



# MEDICAL ETHICS ADVISOR®

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

FEBRUARY 2016

Vol. 32, No. 2; p. 13-24

## → INSIDE

How end-of-life care is changing in emergency departments . . . . . cover

Emergency nurses report barriers to ethical end-of-life care . . . . . 15

Ethical debate rages over use of gene-editing technology . . . . . 16

Why end-of-life dementia care costs raise ethical concerns . . . . . 17

Ethical responses if family asks for inappropriate ICU treatments . . . . . 19

Updated Code of Ethics helps nurses challenge unethical policies . . . . . 21

Pathologists report ethical worries over error disclosure . . . . . 22

**AHC** Media

## Growing focus on end-of-life and palliative care in ED setting

*Providers report “explosion of interest”*

**M**ultiple studies demonstrate that screening and referral for palliative care consultation is feasible in the emergency department (ED) setting, according to a recent analysis.<sup>1</sup>

“Over the last few years, there has been a real explosion of interest in the topic,” says **Sangeeta Lamba, MD**, associate professor of emergency medicine and director of ED palliative care at Rutgers New Jersey Medical School in Newark.

To date, 114 diplomates of the American Board of Emergency Medicine

have obtained certification in the subspecialty of Hospice and Palliative Medicine since it was first offered in 2008. “The specialty itself — I call it emergency palliative care — has really grown,” says Lamba.

ED clinicians face competing patient priorities and time constraints, unlike the controlled environment of intensive care units, where the clinical team has some time to develop relationships with the patient and family. “In the ED, you have to do all the same care, but without the luxury of time and of having known the family,” says Lamba.

### EXECUTIVE SUMMARY

While screening and referral for palliative care is feasible in the emergency department setting, success usually hinges on availability of specialized personnel, according to a recent study. Some approaches to ensure ethical end-of-life ED care include the following:

- Create a relatively quiet space for dying patients.
- Ensure every clinician is trained in a comfort-based approach to end-of-life care.
- Take time to discuss the ethics of specific challenging end-of-life cases.

**NOW AVAILABLE ONLINE! VISIT** [www.AHCMedia.com](http://www.AHCMedia.com) or **CALL** (800) 688-2421

**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.

**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, call Tria Kreutzer at  
404-262-5482. Missing issues will be fulfilled by customer  
service free of charge when contacted within one month  
of the missing issue date. Back issues, when available, are  
\$83 each. (GST registration number R128870672.)  
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.

**PHOTOCOPIING:** No part of this newsletter may  
be reproduced in any form or incorporated into any  
information retrieval system without the written permission  
of the copyright owner. For reprint permission, please  
contact AHC Media, LLC. Address: P.O. Box 550669,  
Atlanta, GA 30355. Telephone: (800) 688-2421. Web: www.  
AHCMedia.com.

Copyright © 2016 by AHC Media, LLC. Medical Ethics  
Advisor® is a registered trademark of AHC Media, LLC.  
The trademark Medical Ethics Advisor® is used herein  
under license. All rights reserved.

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

The ED team may experience moral distress if there is conflict in end-of-life decision-making. Physicians sometimes feel unable to adequately address not only the dying patient's physical complaints, but also the person's social and spiritual needs. "The passion for end-of-life care is there. It is part of the routine day-to-day work that we do," says Lamba. She often hears frustration from residents, however, who want to do more, but lack the time necessary to fully focus on the needs of one family.

Creating a private space for grieving families is another challenge in a busy, crowded ED setting. "When a person comes in, our goal is to make a person live and the ED is geared to do so," says Lamba. "When it is obvious that a person is not going to live, we may not be able to provide the environment to fully support the family."

Reserving a separate room or space for dying patients, just as there is a separate area for geriatric or trauma patients, is one approach that some EDs have implemented. "Otherwise, the dying patient is smack in the middle of the room full of noise, and the family cannot grieve peacefully," says Lamba.

In 2009, the Center to Advance Palliative Care created the Improving Palliative Care in Emergency Medicine initiative. (*For more information on how to access CAPC tools, go to <http://bit.ly/231wFWg>.*)

"The team created an online repository of tools and resources for ED clinicians," says Lamba. "That really got emergency palliative care out in the world."

One of the biggest barriers to good end-of-life care in the ED is knowing patient preferences when the patient cannot communicate, says **Terri Schmidt, MD, MS**, a professor

in the Department of Emergency Medicine and a palliative medicine physician in the Department of Hematology/Oncology at Oregon Health & Science University in Portland.

Some patients do have an advance directive, but it is not available when the patient arrives in the ED. Often, advance directives are too vague for ED staff to act on. "Most say something like, 'If I had a terminal illness, I would not want treatment that would only prolong the dying process,'" says Schmidt. "In the ED, we usually do not know if the conditions apply."

Physician Orders for Life-Sustaining Treatment (POLST) forms turn patient preferences into medical orders that are based on the patient's current medical condition and preferences. "However, POLST forms are often not immediately available to EMS [emergency medical services]," says Schmidt.

Some states are developing electronic registries for POLST forms to increase access. The Oregon legislature funded an electronic registry in 2009. "This requires professionals who sign a POLST form to submit it to the registry unless the patient opts out," says Schmidt.

## EPs cannot rely on others

As for whether patients can be screened in the ED for palliative care referral, Schmidt says, "I think the answer is 'Yes, maybe.' EDs are less likely to use a consult service that is only available certain hours."

Currently, there is a shortage of outpatient palliative care services. "Screening would be valuable only if services are available," says Schmidt.

Each of four studies reviewed by the researchers reported increased rates of palliative referral. Additional personnel were needed, though, to perform screening and referral. Success was limited by availability of specialized personnel, since palliative care teams aren't available during off hours.

"In the middle of the night, it's you who has to take care of not only the dying patient, but their loved ones and all the other patients in the ED," says Lamba. Even if a formal palliative care consult team is unavailable, Lamba adds, there is value to screening since social workers or others can assist.

Since emergency physicians (EPs) cannot rely on the fact that palliative care specialists or others will be available, however, they need to master the necessary skills themselves. Thus, says Lamba, "education is a big, big component of taking it to the next step. The focus is on how to train every single emergency physician with the basic skills they need to care for the dying patient."

While communication is one of the cornerstones of emergency medicine residency training, end-

of-life communication poses some unique challenges. "Added to the fact that no one likes to deliver bad news, there is also an increased focus on survivors in addition to the patient," says Lamba.

## Ethicists can help

Schmidt doesn't see ethics consults as a viable option to help clinicians manage end-of-life care in the ED. "Consults are not available 24/7 and they do not occur in a timely fashion," she explains. "However, ethicists can help teach emergency professionals decision-making models."

This can help ED professionals to feel more supported in making ethical decisions involving end-of-life care. "Ethicists probably can't help us real-time in the clinical setting," Lamba says. "But they can support us with ethical dilemmas that really weigh on our minds and our souls over time."

Lamba suggests ethicists hold discussions on particularly difficult cases, such as when the emergency physician knows intubation will be futile but the family disagrees and

wants aggressive care. Similarly, the EP can alert bioethicists if an ethically challenging case is admitted from the ED.

"We can give them a heads-up if we think that it can become a big ethical issue while the person is in-house," says Lamba. "Quality care can start earlier rather than later."

## REFERENCE

1. George N, Phillips E, Zaurova M, et al. Palliative care screening and assessment in the emergency department: A systematic review. *J Pain Symptom Manage* 2016; 51(1):108-119.

## SOURCES

- **Sangeeta Lamba, MD**, Associate Professor of Emergency Medicine and Surgery, Rutgers New Jersey Medical School, Newark. Phone: (973) 972-4823. Email: lambasa@njms.rutgers.edu.
- **Terri Schmidt, MD, MS**, Professor, Departments of Emergency Medicine and Hematology/Oncology, Oregon Health & Science University, Portland. Phone: (503) 494-7003. Email: schmidtt@ohsu.edu. ■

---

# ED nurses ID barriers to ethical end-of-life care

*Dying patients in ED setting points to system failure*

**E**mergency department nurses reported lack of space, time, and staff as challenges to providing good end-of-life care, according to a recent study.<sup>1</sup> Researchers surveyed 1,879 nurses and held focus groups with 17 nurses about care of end-of-life patients, educational needs, availability of resources, and barriers to safe and effective care.

Nurses reported moral distress

due to the mismatch between the goals of emergency care and those of end-of-life care. "This type of care is absolutely at odds with the nature of emergency care. What we want to do is fix them and get them out," says lead study author **Lisa Wolf**, PhD, RN, CEN, FAEN, director of the Institute for Emergency Nursing Research of the Des Plaines, IL-based Emergency Nurses Association. Other

key findings include the following:

- **ED nurses reported difficulty with the emotional burden of caring for dying patients.**

Some focus group participants expressed that one reason they chose emergency nursing as a specialty was because they didn't want to have long, painful interactions with dying patients.

"They said, 'This is not the area

of care that I would choose, which is why I'm not a hospice, medical/surgical, or intensive care unit nurse," says Wolf.

While ED nurses are trained to "do something and do it quickly," she says, in the case of terminally ill patients there are no interventions needed except for comfort care. "This is nearly impossible to do in the ED," Wolf says. "This is a one-to-one kind of patient."

• **ED nurses are knowledgeable and comfortable with providing quality end-of-life care.**

The problem was that they lack time and resources to provide such care. "There was a really pervasive sense that emergency nurses felt strongly that when a chronically ill dying patient comes to the ED, it's a failure of the system," says Wolf.

• **ED nurses reported moral distress stemming from the inability to provide time-consuming care not only to dying patients, but also their families.**

"They wanted to give good care, but were completely stymied from

doing so because of the demands of other patients," says Wolf.

A chaotic, noisy, crowded ED is "a terrible place to die," says Wolf. "We've all had patients who died in hallways. You just feel terrible about it." Here, Wolf offers the following possible solutions to alleviate moral distress of ED nurses caring for dying patients:

• **Improve communication between the ED and community resources.**

The goal is for primary care physicians, hospice, and visiting nurse services to understand the need to keep chronically ill patients who are near death out of the ED. "When pain or respiratory symptoms can't be controlled due to lack of coverage in the community, it's a failure of the system," says Wolf.

• **Make ED nurses aware of all available resources in the organization.**

Some of the focus group participants were unsure if emergency nurses were aware of palliative care services, for instance.

• **Have protocols in place to help ED nurses address the needs of dying patients.**

ED nurses really wanted a protocol or process to utilize in this scenario, "rather than having to wing it on their own every time," says Wolf.

For instance, ED policy might instruct nurses to call a social worker or chaplain to the patient's bedside if palliative care services are unavailable. "Those kinds of procedural things were lacking," says Wolf.

## REFERENCE

1. Wolf LA, Delao AM, Perhats C, et al. Exploring the management of death: Emergency nurses' perceptions of challenges and facilitators in the provision of end-of-life care in the emergency department. *JEN* 2015; 41(5):e23-e33.

## SOURCE

- Lisa Wolf, PhD, RN, CEN, FAEN, Director, Institute for Emergency Nursing Research, Des Plaines, IL. Email: Lisa.Wolf@ena.org. ■

---

# Ethical debate rages on gene-editing technology

*Conditions must be met before proceeding with germline editing, committee says*

International organizations are urging the scientific community to allow time for ethical debate on new human gene-editing technologies.

According to a recent statement from the Organizing Committee for the International Summit on Human Gene Editing, it would be irresponsible to proceed with any clinical use of germline editing "unless and until" these conditions have been met:

• relevant safety and efficacy issues have been resolved, based

on appropriate understanding and balancing of risks, potential benefits, and alternatives,

• there is broad societal consensus about the appropriateness of the proposed application, and

• there is appropriate regulatory oversight. (*The complete statement can be viewed at <http://bit.ly/1QWLI88>.)*

"There is a consensus, or very close to one, that the technique should not be used now to make human babies and that it can be used, with appropriate regulation, to try to treat

genetic diseases in living people," says **Henry T. Greely**, JD, director of the Stanford (CA) Center for Law and the Biosciences and chair of the steering committee at Stanford Center for Biomedical Ethics.

Beyond those areas of agreement, there is no consensus about research use in humans and a variety of uses in non-humans, according to Greely.

In May 2015, Chinese scientists reported editing the genomes of human embryos, re-igniting an ethical debate.<sup>1</sup> Some people strongly

opposed to any possible use of human germline or embryo genome editing saw this as one step that could make that possible, notes Greely.

“Many people, including me, viewed it as an ethical experiment, as the embryos that were edited were triploid and thus non-viable,” he says. Greely notes that there is already widespread use of gene editing technology in non-human animals, for basic research and also for particular applications, such as goats with more meat and longer hair and malaria-immune mosquitos.

“These are likely to continue, and quite possibly without sufficient oversight,” says Greely. “In humans, we have already seen one case of gene therapy.”

The case involved an infant with acute lymphocytic leukemia who received gene-edited blood-forming stem cells. “That kind of somatic cell research will, and should, continue

and accelerate, as [the gene-editing technique known as] CRISPR/Cas9 makes the editing easier,” says Greely. He expects to see limited research use of gene editing in human embryos and possibly human germ cells. However, he doesn’t expect to see efforts at clinical use of embryonic gene editing for several — perhaps many — years.

Greely says the top priority is to have a regulatory apparatus in place to weigh the consequences of the release of gene editing organisms into the environment. “I do not believe

our current regulatory scheme is adequate,” he adds.

## REFERENCE

1. Liang, P, Xu Y, Zhang X, et al. CRISPR/Cas9-mediated gene editing in human triprenuclear zygotes. *Protein Cell* 2015; 6(5):363-372.

## SOURCE

- Henry T. Greely, JD, Director, Stanford (CA) Center for Law and the Biosciences. Phone: (650) 723-2517. Fax: (650) 725-0253. Email: hgreely@stanford.edu. ■

## EXECUTIVE SUMMARY

Ethical debate needs to occur on new human gene-editing technologies, according to a statement released jointly by international organizations. Some recommendations from the statement include the following:

- Relevant safety and efficacy issues must be resolved.
- There needs to be broad societal consensus.
- Clinical use should proceed only under appropriate regulatory oversight.

# Troubling social justice issues stem from cost of dementia care

*Many costs of daily care not covered by health insurance*

**H**ealthcare and caregiving costs for dementia patients in the final five years of life are greater than for patients with cancer, heart disease and other illnesses, according to a recent study.<sup>1</sup>

The amount of the difference surprised the researchers, reports lead author **Amy Kelley**, MD, an associate professor of geriatrics and palliative medicine at Icahn School of Medicine at Mount Sinai in New York City. The researchers reviewed all spending related to healthcare for more than 3,200 Medicare beneficiaries who had died between

2002 and 2008. Some key findings include the following:

- One-quarter of subjects spent more than their baseline total household assets.
  - Forty-three percent of subjects spent more than their non-housing assets.
  - Those with dementia or Alzheimer’s disease spent the most, averaging more than \$66,000, or more than twice that of patients with gastrointestinal disease or cancer, who spent an average of \$31,000.
- “Households of those with dementia face the greatest burden of

costs, on average, particularly with regard to out-of-pocket expenses and the costs of caregiving,” says Kelley.

## Costs aren’t covered

Many costs related to daily care for patients with dementia are not covered by health insurance. The need for supervision, bathing, and feeding may span several years.

“People with dementia need supervision and assistance with many aspect of daily life in order to be safe and have the best quality of life as possible,” says Kelley. “These needs

are progressive, and often continue for many years.”

The study’s findings underscore the importance of individuals and families being aware of the financial risks that older adults face in the last years of life. “It is important for policymakers to know about these costs, so that this information can help shape health and social policy that will best serve our society,” adds Kelley.

Medicare covers medical care, but does not pay for critical components of daily care needs. While supplemental Medicare coverage can defray certain out-of-pocket costs, it does not typically cover caregiving costs.

“We must consider novel ways, through both health and social policy, to provide for the care needs of those with dementia so that older adults get the high-quality care they need and deserve without impoverishing families,” says Kelley.

## Misuse of resources

**Kenneth Covinsky, MD, MPH**, a clinician-researcher at University of California, San Francisco’s Division of Geriatrics, sees troubling social justice issues in the huge financial burdens placed on families.

“Many of the expensive and stressful burdensome concerns for

families stem from costs that are not classically considered ‘medical,’” says Covinsky.

This includes the need to provide assistance with activities of daily living such as bathing and dressing,

“WE MUST CONSIDER NOVEL WAYS, THROUGH BOTH HEALTH AND SOCIAL POLICY, TO PROVIDE FOR THE CARE NEEDS OF THOSE WITH DEMENTIA SO THAT OLDER ADULTS GET THE HIGH-QUALITY CARE THEY NEED AND DESERVE WITHOUT IMPOVERISHING FAMILIES.”

and assistance with tasks such as managing medicines and finances. There is also a need for supervision for persons with dementia because of memory loss, risk for injury, and

sometimes agitation.

“At \$20 to \$25 an hour — a conservative cost for a health aide — these services, over the years they are provided, can quickly eat up all of the resources for a family,” says Covinsky.

Many stressed caregivers could greatly benefit from periods of respite or services like Adult Day Health. “But these services must usually be purchased out of pocket,” says Covinsky. He adds that the health system spends significant amounts of money for medical services that often do much more harm than good in patients with dementia.

“For example, as a clinician, I can spend many hundreds to even thousands of dollars on imaging tests for patients with dementia, which usually are not helpful,” he says. However, clinicians have no ability to order less expensive social services that would be very helpful.

“We actually have huge resources at our disposal, but they are available for all of the wrong things,” says Covinsky.

## REFERENCE

1. Kelley AS, McGarry K, Gorges R, et al. Burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med* 2015; 163(10):729-736.

## SOURCES

- **Kenneth Covinsky, MD, MPH**, Division of Geriatrics, University of California, San Francisco. Phone: (415) 221-4810 ext. 4363. Email: ken.covinsky@ucsf.edu.
- **Amy Kelley, MD**, Associate Professor of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York City, Phone: (212) 241-2631. Email: amy.kelley@mssm.edu. ■

## EXECUTIVE SUMMARY

Costs of end-of-life care for dementia patients in the final five years of life greatly exceed those of cancer and heart disease, according to recent research. Some ethical concerns, according to the study, include the following:

- Costs related to daily care are not typically covered by health insurance.
- Many families spend more than their total household assets.
- Stressed caregivers usually need to purchase Adult Day Health services out-of-pocket.

# Are ethical responses clear to providers if family requests inappropriate care?

*Physicians should provide alternative plan, experts say*

**L**awrence J. Schneiderman, MD, founding co-chair of the University of California, San Diego Medical Center's Ethics Committee, notes one of the more extreme views that emerged during the "patient's rights" movement is that patients have a right to receive any treatments they wish, and that physicians should not impose their "paternalistic" power.

"Some of this notion persists today," says Schneiderman. In his view, physicians should always show compassion and not abandon patients or their surrogates with whom they disagree. Instead, physicians should provide an alternative plan of treatment — that of palliative care, or at the end of life, comfort care.

"This is their obligation, no more, no less," says Schneiderman. "If the institution has a defined futility policy, they can invoke that."

If after suitable efforts at conflict resolution, the disagreement persists, physicians can suggest transfer to another facility willing to take the patient.

"In my experience, the futility policies of most hospitals are centered on patient benefit," says

Schneiderman. "However, there is a respectable minority of hospitals that claim to be willing to accede to whatever patients or their surrogates demand." Both of these policies can be regarded as providing a standard of care, says Schneiderman.

"The latter hospitals can show that theirs is a moral position and not an empty promotion, if they accept the patient and help to avoid a long and painful court conflict," he says.

## Challenges defining futility

A May 2015 policy on responses to potentially inappropriate treatments in ICUs recommends using the term "potentially inappropriate" instead of "futile" when referring to questionable interventions that do not meet the definition of futility.<sup>1</sup>

"While this may allow for more semantically coherent dialogue on this topic, it does not give additional guidance about which treatments should not be offered by providers," says **Janet Malek**, PhD, an associate professor of medicine and medical

ethics at Baylor College of Medicine's Center for Medical Ethics and Health Policy in Houston. Instead, she says it raises a new set of questions: What interventions are inappropriate? Under what circumstances are they inappropriate? Why are they considered to be inappropriate? Who determines whether they are inappropriate?

"The approach advocated by the policy only answers the last of these questions," says Malek. The policy statement proposes a process-oriented, step-wise approach involving a second opinion, hospital review, and facilitation of transfer to another institution before permitting life-sustaining treatment to be withheld.

"The process therefore draws on a progressively wider set of opinions about whether an intervention is inappropriate, without defining the concept itself," says Malek. Where state laws permit, she adds, hospitals may be able to facilitate implementation of existing guidelines by creating policies describing how the approach should be applied in their own institutions.

"While the concept of futility was once used routinely in a variety of contexts, the term 'futile intervention' is now typically reserved to describe medical treatments that would not offer any physiologic benefit to the patient," notes Malek. In other words, if the intervention being considered cannot accomplish the desired goal, it is deemed medically futile. "The joint policy statement recommends that truly futile interventions should not be offered to patients or surrogates," says Malek.

## EXECUTIVE SUMMARY

Ethicists can support providers in several ways if a family requests potentially inappropriate care in intensive care units. Bioethicists suggest the following:

- Make providers aware of recommendations for responses to potentially inappropriate treatments.
- Help to create policies describing how the approach should be applied in their own institutions.
- Educate providers that they are not obliged to provide non-efficacious care.

## What is inappropriate?

Malek says determining whether and why a particular treatment is inappropriate under particular circumstances is a “value-laden process. A variety of different ethical considerations could be used to support a claim that treatment falls into this category.”

Interventions may be inappropriate if they will bring about or prolong significant suffering, are highly unlikely to be successful, or will only delay death. “The extent to which the cost of care should factor into judgments about inappropriateness is currently a matter of controversy,” adds Malek.

**Jamie L. Shirley, RN, PhD**, faculty at the School of Nursing and Health Studies at University of Washington Bothell and a clinical ethics consultant at University of Washington Health System in Seattle, says a key issue is the differentiation between efficacy and appropriateness to meet goals of care.

“Providers are not obliged to provide non-efficacious care,” she says. “If the treatment will not work to address the problem the patient has, then the provider need not offer it, nor accede to a request for this intervention.”

Examples might include use of antibiotics against an infection that medication will not treat, or CPR for a patient with severe multisystem organ failure.

“In this situation, the heart might be briefly restarted, but will inevitably fail again for the same reasons it failed in the first place: that it is not supported by the other failing systems,” says Shirley.

Shirley says these situations are qualitatively different from those in which the treatment will work to prolong a patient’s life, but will also

create increased or prolonged suffering in a situation in which the patient and family have identified “preventing suffering” as one of their goals of care.

“In these situations, it can be helpful for providers to re-orient families to their goals,” she says. “Of course the family wants the patient to live longer, but at what cost in burdens and suffering?”

## Provider distress

Would no reasonable set of values support offering life-sustaining treatment? If so, says Malek, providers may feel their professional integrity is compromised by providing such care.

“In cases where intractable disagreement persists and a healthcare provider feels morally compromised by continuing treatment, a process-oriented approach or a transfer of care to a willing provider may be recommended,” Malek says.

Shirley recommends the following for providers:

- **Separate their own suffering from that of the patient and families.** “There are many choices that feel emotionally burdensome to providers that are genuinely desired by families,” she says.

- **Remember that family expectations are created in large part by awe over the technological prowess of healthcare providers and institutions.**

“When we then say we are going to withdraw that expertise, they are somewhat justified in feeling cheated and/or abandoned,” says Shirley.

- **Humbly acknowledge the limits of healthcare providers’ abilities.**

“This puts providers on the same side as the family, rather than positioning them as adversaries,” she says.

- **Ensure justice concerns are**

**addressed.**

Providers can ask themselves, “Are we treating like cases alike? Is there something about the people in this case that makes us more inclined to stop treatment when we might continue it for others? Or is our decision being made on the basis of important medical difference in the health status of the patient?”

Families involved in these cases are often from socially and economically disadvantaged ethnic and racial groups, notes Shirley. “Their perception may be that we are denying care because they are from those groups — that it is discrimination,” she says. “And this is a question with which we should be concerned.”

The American College of Physician’s 2010 report, *Racial and Ethnic Disparities in Health Care*, reports multiple studies showing that patients from minority groups were less likely to receive curative treatments. “Asking these questions allows the concerns to be made explicit, rather than lingering as unspoken anxiety,” says Shirley.

## SOURCES

- **Janet Malek, PhD**, Associate Professor, Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX. Phone: (713) 798-5169. Email: Janet.Weinstein@bcm.edu.
- **Lawrence J. Schneiderman, MD**, Professor Emeritus, Departments of Family Medicine and Public Health and Medicine, University of California, San Diego. Phone: (858) 534-4206. Email: ljschneiderman@ucsd.edu.
- **Jamie L. Shirley, RN, PhD**, Faculty, School of Nursing and Health Studies, University of Washington Bothell/Clinical Ethics Consultant, University of Washington Health System, Seattle. Email: jamiereg@uw.edu. ■

# Updated nursing Code of Ethics

*Tool can support ethical care*

The American Nurses Association (ANA) recently revised its Code of Ethics, which had not been updated since 2001.<sup>1</sup> First, “we established a working group to make recommendations as to whether changes were actually needed, because the code was quite good as it was,” says **Martha Turner**, PhD, RN-BC, assistant director of the ANA’s Center for Ethics and Human Rights.

More than 3,000 registered nurses submitted comments during a four-year revision process. (*To view the complete Code of Ethics, go to <http://bit.ly/1FsZxy3>.*) Changes were made by a steering committee, and again the code was put out for public comment. “We got another 980 responses with about 1,500 suggestions. We made some final changes, and the board of directors approved it,” says Turner. The group used a qualitative research process, which clustered ideas and identified common themes.

Changes to the code’s nine provisions include updated language to address social media, technology, and genetics. “The first three provisions emphasize the fundamental values of the nursing/patient relationship,” says Turner. The next three provisions address boundaries of duty and loyalty when conflicts arise with employers or colleagues. “The final three provisions address duties beyond our individual patient encounters, to the greater world around us,” says Turner.

The code emphasizes that nurses in any role and any setting have leadership responsibilities. “We talk about differences in the terms for what nurses ‘must’ do, ‘should’ do, and ‘ought to’ do, so the provisions

could be better understood,” notes Turner.

The revised code gives nurses “a solid foundation to stand on in one’s scope of practice,” says **Helen Stanton Chapple**, PhD, RN, MA, MSN, CT, a nurse ethicist and associate professor at Creighton University’s Center for Health Policy and Ethics in Omaha, NE. “That scope has been expanded and broadened in this code.”

The code defines a non-negotiable standard of practice for nurses, says Chapple. “As such, it gives nurses an even firmer basis for voicing ethics concerns and broader arenas in which to invest those concerns,” she says.

## Possible conflict with policies

Turner says the first step is for nurses and others to read the code. Next, they should integrate it into the hospital’s policies and procedures. “If there is a conflict between the code and what nurses are expected to do, it should be resolved so nurses have no question about what to do,” she adds.

The code gives nurses guidance on ethical interactions with colleagues. “If you use the code well, you can anticipate problems that may come up in the work setting,” says Turner. The code can provide much-needed support for nurses who feel they’re being asked to do something unethical. “When a policy comes down from corporate, you can say, ‘Is this consistent with what the code says?’” says Turner.

For instance, nurses may be uncomfortable discharging a patient

home if they know that caregivers are unable to safely care for the patient. In this case, says Turner, nurses can advocate for other arrangements. “That theme of safety is found throughout the code,” she says.

Nurses are often privy to information of which physicians are unaware. “Patients talk to nurses about things that they don’t tell physicians,” says Turner. “It’s often in the middle of the night when patients will discuss their worries or realities in their life.”

The code stresses working as a team. “If we are not being listened to, we need to step forward instead of just saying, ‘Well, it’s not my decision,’” says Turner. “Nurses must pursue these situations until they are resolved.”

If an impaired physician is putting patients at risk, an individual nurse might not be comfortable confronting the issue. “There is strength in numbers,” says Turner. “Nurses collectively on a unit can go forward to management with the code in hand.” The following are some ethical issues addressed in the updated code:

### • Informed consent and genetics.

“Genetics is, in some ways, divisive at this point in time,” says Turner. Some believe that once acquired, genetic information should be available for research generally without specific permission from individuals; others think that every individual should give informed consent for every study. “Nurses may feel conflicted if asked to help with research that’s not as well-defined, or an informed consent that’s not as clear as they think it ought to be,”

says Turner.

- **Ethical problems with research in the clinical setting.**

“If nurses feel the patient is being treated more as a research participant than a patient, they are asked to step forward,” says Turner.

- **Patient privacy involving media access to patient care areas.**

“If there are newsworthy cases where the media is prowling about, nurses need to step forward and say, ‘You are not allowed here,’” says Turner.

- **End-of-life issues, including physician-assisted suicide.**

“Particularly in the states where physician-assisted suicide is becoming legalized, nurses are directed by the code not to participate,” says Turner.

The code won’t necessarily protect nurses from losing their jobs for stepping forward. “The code acknowledges that whistleblowing is not without inherent dangers,” says Turner. “But that does not absolve nurses of the responsibility to speak up.”

#### REFERENCE

1. ANA Code of Ethics for Nurses with Interpretive Statements. 2015.

American Nurses Association. Silver Spring, MD.

#### SOURCES

- **Helen Stanton Chapple, PhD, RN, MA, MSN, CT, Nurse Ethicist/ Associate Professor, Center for Health Policy and Ethics, Creighton University, Omaha, NE.** Phone: (402) 280-2027. Fax: (402) 280-5735. Email: HelenChapple@creighton.edu.
- **Martha Turner, PhD, RN-BC, Assistant Director, Center for Ethics and Human Rights, American Nurses Association.** Phone: (651) 967-1342. Email: martha.turner@ana.org. ■

## Pathologists ill-prepared to disclose errors, says research

*Lack of training, lack of experience contribute*

Virtually all pathologists (97%) reported being involved in a minor or serious error, but only about 39% knew whether the error had been conveyed to the patient, according to a recent survey of 106 pathologists, presented at the 2015 annual meeting of the College of American Pathologists. Other key findings include the following:

- Only 11% of practicing pathologists reported that they had participated directly in disclosing a serious error to a patient.
- Less than half (40.7%) of

practicing pathologists were aware of their hospital’s error disclosure policy.

There are many reasons why pathologists may not feel comfortable disclosing errors to patients, providers, or colleagues, says **Melissa Austin, MD, MBS**, a Bethesda, MD-based pathologist affiliated with Walter Reed National Military Medical Center.

“Lack of training, lack of experience, and lack of necessity all contribute,” she says. Some pathologists view the provider as their client rather than the patient, since

they have more direct interaction with providers.

“That said, I would assert that institutional culture probably plays the greatest role in determining how likely the pathologist is to be involved in error disclosure,” says Austin. She says bioethicists should work to create a focus on quality improvement that destigmatizes errors and error disclosure.

“Pathologists are viewed as partners in the care team, rather than as detached consultants,” says Austin. “It becomes easier and more natural for them to be actively engaged.”

### EXECUTIVE SUMMARY

Although virtually all pathologists reported being involved in an error, only about a third knew if the error had been disclosed to the patient, says a recent survey. Some ethical concerns include the following:

- Pathologists worry that providers don’t fully understand how the error occurred.
- Most pathologists are unaware of institutional disclosure policies.
- Providers may inaccurately imply the error was the pathologist’s fault.

### Communication lacking

Pathologists often view their role as consultants to physicians instead of caregivers to patients, says **Suzanne M. Dintzis, MD, PhD**, associate professor of pathology at University of Washington Medical

Center in Seattle.

A 2011 survey conducted by Dintzis and colleagues showed that many pathologists regarded the end point of the disclosure to be when the error was revealed to the treating physician.<sup>1</sup> They worried, however, that physicians didn't really understand the nature of the error to adequately convey the information to patients and families.

"A lot of the issue involves communication," says Dintzis. "There is also a general feeling that pathologists are not comfortable with their communication skills."

Pathologists aren't sure that providers or patients fully understand what they do. "They worry that the ambiguity of pathology diagnosis isn't fully understood," says Dintzis. "Some of these diagnoses are very subjective, and a lot of what we do is interpretation."

In focus groups, pathologists themselves disagreed on which types of errors should be disclosed. "Many people think that disclosing near misses, where a lab error is caught before it harms a patient, would be unhelpful and possibly deleterious," Dintzis says. Although all the surveyed pathologists believed serious errors should be disclosed, "we know that's not always happening," she adds.

## Direct disclosures?

Pathologists worry that patients may be given misinformation about the error or how it occurred, or that providers never disclosed the error at all. "There's a lot of difference of opinion on how aggressively they should insert themselves in trying to disclose the error, because they don't have a relationship with the patient," says Dintzis.

On the other hand, pathologists want to be sure the error is disclosed, and that it is a true representation of an often complex situation. "There could be a clear-cut explanation for the error that would relieve patient stress," says Dintzis.

When the pathologist is not present, "we worry we will be thrown under the bus," says Dintzis. "For all we know, the clinician might tell the patient, 'The pathologist just totally screwed this up.'"

Many focus group participants felt that pathologists should take the initiative in joining the discussion with the patient. "But almost all didn't think they should do it without the treating clinician's approval, because that's intrusive," Dintzis says.

Most pathologists received no training in error communication and were not aware of resources at their institution. "They thought coaching would be incredibly helpful, but didn't even know that option existed," Dintzis says.

Professional guidelines are silent on the issue of whether a pathologist

should ever directly disclose an error to a patient or family. "Most pathologists would feel we don't want to intrude on the relationship," says Dintzis. "But we want to make sure that the information and apology is complete."

## REFERENCE

1. Dintzis SM, Stesenko GY, Sitlani CM, et al. Communicating pathology and laboratory errors: anatomic pathologists' and laboratory medical directors' attitudes and experiences. *Am J Clin Pathol*. 2011; 135(5):760-765.

## SOURCES

- **Melissa Austin**, MD, MBS. Department of Pathology, Walter Reed National Military Medical Center, Bethesda, MD. Email: melissa.c.austin6.mil@mail.mil.
- **Suzanne M. Dintzis**, MD, PhD, Associate Professor of Pathology, University of Washington Medical Center, Seattle. Phone: (206) 598-1986. Fax: (206) 598-3803. Email: dintzis@u.washington.edu. ■

## CME OBJECTIVES

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

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

## COMING IN FUTURE MONTHS

- Demonstrate financial benefit of ethical policies
- How ethicists can alleviate caregivers' moral distress
- Ethics controversy over pain management "contracts"
- Update on new efforts to simplify informed consent

**EDITORIAL ADVISORY BOARD**

**CONSULTING EDITOR:**

**Arthur R. Derse, MD, JD**  
Director and Professor  
Center for Bioethics and Medical Humanities  
Institute for Health and Society  
Medical College of Wisconsin  
Milwaukee, WI

**EDITORIAL BOARD:**

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

**J. Vincent Guss, Jr.,  
BCC, D.Min**  
Journal of Pastoral Care  
Editorial Board for the  
Association of Professional  
Chaplains  
Director of Medical Bioethics  
Kaiser Permanente West Los Angeles Medical  
Center  
Los Angeles, CA

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

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

**Melissa Kurtz, MSN, MA, RN**  
Bioethics Consultant  
The Montefiore-Einstein Center for Bioethics  
Bronx, NY

**Susan Solverson, BSN, RN, CMSRN**  
Staff RN Educator, Nursing 4P  
Froedtert and the Medical College of Wisconsin  
Froedtert Hospital  
Milwaukee, WI

Interested in reprints or posting an article to your company's site? There are numerous opportunities for you to leverage editorial recognition for the benefit of your brand.

Call us: 800.688.2421

Email us: Reprints@AHCMedia.com

**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.

To reproduce any part of AHC newsletters for educational purposes, please contact The Copyright Clearance Center for permission:

Email: info@copyright.com

Website: www.copyright.com

Phone: (978) 750-8400

## 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. Scan the QR code to the right or log onto AHCMedia.com and click on My Account. Tests are taken after each issue.
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, your browser will be automatically directed to the activity evaluation form, which you will submit online.
5. Once the completed evaluation is received, a credit letter will be e-mailed to you instantly.



## CME QUESTIONS

**1. Which is true regarding end-of-life care in the emergency department setting, according to recent research?**

- A. There is clear evidence that screening and referral for palliative care consultation is not feasible in the ED setting.
- B. The ED team has no ethical obligation to meet the patient's social and spiritual needs because these are not competencies of emergency medicine.
- C. There is no value to screening for palliative care needs if palliative care services are inconsistently available.
- D. Success of screening for palliative care required additional personnel and was limited by hours of availability of palliative care teams.

**2. Which is true regarding care of patients with dementia in the last five years of life, according to recent research?**

- A. Repeated imaging tests are usually helpful in patients with advanced dementia.
- B. Costs related to daily care are not typically covered by health insurance.
- C. Costs of care for cancer and heart disease patients was significantly greater than dementia care.
- D. Providers should inform caregivers that supplemental Medicare coverage covers caregiving costs.

**3. Which is true regarding family requests for potentially inappropriate care in intensive care units, according to Janet Malek,**

**PhD?**

- A. Hospital policies should not specifically address how these requests should be handled since this limits clinicians' discretion.
- B. Where state laws permit, hospitals can create policies describing how the approach should be applied in their own institutions.
- C. Providers generally have an obligation to offer even futile interventions when these are requested by surrogates.
- D. If a treatment will not work to address the problem the patient has, under the law of informed consent, providers have an ethical obligation to accede to a specific request for the intervention.

**4. Which is true regarding disclosure of pathology errors, according to Suzanne M. Dintzis, MD, PhD?**

- A. Pathologists should not insert themselves into the disclosure process because they lack a direct relationship with the patient.
- B. Providers' implications that the error was solely the fault of the pathologist are sometimes necessary to avoid needlessly harming the patient/physician relationship.
- C. Even serious pathology errors don't typically fall under hospitals' disclosure policies.
- D. Pathologists are concerned that patients may be given misinformation about the error or how it occurred, or that providers never disclosed the error at all.