

MEDICAL ETHICS ADVISOR®

*For 24 years, your practical
guide to ethics decision making*



AHC Media LLC

IN THIS ISSUE

- Advance directives and dementia patients at end of life cover
- The right to refuse treatment in psychiatry 124
- Driving and dementia: how to say no 125
- Fixing Sex: The evolution of treatment of intersex patients 127
- Ethics of health care reform 128
- **News Briefs:** 130
 - *TJC takes aim at patient safety failures*
 - *National certification for medical interpreters*
 - *TJC issues Sentinel Event Alert*

Statement of Financial Disclosure:

Arthur R. Derse, MD, JD (Peer Reviewer), Karen Young (Managing Editor), and Russ Underwood (Associate Publisher) report no consultant, stockholder, speakers' bureau, research, or other financial relationships with companies having ties to this field of study.

Advance directives an important tool in treating dementia patients at EOL

Directives reduce treatment decision burden on families

The U.S. Supreme Court ruled in 1997 that patients have a right to palliative care to alleviate pain and suffering. But what if the patient is afflicted with Alzheimer's disease or another form of dementia and is unable to communicate whether he or she is experiencing pain?

Dementia is often a comorbidity in patients with advanced age, which further complicates treatment decisions, according to **Joseph J. Fins**, MD, director of medical ethics at New York-Presbyterian Weill Cornell Medical Center in New York City. This also means that physicians and other clinicians in all medical service areas must try to understand and treat the medical needs of such patients, Fins says.

To describe the serious challenge in treating dementia patients, particularly those with advanced dementia at the end of life, Fins turns to Homer's "The Odyssey."

"It's classically described in the ethics literature as the Odysseus dilemma," Fins says.

As Fins relays the story, Odysseus was taking his boat back to Ithaca to be with his wife, Penelope. On his way home, he knew he would sail past the sirens, whose call would tempt the crew to go back, an action that would not have been in their "actual, authentic interest."

As the poem goes, Odysseus advises his sailors to plug their ears, bind him to the mast, and not to listen to him as they passed the sirens, so that they would ignore his call to go back, which would have led to shipwreck and death. His sailors did as he requested, and the boat returned to Ithaca safely.

In that event, it becomes a matter of "discerning which is the authentic self," Fins tells *Medical Ethics Advisor*. In the modern world, patients sometimes have advance directives, but their mental status is so changed, with such patients often becoming disruptive and combative at end of life, experts say, the challenge is treating the patient according to the advance directive. That advance directive may have

NOVEMBER 2009

VOL. 25, NO. 11 • (pages 121-132)

NOW AVAILABLE ON-LINE: www.ahcmedia.com/online.html
Call (800) 688-2421 for details.

been determined years prior, perhaps after initial diagnosis, before the disease progressed to advanced stages.

Often, the patient will have declared in an advance directive that he or she wants no heroic efforts at end-of-life, but when the end of life comes, that patient who once declared "Do not insert a feeding tube," is insisting that he or she be fed, Fins says.

There is an ethical dilemma — to feed or not to feed, for example.

David H. Brendel, MD, PhD, is an assistant professor of psychiatry at Harvard Medical School and is chair of the institutional review board at McLean Hospital, a psychiatric facility in Belmont,

Medical Ethics Advisor® (ISSN 0886-0653) is published monthly by AHC Media LLC, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. 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 740059, Atlanta, GA 30374.

AHC Media LLC is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

AHC Media LLC designates this educational activity for a maximum of 18 AMA PRA Category 1 Credits™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

This activity is intended for acute care physicians, chiefs of medicine, hospital administrators, nurse managers, physician assistants, nurse practitioners, social workers, and chaplains. It is in effect for 36 months from the date of publication.

Opinions expressed are not necessarily those of this publication. Mention of products or services does not constitute endorsement. Clinical, legal, tax, and other comments are offered for general guidance only; professional counsel should be sought for specific situations.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291, (customerservice@ahcmedia.com). **Hours of operation:** 8:30 a.m.-6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday.

Subscription rates: U.S.A., one year (12 issues), \$499. Add \$17.95 for shipping & handling. Outside U.S., add \$30 per year, total prepaid in U.S. funds. Discounts are available for group subscriptions, multiple copies, site-licenses or electronic distribution. For pricing information, call Tria Kreutzer at 404-262-5482. **Back issues**, when available, are \$83 each. (GST registration number R128870672.)

Photocopying: No part of this newsletter may be reproduced in any form or incorporated into any information retrieval system without the written permission of the copyright owner. For reprint permission, please contact AHC Media LLC. Address: P.O. Box 740056, Atlanta, GA 30374. Telephone: (800) 688-2421. Web: <http://www.ahcmedia.com>.

Managing Editor: **Karen Young**, (404) 262-5423, (karen.young@ahcmedia.com).

Associate Publisher: **Russ Underwood**, (404) 262-5521, (russ.underwood@ahcmedia.com).

Production Editor: **Ami Sataria**.

Copyright © 2009 by AHC Media LLC. **Medical Ethics Advisor®** is a registered trademark of AHC Media LLC. The trademark **Medical Ethics Advisor®** is used herein under license. All rights reserved.

Editorial Questions

Questions or comments?
Call **Karen Young**
at (404) 262-5423.



MA.

Brendel indicates that the ultimate challenge in treating dementia patients is much like a psychiatric patient who may be psychotic, but who has written an advance directive when he or she is in a rational state of mind. If the patient goes into psychosis, that patient may declare he or she does not want a particular medication or other treatment — or even a particular physician to treat him or her. Brendel has written on this topic in two papers, one titled "The Ethics of Palliative Care in Psychiatry" in *The Journal of Clinical Ethics*¹, and as one of four co-authors of a research paper on "The Use of Palliative Sedation of Existential Distress: A Psychiatric Perspective," published in November 2008 in the *Harvard Review of Psychiatry*².

The first article addresses the case of a patient, "Margaret," who was in her 50s and "had developed a terrible dementia," Brendel tells *Medical Ethics Advisor*. "Margaret" had previously been a psychiatric nurse.

"Her kids [were] in their 20s...[and] had taken care of her for years, and she became incredibly combative; she always looked like she was in pain, but physically, she was in perfectly good shape," he recalls. "We couldn't find a problem with any organ except her brain."

Brendel says that several treatments were used, from a variety of medications to electroconvulsive therapy (ECT), but nothing worked.

"It looked as if she was in distress; she was sometimes assaultive on the unit, and ultimately the family felt that — and this was a woman who had written an advance directive, saying that she didn't want any kind of heroic care or anything like that, if she had a terminal illness," he says. "Ultimately, we did bring in a palliative care consultant, and she went to hospice."

According to the article on "Margaret's" case, the authors write, "her agitation and continual cries of distress suggested extreme pain and suffering. But the unknowable nature of this pain may have contributed to the discomfort with adopting a palliative care approach."¹

The aging of the U.S. population and growing numbers of dementia patients suggest that psychiatrists, along with general medical practitioners and gerontologists, "will increasingly be faced with similar problems in the coming years," the paper suggests.

"Up to now, psychiatrists have been understandably reluctant to think of palliative care as a possibility for treatment-refractory agitation in

dementia. But patients such as Margaret make it imperative that we entertain this option thoughtfully, that we heed real-event advance directives, and formulate treatment plans in collaboration with family members, clinical ethicists, palliative care clinicians, and specialists in related areas," the authors write.¹

Advance directives an important tool

"The palliative care approach to dementia is further complicated by difficulties in establishing and implementing clear advance directives for patients with dementia," Brendel writes, along with co-author, **Julieta Bleichmar Holman, MD.**¹

The Alzheimer's Association, based in Chicago, receives many calls from individuals or their families regarding advance directives among the 275,000 calls that its Contact Center receives annually, according to **Beth A. Kallmyer, MSW**, director of family & information services for the association.

"The Alzheimer's Association actively encourages people to set up advance directives," says Kallmyer, noting that it is important for patients and their families to take the time to discuss this option.

"Even as people get diagnosed earlier, one of the benefits is that they can participate in this [discussion]," she says. "As people participate and make their own decisions and are able to do that — that empowers them."

It also reduces the burden on the family as different treatments may be indicated as the disease progresses toward end-of-life care.

"If the person with the disease, for example, says, 'I do not want a feeding tube if I get to the point where I cannot swallow anymore' and makes that clear — and has the right advance directives in place — later on, when the patient is unable to communicate those wishes and isn't eating properly and isn't swallowing well, the family will not have to make the agonizing decision of, 'Do we put a feeding tube in, or do we not?'" Kallymer says. "That decision has already been made."

However, Brendel and Holman write that "Despite concerted efforts in recent years to encourage individuals to specify wishes for end-of-life care, most patients with terminal illnesses lack advance directives.

"Margaret's story underscores the need for continued public education on the importance of advance directives," they write.¹

In fact, the authors write, the "unfortunate reality" about advance directives is that "they often go unheeded."

But Fins says that advance directives are binding under federal law under the Patient Self-Determination Act.

"Psychiatric advance directives are not perfect," Brendel tells *Medical Ethics Advisor*, "because clinicians may be put into a position where they have to figure out who is the real person here — is it the person who signed the psychiatric advance directive in a previous state of mind, or is the person I see right before me, who I need to treat now with respect?"

Mark Salzer, PhD, associate professor and director, UPENN Collaborative on Community Integration of Individuals with Psychiatric Disabilities at the University of Pennsylvania in Philadelphia, says psychiatric advance directives, for example, are "actually a nice tool — a nice way for patients to express their rights to make decisions about treatment." Part of Salzer's work is in the area of community integration for people with psychiatric disabilities, involving promoting self-determination and patients' rights.

He notes that advance directives can allow patients to determine everything from which medications they will or will not take to which physicians they will allow to treat them.

Although he acknowledges there are problems with psychiatric advance directives, especially in terms of implementation, he appreciates their

SOURCES & RESOURCES

- **Alzheimer's Association**, Chicago. Web site: www.alz.org.
- **David H. Brendel, MD, PhD**, Director of Medical Ethics and Chair of the Institutional Review Board, McLean Hospital, Belmont, MA.
- **Joseph J. Fins, MD**, Chief of the Division of Medical Ethics; Professor of Medicine, Professor of Public Health, and Professor of Medicine in Psychiatry. He is also Director of Medical Ethics at New York-Presbyterian Weill Cornell Medical Center. E-mail: jjfins@med.cornell.edu.
- **Mark Salzer, PhD**, Associate Professor and Director, UPENN Collaborative on Community Integration of Individuals with Psychiatric Disabilities, University of Pennsylvania, Philadelphia. E-mail: Mark.Salzer@uphs.upenn.edu.

value in empowering patients before they are ruled incompetent, as well as from a crisis-planning perspective.

"For some individuals who are hospitalized frequently, that can be helpful therapeutically," Salzer says.

References

1. Holman, JB; Brendel, DH. "The Ethics of Palliative Care in Psychiatry." *The Journal of Clinical Ethics*. 17:4, 333-338.
2. Zev Schuman-Olivier; David H. Brendel; Marshall Forstein; Bruce H. Price (2008) "The Use of Palliative Sedation for Existential Distress: A Psychiatric Perspective," *Harvard Review of Psychiatry*, 16:6,339-351. ■

All patients have the right to refuse treatment

Treatment decisions not always autonomous

Every patient in the United States has the legal right to refuse medical care — even when that care would help the patient, experts agree.

With psychiatric care, things can get a little trickier, but those same experts agree that psychiatric patients are due the same rights as someone under any other type of medical care.

"The right to refuse psychiatric care is no different than the right to refuse any medical care, even if it may be a person with cancer who says, 'No, I just don't want to go through that chemo,' even though it would clearly help that person," says **Andrew Penn**, JD, of the Bazelon Center for Mental Health Law in Washington, DC, which is an advocacy group for the rights of patients specifically with mental illness.

"And yet," Penn explains, "it doesn't always work out that way. Treatment people . . . they give less credence often to the personal or individual decisions or desires in that [psychiatric] context."

The right to refuse treatment is a "huge issue, especially for psychiatric patients, [including] the issues of competency, forced treatment, involuntary outpatient commitment; those kinds of things are huge topics in our field," says **Mark Salzer**, PhD, associate professor and director, UPENN Collaborative on Community Integration of Individuals with Psychiatric Disabilities at the University of Pennsylvania in Philadelphia.

At McLean Hospital, a psychiatric hospital in

Belmont, MA, **David H. Brendel**, MD, PhD, agrees that psychiatric patients have the right to refuse treatment. He also chairs the Institutional Review Board at McLean and chairs the ethics committee for McLean.

"There are many patients at McLean and other psychiatric hospitals that are involuntarily committed, but just because they are involuntarily committed doesn't mean they lose all their [rights]," Brendel explains.

"They can still refuse medication and other forms of treatment if they want, unless the treating physician chooses to pursue other legal means to force medication — that's an area that sometimes doesn't get enough attention," he says.

Not only do they have the right to refuse treatment, they have the right to refuse to be a participant in clinical research studies, Brendel says. At McLean, for example, there are about 300 "active research studies."

"Many of those studies do include patients — some of them patients who are quite psychiatrically ill — major mood disorders, psychotic disorders, dementia," he notes.

McLean takes informed consent a few steps further to insure that patients are treated fairly when it comes to research conducted with patients at the hospital. For example, Brendel says that if a clinical researcher wants to do a study on an inpatient, the hospital does not allow the researcher to approach that patient directly, even if the patient was committed involuntarily.

Although flyers and advertisements are two ways to recruit patients, whereby the patient might volunteer, there are other methods of recruitment. Brendel says that a researcher may also approach a patient's physician to say, "Based on an initial review of this patient's record, I think this person might be eligible for the study — is it OK if we approach the patient about the research?"

"The IRB usually requires the treating physician, who has no particular stake or interest in the research, to first talk it over with the patient, so the patients are not in any way feeling pressured or coerced," Brendel says. "So, they're not being flooded with multiple researchers asking them to be in multiple studies."

The treating physician can, in those cases, decide if the patient is "up for it, whether it might be upsetting to the patient, and whether the patient might be eligible," Brendel says.

The McLean IRB also often requires the treating physician to conduct a competency assessment in order to determine if the "patient can

understand the risks and benefits of the research and meaningfully consent to participate," Brendel tells *Medical Ethics Advisor*.

"And in particularly risky research, we have the requirement that another clinician, who is completely independent of the research study in question, does that competency evaluation [to determine] that the patient is competent to understand and sign the consent form," Brendel says.

But there are other ways for approaching psychiatric patients to participate. Brendel says that if a patient is determined to be competent to provide — or not provide — informed consent, "then nobody else would have the right to override that in any way."

"Where it becomes interesting, and I think, important is [when the patient] is judged not to be competent to participate in the research," Brendel says. "In that case, there may still be an indication to do the research. In fact, in some cases, the research is being done for that very reason, that is, to treat people with really major disorders — psychotic disorders or dementia disorders."

In cases where the patient is not determined to be competent to decide to participate or to refuse to participate, McLean has "policies for surrogate consent, which again, the IRB reviews very carefully."

In those cases where the risk associated with participating in a particular research project is considered minimal, a surrogate family member might be allowed to give consent for a patient to participate. In cases where there could be significant risk to the patient, McLean might increase the requirements for surrogate consent, "even to the point that we might require a legally appointed guardian" Brendel notes.

"The IRB is often making judgments about the risk-benefit profile of the research," he says. ■

SOURCES

- **David H. Brendel**, MD, PhD, Director of Medical Ethics, and Chair of the Institutional Review Board at McLean Hospital, Belmont, MA.
- **Andrew Penn**, JD, Senior Staff Attorney, Bazelon Center for Mental Health Law, Washington, DC.
- **Mark Salzer**, PhD, Associate Professor and Director, UPENN Collaborative on Community Integration of Individuals with Psychiatric Disabilities, University of Pennsylvania, Philadelphia. E-mail: Mark.Salzer@

Bill would allow physicians to report unsafe drivers

President of the medical society frowns on strictures

The Massachusetts Legislature's Joint Transportation Committee has drafted and recommended a bill that would allow physicians and law enforcement officers "to make a report to the registrar if there is cause to believe that an operator is unable to safely operate a motor vehicle," according to a summary of the legislative bill.

That bill, as of mid-October, had been sent to the state's House Ways and Means Committee for further consideration, according to House Transportation Committee Research Analyst, **Andrew J. Keegan**. It had not — at that time — been funded or approved.

The proposed legislation also "would allow for the immunity from civil liability for any physician or law enforcement officer making a report," according to the bill summary.

The American Medical Association in Chicago considers the safety of older drivers to be a public health issue. But the matter of suggesting to a patient who may be mentally or cognitively impaired — such as those with impaired vision, motor skills, or impaired cognition, is a delicate, thorny issue for physicians, based on a review of the AMA's policies and suggestions addressing how physicians should approach this topic with a patient.

According to information on the legal and ethical responsibilities of the physician, "Protecting the patient's physical and mental health is considered the patient's primary responsibility," although the information does not constitute legal advice, the AMA documents indicate.

However, this chapter acknowledges that "Driving is a difficult topic to address, particularly when there is the risk of damaging the patient-physician relationship, violating patients confidentiality, and potentially losing patients."

Needless to say, common sense suggests that if not handled correctly or sensitively, this conversation — where a physician suggests that a patient no longer drive — can have a negative impact on even long-standing doctor-patient relationships.

There is some question as to whether a physician should be able to report to a government body that his or her patient should not drive, however.

In a comment to the *Boston Globe* on the proposed bill and the powers it entails for physicians, **Mario Motta**, MD, a cardiologist and president of the Massachusetts Medical Society, was quoted as saying, "Physicians shouldn't be in a position of being a policeman. Physicians are supposed to be in a position to advocate for their patients, and this is not that at all."

Dementia and driving

The Alzheimer's Association receives 275,000 calls annually to its Contact Center, which offers resources and advice on topics of concern to these patients and their families, from driving to advance directives.

Beth A. Kallmyer, MSW, director of Family & Information Services for the Chicago-based organization, does not break out statistics on the number of calls per topic, but she tells *Medical Ethics Advisor* that if the organization tracked the calls related to driving, the numbers would be "compelling."

Kallmyer notes that in American society, "driving represents independence for seniors, for everybody."

"The most important message, I think, about driving is that if somebody has Alzheimer's, or they get diagnosed, it doesn't mean they have to stop driving right then. But there will come a time when they have to stop driving — there's a time when it is no longer safe."

She says the association's approach is individualized, as needs vary from person to person.

"We believe that people need consultation and assistance and support in how to raise the issue with their family member, and also how to provide them with options, so they can continue to get around and still maintain a level of independence," Kallmyer says.

She also notes that families "walk a fine line with Alzheimer's in terms of wanting to respect the person's autonomy and independence but also needing to make sure they are safe."

Among the behaviors indicating that it may be time for a patient with the disease to stop driving, according to the association's web site, are: forgetting how to locate familiar sites; failing to follow traffic signs; driving at speeds that are not appropriate; or becoming angry and

confused while driving.

Involving the patient's physician

One approach the association suggests for families in addressing the topic specifically calls for the involvement of the patient's physician.

"We suggest families sometimes work with patients in telling them that they can't drive [and] to raise that issue of the doctor suggesting they don't," Kallmyer says. "And again, it's about safety. Some people with the disease will listen to what the doctor says, so we think of it in terms of a prescription, where the doctor says, 'It's not OK for you to drive, because the disease is impacting your brain.'"

For some people, the news from the doctor is all they need to determine that they will no longer drive — that is, for those patients who trust their physician. The contact center staff will often ask a family member what his or her parent's relationship is with his or her physician.

"[We ask questions like] 'Does he trust his doctor? Does he listen to his doctor? Because if that's the case, and they trust the doctor, then this is sometimes a good route to suggest,'" Kallmyer explains. "If the person doesn't trust doctors and doesn't have a good relationship with his doctor, it's not a good way to go."

When the patient's relationship with his or her physician is not a strong, trusting relationship, and if the family members, particularly if they are adult children of the patient, don't feel comfortable with making that decision for their parent, another person must be selected.

"Sometimes this kind of news comes better from a peer, or someone the person with the disease really respects or relates to, like a sibling, long-term family friend, a minister, or somebody in their life that they would respect," Kallmyer says. "So, it's not always that doctor — it might be somebody else." ■

SOURCES

- **Alzheimer's Association**, Chicago. Web site: www.alz.org
- **Andrew J. Keegan**, Research Analyst, Joint Committee on Transportation, Office of State Rep. Joseph F. Wagner, State of Massachusetts, Boston. Tel. (617) 722-2400.

'Fixing Sex' author's goal was to reflect all stakeholders

Treatments began changing in 90s

When Katrina Karkazis, PhD, MPH, began her research in 1997 for her dissertation on intersex patients — or patients born with features of both the female and male sex — she said when she told people what she was working on, the standard answer was “Huh? What’s that?”

Today, that never happens, says this research scholar at the Stanford Center for Biomedical Ethics in Palo Alto, CA.

In 1997, there was “a huge amount of debate” on the topic of intersex patients. Activism on this topic began around 1993, so she says that by 1997, “things were kind of at a fever pitch, and by 2000, things were very much in crisis.”

The trigger for the idea to complete her dissertation on intersex patients was an article that she had read by Suzanne Kessler on this topic in 1993.

“I never forgot that article that she wrote,” Karkazis tells *Medical Ethics Advisor*. “And what I realized at the time was that no one had interviewed all of the stakeholders that were involved in thinking about care for these children.

“And I really felt like we couldn’t understand what the debates were about if we didn’t talk to the three primary groups — those are the parents, the adults who had been treated, and the clinicians who treat the children and work to help the parents.”

News magazine programs and talk shows like Oprah Winfrey’s have helped to increase public awareness of the issue, as have activists; in fact, media coverage like this was included in her field research on the topic.

The difficulty in writing about this topic was that Karkazis says she felt as if she was writing for all three groups of stakeholders.

“But there was no question that part of what I was doing in writing it was having a conversation with [physicians],” she explains. “Because in following the debate, things that I heard doctors say repeatedly — some of those things I wanted to question and think about in a more complicated way. And this was, in part, my way of doing it — through the pages of the book.”

Although she says she can’t imagine that a large number of physicians have read the book,

Karkazis says she has received “fantastic feedback” from clinicians, who have told her that what she wrote was not easy to hear, but that they felt like she was “fair.”

She says she knows that what she or some of the people she interviewed had to say would not be easy for some physicians to hear.

“But I never wanted to say it in a way that closed off someone’s ability to hear it, and so, not to screech, not to use inflammatory language, but to really [reflect] all sides respectfully.”

In the book, she reflects on the treatment protocol established in the 1950s by John Money and colleagues at Johns Hopkins University in Baltimore.

She writes, “Emphasizing thorough but swift clinical workups to determine the etiology, clinicians determine a sex for these infants, and surgeons then modify the infant’s body, especially the genitals, to conform to the assigned sex.”

Although “widely accepted” by physicians for four decades, this protocol changed “dramatically” in the 1990s, she writes.

“[Treatment] has definitely changed,” she tells *MEA*. “And for 40 years, there were challenges to this treatment . . . but nothing that really took hold.

“My sense is from my work that if clinicians deviated from what [Money] wrote, they did it quietly,” she explains. “They weren’t publishing about it; they weren’t necessarily telling others, but they certainly had doubts and questions.”

In the mid-90s, activists — some including people who had been treated they now felt inappropriately as infants — began to openly challenge existing protocols. And then, the debate evolved to include those clinicians who had “been quietly rethinking care.”

“So, in some cases, legal scholars, ethical scholars, people from other disciplines and also people from within medicine, started to sort of say, ‘Wait a second; let’s rethink this,’ ” she says. “As you can imagine when that happened, medicine was resistant.”

Clinicians suggested that the only evidence against the standard surgery protocols was anecdotal and voiced by a “small minority of unhappy patients.”

In about 2006, a new standard of care was initiated, which included, Karkazis says, “some new thinking on surgery, and a more conservative approach to surgery.”

Also, she notes, there were improvements in what is referred to as patient-centered care,

"which is really this idea that you need to be honest with patients, which hadn't been the case [historically]."

"Clinicians never meant poorly by being dishonest; they really felt it was protective — that this would just be so hard to deal with, and some of the information was so difficult, that wouldn't we be doing better by sparing them?" she explains. "We know now in medicine that honesty is the best policy."

In addition to the change in surgical protocols, a new consensus statement also suggested that intersex patients must have good psychosocial care. Even Money in the 1950s suggested this, but it has not happened, Karkazis says.

"I think there are a couple of reasons [why psychosocial care hasn't been provided]," she says. "...I think the belief that if we kept quiet about the conditions — the less you know, the better you are. That was part of it."

Today, there are still barriers to adequate psychosocial care, she says.

Reimbursement for providing that psychological care to intersex patients — and their parents — is one such barrier.

"That has to do with insurance and reimbursement codes," she explains. "The child is the patient, but the parents are the ones who need the initial support. There's just not a framework for it."

Another barrier has been the "idea that one needs specialized training in these conditions to be able to help families."

"I agree that that would be useful," Karkazis says. "But from my talking to parents and families, I think that some of the issues that they deal with are some that are true for parents with a child with any chronic condition, or birth defect, or any type of situation where the parents have to reimagine their child's life after birth."

In the end, her goal was to initiate dialogue on this topic.

"What I hoped [the book] would do was raise questions, and question marks about what might have been habit in terms of clinical practice, and say, 'Wait a second: why do I do this? Do I need to do it this way? Can I do it better? And what else do we need to know or study?'

Toward the goal of further discussion on the topic, Karkazis has helped co-found an organization to promote dialogue on intersex patients and their care. That organization is called Accord Alliance, which can be researched at www.accordalliance.org. ■

SOURCE

- **Katrina Karzakis**, PhD, MPH, research scholar, Stanford Center for Biomedical Ethics, Stanford University Medical School, Palo Alto, CA. E-mail: Karkazis@stanford.edu.

Reference

1. Fixing Sex: Intersex, Medical Authority, and Lived Experience. Katrina Karkazis. Duke University Press, Durham, NC. 2008.

Health care reform discussion continues

Legislative process moves ahead

I believe that underlying [the health care reform] debate is our national schizophrenia over whether health care is a social good or an economic good. We often say the former, but the reality is the latter. We say health care is a 'right' not a 'privilege,' and we deplore that not everyone has access to health insurance.

But we also believe that there should be competition in health care and that 'the market' should prevail. Because the real underlying value of American health care is "market-based competition," perverse financial incentives have developed."

— **Blair L. Sadler**, writing in The Hastings Center's Health Care Cost Monitor blog, on July 13, 2009. Sadler, JD, is a past president of the Rady Children's Hospital in San Diego; a senior fellow at the Institute for Healthcare Improvement in Boston; and a faculty member at the Rady School of Management at the University of California, San Diego. Sadler is a Hastings Center Fellow and board member.

According to **Nancy Berlinger**, PhD, MDiv, deputy director and research scholar at The Hastings Center in Garrison, NY, Sadler's commentary points to the classic dilemma, which Sadler also refers to, of "margin vs. mission — no margin, no mission."

She interprets his comments as alluding to the health/wealth gradient, which is the idea that the higher your wealth, the better your health. Also borne out in studies is the fact that the poorer

one's health, the more likely that individual is to have lower income.

"People are in the hospital because they're sick. But the conditions that brought them to the hospital may have something to do with their income or their economic circumstances."

Perhaps someone decided to forego an important diagnostic test, and a disease was diagnosed at a much later date — or treatment or medication was too expensive, so a chronic disease became acute. These are all realities in today's health care system, Berlinger says.

"It hasn't been explained by any one factor," she says.

Berlinger says that countries that want their populations to have better health can either "work it on the income side and hope that if people's fortunes rise, their health will be better for various reasons — or you can promote better health."

While it is true that to some degree people's health is determined by lifestyle and genetics — not their access to health care — there are still people "who have catastrophic health problems no matter what," she says.

There are people who maintain healthy lifestyles who — due to genetics or environment — develop catastrophic diseases.

"You need to make sure that the treatment you have will enable you to either be cured of this disease, or to live with this disease," Berlinger says. "But it's not an option not to have health care in those cases."

Physicians should be concerned with this — not only because by definition of their profession, they are in an ethical relationship with their patients — but also on a very practical level, Berlinger says.

"I used to have a colleague who would say, 'It comes down to, do we believe people should die in the streets or not? . . . If you don't think people should die in the streets, you're going to have to figure out how you're going to pay for their care.'"

But then questions arise, she says, like, "Who is going to pay the doctors? Should the doctors work for free? Well, maybe we don't think that. So, if we need to train the doctor, and the doctor needs to get a paycheck, who is going to pay for it if this person who would otherwise die in the streets can't afford to pay?"

"What do we do? We call that safety net, charity care, unreimbursed care. We have policies like EMTALA," she notes.

To the question of whether access to health care is a human right, Berlinger responds, "Here's what a lawyer would say, [and] I mean that in the best possible sense: A human rights lawyer would say that 'a right isn't a right unless it's actionable.'

"It can't just be that somebody tells you you have a right," she explains. "Because somebody else might say, 'Well, how do I get that right? How do I use it in practice?'

"We can't just say it's a right — it's out there somewhere and maybe someday you'll get to use it. No. You have a positive obligation to help people use their rights."

Berlinger maintains that it's not enough to say health care is a right.

What are reform options?

Robert J. Barnet, MD, MA, a cardiologist and senior scholar at the Center for Clinical Bioethics at Georgetown University in Washington, DC, suggests as one option medical cooperatives.

Like many, one of his primary concerns is the lack of meaningful access to basic health care for millions in the United States. He suggests undertaking health care reform that: prohibits denial of coverage for pre-existing conditions; prohibits the discontinuation of coverage with illness or loss of employment; and establishes nationwide portability.

Barnet also suggests "meaningful" malpractice reforms that: establish national standards; establish a cap on pain and suffering; recognize the potential benefit of a Medicare-like health care system for children; and tighten rules for expert witnesses. ■

SOURCES

• **Robert J. Barnet**, MD, MA, FACP, FACC, Senior Scholar, Center for Clinical Bioethics, Georgetown University, Washington, DC.

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

TJC takes aim at patient safety failures

The Joint Commission (TJC) says it is teaming up with top hospitals and health systems across the United States to use new methods to find the causes of and put a stop to dangerous and potentially deadly breakdowns in patient care.

TJC, based in Oakbrook Terrace, IL, is launching the Center for Transforming Healthcare, and the organization says its first initiative is tackling hand-washing failures that contribute to health care-associated infections that kill nearly 100,000 Americans each year and cost U.S. hospitals \$4 billion to \$29 billion annually to combat.

Eight hospitals and health systems volunteered to address hand-washing failures as a critical patient safety problem — “one that requires fixes far more complex than just putting up signs urging caregivers to wash their hands.”

“Demanding that health care workers try harder is not the answer. These health care organizations have the courage to step forward to tackle the problem of hand washing by digging deep to find out where the breakdowns take place, so we can create targeted solutions that will work now and keep working in the future,” said **Mark R. Chassin**, MD, MPP, MPH, president of The Joint Commission, in a news release.

Participants in the center’s first project are:

- Cedars-Sinai Health System, Los Angeles
- Exempla Lutheran Medical Center, Wheat Ridge, Colorado
- Froedtert Hospital, Milwaukee
- The Johns Hopkins Hospital and Health System, Baltimore
- Memorial Hermann Health Care System, Houston
- Trinity Health, Novi, MI
- Virtua, Marlton, NJ
- Wake Forest University Baptist Medical Center, Winston-Salem, NC. ■

CME answers: 17. A; 18. D; 19. B; 20. B.

Certification for medical interpreters launches

A national certification program is being launched for language interpreters who work in the medical field, called the first National Certification for Medical Interpreters.

The CMI designation will first be available to Spanish-language interpreters, with national certification rolling out for several other languages in 2010.

“Hospitals across the country should provide their patients with qualified interpreters that can prevent the miscommunications and subsequent medical errors that still occur far too often in some of today’s hospitals,” said **Mursal Khalif**, senior director of multilingual services, Cambridge Health Alliance, Cambridge, MA. “A national certification for medical interpreters has been desperately needed to ensure the safety of LEP patients, and I am extremely delighted that we now have a national standard in place.”

The launch of the certification program was reported simultaneously with the inaugural members of the National Board of Certification for Medical Interpreters, which says it is an independent, non-profit certification entity, founded to oversee the certification process. ■

TJC issues Sentinel Event Alert

A Sentinel Event Alert issued in late August by The Joint Commission (TJC) urges health care leaders to step up efforts to prevent errors by taking the zero-defect approach used in other high-risk industries, such as aviation and nuclear energy.

TJC is advocating greater involvement of health care trustees, executives, and physician leaders, contending that the overall safety and effectiveness of a health care facility depends on administrative and clinical leaders who set the tone, create the culture, and drive improvements.

“Health care leaders are directly responsible for establishing a culture of safety,” says **Mark R. Chassin**, MD, MPP, MPH, president of TJC. “This alert provides leaders with concrete strategies for demonstrating a commitment to safety and to improving patient outcomes.”

To improve patient safety, TJC's Sentinel Event Alert recommends that the governing body, CEO, senior managers, and medical staff leaders at health care organizations take a series of 14 specific steps. ■

CME objectives

After reading each issue of *Medical Ethics Advisor*, you will be able to do the following:

- 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. ■

To reproduce any part of this newsletter for promotional purposes, please contact:

Stephen Vance

Phone: (800) 688-2421, ext. 5511

Fax: (800) 284-3291

Email: stephen.vance@ahcmedia.com

To obtain information and pricing on group discounts, multiple copies, site-licenses, or electronic distribution please contact:

Tria Kreutzer

Phone: (800) 688-2421, ext. 5482

Fax: (800) 284-3291

Email: tria.kreutzer@ahcmedia.com

Address: AHC Media LLC
3525 Piedmont Road, Bldg. 6, Ste. 400
Atlanta, GA 30305 USA

To reproduce any part of AHC newsletters for educational purposes, please contact:

The Copyright Clearance Center for permission

Email: info@copyright.com

Website: www.copyright.com

Phone: (978) 750-8400

Fax: (978) 646-8600

Address: Copyright Clearance Center
222 Rosewood Drive
Danvers, MA 01923 USA

EDITORIAL ADVISORY BOARD

Consulting Editor: **Cynda Hylton Rushton**
DNSc, RN, FAAN

Clinical Nurse Specialist in Ethics
Johns Hopkins Children's Center, Baltimore

John D. Banja, PhD
Associate Professor
Department of
Rehabilitation Medicine
Emory University
Atlanta

Nancy Berlinger, PhD, MDiv
Deputy Director and
Research Associate
The Hastings Center
Garrison, NY

Arthur R. Derse, MD, JD
Director
Medical and Legal Affairs
Center for the Study
of Bioethics
Medical College of Wisconsin
Milwaukee

J. Vincent Guss, Jr., MDiv
Journal of Pastoral Care
Editorial Board for the
Association of Professional
Chaplains
Chaplain of Falcons Landing
Air Force Retired Officers
Community
Potomac Falls, VA

Marc D. Hiller, DrPH
Associate Professor
Department of Health
Management and Policy
University of New Hampshire
Durham, NH

Paul B. Hofmann, DrPH
President
Hofmann Healthcare Group
Moraga, CA

CME instructions

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

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

COMING IN FUTURE MONTHS

■ The ethics of neuroimaging

■ Bioethics education: From PhDs to weekend seminars

■ Advantages of the POLST form

■ Palliative sedation in existential distress

United States Postal Service Statement of Ownership, Management, and Circulation		
1. Publication Title Medical Ethics Advisor	2. Publication No. 0 8 8 6 - 0 6 5 3	3. Filing Date 10/01/09
4. Issue Frequency Monthly	5. Number of Issues Published Annually 12	6. Annual Subscription Price \$499.00
7. Complete Mailing Address of Known Office of Publication (<i>Not Printer</i>) (Street, city, county, state, and ZIP+4) 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, Fulton County, GA 30305		Contact Person Robin Salet Telephone 404/262-5489
8. Complete Mailing Address of Headquarters or General Business Office of Publisher (<i>Not Printer</i>) AHC Media LLC, 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305		
9. Full Name and Complete Mailing Addresses of Publisher, Editor, and Managing Editor (Do Not Leave Blank) Publisher (Name and Complete Mailing Address) Robert Mate, President and CEO AHC Media LLC, 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305		
Editor (Name and Complete Mailing Address) Karen Young, same as above		
Managing Editor (Name and Complete Mailing Address) Russ Underwood, same as above		
10. Owner (Do not leave blank. If the publication is owned by a corporation, give the name and address of the corporation immediately followed by the names and addresses of all stockholders owning or holding 1 percent or more of the total amount of stock. If not owned by a corporation, give the names and addresses of the individual owners. If owned by a partnership or other unincorporated firm, give its name and address as well as those of each individual. If the publication is published by a nonprofit organization, give its name and address.) Full Name AHC Media LLC Complete Mailing Address 3525 Piedmont Road, Bldg. 6, Ste 400 Atlanta, GA 30305		
11. Known Bondholders, Mortgagors, and Other Security Holders Owning or Holding 1 Percent or More of Total Amount of Bonds, Mortgages, or Other Securities. If none, check box → <input type="checkbox"/> None Full Name Thompson Publishing Group Inc. Complete Mailing Address 805 15th Street, NW, 3rd Floor Washington, D.C. 20005		
12. Tax Status (For completion by nonprofit organizations authorized to mail at nonprofit rates.) (Check one) The purpose, function, and nonprofit status of this organization and the exempt status for federal income tax purposes: <input type="checkbox"/> Has Not Changed During Preceding 12 Months <input checked="" type="checkbox"/> Has Changed During Preceding 12 Months (Publisher must submit explanation of change with this statement)		
PS Form 3526, September 1999 See instructions on Reverse		

CME Questions

17. Joseph J. Fins, MD, director of medical ethics at New York-Presbyterian Weill Cornell Medical Center in New York City, says that the challenge in offering palliative care to patients with dementia is that of discerning which is the authentic self.
- A. True
B. False
18. Which state currently has legislation pending that would allow physicians and law enforcement officers to report patients who, in their opinion, should not be allowed to drive, to that state's driver registrar?
- A. Georgia
B. Indiana
C. California
D. Massachusetts
19. The Alzheimer's Association in Chicago suggests that physicians are always the best choice in telling patients with dementia that they can no longer drive.
- A. True
B. False
20. Fixing Sex author, Katrina Karkazis, PhD, MPH, says that the standard protocol for treatment of intersex patients originated with John Money at which institution in the 1950s?
- A. Weill Cornell Medical College
B. Johns Hopkins University
C. University of Minnesota
D. Stanford University Medical School

13. Publication Name Medical Ethics Advisor	14. Issue Date for Circulation Data Below September 2009		
15. Extent and Nature of Circulation			
a. Total No. Copies (<i>Net Press Run</i>)	Average No. of Copies Each Issue During Preceding 12 Months	Actual No. Copies of Single Issue Published Nearest to Filing Date	
(1) Paid/Requested Outside-County Mail Subscriptions Stated on Form 3541 (Include advertiser's proof and exchange copies)	551	487	
(2) Paid In-County Subscriptions (Include advertiser's proof and exchange copies)	304	268	
b. Paid and/or Requested Circulation (3) Sales Through Dealers and Carriers, Street Vendors, Counter Sales, and Other Non-USPS Paid Distribution	0	0	
(4) Other Classes Mailed Through the USPS	7	7	
c. Total Paid and/or Requested Circulation (Sum of 15a and 15b/2)	378	325	
d. Free Distribution by Mail (Copies Complimentary and Other Free)	(1) Outside-County as Stated on Form 3541	12	11
(2) In-County as Stated on Form 3541	0	0	
(3) Other Classes Mailed Through the USPS	0	0	
e. Free Distribution Outside the Mail (Carriers or Other Means)	20	20	
f. Total Free Distribution (Sum of 15d and 15e)	32	31	
g. Total Distribution (Sum of 15c and 15f)	410	356	
h. Copies Not Distributed	141	131	
i. Total (Sum of 15g and h.)	551	487	
Percent Paid and/or Requested Circulation (15c divided by 15g times 100)	92%	91%	
16. Publication of Statement of Ownership Publication required. Will be printed in the November 2009 issue of this publication.	<input type="checkbox"/> Publication not required.		
17. Signature and Title of Editor, Publisher, Business Manager, or Owner President and CEO	Date 9/27/09		
I certify that the information furnished on this form is true and complete. I understand that anyone who furnishes false or misleading information on this form or who omits material or information requested on the form may be subject to criminal sanctions (including fines and imprisonment) and/or civil penalties.			
Instructions to Publishers			
1. Complete and file one copy of this form with your postmaster annually on or before October 1. Keep a copy of the completed form for your records.			
2. In cases where the stockholder or security holder is a trustee, include in items 10 and 11 the name of the person or corporation for whom the trustee is acting. Also include the names and addresses of individuals who are stockholders who own or hold 1 percent or more of the total amount of bonds, mortgages, or other securities of the publishing corporation. In item 11, if none, check the box. Use blank sheets if more space is required.			
3. Be sure to furnish all circulation information called for in item 15. Free circulation must be shown in items 15d, e, and f.			
4. Item 15h, Copies not Distributed, must include (1) newsstand copies originally stated on Form 3541, and returned to the publisher; (2) estimated returns from news agents, and (3), copies for office use, leftovers, spoiled, and all other copies not distributed.			
5. If the publication had Periodicals authorization as a general or requester publication, this Statement of Ownership, Management, and Circulation must be published; it must be printed in any issue in October or if the publication is not published during October, the first issue printed after October.			
6. In item 16, indicate date of the issue in which this Statement of Ownership will be published.			
6. Item 17 must be signed.			
Failure to file or publish a statement of ownership may lead to suspension of second-class authorization.			
PS Form 3526, September 1999 (Reverse)			