sup>

“We are still early on, and the process will take years to evolve. But the key thing is to keep things moving forward so as not to lose momentum and interest,” reports **Joseph Fins**, MD, MACP, immediate past president of ASBH. Clinical ethics consultations should not be taking place without any oversight or standards, he underscores. “People should be competent and capable of doing what they do, and we should have a process for regulating that,” says Fins, the E. William Davis, Jr., MD, professor of medical ethics, professor of medicine, and chief of the Division of Medical Ethics at Weill Cornell Medical College in New York City. Fins is also director of medical ethics and attending physician at New York Presbyterian Hospital/Weill Cornell Medical Center.

The current process is a pilot designed to determine what eligibility and the final process will look like, says **Felicia Cohn**, PhD, president of ASBH and bioethics director for Kaiser Permanente Orange County (CA).

### EXECUTIVE SUMMARY

An American Society for Bioethics and Humanities (ASBH) task force is developing a two-step quality attestation process. This will result in a national standard to assess clinical ethics consultants.

- Credentialing of ethics consultants varies widely at hospitals currently.
- Individuals would first submit a portfolio including educational background and case discussions.
- Items would be evaluated to determine an individual's eligibility to take an oral examination.

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“The task force has developed a blueprint. This is likely to evolve as we learn more throughout the pilot,” she says. “We have started with a focus on a two-step process, including a portfolio and an oral examination, but our assessment may suggest different or better mechanisms.”

With funding from the Macy and Greenwall Foundation, the task force, led by Fins and **Eric Kodish, MD**, professor and chairman of the Cleveland Clinic Foundation’s Department of Bioethics, has outlined the process and is developing metrics to evaluate and score items submitted by individuals. The applicant’s educational back-

ground, case writeups, letters of recommendation, and a philosophy of consultation will determine whether an individual is eligible to take an oral examination.

“In the absence of accredited programs and a training pathway that would be uniform for everybody, we have to go through the process of determining the eligibility criteria,” explains Fins. While individuals who attend medical schools and residency programs are able to take board certification examinations to establish their competency, no such process currently exists for those who perform clinical ethics consultations.

The process is slow and deliberate, says Fins, and “is really a proxy for board eligibility that one would normally have by going through an accredited program. But since we don’t have accreditation for programs yet, that additional task has to be determined on an individual basis.”

Approaches to credentialing of ethics consultants vary widely at hospitals, and many lack established ethics programs. “The vast majority of people practicing clinical ethics are not regulated, so we don’t really know the quality of the job,” says Fins. “It’s especially hard when there is only one person doing it.”

## Inconsistent outcomes

If a patient has the same circumstance, makes the same request, and is located in the same state with the same laws as another patient, he or she might still get a different outcome from an ethics consultation.

“That variation should be troubling. People who are similarly situated should be treated the same,” says Fins. “There should be standards that are upheld.”

If a patient is going to have a ventilator withdrawn, for instance, it should be handled the same way at all hospitals within the same legal jurisdiction, argues Fins.

“The idiosyncrasies of the practitioners or the consultant or the hospital shouldn’t determine what happens,” says Fins. “Rather, there should be a standard approach to these problems.” The approach should be based on the ASBH core competencies, he adds, which reflect a national consensus on clinical ethics practice.

“ASBH is the professional home for many individuals who engage in clinical ethics, many of whom have been working toward developing consensus regarding the need for this process for a long time,” says Cohn.

In addition to the goal of assuring competence of clinical ethicists, says Cohn, other goals are enhancing the professionalism of the field and improving patient care.

“Developing a reliable, credible, and professional process for a multidisciplinary field will take time,” adds Cohn. “We wish to balance the need to get this done with the need to get this done well.”

Medical Ethics Advisor® (ISSN 0886-0653) is published monthly by AHC Media, LLC, One Atlanta Plaza, 950 East Paces Ferry Road NE, Suite 2850, Atlanta, GA 30326. Telephone: (404) 262-7436. Periodicals Postage Paid at Atlanta, GA 30304 and at additional mailing offices.

**POSTMASTER:** Send address changes to Medical Ethics Advisor®, P.O. Box 550669, Atlanta, GA 30355.

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### EDITORIAL QUESTIONS

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## Bioethicists' possible expanded role

One concern in the bioethics community is that the examination won't adequately consider the day-to-day experiences of those working in the field, such as the ability to run meetings with the patient's family and come to a consensus with providers. A written exam might not capture the ability of an individual to talk to a family refusing a treatment based on a religious objection, for instance.

"It's like taking a written exam for surgery but never having operated," says Fins. "We are aware of that, and we are working to capture a wider range of experience in the instrument."

Fins says that in his opinion, a national standard for credentialing of individuals who perform ethics consults will help legitimize the specialty. "We're at a stage where we have reached a consensus for the first time in our history — perhaps a fragile consensus, but a consensus nonetheless — that this is something we should do, and we have outlined a blueprint for this," says Fins. "That's a monumental step forward."

Fins believes that ultimately, the national standard could facilitate the ability of ethicists to meet broader societal needs. "We've got monumental changes in health care. There are disruptions in patients' experience," he says, such as family doctors no longer managing hospitalized patients. "Having ethicists in hospitals as stewards of fairness and equity and access, is something that is a new role."

Fins would like to see The Joint Commission require credentialing of individuals who perform ethics consults in hospitals. "An accreditation standard would convert this specialty into actual consultative work, versus what is still, in many places, a volunteer experience," he explains.

Ethicists can then be more involved in guiding the restructuring of the health care system, says Fins, "because they'll have a front row seat — and a sanctioned front row seat." ■

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# New recommendations for palliative and end-of-life stroke care

*"Profound implications for patients"*

The palliative care needs of patients with serious or life-threatening stroke and their families are "enormous," according to a 2014 statement from the American Heart Association/American Stroke Association on palliative and end-of-life care in stroke.<sup>1</sup>

The statement is "a recognition that there is a lot of palliative care need, but not a lot of explicit guidance from the broader field," says **Robert G. Holloway, Jr., MD, MPH**, the statement's lead author. Holloway is professor and chair of University of Rochester (NY)'s Department of Neurology.

The statement gives physicians, nurses, and social workers who care for stroke patients "a road map" on how to incorporate good palliative care into their practice, he says.

"The statement is incredibly comprehensive, relevant, and timely. It should be viewed as a declaration and call to action more than a mere statement," says **John G. Carney, MEd**, president and CEO of the Center for Practical Bioethics in Kansas City, MO. He says "the implications are huge" for both acute and palliative care providers.

"By and large, the neurological community has good stroke teams in place, but these tend to focus on acute management," says Holloway. "This shines a light on areas of practice that we may not have paid as much attention to."

Here are some specific ethical considerations the statement addresses:

- **Methods to address uncertainties of prognosis in stroke patients.**

For example, providers may have to explain risk factors involving recovery of swallow after a stroke,

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## EXECUTIVE SUMMARY

A 2014 statement from the American Heart Association/American Stroke Association gives guidance to providers for how to incorporate good palliative care into their practice, including:

- Addressing uncertainties of prognosis in stroke patients;
- Resolving conflicts involving feeding and artificial nutrition; and
- Transitioning patients to palliative care and/or hospice referrals.

or risks and benefits of surgical options, such as a craniectomy.

• **How to build trust in a crisis situation when time is of the essence, and how to interact with surrogate decision makers.**

“This happens in other palliative care situations as well. But the stroke population is one of the most ethically complex situations that confront families,” Holloway says. Providers may have to resolve conflicts with family members over whether artificial nutrition is the best approach in an elder stroke patient, for example.

• Approaches for the decision-making process involving discontinuing life-sustaining interventions and transitioning patients and families to palliative care and/or hospice referrals.

• Management of specific pain syndromes unique to stroke patients, as well as symptoms such as delirium, anxiety, and cognitive dysfunction that commonly occur after stroke.

“That is probably the most unique element in the statement. It is something that is not found in other palliative care guidelines,” Holloway says.

• **Interacting with organ procurement organizations.**

The guidelines can also help bioethicists who do clinical ethics consultations involving stroke patients, says Holloway. “Ethics consultants deal with these situations all the time, but this provides some details specific to the stroke population,” he explains. “This can help them when they talk through these issues, mostly with surrogates.”

## Palliative care “sorely lacking”

Stroke patients traditionally receive aggressive acute interventions, but many fail to receive palliative care. “The capacity of the vast majority of palliative care programs and hospices to respond to the needs of these patients is sorely lacking,” says Carney.

These skill sets are not readily available in community-based settings. “When you examine the outcomes for these patients, the ‘ought’ of embracing these recommendations is clearly evident,” says Carney.

There is a need to build the competencies of palliative care providers, he argues, to support stroke patients in non-acute settings. “We have to accept the significant investment that it will take to wed the clinical ethical concerns with common practice,” says Carney.

## Impact on patients

Carney says that the recommendations could have

“profound implications for the care of stroke patients,” and that disease burden, high mortality and morbidity, and significant symptomatology should make a palliative care consult automatic rather than optional.

“We should be able to achieve the outcomes expressed by the overwhelming majority of patients — to die at home, untethered, surrounded by family and loved ones,” he says.

Hospices are typically well-equipped to provide standard comfort measures for those living with anticipated trajectories of progressive of illness over a predictable period of time. “While they may be good at providing supportive care for those patients, they may be less proficient at providing intensive and aggressive palliative care interventions,” says Carney.

Carney points to the use of the terms “intractable” and “refractory” in the statement, which underscores the intensity of palliative care services for this patient population.

“These kinds of high-intensity services may be difficult for many hospices to provide due to limitations they have in resources — and, unfortunately, in skill sets as well,” he says, adding that there is a need for excellent hospice and palliative care in the acute care setting.

“Direct admission to hospice inpatient care for highly complex patients in the final stages of dying should not be discounted because it is hard to do,” says Carney. ■

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# Time constraints on physicians: Potential threat to patients’ trust

*Greater focus on the way physicians communicate*

U ntil there are changes that address the system-level problems in our increasingly stressed health care delivery system, “physicians will be caught, at the indi-

vidual level, in behaviors that can breed distrust,” says **Charity Scott**, JD, MSCM, Catherine C. Henson Professor of Law at Georgia State University College of Law in Atlanta, GA.

Trust is essential for the provision of high-quality, appropriate care, says Scott, as if patients don't trust their doctors, they won't seek treatment in the first place. “Even if they go into the doctor's office, mistrustful patients may withhold key information that could be critical to providing the right care under the circumstances,” she says.

Trust depends on honesty, transparency, and integrity, notes Scott. “I'm not sure that physicians need remedial classes on these virtues, so much as they need to be supported by systems of health care delivery that promote the opportunity to behave in these ways,” she says.

## Connecting with patients

Many medical schools have increased their focus on cultivating communication skills with colleagues and patients. “Connecting with patients on a personal level that effectively conveys care and concern for the patient's well-being is a skill that requires persistence and refinement over years of practice,” notes **Ben A. Rich**, JD, PhD, professor and School of Medicine Alumni Association Endowed Chair of Bioethics at University of California — Davis Health System.

There is much a greater emphasis on physicians' ability to communicate and understand patients' needs, says **Patrice M. Weiss**, MD, chair of the Carilion Clinic and professor at Virginia Tech Carilion School of Medicine, both in Roanoke, VA.

“Medical education is now problem-based and case-based, as opposed to the traditional memorization of drugs, bugs, and metabolic pathways,” she says. “Physicians and trainees are being educated in emotional intelligence, not just medical facts.”

A 2014 study reviewed 10 randomized, con-

trolled trials which assessed the effects of interventions intended to improve patients' trust in doctors. These included providing physicians with additional training, providing patients with education, and providing patients with additional information about doctors in terms of financial incentives or consulting style.<sup>1</sup>

The study found that overall, there is insufficient evidence to conclude that any intervention increases or decreases trust in doctors.

“The review was a little surprising. To date, there is no convincing evidence that much of what we do increases trust,” says **Brian McKinstry**, MD, one of the study's authors and director of the Health Services Research Unit, The University of Edinburgh.

“Doctor education, with personalized feedback in terms of improving empathic skills, may increase trust,” says McKinstry. “But there is little other evidence that short courses on communication make much difference.”

Rich says he is unaware of any persuasive evidence of a significant erosion in patient trust of physicians in recent years. “There was such evidence two decades ago, with the rise of managed care,” he adds.

At that time, patients' perception was that physicians' independent exercise of clinical judgment and discretion in the pursuit of their patients' best interests had been co-opted by managed care organizations, in pursuit of their goals of reducing costs and minimizing expensive therapies and specialty care.

“This widespread patient perception actually led to significant changes in the policies, procedures, and protocols by which managed care organizations operated,” says Rich. “The most draconian cost-limiting measures were either eliminated or significantly moderated.” Here are some current challenges to establishing effective patient-physician relationships:

- **Time constraints are increasingly being placed on clinic visits.**

This is occurring across all health care delivery settings except concierge practice, says Rich, and poses difficulties for developing and maintaining an effective patient-physician relationship.

“This is the greatest threat to patient trust in physicians at this time, in my view,” says Rich.

Physicians today are feeling inordinate pressures on their time and their finances, says Scott. These stem from fear of lawsuits, administrative and payment headaches, technology glitches, and overwhelming workloads.

“These and other stresses strain their abilities to do the right thing by patients,” she says.

- **The rise of hospital medicine created a new category of physician — the hospitalist — who is responsible for the general medical management of inpatients.**

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## EXECUTIVE SUMMARY

Time constraints placed on physicians is a potential threat to patients' trust, according to bioethicists. There is insufficient evidence to conclude that any intervention may increase or decrease trust in doctors, concludes a 2014 study.

- Medical schools have increased their focus on cultivating communication skills.
- Hospitalists may be perceived as pursuing the institution's, rather than the patient's, best interests.
- Certain racial and ethnic groups are distrustful of physicians generally.

“This dramatic change in inpatient care has rendered primary care physicians who manage their patients when hospitalized an artifact of history,” says Rich.

Understandably, hospitalist physicians find it challenging to engage with sick patients whom they encounter for the first time upon admission, says Rich, and whose responsibilities to the patient will in all likelihood come to an end upon discharge.

“For inpatients who require specialty care such as surgery, there is always the potential for mixed messages or even serious misunderstandings concerning the patient’s medical status,” says Rich. Since hospitalists are often hospital employees, they may be perceived by some patients as merely agents of the hospital pursuing the institution’s, rather than the patient’s, best interests, he adds.

• **Certain racial and ethnic groups are distrustful of physicians generally, based on previous difficulties encountered in seeking and receiving medical treatment.**<sup>2,3</sup>

This is particularly relevant when a patient’s condition warrants a shift from disease-directed to palliative measures, according to Rich.

“Those who have felt marginalized by the health care system may fear that the shift in the goals of care is not the product of an objective medical judgment but a determination that this particular patient just is not worth continuing high cost care,” he explains.

These groups may be extremely reluctant to discontinue life-sustaining interventions or to agree to changing the patient’s status from full code to do not resuscitate, says Rich. “Gaining their trust in such circumstances can pose a significant challenge,” he adds. ■

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# Ethics of giving patients access to EMRs

*Medical paternalism “no longer acceptable”*

A growing number of organizations are giving patients access to their electronic medical records (EMRs), and, in some cases, allowing patients to communicate with providers to correct inaccuracies.

“Advocates of increased patient access to their medical records argue that this will result in improved care and better communication,” says **Blair Henry**, BSc, MTS, an ethicist at Sunnybrook Health Sciences Centre in Toronto, Ontario, Canada.

Traditionally, few patients viewed their medical records. “This is not surprising, given that patients are not routinely advised of their right to look over their medical records, and that a request to view their chart necessitates an appointment with a health care professional to help interpret what they are seeing,” says Henry. Other obstacles are the cost and long wait times typically involved in obtaining the records.

Growing emphasis on promoting transparency, however, is motivating an increasing number of hospitals to give patients access to their EMR, says **Paul B. Hofmann**, DrPH, FACHE, president of Hofmann Healthcare Group, a Moraga, CA-based consulting firm specializing in health care ethics.

“Legally and ethically, the issue of what to do about personal health information is well established,” says Henry. “The patient owns the data, and the custodian of the chart — the physician or hospital — owns the system it’s held in.”

One concern is that evidence of inaccuracies could decrease the patient’s trust in their medical team. “Anyone dealing with medical charts knows that errors in transcription of information into charts is an all-too-common phenomenon,” says Henry.

From the perspective of those entering patient information in the medical record, Hofmann says there are both practical and ethical implications. For example, he notes, nurses, physicians, and others must think more carefully about documenting observations regarding a patient’s attitude and behavior affecting his or her treatment and prognosis.

“However, not charting relevant information can obviously compromise continuity of care, and does not serve the patient’s best interests,” says Hofmann. “Striking the right balance will remain a significant challenge.”

Patient access to EMRs, coupled with the adoption of new technologies such as remote health data monitoring and patient-reported outcomes measurement systems, says Blair, “just might be the leading edge of a digital revolution that can change fundamentally what it means to be a doctor.”

### Is it in patients’ best interest?

In a 2012 study in which 105 doctors shared their notes with more than 19,000 patients in Boston, rural Pennsylvania, and Seattle, virtually all participants supported the idea of seeing their medical notes. None of the participating physicians chose to stop sharing visit notes with their patients once the study ended.<sup>1</sup>

“My feeling is whatever the physician writes in his or her notes should be shared with the patient,” says **Neil J. Farber**, MD, FACP, professor of clinical medicine at the University of California, San Diego in La Jolla, CA. “As a shared decision-making model becomes more widespread, why shouldn’t the patient share in the knowledge that the physician has?”

In the past, one of the main reasons for not giving patients access to their medical records was that it was believed that it could harm them, says **Rosalind Ekman Ladd**, PhD, a visiting scholar in philosophy at Brown University in Providence, RI.

Providers believed patients wouldn’t understand the information, could misinterpret it, and could become confused, anxious, or even suicidal. “Medical knowledge, it was said, is special knowledge which can be understood only with the special training that doctors have,” says Ladd. “Physicians practiced a kind of paternalism, meant to protect the patient.”

These long-held assumptions are now being challenged. “In many ways, patients are better educated now about medical matters,” she says. Medical advances also make learning about a diagnosis less devastating in some circumstances.

“Ethical standards have changed as well,” says Ladd. “Thus, medical paternalism, which includes

withholding information from patients, however well-motivated, is no longer acceptable.”

If physicians fulfill their responsibilities by giving patients truthful information directly, says Ladd, then patients should not find anxiety-producing surprises when they review their EMR.

“In the ideal, this should lead to a more open, honest, trusting relationship, and no suspicion that the doctor is hiding something,” says Ladd. ■

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## New recommendations on ethics of neuroscience research

*Bioethicists should be “prepared to participate”*

The Presidential Commission for the Study of Bioethical Issues’ April 2014 report, *Gray Matters, Integrative Approaches for Neuroscience, Ethics, and Society*, includes recommendations for institutions and individuals engaged in neuroscience research.

“Bioethicists should be prepared to participate in the integration of ethics and neuroscience,” urges **Lisa M. Lee**, PhD, MS, the Bioethics Commission’s executive director.

Progress in contemporary neuroscience offers promise for discovering improved interventions, and perhaps cures, for neurological disorders that affect more than one billion people globally and millions of people in the United States, underscores Lee.

“A single ethical lapse in scientific research can cause a loss of public confidence, which can obstruct the progress of other research,” she adds.

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### EXECUTIVE SUMMARY

Patients are increasingly accessing their electronic health care records, and in some cases correcting inaccuracies in the chart.

- Increased transparency is motivating hospitals to give patients access to their medical records.
- Advocates of increased patient access to medical records argue that this will result in improved care.
- One concern is that evidence of inaccuracies could decrease the patient’s trust in their medical team.

## Direct involvement from bioethicists

The report provides examples to illustrate important ethical issues relevant to neuroscience research. These are neuroimaging and brain privacy; dementia, personality, and changed preferences; cognitive enhancement and justice; and deep brain stimulation research.

“These examples highlight some of the ethical and societal issues that can arise in neuroscience research and the application of research findings,” says Lee.

The Bioethics Commission recommended that institutions and individuals engaged in neuroscience research should:

- integrate ethics across the life of a research endeavor;
- identify the key ethical questions associated with their research;
- take immediate steps to make explicit their systems for addressing those questions;
- include substantive participation by persons with expertise in ethics on advisory and review panels.

“Many of these approaches necessitate direct involvement from bioethicists and other professionals with experience in ethics,” says Lee.

“This volume is a short, high-level overview of the issues,” says **Henry T. Greely, JD**, director of the Stanford Center for Law and the Biosciences and chair of the steering committee at Stanford Center for Biomedical Ethics. “Its recommendations are good, and I hope they are followed. It really adds up to taking the ethical issues seriously.”

The report’s summary of the many ways in which ethics can be integrated into science may be quite useful, adds Greely. “Ethics are most important not for their effects on science, but on people,” he emphasizes. “Consideration of ethical issues is needed to help make sure that people are safe and well-treated.”

Anytime people think they have been harmed by scientific research or its results, or feel they have been

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## EXECUTIVE SUMMARY

An April 2014 report from the Presidential Commission for the Study of Bioethical Issues gives recommendations for institutions and individuals engaged in neuroscience research.

- The report provides examples to illustrate important ethical issues relevant to neuroscience research.
- Bioethicists should be prepared to participate in the integration of ethics and neuroscience.
- A single ethical lapse in scientific research can cause a loss of public confidence.

lied to, cheated, or betrayed by researchers, is bad for science, says Greely. “The consequences of the Public Health Service’s study of untreated syphilis among African-American men — the so-called Tuskegee study — still reverberate,” he says.

There is a clear need, says Greely, to address questions of the safety, efficacy, and long-term personal and societal consequences of neuroscience-based predictions and interventions.

“Right now, issues of the ethics of research are foremost — questions of consent, confidentiality, incidental findings, and so on,” says Greely. “But neuroscience is edging into clinical, consumer, educational, and even legal system use.”

## Prioritization of ethics

The report serves as an important symbolic gesture that ethics should be valued and prioritized, not only by those who conduct neuroscience research, but also by those who support the endeavor of neuroscience, says **Karen S. Rommelfanger, PhD**, neuroethics program director at Emory University in Atlanta.

“As noted in the report, often neuroscientists throughout their careers, as I have done at earlier points in my career as a neuroscientist, conflate ethics with compliance, and think of ethics narrowly as research ethics,” she says.

Rommelfanger notes that the study of neuroscience, unlike many other scientific disciplines, “strikes at the core of who we think we are. Therefore, the ethical questions often move beyond research and professional ethics into the complex terrain of evaluating societal implications of our work.”

These are the very questions that draw students and the public in to learn more about the brain. “This also means that neuroscientists have an enormous responsibility to be revisiting these questions in their own work as responsible stewards of their work,” says Rommelfanger.

Neuroscientists must be afforded the time and resources to consider these questions, she emphasizes.

“The challenge ahead will be addressing how to implement these recommendations,” says Rommelfanger, noting that the financial resources put forward for the BRAIN Initiative are still relatively modest, given the costs associated with conducting neuroscience research.

“Integrating ethics throughout the life of the research project will require a cultural change — starting with having resources that are clearly allocated to ethical inquiry,” says Rommelfanger. ■

## SOURCES

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# Ongoing discussion on end-of-life care is needed

*Patient wishes may change*

Documentation of a patient's end-of-life wishes is "a starting point. But what's more important is having ongoing conversations," according to **Susan Gaeta**, MD, a clinical ethicist, attending physician, and associate medical director in the Department of Critical Care at The University of Texas MD Anderson Cancer Center in Houston.

"Advance care planning has been an issue for a long time, and nationally, we have not been very successful in standardizing a process that works," she says.

Immediately after a young man is diagnosed with multiple sclerosis, for example, he may say that living in a wheelchair is unacceptable to him. "After five years, he may get used to the diagnosis and think that his quality of life is good, so he informs his loved ones and health care providers that if he is in a wheelchair it's OK," says Gaeta.

On the other hand, if a patient is to be readmitted to the intensive care unit (ICU), he or she may recall their prior admission as unpleasant due to delirium or an actual memory, and may not want to be transferred to the ICU.

"The problem is that documentation is static," says Gaeta. "The important thing is to start the conversation with the patient when it's not a crisis — not when the patient is in the hospital in respiratory distress."

If the providers feel that they do not have enough time in their busy day, or are not comfortable having the conversation, a bioethicist or social work counselor can support the providers in doing so, says Gaeta.

## Revisit discussion

Gaeta uses an Advance Care Planning Structure Documentation note to document her conversations with her patients. "What is so fabulous about this note is that it can be filled out by any care team member, including

nurses or midlevel providers," she says.

Providers can document the prognosis and explain the treatment plan. Social workers can document the patient's goals and values, and the chaplain can indicate whether spirituality and/or religion are important to the patient.

"After the first conversation with the patient, any number of 'trigger points' can be used to revisit the discussion," says Gaeta — such as outpatient clinic visit, a change in the patient's health status, an ICU admission, or an event such as marriage, divorce, or death in the family.

"In addition, the medical record states when the note was last updated," says Gaeta. If family members insist that a patient would have wanted to continue life-sustaining treatment, the team can use the note to support the patient's most recent wishes.

"That's not to say it's going to solve everything, but it's definitely a start," says Gaeta. "There will always be cases where someone will question whether the patient noted their wishes under duress."

Ideally, patients will have a conversation with the provider that is documented, with a medical power of attorney present, and share that same conversation with family members. "In some cases, discussions are even videotaped," says Gaeta. "This allows family members to hear the patient expressing their wishes in his or her own words."

Currently, the Centers for Medicare & Medicaid Services requires hospitals and other health care entities to ask about the availability of their advance directives upon admission to the hospital, in order for that institution to receive payment by Medicare or Medicaid. "But we need to go beyond advance directives, and focus on advance care planning," argues Gaeta.

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## EXECUTIVE SUMMARY

An ongoing conversation about patients' end-of-life wishes is needed because patient preferences aren't necessarily consistent. According to ethicists, ideally providers should start the conversation with the patient when the patient's condition is relatively stable and not in crisis.

- Bioethicists can support providers in starting the discussion with the patient.
- Videotaped discussions allow family members to hear the patient's own words.
- Patients may want more life-extending care at the end of life than they thought they would.

## Preferences aren't necessarily stable

There needs to be recognition of the fluidity of people's desires and preferences at the end of life, and concern not just about the patient's prior wishes "but about what is best for the patient in the here and now," says **Alison Karasz**, PhD, one of the study's authors and associate professor in the Department of Family and Social Medicine at Albert Einstein College of Medicine in Bronx, NY.

"In cases where there is conflict between the family and hospital staff about the patient's best interest, hospital staff often try to play the 'prior wishes' card as if to suggest that ending life is what the patient would have wanted," says Karasz.

Patient preferences are not necessarily stable, explains Karasz, and patients often want more life-extending care at the end of life than they thought they would.

In a 2007 study, researchers observed and recorded 24 decision-making meetings between hospital staff and family members of elderly patients identified as being in the last stages of illness, who were unable or unwilling to make the decision for themselves.<sup>3</sup>

"Our research found that when families sit down and try to make a decision, hospital ethicists often try to encourage them to focus on prior wishes, since prior wishes are almost always about refusing life-extending care," says Karasz, one of the study's authors.

Karasz says that there is little consistency between what patients think they would want in terms of end-of-life care, and what they actually do want when they get to the final days of life. "It is not my opinion, based on our study and on the available data, that patients' prior wishes are always the most reliable guide to ethical decision-making at the end of life," she says.

Consideration of a patient's best interests generally took priority over the patient's wishes, according to a 2010 study in which researchers observed and recorded 26 decision-making meetings between hospital staff and family members.<sup>2</sup>

"We found that hospital ethicists sometimes blatantly advised families that, 'If your parent didn't express a wish not to have life-extending care, that doesn't mean she didn't think it,'" says Karasz, the study's lead author.

Clinical ethicists often believe that stopping life-extending care is best for the patient, she says, and point to the patient's prior wishes to persuade family members. Karasz is not in favor of documenting prior wishes in patient charts if it means that life-extending care would be automatically denied because of the

presence of such documentation.

"I believe that the current state of affairs, confusing and messy as it is, leads to important debates among family members and hospital staff in a small number of conflictual, ambiguous situations that do arise," says Karasz. "Most of the time, things go more smoothly." ■

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## SOURCES

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## Lack of data on palliative care: Need to move into mainstream

*Little is known on quality of care for seriously ill*

Currently, quality of life and patient-centered care for people with serious illness is poorly measured, says **Diane E. Meier**, MD, FACP, director of the Center to Advance Palliative Care, a New York City-based organization devoted to increasing the number and quality of palliative care programs in the United States.

"The most prominent measure that attempts to get at these outcomes is the HCAHPS [Hospital Consumer Assessment of Healthcare Providers and Systems] patient experience survey," she says. This covers pain management, and quality of communication from staff.

However this measure misses seriously ill individuals who typically cannot fill out the survey, and those who have died. "Thus, for all of these patients, essential aspects of quality, like goal and preference-concordant care and pain and symptom management, are not measured at all," says Meier. "Also not measured are caregiver stress and duress."

Many more measures are developed that address care quality for relatively healthy people, Meier adds, than for the sickest patients. "These patients are often

too sick to advocate for themselves,” she says.

Meier says one necessary process measurement is whether a goal of care conversation took place with the patient and family, and the quality and documentation of that discussion.

“This process measure would move us a long way towards more patient-centered care,” says Meier, adding that “the holy grail of ethical outcome measurement” is the degree to which care actually provided helps the patient achieve the goals and the kind of life most important to them.

“This is difficult and costly to measure,” she says. “We are not close developing a reliable strategy to capture this information.”

## Many recent developments

The Affordable Care Act (ACA) requires measurements of patient experience. “However, there is no clear mandate that patient-centered domains of care, like psychosocial or spiritual care, be measured,” says Meier.

The ACA does require measurement of some aspects of quality that palliative care impacts substantially, including readmissions and efficiency.

“There is a growing body of research showing how palliative care can reduce readmissions and non-beneficial services,” says Meier. “For those entities that must report on these measures, an effective quality improvement initiative should include palliative care.”

The ACA’s Medicare Shared Savings Program encourages Accountable Care Organizations (ACOs) to provide care more efficiently. “In order for an ACO to improve efficiency of care while improving quality, it will have to manage its most at-risk population,” says Meier.

## Need to be fully integrated

There is a need for palliative care to be fully integrated with a holistic approach to patient care, underscores **Daniel B. Hinshaw**, MD, professor of surgery

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## EXECUTIVE SUMMARY

There is a need for palliative care to be fully integrated with a holistic approach to patient care, including quality measures, according to bioethicists.

- Most current measures address care quality for relatively healthy people.
- Patient experience surveys don’t include most seriously ill individuals.
- The VA measures the quality of end-of-life care with caregiver interviews after a patient’s death.

at the University of Michigan School of Medicine and founding director of the Palliative Care Consultation Service at the Veterans Administration Medical Center, both in Ann Arbor.

“The mistake that happens, unfortunately, with palliative care, is that now that it’s become a medical subspecialty, it’s been buttonholed in a particular spot,” he says. “It really needs to move into the mainstream.”

The quality of end-of-life care is challenging to measure for several reasons. “It’s much easier to get your mind around measures of physical distress,” Hinshaw says — such as the percentage of patients with pain identified on initial screening that received pain management within 24 hours.

“One area that quality improvement efforts need to address, is to try to measure the quality of spiritual care,” says Hinshaw. “The psychological, social and spiritual realms are of profound importance to patients, but are much more difficult to define.”

Providers are often more focused on treating the disease, he says, “and the person who has the disease is often lost in the shuffle.”

One of the ways in which the VA is measuring the quality of end-of-life care is through caregiver interviews after a patient’s death, done by phone and by mail. “The data is collected and collated in such a way that it can be given back to the institutions as feedback, to let them know how they are doing against the larger system,” says Hinshaw. The interviews cover how satisfied the family was with caregivers’ communication, and their perceptions of the quality of pain relief.

“There will always be a necessity for qualitative research methodologies—the careful interviews, focus groups and so forth—no matter how messy it is from the quantitative perspective,” says Hinshaw.

## SOURCES

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## COMING IN FUTURE MONTHS

- Bioethicists can help decrease readmissions
- New research on effectiveness of POLST forms
- Controversy over compensation for kidney donors
- Delayed consent for research participants

## CME QUESTIONS

- Which is true regarding the palliative care needs of stroke patients, according to **John G. Carney**, MEd?
  - There is a need for excellent hospice and palliative care in the acute care setting.
  - The neurological community should address acute management only, not palliative care needs.
  - Palliative care consultations should always be optional as opposed to automatic.
  - Direct admission to hospice inpatient care for highly complex patients in the final stages of dying should be discounted.
- Which is true regarding patients' trust in physicians, according to **Ben A. Rich**, JD, PhD?
  - There is no evidence indicating that certain racial and ethnic groups are distrustful of physicians generally.
  - Additional training provided to physicians has been shown to significantly increase patients' trust.
  - There is clear evidence that use of hospitalists is linked to increased trust.
  - Hospitalists may be perceived as pursuing the institution's, rather than the patient's, best interests.
- Which is true regarding patients' end of life wishes, according to **Susan Gaeta**, MD?
  - An ongoing conversation about patients' end-of-life wishes is needed because patient preferences aren't necessarily stable.
  - The ideal time to begin the conversation with the patient is at the point of an intensive care unit admission.
  - Patients virtually never want more life-extending care at the end of life than they thought they would.
  - Only physicians, not nurses or social workers, should be able to document the patient's wishes.
- Which is true regarding quality of palliative care, according to **Diane E. Meier**, MD, FACP?
  - Most current measures address care quality for seriously ill individuals, as opposed to relatively healthy people.
  - Patient experience surveys are an effective way to assess care of seriously ill individuals.
  - One necessary process measurement is whether a goals of care conversation took place with the patient and family.
  - The Affordable Care Act mandates the measurement of psychosocial and spiritual care.

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