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**AHC** Media

## Report: Stigma Against Mental, Substance Use Disorders Persists

*Even providers have negative reactions*

**A** multipronged, evidence-based national strategy is needed to address continuing stigma associated with mental health disorders and substance use disorders, according to a new report.<sup>1</sup>

“This is really a moral issue. There are implications for every possible group in society,” says **Bernice Pescosolido**, PhD, a member of the committee that produced the report. Pescosolido is director of the Indiana Consortium for Mental Health Services Research. (*The*

*report*, Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change, *can be downloaded at: <http://bit.ly/1qebu3R>.*)

This includes healthcare providers. “Providers are a dedicated group of people, but they grew up in the same society we did,” says Pescosolido. “Stigma goes across all levels of society.”

Providers may ask for a patient to be treated in the psychiatric unit instead of the ICU, even though their problem

### EXECUTIVE SUMMARY

A multipronged national strategy is needed to address stigma associated with mental health and substance use disorders, says a new report from the National Academies of Sciences, Engineering, and Medicine. The problem is even prevalent among psychiatric residents, according to a recent study. Ethical concerns include the following:

- Providers may give up hope for patients’ improvement or recovery.
- Providers may view addiction-related behaviors as dishonesty or even sociopathy.
- Some providers believe rehabilitation or hospitalization for a mentally ill substance-abusing patient is a waste of resources.

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**EDITORIAL QUESTIONS**

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is cardiac, says Pescosolido. In the  
ED setting, clinicians sometimes use  
“frequent flyer” or other derogatory  
names to refer to such patients.

“Structural stigma,” meaning  
less resources for mental health and  
substance use disorders than for other  
medical conditions, compounds the  
problem, adds Pescosolido. She views  
bioethicists as “extraordinary, essential  
partners” in reducing stigma, both  
in medical schools and in clinical  
settings.

“We need to hit stigma at all  
levels,” says Pescosolido. “People  
turn to bioethicists for these types of  
questions.”

## “Not the most likable patients”

In 2015, a psychiatry resident  
and her academic supervisor set out  
to understand what the attitudes of  
the psychiatric residents were toward  
two of the most challenging types of  
psychiatric patients: severely disabled  
psychotic patients and frequently  
relapsing severe substance abusers.<sup>2</sup>

**Jonathan Avery, MD**, the study's  
lead author and assistant professor  
of psychiatry at Weill Cornell  
Medical College in New York City,  
has conducted previous research on  
clinicians' attitudes toward individuals  
with substance use disorders and  
serious mental illness.<sup>3</sup> “I have been  
interested in this topic after numerous  
clinical experiences where it was clear  
that other physicians did not like  
working with these patients,” says  
Avery.

In the 2015 study, the researchers  
examined attitudes of 159 psychiatry  
residents toward four different patient  
types: a patient with schizophrenia, a  
patient with multiple substance use  
disorders, a patient with schizophrenia  
and multiple substance use disorders,

and a patient with major depression.

The researchers found that  
residents' attitudes toward patients  
with substance use disorders are worse  
than their attitudes toward patients  
with depression, schizophrenia, or  
with comorbid substance use disorders  
and schizophrenia.

“Those attitudes get worse over  
the four years of psychiatry training,”  
says study co-author **Bernadine Han**,  
MD, MS.

Han notes that in the ED setting,  
trainees encounter patients with  
substance use disorders who are  
intoxicated, demanding controlled  
substances, and alienated from their  
support systems.

“They are caught in the chaotic  
throes of their illness, and might not  
be the most likable patients under  
those circumstances,” says Han. This  
makes it hard for providers not to  
come away with a sense of futility and  
frustration.

“For some, the relentless pull of  
their disease brings them back to the  
ER in sorry states again and again,”  
says Han.

Knowing these provider attitudes  
is a good starting point for addressing  
the stigma that these patients  
engender in other medical providers,  
says **Thomas R. Kosten**, MD, Jay  
H. Waggoner Chair and professor of  
psychiatry and neuroscience at Baylor  
College of Medicine in Houston.

Psychiatry residents typically  
have very tolerant attitudes toward  
psychiatric patients, adds Kosten —  
otherwise, they would probably have  
chosen another medical specialty.

“However, two groups of patients  
— severely disabled psychotic patients  
and frequently relapsing severe  
substance abusers — can be the most  
challenging in developing empathy  
and non-stigmatizing attitudes,” says  
Kosten.

Avery has a two-year award from

the American Board of Psychiatry and Neurology to study this topic further. “We are now focusing on developing interventions to improve these attitudes by creating online training modules and figuring out how to incorporate trainings into psychiatry residencies,” says Avery.

The investigators found that the residents’ attitudes toward patients with substance use disorders alone and toward patients with schizophrenia and comorbid substance use disorders were more negative than their attitudes toward patients with schizophrenia or depression alone.

Patients with both of these disorders are often seen primarily in the ED — in significant distress, but refusing help. “These attributes make these patients challenging and unrewarding,” notes Kosten.

## Negative reactions could affect judgment

When the study’s findings were presented at the AAP conference, many trainees and younger doctors weren’t too surprised. “Many felt it was ‘sad but true,’” says Han. In contrast, experienced psychiatrists seemed quite disappointed. “They hoped that we had come further than that by now,” says Han.

Han says these are important questions: “What might negative feelings mean for how we treat patients?” “Can we change them?” and, “Does it matter if we don’t?”

When clinicians encounter patients who stir up negative reactions, says Han, the ethical principles of justice, beneficence, and even non-maleficence come into play. “Negative reactions might lead to less willingness to spend time with the patient,” says Han. This means less time by the bedside, or a premature

hospital discharge.

“Negative reactions also may affect our judgment, our decision-making, or our performance of a procedure,” says Han. “That, in turn, could affect the patient’s clinical outcomes.”

Attitudes developed in training can profoundly affect the patients a psychiatry resident sees for the rest of his or her career, notes Han.

“In emergency settings, a patient’s repeated visits and chronic psychiatric or substance-related diagnosis might lead trainees to give up hope for that patient’s improvement or recovery,” she explains.

Health professionals often don’t fully understand that people can and do recover from serious mental illness, says **Dominic A. Sisti**, PhD, assistant professor in the Department of Medical Ethics & Health Policy at the Perelman School of Medicine at the University of Pennsylvania. Sisti is also director of the Scattergood Program for Applied Ethics of Behavioral Health Care.

“Such patients are often assumed to be incompetent when they may not be, and are provided suboptimal treatment, or are turfed away,” says Sisti.

Providers may see the patient’s addiction-related behaviors and thought patterns as evidence of dishonesty or even sociopathy. Some view sending a chronically ill patient to rehab or hospitalization as a waste of limited resources.

“Recognizing our own negative reactions and the way they may be affecting our treatment decisions is important,” says Han.

Kosten says adherence to effective treatments and ways to prevent relapse after acute episodes of illness remain difficult challenges. “We cannot expect therapeutic adherence from our patients when they do not feel respected for their suffering,” he adds.

Kosten sees the central ethical issue as reframing mental and substance use disorders as the health problems they are, as opposed to criminal justice, moral, or social problems. “These are not moral failures, legal problems, or some type of willful misconduct,” he says. “These are brain diseases that have genetic and environmental determinants.”

This requires a sustained national effort to change the dialogue about mental health disorders and about substance use disorders, he says. “Clearly, we in psychiatry need to address these stigmatizing attitudes in our trainees before we can change society’s attitudes more broadly,” he says.

At the institutional level, says Kosten, providers and educators need to be aware of the issue. “Trainees require help in understanding the harm in their attitudes, and how this will block their ability to offer empathic and well-directed help,” he says. ■

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# Family Caregivers Benefit from Early Palliative Care, Says Study

Early palliative care integrated with oncology care benefits not only patients with cancer, but also family caregivers, according to a new study.<sup>1</sup>

Researchers enrolled 350 patients with newly diagnosed incurable lung or gastrointestinal cancers and 275 family caregivers in the study. Half received usual oncology care, and half received usual care in addition to palliative care.

Family caregivers were not required to attend palliative care sessions, but more than half of them did. Family caregivers' quality of life and mood were measured at baseline, 12 weeks, and at 24 weeks. The study's key findings include the following:

- After 12 weeks, caregivers reported fewer depression symptoms and improved vitality and social functioning compared to caregivers of patients receiving strictly medical care.

• After 24 weeks, the lower rate of depression symptoms was persistent, but there was no difference observed in vitality and social functioning.

"Studies have shown that early palliative care helps patients live longer and feel better," says **VJ Periyakoil, MD**, director of palliative care education and training at Stanford (CA) University School of Medicine.

Despite a growing body of evidence, most seriously ill patients are not being referred to palliative care. Primary care doctors, oncologists, and cardiologists may delay referral to palliative care because they're uncertain about the patient's anticipated life span, or because they believe that it is too early to refer.

"All seriously ill patients have the right to see a palliative expert, so they can avail themselves of the great benefits it provides to them and their

family," says Periyakoil.

Periyakoil says ethicists can promote increased access to palliative care for all seriously ill patients by the following:

- advocating for palliative care training in medical curricula,
- referring patients early to palliative care, and
- advocating for policy changes that ensure palliative care is offered to all patients diagnosed with cancer, heart failure, kidney failure, dementia, ALS, and other illnesses very soon after diagnosis.

**Amy S. Kelley, MD, MSHS**, associate professor at Icahn School of Medicine at Mount Sinai's Brookdale Department of Geriatrics and Palliative Medicine in New York City, says the study clearly demonstrates the importance of considering patients as people within the context of a family, however that unit is defined for that person.

"Palliative care should be provided at the same time as other components of high-quality medical care — at the time of diagnosis," says Kelley.

The study's findings demonstrate that family caregivers personally benefit from this added layer of support — either in addition to, or perhaps because of, the benefits experienced by patients. "Clinicians, including oncologists, should offer

## EXECUTIVE SUMMARY

When early palliative care is provided to patients with newly diagnosed cancers, family caregivers' quality of life and mood improve, according to a recent study. Ethicists can facilitate early provision of palliative care with the following:

- advocating for palliative care training in medical curricula,
- referring patients early to palliative care, and
- advocating for policy changes that ensure palliative care is offered very soon after diagnosis.

early palliative care routinely, and patients and families must know to ask for it," says Kelley.

However, significant challenges remain in providing early palliative care to all seriously ill patients. One is that the palliative care work force is small and growing slowly. "It is vastly outpaced by the number of people needing services," says Kelley. "Given the potential benefits for patients and families, overcoming these challenges is perhaps an ethical challenge."

Palliative care programs have expanded in recent years, but access

to high-quality palliative care remains limited in many areas of the country.

"Ethicists can play an important role in advocating for local, state, and federal support to help expand palliative care training, develop the needed workforce, and support research," says Kelley. ■

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# New Initiative Aims to Combat Disparities in Surgical Care, Outcomes

*'Huge questions of social justice' are raised*

A new initiative to support research on disparities in surgical care and outcomes for disadvantaged populations was recently launched by the National Institute on Minority Health and Health Disparities. The initiative will provide grant opportunities on surgical disparities research.

The research will focus on the following five priorities, which were identified at the May 2015 Inaugural National Institutes of Health (NIH)-American College of Surgeons (ACS) Symposium on Surgical Disparities Research Symposium.<sup>1</sup>

1. Improving patient-clinician communication by helping clinicians deliver culturally dexterous, competent care and measuring its effect on the elimination of disparities.

2. Fostering engagement and community outreach by using technology to optimize patient education, health literacy, and shared decision-making in a culturally relevant way; disseminating these

technologies; and evaluating their effects on reducing surgical disparities.

3. Improving care at facilities with a higher proportion of minority surgical and trauma patients.

4. Evaluating the longer-term effect of acute interventions and rehabilitation support within the critical period of injury or illness on functional outcomes and patient-defined perceptions of quality of care.

5. Improving patient-centeredness by identifying expectations for postoperative and post-injury recovery.

"We cannot afford to be the wealthiest nation of all time, with all of the advantages we have, and continue to have widening healthcare disparities. And it hasn't gotten better — it's gotten worse," says **L.D. Britt**, MD, MPH, FACS, professor at Eastern Virginia Medical School and chair of the ACS Committee on Health Care Disparities.

Britt believes that in order to make some real progress, the combined resources of ACS and the NIH are

necessary. "If we can't put a dent in diminishing healthcare disparities, then no one can do it. And I feel strongly we can do it," says Britt.

The problem is multifaceted: patients need to be able to access their providers, providers need guidelines on how to diminish disparities, and the public has to be educated. "We spend more on healthcare than any other nation. But the challenge we've had a consistent problem with is healthcare disparities," says Britt.

Britt expects the initiative will result in some good models, which can then be used across other medical specialties. "If it works in surgery, maybe it can work in medicine," he says. "There's no specialty where disparities have not been a problem."

Britt emphasizes that disparities in healthcare outcomes are ethically unacceptable. "We can accept that some people are wealthy and some are not," he says. "But we should never accept disparities when it comes to clean air, water, education

and healthcare.”

Disparities are a serious concern in cancer care, according to **Simon J. Craddock Lee**, PhD, MPH, assistant professor of clinical sciences at Harold C. Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center in Dallas. “Disparities in lung cancer don’t seem to be related to higher rates of smoking or limited access to healthcare,” he notes. The presence of comorbidities decreased likelihood of surgery in African-American lung cancer patients but not in a comparable set of white patients, found a 2010 study.<sup>2</sup>

“This raised questions about presumptions that physicians may make about African-American patients that they do not make about white patients,” says Lee.

The other contributing factor was usual source of care. “This raises questions about access to healthcare, insurance, as well as other structural barriers to care in African-American communities,” says Lee. Lee’s own study sought to understand lung cancer decision-making among patients treated for in a county safety-net system.<sup>3</sup>

“I found many patients and their caregivers lacked an understanding of their diagnosis and prognosis,” says Lee. For example, some expressed relief when they were told they were not going to need surgery — but did not understand that the physician recommendation was because their cancers was not resectable. Instead, they were relieved because they had an uncorrected assumption that surgery could cause the cancer to spread.

“From an ethical perspective, this raises questions about how physicians approach patient autonomy, and ultimately, informed consent,” says Lee.

In Lee’s experience, low-income

and minority patients do not distrust health systems or physicians. “Rather, low-income and minority patients have enormous respect for their doctors, and don’t like to question them lest they appear to challenge their authority,” says Lee. The problem arises, says Lee, when clinicians mistake that respect and passiveness as lack of engagement.

“Many physicians then don’t always engage to explain more about their presenting disease, possible treatment paths, and likely prognosis,” he says.

It is important to recognize that disparities in surgical outcomes are part of a larger problem of health disparities in general, says **Robert Perlman**, MD, PhD, professor emeritus in the Department of Pharmacological and Physiological Sciences at the University of Chicago.

“We should appreciate that racial and ethnic disparities in health are intimately connected to socioeconomic disparities,” Perlman adds. “These are complex and difficult problems.”

One important part of this problem has to do with geography. “National disparities in healthcare reflect regional variations in the quality of care,” says Perlman. Populations who have bad health outcomes, whether poor people or African-Americans, disproportionately live in regions of the country where health is generally poor.

Perlman notes that life expectancy in Louisiana, which is home to about 1.5 million African-Americans and has a poverty rate of 23.1%, is 75.71 years. In contrast, in Connecticut, which has 360,000 African-Americans and where 8.6% of the population lives in poverty, life expectancy is 80.82 years.

“These huge differences in life expectancy reflect differences in health generally,” says Perlman. “In cities, too, poor people and members of racial minorities tend to live in

communities where health and healthcare is poor.”

As health in the U.S. has improved, health disparities are beginning to decrease, notes Perlman. “That is very good news, indeed. People who currently have poor health outcomes stand to gain the most from improvements in healthcare,” he says.

While the Affordable Care Act is reducing disparities in access to healthcare, this only goes so far. “Disparities in access to healthcare are probably not a major cause of health disparities,” says Perlman.

Neither Medicare in the U.S. nor the National Health Service in the United Kingdom has eliminated health disparities, although they have greatly reduced disparities in access to healthcare. “The problem has more to do with access to the highest quality of healthcare, rather than access to healthcare in general,” explains Perlman.

Perlman believes the stresses that accompany living at the bottom of a socioeconomically hierarchical society are a major factor leading to health disparities. “I’m concerned that increases in income and wealth inequality in the United States will exacerbate the problem of health disparities,” he says.

Perlman says there is little reason to think that the behavior of physicians is a significant cause of health disparities. “Physicians as a group act ethically and do not violate the traditional principles of autonomy, beneficence, non-maleficence, and justice,” says Perlman.

Perlman says there are two ways to reduce health disparities, including disparities in surgical outcomes. “The first is to improve healthcare for everyone, which means especially improving healthcare in regions of the country and in urban communities where care is poor,” he says.

The other goal is reduction of socioeconomic disparities. “This raises huge questions of social justice that need to be debated and discussed by the whole society,” says Perlman.

**Peter Angelos**, MD, PhD, FACS, Linda Kohler Anderson Professor of Surgery and Surgical Ethics and associate director of the MacLean Center for Clinical Medical Ethics at the University of Chicago, sees the central ethical issue when considering disparities in surgical outcomes based on race and ethnicity as one of justice. “It is unjust to treat patients differently based on race or ethnicity,” says Angelos.

Surgeons, as do all physicians, have a moral responsibility to promote their patient’s best interests. “This is based on the principle of beneficence. Whether one considers it on an institutional level or on an individual physician level, we should do all that we can to give our patients the best possible outcome,” says Angelos.

Biases, whether conscious or unconscious, that result in worse patient outcomes should be identified and rectified, says Angelos.

Bioethicists can help by highlighting the issue and continuously raising the question of whether justice is being upheld, he says.

Such an approach will be most effective for conscious biases, he acknowledges. “Perhaps by looking at the clinical encounter between a patient and a surgeon from a perspective different from the involved clinicians, the bioethicist can help to identify those unconscious biases when they are present,” says Angelos. ■

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# Updated Stem Cell Research Guidelines Address Long-standing Ethical Concerns

Updated guidelines on stem cell research from the International Society for Stem Cell Research may alleviate some long-standing ethical controversies.

“The guidelines make some moral choices. If everyone agreed with every recommendation we offered, it would be a sure sign that guidelines aren’t needed,” says **Jonathan Kimmelman**, PhD, who runs the Studies of Translation, Ethics, and Medicine (STREAM) research group and is associate professor in the Biomedical

Ethics Unit at Montreal-based McGill University.

Previous guidelines, released in 2006 and 2008, focused on embryonic stem cell research and on clinical translation of stem cell research. The 2016 guidelines cover all research on human embryos, including controversial gene editing.

“Our hope is that they reduce uncertainty about appropriate conduct in laboratory and clinical investigations involving stem cells,” says Kimmelman.

The guidelines articulate benchmarks and expectations about appropriate research conduct. “This may allay concerns that members of the public, governments, and scientists might have about stem cell research,” says Kimmelman. The following are some issues addressed by the guidelines:

- The guidelines sanction research involving human embryos, provided certain conditions are met.
- They sanction reasonable compensation for women who provide

eggs for research.

“The guidelines will not necessarily assuage concerns among religious communities who believe embryos should never be used in research, or among individuals who would ban any compensation for egg procurement,” notes Kimmelman.

- The guidelines state that stem cells should demonstrate safety and efficacy in rigorous trials before they are commercialized and/or offered to patients outside of trials.

“Those favoring unfettered access to unproven cell-based interventions — and clinics that turn a profit doing so — will likely chafe at our recommendations,” says Kimmelman.

The guidelines address some ethical issues that are already largely resolved. For example, requiring that patients who have decisional capacity give consent before they are enrolled in trials of cell-based interventions, or

that such trials undergo prospective ethical review, is almost universally accepted.

“It is relatively uncontroversial to say that all research involving human embryos and stem cells should undergo an embryo research oversight process,” says Kimmelman.

There is also a general consensus that clinics should not market unproven cell-based interventions to patients. Instead, they should first rigorously evaluate them in the context of well-designed trials, he says.

“There are a number of issues that will likely present challenges, and for which greater guidance will be needed,” says Kimmelman.

One such area is self-organizing tissues — embryonic tissue that, under certain conditions, can organize into embryo-like structures. “Since such structures have not undergone embryonic development,

it can be unclear on where to draw the line between acceptable and unacceptable research activities,” says Kimmelman.

There are also implementation challenges. For instance, saying that clinics should not market unproven cell-based interventions to patients is one thing — enforcement is another matter.

“The same goes for asking scientists to provide balance, and to remain circumspect, when they report their findings to the public or in scientific articles,” Kimmelman says. ■

## SOURCE

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# UK Audit on End-of-Life Care Results in Widespread Negative Media Coverage

*‘Negative slant’ reveals common misconceptions*

“Secret do-not-attempt cardiopulmonary resuscitation (DNACPR) orders,” “imposed without family consent,” and “unforgivable.” These are just a few of the U.K. newspaper headlines that appeared after an audit of 9,302 patients who died in National Health Service (NHS) hospitals conducted by London’s Royal College of Physicians revealed that for 19% of cases, there was no evidence that the DNACPR order was discussed with the patient’s loved ones. In 16% of cases, there was no documentation of a discussion with the patient.<sup>1</sup>

“The DNACPR question was just one of dozens we asked. But, of course,

the press, TV, and radio in U.K. picked up on it. It was widely covered, with a quite negative slant,” says **Sam H. Ahmedzai**, FRCP, the lead author on the study and the clinical lead for the Royal College of Physicians end-of-life care audit committee. Ahmedzai is emeritus professor in the University of Sheffield’s Department of Oncology and Metabolism.

The audit, which had been commissioned by the Healthcare Quality Improvement Partnership for NHS England, covered two aspects of end-of-life care in hospitals. One examined the protocols, policies, governance, and training aspects of

end-of-life care at 140 acute NHS hospitals in England. The second was a retrospective case notes audit of the actual clinical care of patients who died in those hospitals in May 2015.

Ahmedzai appeared on numerous TV and radio shows explaining that DNACPR related only to CPR, and that for the large majority of people who died in English hospitals, there would have been no valid indication for CPR.

“At least in the British health system, we would not routinely offer CPR to people dying from multiple diseases of older age, frailty, and most cases of advanced cancer,” says Ahmedzai. For the 19% of families who were

apparently not informed of the DNACPR decision, Ahmedzai admitted there was no excuse. “Maybe they were notified, but the documentation was just lacking. Clearly, we need to do better there,” says Ahmedzai.

The news coverage revealed a common misconception: that DNACPR orders meant that no care at all was provided. “We saw plenty of evidence that dying patients did, in fact, get good bedside care,” Ahmedzai says. This included attention to hydration and feeding needs, symptom control, and support for their families.

“Some aspects of care, such as assessments of holistic needs and attending to spiritual and cultural needs, were not done so well,” says Ahmedzai. “There were considerable variations between hospitals.”

**Craig M. Klugman**, PhD, a professor in the Department of Health Sciences at DePaul University in Chicago, takes issue with the widespread negative reaction to the report. “It actually was quite a positive report showing improvements in the U.K.’s treatment of dying patients and their family. This demonstrates how headlines can bias our reactions,” says Klugman.

Klugman notes that it’s only certain that no conversation took place in 3% of cases, but the reason why is unknown. “Most likely it was because the patient or family did not want a conversation,” he says. “What also is not mentioned in this headline is that this rate is an improvement of 10% over the 2013 audit.”

The 2016 audit concluded that, compared to 2013, there had been “a broad front in improvements in nearly all aspects of care of the dying.” Media coverage, however, focused on the finding that in 19% of cases in which a DNACPR order was written, there was no documentation that this decision was discussed with the patient’s family.

“Unfortunately, the lay press has

interpreted this as meaning that, in approximately 20% of cases, there was no discussion of the decision not to perform CPR,” says **Andrew Courtwright**, MD, PhD, a physician at Massachusetts General Hospital’s Institute for Patient Care.

There is no way of knowing whether DNACPR was actually discussed in these cases, but not documented. “There are several reasons to suspect that the actual number of DNACPR orders made without discussion were significantly lower than 19%,” says Courtwright.

In 95% of cases in which dying was not unexpected, a discussion of this fact with the patient’s surrogate was documented. “It is unlikely that, a fifth of the time, these conversations contained no mention of a DNACPR,” says Courtwright.

In 2014, the Court of Appeals held that failing to discuss the DNACPR order with a patient’s surrogate was a violation of the European Convention on Human Rights. This created a significant disincentive for physicians to write such orders without surrogate notification, says Courtwright. “What seems most likely is that documentation of these conversations has lagged behind actually having the conversations,” he says.

**Caroline A. Vitale**, MD, AGSE, director of the Geriatric Medicine Fellowship Program at University of Michigan Health System in Ann Arbor, points out that goals of care discussions are commonplace in the U.S. and often include discussion of code status.

“Patients’ care preferences are elicited or sought to be understood from prior conversations, written documents, and/or a documented patient advocate,” says Vitale. It would be extremely rare for a DNACPR order to be placed in the medical chart without the patient’s family or surrogate decision-maker knowing about it, adds Vitale.

In contrast, says Ahmedzai, DNACPR decisions are the norm in English hospitals, and patients are rarely involved. “This is mainly because we leave it too late for direct discussion with them,” he explains. Once it had been documented that the patients were recognized as dying, half had died within the next 36 hours. “Families are normally involved, but there is unacceptable lack of consultation with a sizeable minority,” says Ahmedzai.

Courtwright says there is little disagreement from an ethics standpoint that patients or their surrogates should be involved in some form in a discussion of DNACPR orders. “There remain significant international differences, however, in the extent to which physicians versus patients or surrogates are felt to be the appropriate final arbiters of the DNACPR order in cases of disagreement,” notes Courtwright.

A number of court cases in the U.K. have supported the idea that, while involving patients and surrogates in the decision-making process is essential, whether to perform CPR is ultimately a medical decision. “In contrast, in the United States, DNACPR orders are rarely, if ever, written over the objection of patients or surrogates,” he says.

The media interest also revealed that the British public don’t really understand that DNACPR orders apply only to CPR. Many wrongly assume this means all forms of care are withdrawn. “That may be partly because of some notable cases which went to court in recent years, where competent patients had DNACPR decisions placed on them unilaterally by doctors, and they and their families weren’t even informed,” says Ahmedzai.

**James A. Tulsky**, MD, chair of the Department of Psychosocial Oncology and Palliative Care at Dana-Farber Cancer Institute and chief of the Division of Palliative Medicine at Brigham and Women’s Hospital in

Boston, says if there were situations in which physicians wrote unilateral DNACPR orders and did not inform the families, “that is simply wrong and cannot be condoned.”

However, there are other possible explanations for this outcome. “First, there may be many situations in which goals of care were discussed and a plan of care was agreed upon for which resuscitation would clearly not make sense,” says Tulsky. In such cases, the DNRCPR order wouldn’t be specifically mentioned.

For example, if everyone agrees that a patient is to receive comfort measures only, and that the goal is not to escalate care or go to the ICU, it would not necessarily be wrong to not explicitly mention the DNACPR order. “It is simply a technical detail that carries out the goals of care,” explains Tulsky.

There may have been conversations

where, in fact, the physician did mention the DNACPR order but the family either did not remember, or didn’t understand, what the doctor was referring to.

“Many studies like these show that patient and family recall is far from perfect,” says Tulsky. “While this does not excuse poor communication, it leads to a less sinister conclusion.” ■

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# Study: \$50,000 Would Make Most Americans More Likely to Donate a Kidney

*Yet compensating donors remains illegal*

The majority of U.S voters surveyed by telephone stated they’d be more likely to donate a kidney if they received \$50,000 in compensation, according to a recent study.<sup>1</sup> However, paying donors remains illegal under the National Organ Transplant Act of 1984. The study’s key findings include the following:

- 68% of participants would donate a kidney to anyone, 23% would donate only to certain people, and 9% would not donate.
- 59% said being paid \$50,000 would make them more likely to donate a kidney, 32% said compensation did not sway them, and 9% were negatively

influenced by payment.

The researchers conclude that, “because thousands of lives might be saved should compensation increase the number of transplantable kidneys, laws and regulations prohibiting donor compensation should be modified to allow pilot studies of financial incentives for living kidney donors.”

**Thomas G. Peters**, MD, FACS, FASN, the study’s lead author and professor emeritus in the department of surgery at University of Florida’s College of Medicine in Jacksonville, views the findings as a call to action.

“The striking number is the 59% that would be moved further toward

donation if offered compensation,” he says. “That’s six out of ten people.”

From 2004 to 2013, the authors note, 63,742 patients died or became too sick for a transplant while waiting for a kidney. “The ethical implication, in my view, is that we have a potential source of lifesaving organs that is not being accessed,” says Peters. “Because of that, people who are fully evaluated and deemed appropriate for treatment with a kidney transplant are dying while they are waiting.”

While some programs reimburse donors for lost wages, travel expenses, and follow-up care, many donors do not qualify. “The ethical question, in

my view, is that we have identifiable, salvageable individuals who are facing needless death because we don't have the means to save them," says Peters. "These people have a name, they are cared for by a particular medical center in America, and are on a waiting list."

Peters uses the analogy of an orthopedic surgeon caring for a patient needing a knee replacement, who could put in an artificial knee, enabling the patient to walk that same day. "It's the same with kidneys — only we can't replace the kidney we'd use today with a kidney we might get tomorrow from a living donor," he says.

The following are ethical arguments used against paying kidney donors:

- **Such payment would commodify body parts.**

"The fact is, though, that in America it's legal to pay surrogate mothers, and ova and sperm donors," Peters says. "And certainly everyone in the transplant endeavor is paid." That includes the hospital, the transplant surgeon, the transplant coordinator, nurses on the transplant floor, and immunology experts. "Everybody is paid but the donor," says Peters.

- **A black market for organs could develop.**

"But our concept is that this all would be highly regulated," says Peters.

- **Payment could coerce persons to perform an act that they ordinarily would not perform: donating a kidney.**

"Well, that's the whole idea. That's what we want," says Peters. "Even though our paper indicates that the vast majority of people are willing to give a kidney to anyone or someone, over 90%, it really doesn't happen."

What people say they'll do is not necessarily what they do in reality, he says.

"In our cohort of respondents, most people were positive about donating," says Peters. "But if you offer the money,

that moves the needle. And it might move it in real time."

Peters says it's important to consider the history behind the National Organ Transplant Act of 1984, which made it illegal for individuals to sell organs. "Those persons who said we should not pay donors were mostly the transplant surgeons, who opined at the time that altruism was the motivation that ought to drive organ donation," says Peters.

The idea was reinforced when a businessman attempted to start a brokerage service paying individuals for kidneys, which was completely unregulated. "We were all appalled by that," says Peters. Peters and others met with former Vice President Al Gore, at the time a Tennessee Congressman, who wrote into the bill the clause about barring compensation.

"However, Gore said at the time, that if the circumstances of organ donation without compensation does not meet the need, then we should reconsider whether or not some form of compensation should be tried," says Peters. "That is something that is very seldom spoken about."

The origins of the law, says Peters, "were largely the brainchild of those of us who were practicing at the time." Though the numbers of individuals on a waiting list who died needing a kidney were small at the time, Peters still viewed the deaths as needless. "There were not a lot of people who agreed with me at the time. I was outspoken about this and did not have a lot of collegial support," he says.

Over the next decade or two, the

numbers of people on the transplant recipient list grew. "We were able to save more and more lives, but the lives we were saving were of a miniscule number compared to the need," says Peters.

The need is now so great, and the resources so scant, says Peters, that other approaches are needed to increase the recovery of transplantable organs. "A lot of smart people have tried to do it," says Peters. "All of the ideas for the last 30 years that have been tried have failed."

Pennsylvania Congressman Matt Cartwright recently introduced legislation that would allow for certain non-cash incentives, such as contributions to a retirement fund, to compensate donors.

"There is no question that what we are doing currently is failing," says Peters. "Even the opponents say we have to improve organ donation. It's failing, and it is costing lives needlessly." ■

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## COMING IN FUTURE MONTHS

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## CME/CE QUESTIONS

**1. Which is true regarding stigma**

**associated with mental health and substance use disorders, according to a recent study?**

- A. Residents' attitudes toward patients with substance use disorders are worse than their attitudes toward patients with depression.
- B. Residents' attitudes toward patients with substance use disorders showed marked improvement over their four years of training.
- C. Residents' attitudes toward patients with comorbid substance use disorders and schizophrenia improved significantly after educational interventions.
- D. Psychiatric residents' attitudes toward patients with substance use disorders were surprisingly positive compared to prior studies.

**2. Which is true regarding palliative care and family caregivers of patients with newly diagnosed cancers, according to a recent study?**

- A. Early palliative care benefited patients as expected, but had no measurable effect on family caregivers.
- B. Most patients saw little or no benefit from early palliative care.
- C. Family caregivers who attended palliative care sessions reported fewer depression symptoms.
- D. Family caregivers were disappointed with the quality of the palliative care provided.

**3. Which is true regarding updated guidelines on stem cell research?**

- A. The guidelines stop short of sanctioning any type of research involving human embryos.
- B. The guidelines state that stem cells should demonstrate safety and efficacy in rigorous trials before they are offered to patients outside of trials.
- C. The guidelines oppose compensation for women who provide eggs for research on the ethical grounds that the practice commodifies body parts.
- D. The guidelines advise against obtaining consent from patients with decisional capacity before enrollment in trials of cell-based interventions, as this is overly burdensome.

**4. Which is true regarding compensation for kidney donation, according to a recent survey?**

- A. The vast majority of participants said they would donate, but only to certain people.
- B. Most said that payment would negatively influence their decision to donate.
- C. More than half of participants said being paid \$50,000 would make them more likely to donate.
- D. Very few participants felt compensation would make them more likely to donate.