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September 2011: Vol. 27, No. 9  
Pages 97-108

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## How present is the idiom 'off the record' in healthcare?

**W**hat is an ethical physician to do when a patient provides pertinent information but insists that it be kept “off the record?” While there is an expectation of confidentiality between doctor and patient, there are instances when a patient will only reveal certain information if the doctor agrees not to record it in their medical files. While most patients wouldn't expect a doctor to keep anything secret, some doctors have found that this situation happens more often than they are comfortable with.

Ethical issues can arise when a patient has waived confidentiality and agreed to release their medical records to others, such as an employer or insurance company. After the patient has made this waiver, has he lost his right to ask that something be kept “off the record”? Is a physician responsible for keeping the secrets of a patient, at his request, even after he has specifically said to others that he is releasing his information? Furthermore, how does this affect making critical decisions based on the assumed accuracy of the records?

Ethical dilemmas also extend to safety of the patient and other healthcare workers, because medical records are meant to convey all information to other healthcare providers, says **Deborah L. Kasman MD, MA**, medical bioethics director, Kaiser Permanente Medical Center, Baldwin Park, CA. “If I do not record an incident of domestic abuse after seeing bruises, and another provider sees bruises, he or she might run tests looking for a blood disorder,” Kasman says. “The patient's true cause of the problem may continue untreated.”

She notes that if the record of domestic abuse is not included, the next provider also could make an inaccurate assessment of high blood pressure,

### EXECUTIVE SUMMARY

Ethical issues arise when a patient has waived confidentiality and agreed to release their medical records to others, such as an employer or insurance company, yet ask their physician to keep certain information “off the record.”

- Some doctors have found that this practice is happening more often.
- Patients might be attempting to avoid possible consequences of having their condition documented such as significant past medical history, results of drug testing, or extra-marital sexual encounters.
- The ramifications of keeping information off the record will vary with the type of information.

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anxiety, depression, or another condition, and mistreat the root of other problems. “I use this example, because if domestic abuse is in the chart, the patient may feel embarrassed, and if the perpetrator saw the documentation, there could be inflammatory consequences at home,” Kasman says. “I also use this example, because if there is suspected domestic abuse, and the perpetrator is not convicted, there are other implications to this record in the chart.”

A patient’s request that healthcare-related information be kept off the record, places the physician in a difficult situation. While physicians are obligated to protect a patient’s private information and to maintain confidentiality, they are also obligated to

keep accurate records of relevant information, to avoid harm to patients, to make treatment recommendations that are likely to benefit the patient, to be responsible stewards of healthcare resources, and to protect their colleagues from harm, says **Felicia Cohn, PhD**, bioethics director at Kaiser Permanente, Orange County, CA. “Such a request creates an ethical conflict between these values,” Cohn says. “Which values conflict will depend on the actual circumstances of the request.”

Key considerations include the precedent the act will establish and both the short-term and long-term consequences of the act to the patient and others, she says. “While electing to prioritize confidentiality may appear justified or inappropriate in the immediate situation, reflection on the implications is important,” Cohn says.

Another ethical dilemma concerns the provider-insurer relationship, Kasman says. “A bill is still generated,” she says. “When the diagnosis codes on the billing form are inaccurate, in essence the provider could be considered to [be lying] to the insurer.”

Although these so-called lies might take the form of lying by omission, it launches the slippery slope between trust with the insurers for accurate billing information, according to Kasman. “On the small end of the scale, it could be considered stretching the truth, unless the provider truly does not bill for his or her time for the issue,” she says. “But if lab tests or cultures are required, then the billing coding, again, could in essence be a lie. This is the start to what, in the most excessive of situations, could be considered fraud.”

**Lee Tannenbaum, MD**, board certified addiction specialist, Bel Air Center for Addictions, Bel Air, MD, notes, “I think that patients think that things are more ‘off the cuff’ than they actually are. It is only when patients begin to think about specific pieces of information, and they are involved in some type of process where they are at risk for having their medical records examined, that they think of asking for off the record.”

According to Cohn, the most important thing a physician can do is to ask the patient, ‘why?’ “An informed response will be much more effective than one based on assumptions or an emotional reaction,” she says. With this knowledge, the physician can address the reasons for the request and the implications for honoring it or not, and work with the patient to determine what and how best to document, says Cohn. “Patients often share information with their healthcare professionals that they would not reveal even to family or close friends. Some of this information is relevant to their health, while

Medical Ethics Advisor® (ISSN 0886-0653) is published monthly by AHC Media, a division of Thompson Media Group 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 105109, Atlanta, GA 30348.

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#### EDITORIAL QUESTIONS

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other information may not be.”

The physician should work with the patient to assess the options available, such as honoring the request, documenting fully, documenting only what is necessary, and using alternative language, she suggests.

## **Suffering the consequences?**

Tannenbaum believes some patients are attempting to avoid possible consequences of having their condition, or the extent of their condition documented.

Significant past medical history, results of drug testing or history of drug use, and extra-marital sexual encounters are a few of instances in which a patient would ask a physician to keep mum, and these situations are ones in which it gets tricky. “It gets to the core of trying to help people and the idea that I should do no harm. I want to be able to help patients get appropriate healthcare and avoid preventable consequences,” says Tannenbaum. “For example, I would want a patient who had contracted a sexually transmitted disease from an extra-marital affair to be able to get effective treatment, but if he fails to confide in me, because of his fear of what will be in his permanent medical record, this may not happen, and he could in fact go on to put others at risk,” he says.

In a worst case scenario, a physician could harm a patient by hiding information, Kasman says. “If the hidden information causes medical harm to the patient, the doctor could be accused of malpractice, and the harm to the patient could lead to a justifiable settlement,” she says. Also, if the insurance company finds out about ‘mis-coding’ to protect the patient, they can drop the physician from their panel. “I suspect there could be fines or charges related to medical fraud, regarding miscoding to the insurers,” says Kasman.

“I would say this form of having the patient influence record keeping does not occur that often, but does occur, possibly more often with employment physicals. Someone could ask to keep past medical illness off the form for an insurance physical, but that is fraud, and would have consequences to the doctor.”

## **An issue of trust**

If the doctor agrees to collude with the patient, he is forfeiting the trust of the court system, employers, insurance companies, and others, says Tannenbaum.

There are two sides to the trust issue, Kasman

says. “If I lie in the chart to protect my patient and to gain their trust, to protect the patient, essentially I am practicing a form of paternalism, she says. “I am also asking the patient to trust me because I will lie for them.”

She believes that in the long run, the patient can ask for the physician to lie on the chart, and lie to the insurers for their benefit, they could also ask if the physician is lying to them, and it could erode trust. “So this issue of being true to one’s profession, is clearly an ethical issue that impacts the [concern] of patient trust,” Kasman says.

According to Cohn, there are several other reasons why a patient would want certain information kept off the record. “An athlete may wish not to document an injury or condition that might limit or preclude his ability to play; a patient diagnosed with HIV may want to avoid the stigma associated with that diagnosis or difficulties obtaining insurance due to this pre-existing condition,” says Cohn. Other reasons could be an employee seeking to remain on disability might not want his recovery documented. “A young girl may fear that her parents will learn of an unintended pregnancy or a sexually transmitted disease. A woman may fear that her abusive partner will discover she disclosed the source of her injuries and will punish her for doing so. There will be good reasons and bad, based in fear, embarrassment, misunderstanding, and other emotions and concerns,” says Cohn.

The problem is significant, Tannenbaum says. “It puts me in the position of violating professional codes of conduct, it exposes me to malpractice concerns, and it changes the rules of the doctor/patient relationship. The patient is asking me to become more of a friend to them than a physician, willing to jeopardize my personal welfare and ethics on their behalf,” he says. “This is a boundary that I do not want to cross.”

## **The rights of the patient**

While a patient does have rights, they cannot expect an insurance company to pay for care without certain information, such as a diagnosis, according to Tannenbaum.

“I will document everything for my own protection, but the patient does not have to reveal to anyone that he has seen me for any reason or consent to the release of his medical records,” he says. “If the patient chooses to lie on an insurance form, or in court, that is their prerogative; however, a patient does not have the right to ask me to be complicit in their attempts to commit fraud.”

Cohn notes that though there are requirements regarding some documentation — for example, prescriptions or informed consent — what is written in the medical record is largely a matter of health-care professional discretion. Documentation varies based on training, experience, the patient’s needs, the perceived relevance to clinical care, and even the time available for documentation and the clinician’s memory.

“The ramifications of keeping information off the record will vary with the type of information, Cohn says. “For example, there may be no ramifications, responsibility for harms to a patient, responsibility for harms to other healthcare professionals, or legal issues such as accusations of insurance fraud.”

## SOURCES

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# Study eyes EOL trends for Medicare patients

*Findings indicate more time is spent in the ICU*

A new study from the Dartmouth Atlas Project seems to indicate the “report card” for Medicare patients at the end of life (EOL) is a mixed bag of pluses and minuses.

On the positive side, the study, “Trends and variations in end-of-life care for Medicare beneficiaries with severe chronic illness,” showed that Medicare beneficiaries with severe chronic illness spent fewer days in the hospital at the end of life in 2007 than they did in 2003, and they were less likely to die in a hospital and more likely to receive hospice care. On the other hand, they were more likely to be treated by 10 or more doctors in the last six months of life in 2007 (36.1%) than they were in 2003 (30.8%), and the average number of days in the intensive care unit (ICU) increased to 3.8 from 3.5.

“The fact that these patients are spending less time in the hospital is connected with the fact that they are spending more time in hospice,” notes lead author **David Goodman**, MD, MS, the co-principal investigator of Dartmouth Atlas of Health Care, professor of pediatrics and of health policy, and director,

Center for Health Policy Research, at the Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH. “But the fact remains that these are the two domains where patients receive higher-intensity care, and there were more ICU days. And it’s not just the ones left in the hospital who are sicker patients; there are more numbers of ICU days across the entire population of those who died, so there is a real increase of ICU care in this population. Patients certainly spend less time on general hospital wards, but they spend more time on the ICU.”

Goodman says the medical profession is uncertain as to the reason for this situation and adds, “This is not true for every hospital. It’s fascinating that there are some hospitals where their change is in parallel with this study, while others have defied this general trend.”

In other words, he says, it is not the “destiny” of any specific facility to have these patients spend more time in the ICU. “I think one of the important factors that tend to shape the local experience is how local healthcare systems invest and what they invest in,” says Goodman. “Places that make relatively greater investment into ICU units can be providing valuable care for certain patients, but they can have unintended consequences as well.”

## Trends must be reversed

Goodman says that for things to improve in hospitals, health systems and providers must “unlearn” certain assumptions. “In places that have grown their population of physicians and subspecialists, that is the capacity that gets used,” he explains.

“I am a trained physician,” he continues. “The classic way we think of ourselves is that our job is to gather as much information as we can about the patient and their condition. We have knowledge of treatments, we learn about the patient’s condition, and we make a recommendation.”

But that common role of making recommendations does not work today, says Goodman, and it won’t in the future, particularly for very sick patients. “It assumes we understand all of the care options, and often we don’t,” he says. “Oncologists, for example, are very much focused on curative care, but they won’t be experts on palliative care. They may not understand what the patients’ values are; studies have shown that doctors often use their own value sets. That approach is well-intentioned, but it misses the mark.”

What’s more, there is no correlation between intensity of care and measures of technical quality, Goodman continues. “When you spend many more

days in a hospital ICU, you see many different doctors, but the quality of care tends to be lower,” he says. “We think that’s because care becomes disordered. There are more handoffs, and more chances for missed communication.”

In addition, he says, electronic medical records (EMRs) do not solve that problem. “EMRs rarely extend to full care, especially in chronic care facilities,” Goodman says.

## Reduce spending, improve quality

Risa Lavizzo-Mourey, MD, MBA, president and CEO of the Robert Wood Johnson Foundation, a long-time funder of the Dartmouth Atlas Project said that another implication of the study’s findings is that “providers can look for insights into potential savings they can achieve through improved care of chronic illness that allows patients to remain safely out of the hospital.” Lavizzo-Mourey released the statement to accompany the study’s publication.

Goodman agrees. “We shouldn’t be surprised we’re spending more money on healthcare than any other developed country in the world, but there might be opportunities to do a better job with less money, particularly when some patients get expensive care they do not want,” he says. “There are opportunities for accomplishing greater efficiencies thoughtfully. I’m not talking surgery with dull tools, but crafting our models of care and reimbursements so we can deliver higher quality for less cost.”

End-of-life care is one place where we know if patients get palliative care services early in the care of chronic illness, they have a much better experience, he says. “They generally have a lower intensity of care, which saves money, and at least in cancer care, there are studies that show they actually live longer,” says Goodman.

### SOURCE

For additional information, contact

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## Informed consent docs should be short, sweet

An in-depth review of consent forms provided to volunteers for HIV/AIDS research in the United States and abroad about study procedures, risks, and

benefits has found that the forms were extremely long and used wording that might have been complex enough to hinder full understanding, according to bioethicists at The Johns Hopkins University in Baltimore, MD.

A systematic analysis of 124 informed-consent documents for U.S. government-sponsored, multinational HIV/AIDS research conducted in 2006 revealed that the forms spanned more than 20 pages, says the study’s lead investigator, **Nancy Kass**, ScD, deputy director for public health at the Johns Hopkins Berman Institute of Bioethics in Baltimore, MD. “While we were familiar with many fairly long consent forms for several different types of studies, we were honestly surprised to see that the median length was 22 pages, and the median length for adult forms was a full 27 pages,” Kass says.

Their study, described in the August issue of the *Journal of General Internal Medicine*, and funded by the National Institute of Allergy and Infectious Diseases, also found that commonly misunderstood research concepts — namely, randomization and placebos — seemed to be explained with far less attention. For instance, whereas confidentiality sections had a median length of about two pages, randomization was treated to just 53 words.

Randomization is one of science’s most trusted tools for minimizing biases in studies. But when studies spend so much time explaining why they are testing a new medicine or approach, and so little on randomization itself, participants might be left not realizing that half of them will get a different medicine, or perhaps no medicine at all, Kass points out. This “unfortunate” trend might be because research regulations don’t require that forms explain such concepts, she says. Indeed, her study shows that researchers spend considerable time on the key concepts regulations require them to cover, such as purpose, procedures, and risks.

Kass also found that most of the forms weren’t as readable as they should be. Generally, institutional review boards recommend that consent documents be written at or below the eighth-grade level. But the majority of the forms that Kass reviewed required readers with at least a ninth-grader’s comprehension. Such findings, while still not meeting commonly agreed-upon standards, demonstrate lower readability than consent form studies from decades past.

By making informed consent documents so long and complex, researchers neglect their ethical duty to describe their research in ways that help participants truly understand, Kass concludes. In this study, all of the consent forms were based on templates provided by the funder, and researchers themselves might have

had little authority to change or shorten them.

“In this study, the forms that researchers were given by their funders as models — what we call ‘template’ forms — were themselves very, very long,” Kass explains. “I imagine many researchers wish they could use methods that were not only shorter, but maybe that used strategies other than written communication altogether.”

The authors cite data on literacy rates in the United States and abroad, in light of the rise in research in developing countries, where half or more of the populations are illiterate. For instance, literacy rates in India, Bangladesh, and Senegal are 63%, 55%, and 42%, respectively. Almost half of Americans read at or below the eighth-grade level, the authors state.

As long as these template forms, which come from research funders, remain lengthy, the investigators and review boards in the field will assume they must use those forms, Kass says. So, the overall goal of the study is to supply hard facts that policy specialists can use as they consider developing recommendations for shortening and simplifying consent forms, or for, otherwise, helping participants in complex clinical research understand what they are joining.

## RESOURCE

“Length and complexity of U.S. and international HIV consent forms from federal HIV network trials,” can be found at <http://www.springerlink.com/content/n2671q0593647610>. ■

## Awards to honor palliative, EOL care

*7 recognized as Circle of Life honorees*

The Circle of Life Award celebrates programs across the nation that has made great strides in palliative and end-of-life care. This is the 12th year for the Circle of Life Award.

Circle of Life nominations were received and reviewed by a selection committee that included leaders from medicine, nursing, social work, and health administration. The committee visited programs that respect patient goals and preferences, provide comprehensive care, acknowledge and address the family or caregivers’ concerns and needs, and build systems and mechanisms of support that will ensure that the programs continue. The programs selected serve as innovative models for other

communities.

Three programs that expand the reach of palliative and end-of-life care will be recognized as the 2011 recipients of the Circle of Life Award: Celebrating Innovation in Palliative and End-of-Life Care, along with four others that will be awarded Citations of Honor.

The programs share overriding themes of compassion, dedication, and collaboration. **Gilchrist Hospice Care** in Hunt Valley, MD, has successfully integrated palliative care across hospital, hospice services, physician groups, patient homes, and long-term care and assisted living facilities. **St. John Providence Health System** in Detroit has hardwired palliative care into every service and educated staff, so that no matter where an individual enters the system, they are evaluated for palliative care needs. **The Center for Hospice & Palliative Care** in Cheektowaga, NY, provides an extensive care continuum and a sophisticated palliative care institute, with strong emphasis on collaboration, physician leadership, and clinical research.

Each of these innovative programs recently received a Circle of Life Award at a ceremony in San Diego.

“A patient needing palliative or end-of-life care faces difficult challenges that must be addressed with skill and unique expertise,” said AHA president and CEO, **Richard Umbdenstock, FACHE**. “These winners exemplify what the healthcare field is striving for: compassionate care for patients and families at all times. These innovative programs serve as guiding lights for others on this path.”

Citations of Honor were awarded to:

- **Dartmouth-Hitchcock Medical Center** in Lebanon, NH, in recognition of its strong commitment to inpatient and outpatient palliative care, regional focus, and end-of-life and palliative care research and education;
- **John H Stroger Jr. Hospital** of Cook County in Chicago for its commitment to treating a diverse population with complex needs, including helping dying immigrant patients fulfill wishes to return to home countries;
- **St. Mary’s Healthcare System** in Athens, GA, for embedding palliative care throughout the hospital and a culture change on the community level;
- **University of Pittsburgh Medical Center** in Pittsburgh, for providing close to seamless palliative care delivery and working to spread palliative care across the entire 18-hospital system.

The 2011 awards are supported, in part, by the California HealthCare Foundation, based in Oakland, CA, and the Archstone Foundation

in Long Beach, CA. Major sponsors are the American Hospital Association, the Catholic Health Association, National Consensus Project for Quality Palliative Care, and the National Hospice and Palliative Care Organization & National Hospice Foundation. The American Academy of Hospice and Palliative Medicine and the National Association of Social Workers are Circle of Life cosponsors. The Circle of Life Award is a program administered by the Health Research & Educational Trust.

## RESOURCE

For more information on the Circle of Life Awards, visit [www.aha.org/circleoflife](http://www.aha.org/circleoflife). ■

# Chatting about faith boosts patient approval

**H**ospitalized patients who had conversations about religion and spirituality with the health-care team were the most satisfied with their overall care. However, 20% of patients who would have valued these discussions say their desires went unmet, according to a new study by Joshua Williams from the University of Chicago and his colleagues.<sup>1</sup> Their work appears online in the *Journal of General Internal Medicine*.

Religious and spiritual concerns are particularly prominent during times of illness, suffering, and death. Some medical leaders and policymakers in the United States have urged healthcare systems and providers to give due attention to patients' spiritual concerns. However, there is disagreement about which members of the healthcare team should ask about and address these concerns. According to hospitalized patients in this study, whom they speak to makes no difference. The important factor appears to be that they have these discussions.

Williams and team analyzed data collected between January 2006 and June 2009 on 3,141 patients enrolled in the University of Chicago Hospitalist Study. In particular, the authors were interested in whether patients wanted to have their religious or spiritual concerns addressed in the hospital, whether anyone talked to them about religious and spiritual issues, and which member of the healthcare team spoke with them about these issues. They also looked at patient-satisfaction ratings for overall hospital care.

They found that 41% of patients wanted to discuss religious or spiritual concerns with someone while in the hospital, and 32% of all patients said

some discussion did occur. Among those who had taken part in discussions, 61% spoke with a chaplain, 12% with a member of their own religious community, 8% with a physician, and 12% with someone else.

Half of the patients who wanted a discussion did not have one (20% of patients overall), and one in four who did not want a conversation about spiritual issues had one anyway. "It did not appear to matter if patients said they wanted such a conversation," said the study's senior author, **Farr Curlin**, MD, associate professor of medicine at the University of Chicago. "Even patients who did not want the conversation had higher rates on all four of the study's patient-satisfaction measures." Those measures were: satisfaction with the doctors' care, always had confidence and trust in doctors, excellent teamwork among doctors and nurses, and overall care was excellent.

The authors also found that older patients, African Americans, women, those who were less educated, and those in severe pain were more likely to have discussed their religious and spiritual concerns with someone in the hospital.

The authors conclude: "Many more inpatients desire conversations about religious and spiritual concerns than actually experience such conversations. Our findings suggest that physicians, nurses, healthcare organizations, and pastoral care departments may address an unmet need and simultaneously improve patient satisfaction by talking to patients about religious and spiritual concerns in the inpatient setting."

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# Veterans, families, and end of life

**A**bout 25% of all Americans who are dying are veterans. Yet only 4% of dying veterans die within the Veterans Affairs (VA) Healthcare Network; most veterans are cared for by hospice and healthcare professionals in the community.

Veterans share a unique culture. However, veterans from different wars might have had different experiences in battle or upon returning home, and

these experiences might greatly impact end-of-life care.

The concept of stoicism is taught to soldiers for a valuable reason: it is essential on the battlefield. But when a veteran is facing illness and death, being “strong” and not allowing oneself to experience pain can sometimes interfere with peaceful dying or effective bereavement.

Some veterans who served in a dangerous duty assignment might have post-traumatic stress disorder (PTSD). If PTSD surfaces at the end of life, counselors should be contacted to respond to the veteran’s needs.

Many hospices use veterans and their family members as hospice volunteers. Pairing a veteran volunteer with a dying veteran patient often results in a strong, mutual camaraderie; veterans and their families have a strong sense of unity toward each other.

Hospices and other organizations can find ways to thank veterans for serving their country, as well as thanking family members who are often the “unsung heroes.” Certificates of gratitude or an American Flag pin are simple yet meaningful ways to demonstrate that their service and sacrifice are valued.

Some veterans have seen, or feel they have caused, trauma that still troubles them. Hospice professionals can appropriately explore a possible need for forgiveness, which might facilitate inner peace. ■

## Obese children to be placed in foster care?

According to a commentary that appears in *The Journal of the American Medical Association* (JAMA), two Harvard doctors believe that severely obese children should be placed in foster care.<sup>1</sup>

The writers of this commentary pose the question, is extreme obesity considered medical neglect? Although this proposition will not happen anytime soon, if at all, just the discussion alone has sparked a great deal of controversy and outrage.

While admonishing an overweight child to foster care might seem like an extreme last resort, the writers of the commentary insist that the lack of skilled parenting is one of the key reasons for an obese child. This statement has sparked an intense debate all around the country on the internet and other media outlets.

The authors of the commentary say that many biological, psychosocial, and behavioral factors affect energy balance and therefore, any excessive weight

gain by a child is primarily the fault of the parents. That would make it the parents responsibility to help the child ignore ever-present junk food marketing, make sure the child is physically active on regularly and promote other healthy lifestyle choices. The authors blames “parenting deficiencies” which can contribute or cause weight issues with children.

Inadequate or unskilled parenting can leave children vulnerable to obesigenic environmental influences, according to the commentary. The writers say that emotional distress and depression, or other psychological problems arising from abuse or neglect, might exacerbate the situation by leading to disordered eating and withdrawal from sports and other social activities.

The commentary says that foster care is more ethical than obesity surgery because long-term effects of the operation in children are unknown. It goes on to say that in severe instances of childhood obesity, removal from the home might be justifiable from a legal standpoint because of imminent health risks and the parents’ chronic failure to address medical problems.

While there are certain cases when children are placed in foster care due to medical neglect, it usually occurs when there are life-threatening consequences.

## REFERENCE

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## Ethics office supports community researchers

### *Guidance and resources offered*

Seeing a need for ethics guidance for local groups attempting to conduct community-based research, an organization in Kitchener, Ontario, has created an independent Community Research Ethics Office (CREO).

The recently launched CREO, housed in an existing community research center, provides guidance for investigator’s planning projects, as well as online resources and its own research ethics board (REB, the equivalent of a U.S. IRB), to review proposals as needed.

Norah Love, MA, coordinator of the CREO, says it came in response to requests from local community researchers. In 2008, the Centre for Community Based Research, which has served the area for nearly

20 years, invited researchers to talk about the challenges they faced. “The overwhelming response from that meeting was that there is a need for more support in our region for community-based research,” Love says. The center launched a needs assessment and feasibility study and brought back a proposal for the formation of a CREO in 2010.

Researchers assisted by the CREO will include those from not-for-profit organizations or independent consultants conducting social science research. Projects also can include activities not always seen as research, such as program evaluations and needs assessments. **Bill Marr**, PhD, chairman of the REB at nearby Wilfrid Laurier University and now the CREO’s REB chairman, says Canadian regulations do not cover these types of activities.

“Although there is privacy legislation in Canada, there’s really not legislation either at the federal or provincial level that covers what you and I would understand as the ethical norms of collecting information from people,” Marr says.

## Unaffiliated researchers

In Canada, research conducted through an institution that receives funding from government agencies would require the use of an established REB. But the CREO notes that research increasingly is being conducted outside of these types of institutions.

Unaffiliated groups say they want support on ethical issues without having to partner with a university or other institution to obtain it, Love says.

“People want to have review of a project for their own quality assurance purposes,” she says. “They want partnerships for the sake of partnerships as opposed to partnerships for the sake of having a review.”

The CREO provides support in several ways, depending upon the researcher’s needs. A consultation service can help identify potential ethical issues with a project and guide the researcher in addressing them. The CREO can provide training sessions or workshops for researchers and community members involved in studies. If the researcher wishes, he or she can submit a proposal to the CREO REB for a formal review. A web site ([www.communityresearchethics.com](http://www.communityresearchethics.com)) provides links to useful information about ethical issues.

“One thing that was quite evident from community forums was that organizations wanted a web site where they could go and find information about things like how to undertake community-based research, how to do it ethically,” Marr says.

Love says there are many sets of guidelines avail-

able, but no complete agreement as to how to handle these issues. “There’s no one set of guidelines they can go to to learn how to train community researchers, for example,” she says. “They have to sift through so many resources, and they don’t have a clear understanding of what the best practices are. [Researchers] are hoping to have a place or a group in the community that can help be a consistent voice for community-based research and how to conduct it.”

In addition to Marr, there are 10 other members of the volunteer REB, including those with experience as researchers, former participants, and those with REB experience. “We wanted to have a multi-disciplinary mix,” Marr says.

## Researching the research needs

A major strength of the CREO’s approach is that it did its own community-based research before going forward with a plan, Love says. Other communities in the United States and Canada who are interested in the idea should not skip those important steps of engaging the community to be served and listening to their concerns and suggestions upfront, she says.

“We really did model community-based research in the development of a community research ethics office,” she says. “The idea is that if we’re developing something collaboratively, then hopefully it will be of use to the people who developed it in the first place.”

One challenge for the office will be funding. Its pilot year has been funded by a grant from an Ontario government foundation, but Love and Marr are unsure where continuing funding will come from. ■

## Medical profession said hurt by violations

Doctors need to become more aware of how governments subtly, but profoundly, interfere with their professional obligations and results in patients’ human rights being violated, says a law scholar at the Johns Hopkins Berman Institute of Bioethics in Baltimore, MD, in a commentary recently published in *The Journal of the American Medical Association* (JAMA).<sup>1</sup>

Social policies restrict physicians from doing what’s best for certain patients, says co-author **Leonard Rubenstein**, JD, an associate faculty

member at the Berman Institute. The piece was co-written by Farrah Mateen, MD, a Sommer Scholar in the Department of International Health at the Johns Hopkins Bloomberg School of Public Health, in Baltimore, MD.

The authors cite glaring human rights violations overseas. In Turkey, doctors have been asked by schools and state institutions to verify a female's virginity, with nearly half of Turkish physicians in a survey saying they have performed such examinations. In the 1990s, doctors in Peru carried out a government policy to sterilize rural, indigenous people, including a reported 300,000 tubal ligations and 20,000 vasectomies.

The article also details how government-enforced human rights violations occur in Egypt, where men suspected of having homosexual sex have been forced to undergo anal inspections by doctors from the Forensics Medical Authority, an agency of Egypt's Ministry of Justice. "While physicians can't address these infringements on their own, they can and should act collectively to stand up for the human rights of patients, both for their own sake and in order to fulfill their professional obligations," says Rubenstein, who focuses on the intersection of bioethics and human rights. "In many countries, restrictions on providing medication for pain are so draconian as to prevent doctors from meeting patients' needs for pain relief."

Rubenstein says the issue is largely unrecognized in the United States, even though examples abound of how laws in this country undermine professionalism in medical practice. For instance, in North Dakota, the state outlawed an approved pill for first-trimester abortions, which then forced doctors to perform a surgical abortion, even though most physicians would say a drug is safer and less intrusive, Rubenstein says. (A state court recently issued a temporary injunction against this law.)

In the United States, Rubenstein contends that the most notorious example of how some laws result in human rights violations and thwart doctors' efforts to act on professional judgment is the treatment of Guantanamo Bay detainees by military physicians. Rubenstein points to doctors who force-fed inmates on hunger strike at the facility through the use of five-point restraint chairs, based on command decisions rather than independent clinical judgment. "It is worth noting, too, that U.S. policy requires physicians to act contrary to international and domestic ethical standards," says Rubenstein, a senior scholar at the Center for Public Health and Human Rights at the Bloomberg School of Public Health. "We also know that doctors at

Guantanamo were constrained in the medical interventions they could provide for detainees who were tortured."

The *JAMA* essay begins by explaining how the trust placed in physicians rests on the assumption that they will follow three fundamental principles of professionalism: acting in patients' best interests, respecting their autonomy, and heeding social justice concerns -- in other words, considering available resources and the needs of all patients, while at the same time taking care of an individual patient.

The article also asserts that more systemic biases, which doctors cannot defeat through individual actions, can discourage them from following those principles in unseen ways. For example, the passage of prejudice against certain groups, such as those at higher risk of HIV infections, can perpetuate the devaluation of those groups and lead to restrictions on appropriate clinical options for physicians. In the article, the authors say such stigma has led some "governments to minimize education on treatment and management of HIV patients."

The authors conclude that physicians have an obligation to address threats to human rights and medical professionalism, if not by isolated acts, then through collective advocacy. Doctors should turn to professional societies to provide leadership and increase public awareness on human rights.

"Organizations like these can protect physicians from becoming tools for discriminatory or cruel treatment of patients," Rubenstein says.

## REFERENCE

1. Mateen FJ, Rubenstein LS. Government policies in violation of human rights as a barrier to professionalism. *JAMA* 2011. Doi:10.1001/jama.2011.1082. ■



## Call for renewal of bioethics in military

Bioethicist Steven Miles, MD, professor, University of Minnesota in Minneapolis, has called for a renewal of military medical ethics in

the United States.

In a recent *Bioethics* article, Miles says that medical ethics in the United States “has not articulated a vision to strengthen the military-civilian dialogue to ensure that standards of medical ethics do not evolve simply according to the dictates of military policy.”<sup>1</sup>

The trial of Nazi medical leaders at Nuremberg “had a profound effect on research ethics,” and U.S. experiences, including exposing soldiers to thermonuclear blasts, during the Cold War “all led to debate and policy change,” he said. However, Miles is concerned that lessons have not been learned from what he sees as more recent violations of medical ethics in the U.S. military.

He criticized how the American Medical Association (AMA) responded to the mistreatment of prisoners at Abu Ghraib prison in Iraq. He also claimed that prophylactic drugs were administered to 250,000 deployed soldiers to protect them from potential exposure to chemical or biological weapons in combat, but he says that the efficacy of these drugs “was theoretically plausible but not clinically proven.”

## REFERENCE

1. Miles SH. The new military medical ethics: legacies of the Gulf Wars and the War on Terror. *Bioethics* 2011. Doi: 10.1111/j.1467-8519.2011.01920.x. ■

## Stem cell law thrown out

A lawsuit that had threatened to end the Obama administration’s financing of embryonic stem cell research recently was thrown out.

The decision, by Chief Judge Royce C. Lamberth of Federal District Court for the District of Columbia, will allow the United States to continue supporting a search for cures to deadly diseases over protests that the work relies on destroyed human embryos.

Administration policy allows research on embryonic stem cells that were acquired long ago through private funding or from embryos that parents have donated after being informed of other options such as donating to an infertile woman. ■

## Medicare hospice faces scrutiny

Government auditors recommended increased federal oversight of hospices after an analysis found that palliative care for nursing home patients has jumped by nearly 70% since 2005.

*continued on p. 108*

### CME INSTRUCTIONS

To earn credit for this activity, please follow these instructions.

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### CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

### COMING IN FUTURE MONTHS

- The bioethics of HIV testing
- Is there a new Hippocratic Oath?
- Disaster preparedness for the mentally impaired
- Ethical issues in palliative sedation

A report by the Department of Health and Human Services (HHS) Office of Inspector General (OIG) says that some hospices might be seeking out patients in nursing homes who meet certain characteristics and have a greater chance of living longer. The report called on the Centers for Medicare & Medicaid Services (CMS) to reform the program's payment system to lessen the incentive for this strategy.

This development is also making waves because previous OIG work had found many hospice claims for nursing facility patients to be improper, according to reports. The report goes on to say that in 2006, 82% of claims reviewed by the OIG did not meet the requirements for Medicare coverage. ■

## CME QUESTIONS

1. According to medical ethics experts, what are possible ramifications of keeping patient information "off the record?"
  - A. Responsibility for harm coming to a patient.
  - B. Possible accusations of insurance fraud.
  - C. Responsibility for harms to another healthcare professional.
  - D. All of the above
2. What percentage of hospitalized patients who would have had valued conversations about religion and spirituality with the healthcare team said their desires went unmet?
  - A. 10%
  - B. 20%
  - C. 43%
  - D. 66%
3. Review boards recommend informed consent documents be written at or below what grade level?
  - A. Ninth grade
  - B. Fifth grade
  - C. Eighth grade
  - D. 12th grade
4. True or False: According to a commentary that appears in The Journal of the American Medical Association (JAMA), the authors say one of the key reasons for an obese child is the lack of skilled parenting.
  - A. True
  - B. False

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