MEDICAL ETHICS ADVISOR®

FOR OVER 25 YEARS, YOUR PRACTICAL GUIDE TO ETHICS DECISION MAKING

JUNE 2016 Vol. 32, No. 6; p. 61-72

## INSIDE



# Experts: Create Hospital Policies on Ethics of Deactivating ICDs

*Provide institutional support*

Recently, a letter from the family of a man who died of lung cancer was presented to University of Michigan Health System in Ann Arbor's ethics committee. "It spurred the development of an organizationwide policy for deactivation of implanted cardiac devices," says **Adam D. Marks**, MD, MPH, a clinical ethicist and associate director of the university's Hospice and Palliative Medicine Fellowship.

The clinical team had transitioned the man to comfort measures to allow a natural death, but he entered into a prolonged dying phase. For the next several days, he was unconscious and unresponsive.

"This was dragging on longer than the physician or family anticipated," recalls Marks. "They asked if we were doing anything that was prolonging the dying process."

The family asked if the pacemaker could be deactivated. Clinicians declined to do so because they viewed it as euthanasia. "The family found it extremely distressing," says Marks.

## EXECUTIVE SUMMARY

Addressing implantable cardiac devices in hospital policies on withdrawal of life-sustaining interventions can support clinicians and prevent arbitrary decision-making. Bioethicists can do the following:

- Educate providers on the ethical consensus that pacemaker deactivation is not considered euthanasia.
- Work hard to resolve concerns of resistant clinicians.
- Explicitly include pacemakers, implantable cardioverter-defibrillators, and left ventricular assist devices.



**Financial Disclosure:** Consulting Editor **Arthur R. Derse**, MD, JD, Nurse Planner **Susan Solverson** BSN, RN, CMSRN, Managing Editor **Jill Drachenberg,** Associate Managing Editor **Dana Spector,** and Contributing Editor **Stacey Kusterbeck** report no consultant, stockholder, speakers' bureau, research, or other financial relationships with companies having ties to this field of study.

AHC Media

MEDICAL ETHICS ADVISOR®

***Medical Ethics Advisor®,***
ISSN 0886-0653, is published monthly by
AHC Media, LLC
One Atlanta Plaza
950 East Paces Ferry Road NE, Suite 2850
Atlanta, GA 30326.

Periodicals Postage Paid at Atlanta, GA 30304 and at additional mailing offices.
GST Registration Number: R128870672.

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

**SUBSCRIBER INFORMATION:**
Customer Service: (800) 688-2421.
customerservice@ahcmedia.com.
www.AHCMedia.com
Hours of operation: 8:30 a.m.-6 p.m. Monday-Thursday; 8:30 a.m.- 4:30 p.m. Friday.

**SUBSCRIPTION PRICES:**
U.S.A., Print: 1 year (12 issues) with free CE nursing contact hours, $519. Add $19.99 for shipping & handling. Online only, single user: 1 year with free CE nursing contact hours, $469. Outside U.S., add $30 per year, total prepaid in U.S. funds.

**MULTIPLE COPIES:** Discounts are available for group subscriptions, multiple copies, site-licenses, or electronic distribution. For pricing information, please contact our Group Account Managers at Groups@AHCMedia.com or 866-213-0844.
Missing issues will be fulfilled by customer service free of charge when contacted within one month of the missing issue's date.

**ACCREDITATION:** 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 enduring material for a maximum of ***1.5 AMA PRA Category 1 Credits™***. Physicians should only claim credit commensurate with the extent of their participation in the activity.

AHC Media is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. This activity has been approved for 1.5 nursing contact hours using a 60-minute contact hour.

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.

**MANAGING EDITOR:** Jill Drachenberg (Jill.Drachenberg@AHCMedia.com)
**ASSOCIATE MANAGING EDITOR:** Dana Spector
**DIRECTOR OF CONTINUING EDUCATION AND EDITORIAL**: Lee Landenberger.



**EDITORIAL QUESTIONS**
Questions or comments?
Call **Jill Drachenberg** at (404) 262-5508

Nurses brought the question to the ethics committee, which reviewed the case and the literature. "We found broad consensus that pacemaker deactivation is not considered euthanasia, and is an appropriate practice," says Marks. "The family had the right to request its removal."

Not all clinicians agreed. "Some felt strongly it was unethical to deactivate pacemakers," says Marks. "Others did not feel supported by existing policies."

The institution's longstanding policy stated that competent adults had the right to request withdrawal of life-sustaining therapies. However, some clinicians didn't feel this covered pacemakers.

The ethics committee responded by creating a specific policy on implantable cardiac devices. "Some 1.2 million Americans are living with these devices currently," says Marks. "We can expect more conflicts like this to occur."

## Some policies omit devices

Even if hospitals have policies in place regarding withdrawal of life-sustaining interventions, these don't always include implantable cardiac devices.

"Ethics committees may wish to undertake this issue in order to avoid arbitrary decision-making at the bedside," suggests **Leslie M. Whetstine**, PhD, an associate professor of philosophy at Walsh University in North Canton, OH.

Withdrawal of implantable cardiac devices has been a primary focus of **Paul S. Mueller**'s research for the past 15 years. "My interest in the topic started with a dying patient from whom life-sustaining treatments were being withdrawn, and whose family requested device deactivation," says Mueller, MD, MPH, a professor of biomedical ethics at Mayo Clinic in Rochester, MN.

Multiple ethics consults centered around this scenario. "We have not had too many in recent years, as the matter is largely resolved," says Mueller. Clinicians utilize end-of-life care order sets that specifically address management of cardiac devices in dying patients.

In Mueller's view, the same ethical considerations apply as with other life-sustaining treatments such as ventilators or dialysis. "Once started, a patient is not mandated to continue with a treatment," says Mueller. "The treatment should not be the master of the patient."

Patients or surrogates might request device deactivation because the device no longer serves their healthcare-related goals and values. A dying patient with an implantable cardioverter-defibrillator (ICD) may wish to avoid uncomfortable shocks at the end of life. A patient with a pacemaker may perceive the device as a barrier to a natural death.

"The intent of device deactivation is not patient death," says Mueller. "The intent is removal of a treatment that is perceived by the patient as burdensome."

Implantable devices are life-sustaining treatments that can be withheld or withdrawn for the same reasons that clinicians withhold or withdraw other therapies, says **Daniel P. Sulmasy**, MD, PhD, MACP, associate director at the University of Chicago's MacLean Center for Clinical Medical Ethics. The devices may no longer be doing for the patient what they were implemented to do, or the patient or family judges them more burdensome than beneficial.

"Psychologically, it can seem more uncomfortable to deactivate an ICD," says Sulmasy. "But the mere fact that it is located inside the patient does not mark a moral difference." The device is not part of the patient the way a heart transplant would be, says Sulmasy, as it's controlled by the medical team, gets its energy from an external source, and does not grow or interact with the rest of the patient's body.

Sulmasy says bioethicists can help in the following ways:

**• Educate staff on the ethical consensus that the devices are life-sustaining treatments, and that deactivation is a form of allowing to the patient to die a natural death.**

"Hospital bioethicists could do this through grand rounds presentations or in-service educational programs," Sulmasy suggests.

**• Assist in updating policies on discontinuation of life-sustaining treatments to explicitly include pacemakers, ICDs, and left ventricular assist devices (LVADs).**

Sulmasy advises against writing separate policies to cover such devices. "It is better to develop an understanding that they belong under the umbrella of forgoing life-sustaining treatments," he says.

**Joanne Lynn**, MD, director of the Center for Elder Care and Advanced Illness at Washington, DC-based Altarum Institute, says patients who are offered an ICD are owed honest information.

"As it is being monitored, discontinuation should always be an option," says Lynn. "And in every setting — including home care — it must be possible to discontinue it quickly." A strong magnet can be taped over the device to block its function until more definitive discontinuation can be arranged, for instance.

Lynn says ethicists should ensure that ICD implementation forms are honest about the merits of the devices. Equally important is for clinicians to know how to get a device deactivated and be comfortable with the process.

"Patients and family members sometimes think that deactivating an ICD is tantamount to suicide," says Lynn. "But they need information to better understand this device."

## Some cardiologists object

Mayo Clinic's cardiologists sometimes object to device deactivation, especially in pacemaker-dependent patients. "We don't force them to carry out the deactivations," says Mueller. Instead, a process was implemented allowing the patient's care to be transferred to an alternative provider.

Some clinicians view discontinuation of an LVAD as ethically problematic. They view the device as an artificial organ that becomes part of the patient.

"They argue that if a clinician would not remove a transplanted organ after the fact, then one could not legitimately stop an LVAD," says Whetstine. Thus, they conclude that stopping an LVAD is tantamount to physician-assisted death or even euthanasia.

"Others reject this position, asserting that what matters is the right of patients or surrogates to determine their medical care in light of their values," says Whetstine. According to this perspective, the clinician has not killed the patient, but the patient dies of his underlying condition of heart failure. "This distinction between killing a patient and allowing a patient to die is supported in both ethics and the law," says Whetstine.

Whetstine says bioethicists can serve as a unique voice in support of the clinical team by raising ethical questions for consideration early, before therapy has been initiated. Ongoing consultation with a palliative care team "is paramount," adds Whetstine. "It helps ensure that the patient, family, and clinician understand the debate surrounding this issue and their available options."

When a University of Michigan committee was developing a policy on deactivation of implantable cardiac devices, it encountered stiff resistance. Certain members of the electrophysiology division were uncomfortable with the language of the policy. "It took us a good year to iron all that out," reports Marks.

Ethicists worked very hard to continue the dialogue with individuals who expressed concerns. "We met with them time and time again. Eventually, we got to a point of shared understanding," says Marks.

Ethicists attended meetings in the cardiology division and invited cardiologists to ethics meetings. Some cardiologists asked for specific language about the informed consent process and conscientious objectors, which was added.

Hospital administrators wanted to know if other institutions had similar policies in place. Ethicists pointed to a consensus statement and a Mayo Clinic study on the topic.[1,2]

"With that information, they were comfortable moving forward," says Marks. The policy states that it is ethically appropriate and reasonable to deactivate implantable cardiac devices after an informed consent process is performed with the patient and family.

"Previously, some clinicians believed it was ethically appropriate to withdraw the devices but

were concerned about the legal implications," says Marks. They now have a document to refer to that has been vetted by ethicists and the legal department.

"It's not just you shooting from the hip," says Marks. "Even in the face of resistance, clinicians know they are acting with the full support of the institution behind them."

## REFERENCES


1. Lampert R, Hayes DL, Annas GJ, et al. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 2010; 7(7):1008-1026.
2. Kapa S, Mueller PS, Hayes DL, et al. Perspectives on withdrawing pacemaker and implantable cardioverter-defibrillator therapies at end of life: Results of a survey of medical and legal professionals and patients. *Mayo Clinic Proceedings* 2010; 85(11):981-990.


## SOURCES


- **Joanne Lynn**, MD, Director, Center for Elder Care and Advanced Illness, Altarum Institute, Washington, DC. Phone: (202) 776-5109. Email: Joanne.Lynn@altarum.org.
- **Adam D. Marks**, MD MPH, Associate Director, Hospice and Palliative Medicine Fellowship, University of Michigan, Ann Arbor. Phone: (734) 764-6831. Fax: (734) 647-8535. Email: adamarks@med.umich.edu.
- **Paul S. Mueller**, MD, MPH, Consultant and Chair, Division of General Internal Medicine/Professor of Biomedical Ethics, College of Medicine, Mayo Clinic, Rochester, MN. Phone: (507) 538-6341. Fax: 507-284-4959. Email: mueller.pauls@mayo.edu.
- **Daniel P. Sulmasy**, MD, PhD, MACP, Associate Director, MacLean Center for Clinical Medical Ethics, The University of Chicago. Phone: (773) 702-0912. Fax: (773) 702-0090. Email: dsulmasy@uchicago.edu.
- **Leslie M. Whetstine**, PhD, Associate Professor, Philosophy, Walsh University, North Canton, OH. Phone: (330) 244-4697. Email: lwhetstine@walsh.edu. ■


# "Big Data" in Healthcare has Some Ethicists Concerned

*Individual autonomy weighed against common good*

President Barack Obama's Precision Medicine Initiative seeks 1 million volunteers to share genetic data and biological samples. The goal is to develop targeted approaches to diseases — but there are important ethical implications as well, says **Melinda C. Hall**, PhD, an assistant professor of philosophy at Stetson University in Deland, FL.

"While we clearly know the importance of an individual's right to privacy and informed consent, we know less about the benefit to the public good of massive, aggregated health data," says Hall.

Hall names the following two important ethical questions:

**• Will those who volunteer their data benefit or be fairly compensated?**

**• Who controls the data once it is collected?**

The promise of huge advances in health and medicine from whole genome sequencing is still relatively unfulfilled. "And it may remain so," adds Hall. "We should not be duped into skipping over concerns about informed consent and privacy rights for speculative goods."

Current regulations on research and patient privacy don't require consent for de-identified data. "So if it's de-identified, you can use it. But patients may still object that they don't want their data used," says **Sharona Hoffman**, JD, professor of law and bioethics at Case Western Reserve University School of Law in Cleveland.

There is a question as to whether data can ever really be de-identified. Publicly available information, such as voter registration records, might enable experts to link de-identified data to individuals in some cases.

"People should be aware that their data can be put to lots of uses that they might not know about," says Hoffman. One example is "data brokers" who mine data from numerous publicly available sources, including hospital discharge records, and sell it to interested parties. "There are questions about whether privacy is adequately maintained," says Hoffman. This can lead to discrimination, or people being harassed by aggressive marketers.

Some argue that if individuals choose to withhold their data from research, they become "free riders" benefiting from medical research without contributing. "People are grappling right now with whether,

and to what degree, the common good should prevail over individual autonomy," says Hoffman.

One question is whether it's ethically permissible for researchers to obtain a "blanket" consent for de-identified data that's likely to be used for numerous purposes in the future.

"You are basically providing consent and not knowing what it will be used for," says Hoffman. "Is that meaningful, or should you be contacted every time a researcher wants to use the data for a new project?" A patient might willingly consent to his or her data being used for a particular research project. That same person might vehemently object to the data being used years later for cloning or stem cell research.

"There will have to be more public education," says Hoffman. "The public needs to understand the huge amount that we can do in terms of records-based research, but also understand the risks."

Distributive justice is the primary ethical issue with use of de-identified health data, in Hall's view. "The individuals and populations from whom data is collected should, eventually, benefit from the collection of that data," she says.

In some cases, individuals aren't even aware their health data is being collected. This raises concerns about informed consent. "When data is collected from individuals who have not consented to the data's use in research, that data is unethically used," says Hall.

Engaging in a clinical trial, which itself has no therapeutic value, is a different matter than allowing the collection of one's data after lab work or during clinical visits, says Hall.

"Yet, the data collected is a primary driver of profit for corporations, including those in the pharmaceutical industry," Hall says. Those from whom the data is collected are not being paid. In some cases, they pay to share it.

> "THE INDIVIDUALS AND POPULATIONS FROM WHOM DATA IS COLLECTED SHOULD, EVENTUALLY, BENEFIT FROM THE COLLECTION OF THAT DATA."

"So one distributive question is: Why don't those who provide data profit from data?" says Hall.

For example, thousands of consumers pay to share their genomic data with 23andMe, a company that sells limited genetic analysis, but also acts as a massive biobank of that genetic data. Individual users send in a saliva sample and can choose to answer a variety of survey questions regarding lifestyle. "This valuable genetic data and related health data contributes to 23andMe's billion-dollar valuation, while users do not profit-share," says Hall.

Data should benefit those from whom it is collected, says Hall — either in terms of monetary compensation or health-related benefits. The widely publicized 2013 publication of Henrietta Lacks' genome without permission from her descendants brought this issue to the spotlight.[1]

"A highly profitable immortalized cell line resulted from her biopsy," notes Hall. "This health data is used in research, yet does not benefit those from whom the data was collected."

De-identified health data should benefit the public and future generations, says Hall, "while at the same time providing tangible benefit for the person whose data is collected."

## EXECUTIVE SUMMARY

"Big data" is becoming increasingly important in healthcare, with the Precision Medicine Initiative and numerous other quality initiatives seeking de-identified information to improve care. Some ethical concerns include the following:

- Even de-identified data carries privacy risks.
- Individuals who volunteer their data don't always benefit.
- With "blanket" consents, data could later be used in a way that is objectionable to the individual.

## REFERENCE

1. Andrews BJ, DePellegrin T. HeLa sequencing and genomic privacy: The next chapter. *G3: Genes, Genomes, Genetics* 2013; 3(8):vii.

## SOURCES

- **Melinda C. Hall**, PhD, Assistant Professor of Philosophy, Stetson University, Deland, FL. Phone: (386) 740-2507. Fax: (386) 822-7582. Email: mchall@stetson.edu.
- **Sharona Hoffman**, Professor of Law & Bioethics, Case Western Reserve University School of Law, Cleveland. Phone: (216) 368-3860. Email: sxh90@case.edu. ■

# Ethical Debate Continues on Resident Work Hour Limits

Ethical concerns involving residency work hour limits persist, long after the Accreditation Council for Graduate Medical Education (ACGME) introduced restrictions in 2003 and again in 2011.

"The movement to restrict resident duty hours is most commonly attributed to the now-infamous Libby Zion case," says **Philip M. Rosoff**, MD, MA, professor of pediatrics and medicine at Duke University Medical Center's Trent Center for Bioethics, Humanities, and History of Medicine in Durham, NC.

In 1984, a young woman, Libby Zion, was admitted to the hospital with apparent dehydration and altered mental status. "There were no senior attending physicians directly involved in her care. The harried, and presumably exhausted, intern and resident on call were primarily responsible for her management," says Rosoff.

After the patient's death, her father launched a high-profile campaign to change the system of postgraduate medical education whereby residents worked long and grueling hours, sometimes over 100 hours a week.

"The underlying assumption for these efforts has always been that Ms. Zion's death could have been prevented if the residents caring for her were not so tired, and if they had been properly supervised by an experienced doctor," says Rosoff.

Over the years, improved supervision and limited duty hours for residents have been enacted, each further decreasing the number of consecutive hours residents can work.

"The assumption is that residents who are more rested and whose work is more closely overseen by attending physicians — even on the 'graveyard' shifts — would provide safer and better care," says Rosoff. It is unclear if these expectations were realized, however, and whether there were any unintended consequences.

"Residents are certainly more rested. But in order to avoid the onerous penalties associated with duty hour violations, hospitals are rigorous in the enforcement of the rules," says Rosoff.

This means residents are sometimes forced to leave patients in the middle of an evolving clinical encounter. "This could prove to be corrosive to the development and maintenance of a doctor-patient relationship," says Rosoff.

Residents are sometimes unable to follow the progression and evolution of acute illnesses from hospital admission onward. "On the other hand, it could be argued that all of these negatives could be balanced, if not overridden, by any benefits that could accrue to patients, hospitals, and, of course, doctors themselves," says Rosoff.

More "handoffs," which put patients at risk for communication errors, are occurring. "We may have traded one kind of risk with another, which could possibly be even worse," says Rosoff.

Rosoff sees potential harm in the way new doctors are educated. "Many would hold that there was inherent value in the intense, experiential involvement of physicians-in-training with their patients, despite the fatigue that was a necessary adjunct," he says.

The more patients residents see under the guidance of senior physicians, the more expertise they presumably gain, adds Rosoff. "One wonders if this time-honored method of training may have been jeopardized by the zeal with which duty hours have been embraced and implemented," he says.


## EXECUTIVE SUMMARY

Efforts to limit work hours of residents spurred ongoing debate over whether patients are, in fact, safer as a result. Some ethical considerations include the following:

- The patient/physician relationship may be harmed if residents are forced to leave in the middle of an evolving clinical encounter.
- Residents may be hindered from following the progression of acute illnesses.
- Attendings are likely working more hours as resident work hours are curtailed.


## Multiple ethical concerns

**Aviva L. Katz**, MD, MA, CIP, FACS, FAAP, core faculty at University of Pittsburgh's Center for Bioethics & Health Law and director of the ethics consultation service at Children's Hospital of Pittsburgh, sees several ethical concerns with residency work hour limits.

"It is important to recognize that

the traditional workload of residents, particularly surgical residents, was not developed in a prospective, evidence-based fashion," she says.

Excessive work hours were developed to meet the need of caring for patients, says Katz — not to meet specific educational needs. She argues that the real failing in the Libby Zion case was not work hours, but lack of supervision.

Another consideration is that attendings are likely working more hours as resident work hours are curtailed. "There is no oversight regarding attending work hours, and they are just as vulnerable to the effects of acute and chronic sleep deprivation," says Katz.

Research clearly shows acute and chronic sleep deprivation have negative effects on physical and emotional health, and may have negative effects on cognitive abilities. "So there is a potential that we are exposing patients, and residents themselves, to harm when work hours are excessive," says Katz. "This has been very hard to demonstrate with observational research, as patient care is a team sport." Many people are involved in a patient's care, including the resident who has worked for over 24 hours.

Katz rejects the argument that shielding patients from sleep-deprived residents did more harm than good because residents won't become skilled attendings. "This is a false argument, and ignores the history of the development of residency," she says. "We can do better than hoping that residents will learn what they need if we just keep them captive long enough."

### SOURCES


- **Aviva L. Katz**, MD, MA, CIP, FACS, FAAP, Core Faculty, Center for Bioethics & Health Law, University of Pittsburgh/Director, Ethics Consultation Service, Children's Hospital of Pittsburgh. Phone: (412) 692-8778. Fax: (412) 692-8299. Email: aviva.katz@chp.edu
- **Philip M. Rosoff**, MD, MA, Professor of Pediatrics & Medicine, Trent Center for Bioethics, Humanities & History of Medicine, Duke University Medical Center, Durham, NC. Phone: (919) 668-9025. Fax: (919) 668-1789. Email: philip.rosoff@duke.edu. ■


# Providers' Bias Against Obese Patients Affects the Care Patients Receive

A growing body of research reveals that clinicians are frequently biased against obese patients — and that patients are harmed as a result. In a notable study of nearly 2,700 adults, 69% reported weight stigma from physicians.[1]

"We have consistent data that weight stigma is prevalent in healthcare settings — including, but not limited to, physicians. We also have mounting data that weight stigma causes harm," reports **Scott Kahan**, MD, MPH, director of the National Center for Weight and Wellness. Kahan is chair of the clinical committee for The Obesity Society and is leading a project to create an ethical framework for obesity care.

"In addition to emotional harm, weight stigma has been shown to affect physical health: increased blood pressure, increased stress hormones, and increased blood vessel reactivity," says Kahan. Recent studies suggest that stigma increases unhealthful eating behaviors and decreases motivation for exercise.

"The core ethical principles of beneficence, nonmaleficence, and justice are all relevant when it comes to appropriate and nonjudgmental care of all patients," says Kahan.

## Duty to care for "all in need"

If the clinician is not able to be objective with the goals of care because they have a bias regarding a patient's weight, "then their duty is to bring in others to help ensure they are providing appropriate interventions," says **Nneka O. Sederstrom**, PhD, MPH, FCCP, FCCM, director of the Office of Ethics at Children's Hospitals and Clinics of Minnesota in Minneapolis.

The "easy out" of transferring care to another provider is simply not acceptable in this case, says Sederstrom. According to Sederstrom, this would be no different than if the provider chose not to care for a patient due to their race, age, or gender. "They are not able to walk away because they object to the person's size," says Sederstrom. "A provider's duty is to care for all in need — not pick and choose only those that they believe are worth it."

**Amy M. VanDyke**, PhD, system ethicist at Mount Carmel Health System in Columbus, OH, says the experience of stigma by the patient from their doctor diminishes

the likelihood of benefit from the relationship. "It can, in fact, cause both physical and emotional harm in the process," says VanDyke.

Biased physicians may view patients who struggle with weight as lazy, sloppy, or having low intelligence. "When these attributions are unreflectively accepted by doctors, this can quite understandably cause patients to react negatively," VanDyke says.

With regard to overweight or obese patients, physicians can fail to respect autonomy in the following ways, says VanDyke:

**• Physicians may fail to address or even acknowledge a patient's obesity.**

"Patients are denied the opportunity to avail themselves of assistance and education about associated and potentially serious medical problems related to their weight," says VanDyke.

**• Physicians may fail to discuss all possible treatment options for weight loss.**

"The patient may not see certain options as being viable or, conversely, may not be motivated to take alternative actions — which are less invasive — to avoid the more invasive options," says VanDyke.

**• Physicians might attribute symptoms unrelated to obesity to the patient's weight.**

If a patient feels stigmatized by their physician, he or she might delay seeking care until later in the disease process when treatments may be less effective.

"As it is known that overweight and obese patients are disproportionately burdened by some forms of cancer and other diseases, it is especially important that such patients undergo routine surveillance," says VanDyke.

## Bioethicists should be aware

Kahan says at a minimum, bioethicists should become aware of the ubiquity and negative effects of weight stigma. "Weight stigma is so ingrained in our society that I fear that many bioethicists harbor stigmatizing beliefs and judgments about persons with obesity," says Kahan.

Kahan experienced this while on a panel with a leading academic bioethicist. "I was shocked when he suggested that we should consider intentionally shaming people to lose weight, similar to what had been done in the tobacco world to shun people to stop smoking," he says. "I can't think of anything more inappropriate or counterproductive."

Bioethicists have a moral obligation to be attentive to provider attitudes or healthcare system practices which inadvertently or directly support stigma or bias toward obese patients, says VanDyke. She urges bioethicists to utilize the following approaches:

**• Highlight research findings and patient experiences in this area with grand rounds or graduate medical education sessions.**

"Gently challenge the prevailing attitudes and practices which may be stigmatizing to patients," says VanDyke.

**• Write articles on how stigma and bias marginalizes patients at an unhealthy weight.**

"This can impair utilization of healthcare services even when sufficient access is present," says VanDyke. "It ultimately harms a patient's prospects for a healthy life."

## EXECUTIVE SUMMARY

Evidence suggests that providers are frequently biased against obese patients, and patients are harmed as a result. Experts say bioethicists can do the following:

- Become aware of the ubiquity and negative effects of weight stigma.
- Be attentive to provider attitudes or healthcare system practices which support stigma or bias toward obese patients.
- Provide grand rounds or education sessions to highlight research findings and patient experiences.

## REFERENCE

1. Puhl RM, Brownell KD. Confronting and coping with weight stigma: an investigation of overweight and obese adults. *Obesity* 2006; 14(10):1802-1815.

## SOURCES

- **Scott Kahan**, MD, MPH, Johns Hopkins Bloomberg School of Public Health/National Center for Weight and Wellness, Washington, DC. Phone: (202) 223-3077. Email: kahan@jhu.edu.
- **Nneka O. Sederstrom**, PhD, MPH, MA, FCCP, FCCM, Director, Office of Ethics, Children's Hospitals and Clinics of Minnesota, Minneapolis. Phone: (612) 813-6159. Fax: (612) 813-6807. Email: Nneka.Sederstrom@Childrensmn.Org.
- **Amy M. VanDyke**, PhD, System Ethicist, Mount Carmel Health System, Columbus, OH. Phone: (614) 546-4065. Fax: (614) 546-3875. Email: Amy.VanDyke@mchs.com. ■

# Palliative Care Can Offset Costs of Aggressive End-of-life Care

Cancer patients who receive aggressive end-of-life care incur 43% higher costs than those managed nonaggressively — but palliative consultation may partially offset these costs, according to recent research.[1]

Some key findings of the study, which analyzed data on 107,253 patients who died of cancer in Ontario, Canada from 2005 to 2009, include the following:

**• The mean per-patient cost over the final month was $18,131 for patients receiving aggressive care, and $12,678 for patients receiving nonaggressive care.**

**• Patients who received chemotherapy in the last two weeks of life sustained higher costs than those who did not.**

**• For individuals receiving end-of-life care in the highest cost quintile, early and repeated palliative care consultation was associated with reduced mean per-patient costs.**

Prior research established quality measures to optimize the care of cancer patients at the end-of-life. "Most of these studies have documented that aggressive medical care, including intensive care stays or chemotherapy administered in the last days of life, offers little chance of clinical benefit but notable consequences, including toxicities that impair quality of life," says **Matthew Cheung**, MD, the study's lead author. Cheung is an associate scientist at Sunnybrook Health Sciences Centre in Toronto.

The researchers set out to determine the costs associated with aggressive care in the end-of-life period. "We were not surprised to find that aggressive care — which includes hospitalizations, intensive care, and administration of chemotherapy — was more costly than non-aggressive care," says Cheung.

However, the research team was surprised to find that access to palliative care preceding the final month of life was associated with less aggressive care — and lower costs of care.

"We speculate that access to palliative care may provide patients and families the outlet to discuss end-of-life preferences and initiate planning," says Cheung. This might result in less aggressive care toward the final days of life.

"This study suggests that an investment in palliative care could meaningfully reduce costs toward the end of life, potentially offsetting the intrinsic costs associated with developing such programs," says Cheung.

The research team is interested in further defining the optimal timing and nature of palliative consultation. The goal is to optimize resource utilization and, more importantly, patient outcomes.

"We hope decision-makers might explore the potential that increasing access to palliative services might temper the tendency toward aggressive care — and, ultimately, offset costs," says Cheung.

## REFERENCE

1. Cheung MC, Earle CC, Rangrej J, et al. Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer* 2015; 121: 3307–3315.

## SOURCE

• Matthew Cheung, MD, Associate Scientist, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada. Phone: (416) 480-4928. Fax: (416) 480-6002. Email: Matthew.Cheung@sunnybrook.ca. ■

# Do Physicians Get Incentives for Patients' Donations?

*Mere appearance of conflict is damaging*

Grateful patient philanthropy (GPP) is "very widespread, involving many, if not most, major departments at academic medical centers," says **Joseph A. Carrese**, MD, MPH, FACP, a professor of medicine at Johns Hopkins University and core faculty at the Johns Hopkins Berman Institute of Bioethics.

GPP can address some very important mission-based activities: research programs, clinical programs, and educational activities, adds Carrese.

But what if institutions offer financial incentives to doctors for getting gifts from their own patients? Carrese sees this practice as

"qualitatively different in an important way" from involving physicians in the overall process of GPP.

"The worry is that money that directly goes into the pocket of the physician in question may unduly influence him or her, and affect his or her behavior and interactions with patients in ways that might not be ethically appropriate," says Carrese.

In a 2015 survey of 405 physicians, a small minority (3%) described being offered a financial incentive to encourage them to solicit donations from their own patients.[1] Carrese says the main concern is that the physician's primary ethical and professional duty to patients will be undermined in favor of a secondary interest — in this case, personal financial gain.

"We should be taking steps to 'shore up' our ability to maintain the expected ethical and professional standards, and avoid actions that would undermine this objective," he says.

Carrese says institutions need to establish "bright ethical lines" for unacceptable GPP practices — such as giving bonuses to physicians — and turn to existing guidelines and literature for guidance.

Physicians should avoid directly soliciting their own patients, especially at the time of a clinical encounter, the American Medical Association's Council on Ethical and Judicial Affairs recommended in 2004.[2]

A 2013 study interviewed 20 department of medicine physicians at Johns Hopkins, all of who had relationships with multiple patients who made philanthropic contributions.[3] The following ethical concerns were identified: the effect of the gift on the doctor-patient relationship; gift acquisition considered to be beyond the physician's professional role; justice and fairness; and vulnerability of patients.

Some physicians reported being troubled by these ethical concerns. More than half (55%) expressed the view that there were no ethical issues involved with grateful patient philanthropy. "Several physicians commented about strategies they employed to guard against pitfalls," says Carrese, one of the study's authors. These include the following:

• maintaining clarity that the primary relationship with the patient is the clinical relationship, not the philanthropic relationship,

• not allowing the philanthropy to affect the care provided to the donor or to other patients who are not donors,

• being especially cautious regarding potential donors who are vulnerable as a consequence of their illnesses, and

• delegating cultivation and solicitation of financial gifts to development professionals, so as to not compromise the doctor-patient relationship.

Institutions need "strategies focusing on awareness, education, and efforts to promote high ethical and professional standards" for GPP, the researchers wrote. Carrese suggests institutions implement the following practices:

**• Include education about ethical considerations related to GPP as part of initiatives to encourage doctors to get involved in this activity.**

**• Allow doctors to opt out of GPP activities if it makes them feel ethically or professionally uncomfortable.**

**• Provide support to doctors when asking them to get involved in GPP activities, such as access to experienced development professionals.**

Carrese is most comfortable with doctors being involved in GPP when the patient is the one who initiates the idea. "To the extent that a GPP activity is initiated by someone other than the patient — and the more aggressive those non-patient-initiated activities are — the greater the chance of an ethical transgression," he says.

More institutions are looking at physicians not as healers for those in need, "but rather, as revenue generators," according to **Craig M. Klugman**, PhD, a professor in the Department of Health Sciences at Chicago-based DePaul University.

"With a corporate model of healthcare, physicians are being pressured to increase the number of patients they see," says Klugman. "When that is not enough, they are also asked to bring in grants and donations."

Klugman says asking physicians to solicit donations from patients is unethical, regardless of whether the

## EXECUTIVE SUMMARY

Some institutions encourage physicians to solicit donations from grateful patients. A small minority of physicians report being offered financial incentives for doing so. Some ethical concerns with this practice include the following:

- Patients may believe a contribution is necessary to see the physician.
- Contributors may receive preferential treatment
- There is an apparent conflict of interest between the patient's best interests and soliciting funds for the institution.

physician receives a financial incentive for doing so. This is because it creates a conflict of interest.

"As a patient, the idea that my physician would be looking at me as a checkbook rather than someone in need is destructive to the physician-patient relationship," says Klugman.

The problem is that physicians are obligated to practice based on patients' best interests, and at the same time are beholden to the institution to solicit funds. "The two goals are often at odds," Klugman says. "It destroys trust, which is the foundation of all that we do."

Soliciting donations strains the physician's fiduciary relationship with their patients, says Klugman. "Physician as fundraiser brings a third party into the relationship: the institutional advancement office," he says.

Having less power and being in a vulnerable position, patients rely on physicians to be trustworthy and honest. "This arrangement is challenged when the physician is less than trustworthy, the patient's well-being isn't the ultimate and sole goal of the relationship, and there is a third party involved," says Klugman.

Financial bonuses give the appearance that the patient's best interest and care is not the physician's first priority, he says. Klugman sees this as similar to when physicians are rewarded by drug companies for being a frequent prescriber of a certain medication.

"Even if a conflict of interest can be managed — which is debatable — the appearance of the conflict can be damaging to the patient's perception of the physician as his or her advocate," says Klugman.

Studies show that most physicians believe that conflicts of interest with drug companies negatively affects their prescribing for patients.[4]

"Why would the results be any different just because the third party is inside the hospital rather than out?" asks Klugman. Patients may perceive that a donation to a doctor becomes necessary in order to be seen by that doctor.

"This is similar to concierge medicine, where an annual fee ensures medical care," says Klugman. "Physician as fundraiser implies the same idea: To see your doctor, you need to donate."

Whether true or not, says Klugman, "it is the appearance that damages the ability of physicians to do their jobs, and of patients to trust them in doing it." Klugman worries that knowledge of a potential payoff can also have unconscious biases that affect professional behavior. "The patient who is a potential big donor may get a VIP suite, a better room, a better food menu, and more attention," says Klugman.

These perks may not always be positive. Contributors may get more diagnostic tests than someone else would for similar symptoms, for instance. "More tests means more artifacts found, leading to more interventions and treatments for conditions that would probably never bother one in a lifetime," says Klugman.

Social justice is key concern. Would patients of lower socioeconomic means get less time with the doctor or fewer tests? "Whether this would be seen in evidence or not, the appearance or belief is damaging enough," says Klugman.

## REFERENCES


1. Walter JK, Griffith KA, Jagsi R. Oncologists' experiences and attitudes about their role in philanthropy and soliciting donations from grateful patients. *J Clin Oncol* 2015; 33:3796-3801.
2. American Medical Association (2004) Physician participation in soliciting contributions from patients. The Council on Ethical and Judicial Affairs. CEJA 7-A-04. Available at: http://bit.ly/1sn4wLk.
3. Wright SM, Wolfe L, Stewart R, et al. Ethical concerns related to grateful patient philanthropy: the physician's perspective. *J Gen Intern Med*. 2013; 28(5):645-651.
4. Spurling GK, Mansfield PR, Montgomery BD, et al. Information from pharmaceutical companies and the quality, quantity, and cost of physicians' prescribing: a systematic review. *PLoS Med* 2010; 19;7(10):e1000352.


## SOURCES


- **Joseph A. Carrese**, MD, MPH, FACP, Core Faculty, Johns Hopkins Berman Institute of Bioethics, Baltimore. Phone: (410) 550-2247. Fax: (410) 550-3403. Email: jcarrese@jhmi.edu.
- **Craig M. Klugman**, PhD, Professor, Department of Health Sciences, DePaul University, Chicago, IL. Phone: (773) 325-4876. Fax: (773) 325-8430. Email: Cklugman@depaul.edu. ■


## COMING IN FUTURE MONTHS

- Ethical controversy over stem cell research guidelines
- Update on stigma against people with mental health disorders
- Ethical concerns if cost of care is part of decision-making
- Efforts to combat disparities in surgical outcomes

MEDICAL ETHICS ADVISOR®





# CME INSTRUCTIONS

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

1. Read and study the activity, using the provided references for further research.
2. Log on to AHCMedia.com, then select "MyAHC" to take a post-test.
3. Pass the online tests with a score of 100%; you will be allowed to answer the questions as many times as needed to achieve a score of 100%.
4. After successfully completing the test, a credit letter will be emailed to you instantly.
5. Twice yearly after the test, your browser will be directed to an activity evaluation form, which must be completed to receive your credit letter.

# CME QUESTIONS

**1. Which is true regarding deactivation of implantable cardiac devices?**

A. Pacemaker deactivation is euthanasia.
B. Families do not have the right to request pacemaker deactivation.
C. Clinicians benefit from policies on withdrawal of care that are specific about whether implantable cardiac devices are included.
D. Policies on deactivation of pacemakers should require ethics consultation in every case.

**2. Which is true regarding ethical uses of de-identified healthcare data?**

A. There are no privacy concerns because there is no way to link data to specific individuals.
B. Researchers are legally obligated to obtain consent each time the data is used.
C. Patient privacy regulations make no distinction between identifiable data and de-identified data for informed consent requirements in research.
D. Current regulations on research and patient privacy don't require consent for de-identified data

**3. Which is true regarding healthcare providers' bias against obese patients?**

A. Though bias exists, there is no evidence that it harms patients clinically.
B. Multiple studies show weight stigma harms patients emotionally and physically.
C. If providers are biased regarding a patient's weight, transferring care to another provider is an ethically acceptable alternative.
D. To respect patients' autonomy, providers should not address weight loss options unless the patient requests the information.

**4. Which is true regarding end-of-life cancer care, according to a recent study?**

A. Aggressive end-of-life care costs without palliative care were equivalent to care that was managed with palliative care.
B. Palliative care consultation resulted in higher costs for end-of-life care.
C. Palliative care partially offset costs when cancer patients received aggressive end-of-life care.
D. There was no link between palliative care provision and cost of care.