



# MEDICAL ETHICS ADVISOR®

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

JULY 2018

Vol. 34, No. 7; p. 73-84

## ➔ INSIDE

System adds clinical ethics consultation notes in EHR . . . . . 76

New policy takes neutral stance on physician-assisted suicide . . . . . 78

Companion presence affects presurgery discussions in unexpected ways . . . . . 78

Nursing organization urges action on moral distress . . . . . 79

New data on aggressive treatment preferences and ED visits . . . . . 80

New guidance helps clinicians navigate demands for nonbeneficial care . . . . . 80

Ethical concerns if older adult with cognitive impairment lives alone . . . . . 82

Responses if patients revoke consent due to complications . . . . . 83

## Certification Now Possible for Clinical Ethics Consultants: Applicants Are 'Agents of Change'

*Program validates ethicists' expertise*

**A**re individuals who perform clinical ethics consultations qualified to do so? For the first time, it's possible to demonstrate this with a credential.

The American Society for Bioethics and Humanities (ASBH) Healthcare Ethics Consultant—Certified (HEC-C) program is “the first of its kind to identify and assess a national standard for healthcare ethics consultants,” says **Felicia Cohn**, PhD, chair of the Health Care Ethics Consultation Certification Commission.

The certification recognizes the

consultant's proficiency in identifying, counseling, and resolving ethical issues and leading healthcare ethics policy at the institutional level.

“Ultimately, becoming certified validates the healthcare ethics consultant's role in ensuring ethical decision-making and care practices within the healthcare setting,” says Cohn.

ASBH president **Alexander A. Kon**, MD, FAAP, FCCM, says the organization has “worked toward improved quality and consistency in healthcare

ethics consultation for nearly two decades. Certification of healthcare

**IT RECOGNIZES THE CONSULTANT'S PROFICIENCY IN IDENTIFYING, COUNSELING, AND RESOLVING ETHICAL ISSUES AND LEADING HEALTHCARE ETHICS POLICY AT THE INSTITUTIONAL LEVEL.**

**RELIAS**  
Formerly AHC Media

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

**Financial Disclosure:** Consulting Editor **Arthur R. Derse**, MD, JD, Nurse Planner **Susan Solverson**, RN, BSN, CMSRN, Editor **Jill Drachenberg**, Editor **Jesse Saffron**, Editorial Group Manager **Terrey L. Hatcher**, and Author **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, a Relias Learning company  
111 Corning Road, Suite 250  
Cary, NC 27518

Periodicals Postage Paid at Cary, NC, and at additional  
mailing offices.  
GST Registration Number: R128870672.

**POSTMASTER:** Send address changes to:  
*Medical Ethics Advisor*  
111 Corning Road, Suite 250  
Cary, NC 27518

**SUBSCRIBER INFORMATION:**  
Customer Service: (800) 688-2421.  
Customer.Service@AHCMedia.com.  
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 hours, \$519.  
Add \$19.99 for shipping & handling. Online only, single  
user: 1 year with free CE, \$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.

**ACCREDITATION:** Relias Learning is accredited by the  
Accreditation Council for Continuing Medical Education  
(ACCME) to provide continuing medical education for  
physicians.  
Relias Learning 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.

Relias Learning, LLC, is accredited as a provider of  
continuing nursing education by the American Nurses  
Credentialing Center's Commission on Accreditation.  
Contact hours [1.5] will be awarded to participants who  
meet the criteria for successful completion. California  
Board of Registered Nursing, Provider CEP#13791.

This activity is intended for acute care physicians, chiefs  
of medicine, hospital administrators, nurse managers,  
physician assistants, nurse practitioners, social workers,  
and chaplains.

This activity 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.

**AUTHOR:** Stacey Kusterbeck  
**EDITOR:** Jill Drachenberg  
**EDITOR:** Jesse Saffron  
**EDITORIAL GROUP MANAGER:** Terrey L. Hatcher  
**SENIOR ACCREDITATIONS OFFICER:** Lee Landenberger

**PHOTOCOPYING:** No part of this newsletter may  
be reproduced in any form or incorporated into any  
information retrieval system without the written permission  
of the copyright owner. For reprint permission, please  
contact AHC Media, LLC. Address: P.O. Box 74008694  
Chicago, IL 60674-8694. Telephone: (800) 688-2421. Web:  
AHCMedia.com.

Copyright © 2018 by AHC Media, LLC, a Relias Learning  
company. *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

ethics consultants is the natural next  
step.”

Over time, the certification  
program will improve the overall  
quality of healthcare ethics  
consultation, thereby improving  
patient care and decreasing moral  
distress, says Kon.

“We believe that certification  
is one very important step in the  
professionalization of the field,” adds  
Kon.

Healthcare ethics consultants  
come from a variety of qualifying  
backgrounds. Often, they serve  
in multiple roles at multiple  
organizations. These include serving  
on ethics committees; performing  
ethics consultations with patients,  
families, and healthcare providers;  
writing policies and guidelines; and  
identifying organizationwide ethics  
opportunities.

In addition to demonstrating their  
clinical expertise and commitment to  
high-quality patient care, says Cohn,  
consultants who obtain the HEC-C  
credential “will serve as an agent of  
change within the healthcare ethics  
field.”

Leaders in healthcare ethics  
often oversee their facility’s ethics  
consultation service or ethics  
committee. They may be responsible  
for, or a resource for, executive  
decision-making. “Although this  
group may feel like their many

years of hands-on experience negate  
their need for certification that tests  
fundamental knowledge, certification  
will provide evidence of their  
expertise,” says Cohn.

Cohn would like to see ethics  
leaders encourage novice or mid-level  
healthcare ethicists, and perhaps even  
medical staff with ethics expertise,  
to obtain certification. The HEC-C  
program assesses the core knowledge  
and competencies healthcare ethics  
consultants need to:

- effectively and accurately  
provide service to patients, families,  
and patient care colleagues;
- contribute to institutional  
policies and procedures related to  
ethical decision-making at all levels  
of patient care.

“Any new program of importance  
is likely to be met with some  
controversy,” notes Cohn.

Recognizing this, ASBH followed  
a comprehensive and carefully  
designed process to research the  
need for healthcare ethics consultant  
certification. “This was done through  
broad environmental scanning and  
needs assessment, following National  
Commission for Certifying Agencies  
criteria,” says Cohn.

The Healthcare Ethics  
Consultation Certification  
Commission “brings crucial  
content expertise to the table, and  
reflects the diversity of healthcare

## EXECUTIVE SUMMARY

The Healthcare Ethics Consultation Certification is the first program to  
identify and assess a national standard for healthcare ethics consultants. The  
certification assesses consultants’ ability to:

- lead healthcare ethics policy at the institutional level;
- effectively and accurately provide service to patients, families, and  
colleagues;
- contribute to institutional policies and procedures related to ethical  
decision-making.

ethics consultant roles across the healthcare spectrum,” says Cohn. A knowledge-based process was used to develop candidate criteria and the examination.

Questions and concerns are expected due to the newness of the program and the diversity of professionals involved in healthcare ethics consults. “These will be addressed as the program moves forward,” says Cohn.

The impact of the new certification will depend in part on how valued the practice of ethics already is at a given institution. This varies widely. “I think at the very least, the inherent good of having some sort of certification is that it will establish some sort of baseline as to what’s required,” says **Paula Goodman-Crews**, MSW, LCSW, co-director for Kaiser Permanente’s Southern California bioethics program.

At Kaiser Permanente, there’s already a general consensus that ethicists are very well-qualified. “Our leadership is very supportive and values our work,” says Goodman-Crews.

Certification would be most useful at hospitals and health systems that are building up their ethics programs. “It serves as a safeguard to help us be more confident that the person is skilled and has the competency to do ethics,” Goodman-Crews says.

Healthcare institutions that do not have dedicated ethicists would benefit from encouraging members of the bioethics commission to seek certification, she says: “It’s always a good idea to augment the collective competencies of bioethics committee members.”

Widely varying practices for ethics consultations are well-established. Only 41% of consultants had formal supervised training in ethics

consultation, found one study — and while most (65%) always made recommendations, some (6%) never did.<sup>1</sup> “That really opened all of our eyes on the variability in how we practice,” says Goodman-Crews.

When hiring ethicists for Kaiser Permanente’s Southern California region, Goodman-Crews saw that finding the right skill set was a

**“A WRITTEN TEST PROBABLY CAN’T ACCOUNT FOR THOSE KINDS OF SKILLS. BUT IT’S ONE TOOL IN THE TOOLBOX THAT’S GOING TO ENABLE US TO MAKE SURE WE HAVE PEOPLE WHO ARE SKILLED.”**

challenge. Many applicants had authored papers or were teaching at medical or law schools, but lacked clinical experience. “There’s been a proliferation of people with master’s degrees in bioethics, but most of the programs don’t have any clinical fellowship attached to them,” says Goodman-Crews. “Over the years, we’ve started hiring people with clinical training.”

The value of certification is lost on hospital leaders who don’t realize that ethicists need a specific skill set. “There is a belief that if you are a good doctor or nurse, you are ‘ethical.’ But that has no bearing on being able to actually handle the dynamics of an ethical conflict,” says Goodman-Crews.

Absence of regulatory requirements means that at some organizations, ethics just doesn’t register as a priority. The Joint Commission has required hospitals to employ a mechanism for resolving ethical dilemmas in patient care for more than two decades — yet the accrediting body has never specified how to do this.

Goodman-Crews has been involved in dozens of Joint Commission surveys at various organizations. Occasionally, a surveyor brings up something related to ethics, such as a patient’s advance directive that cannot be found in the chart. “But I can’t remember any time when they’ve ever asked about the qualifications of people doing ethics consultation,” she says.

If the organization passes the survey “and no one is calling the institution out on ethics practice, many will probably see no reason to require certification,” says Goodman-Crews.

The ability to communicate, build rapport, and demonstrate tolerance, trust, empathy, and compassion also are important parts of being an ethicist. “A written test probably can’t account for those kinds of skills,” says Goodman-Crews. “But it’s one tool in the toolbox that’s going to enable us to make sure we have people who are skilled.” ■

## REFERENCE

1. Fox E, Myers S, Pearlman RA. Ethics consultation in United States hospitals: A national survey. *Amer Journ Bioethics* 2007; 2(7):13-25.

## SOURCE

- **Alexander A. Kon**, MD, FAAP, FCCM, Clinical Professor of Pediatrics, University of California, San Diego School of Medicine. Email: kon.sandiego@gmail.com.

# Clinical Ethics Consult ‘Needs to Be in the Chart’

*‘Dynamic and effective’ system facilitates quality review*

Ethics documentation isn’t always reviewed by the clinical team, assuming it exists in the medical record at all. A recent paper offers a suggested framework to ensure that clinical ethicists’ notes are included in the electronic health record (EHR).<sup>1</sup>

“A clinical ethical consultation is an intervention. It is advisory, obviously, but it’s an intervention that is trying to shape care. And it needs to be in the chart,” says **Nancy Neveloff Dubler**, one of the paper’s authors. Dubler is adjunct professor in the division of medical ethics at NYU Langone Medical Center, professor emerita at the Albert Einstein College of Medicine/Montefiore Medical Center, and consultant for ethics at the New York City Health and Hospitals Corporation.

Ethicists created a template that instructs providers to chart ethically relevant medical facts, ethically relevant social facts, ethical issues that arise, a discussion of those issues, and a recommendation.

“In addition to that, what we built into the ethics format was a set of paragraphs which are short discussions of the most common issues that arise,” says Dubler. These provide some guidance on possible approaches to the consultation and a framework for documentation, “so you are not recreating the wheel on the issue of

capacity every time you write a chart note,” says Dubler.

The ethics chart note has these three purposes, says Dubler:

- to affect the care of the patient;
- educate the staff;
- permit a peer review assessment of the quality of the process.

“That’s what we build into our system — and it’s been pretty fabulous,” says Dubler.

The only way to evaluate the quality and the effectiveness of clinical ethics consultations is by reviewing the chart note, according to a previous paper.<sup>2</sup> “We put those two things together, and we have taken it to the next step with the EHR,” says Dubler, the report’s lead author.

The chart notes on every ethics consult at New York City Health and Hospitals are sent to a different institution within the system for review. The most interesting notes become the basis of bimonthly meetings for ethics consultants.

“We look at how we do the consults, the issues they raise, and is there something more we need to do?” says Dubler. “We now have the systems in place to do it.”

A reviewer recently noted that a particular consultant’s notes weren’t in the approved format and didn’t include some basic interventions that are

expected for every consultation. “For example, you must go and see the patient. Even if the patient is moribund, that is the person that the family sees; and therefore, you must have a sense of what their vision projects,” says Dubler.

There was no indication in the notes that the patient had been seen, nor was there much information about the patient’s social situation. “They were very sketchy. The way it stood, it looked like the consultation was not adequate,” says Dubler. The head of the institution’s ethics consultation service indicated that the consultant was highly skilled but lacked documentation skills. Dubler then met with the consultant and suggested ways to improve how future cases are documented.

“I think that’s a useful intervention because the chart note is what conveys to the rest of the staff what happened,” says Dubler. If the chart note isn’t adequate, the ethicist isn’t giving clinicians the tools they need to think about the care of the patient.

A good consultation that helps to manage conflict is “always in the greater interest of risk management,” adds Dubler. “When there are cases that go to court, it has been noted that a good clinical ethics consultation is often helpful.”

Chart notes are displayed on a screen for the group of about 50 ethicists to review. “Oftentimes, people will suggest ways that a mediation could have been more effective, or make other suggestions about how to improve the quality of the consultation,” says Dubler.

All participants sign confidentiality agreements and no visitors are

## EXECUTIVE SUMMARY

Clinical ethics consultation notes are not always included in the electronic health record, but should be included for the following reasons:

- to affect the care of the patient;
- to educate the staff;
- to permit a peer review assessment of the quality of the process.

permitted to attend, including students. “That’s a bit of a loss to me,” says Dubler. “But the office of legal affairs was very concerned, since we are using actual chart notes, that we severely restrict those people who could be part of the review, which is perfectly reasonable.”

The EMR charting facilitates review of the effectiveness, efficiency, and appropriateness of consults. “It has created a dynamic and effective system,” says Dubler. The components are as follows:

- the chairs of the ethics committee designate individuals as having the requisite knowledge and skills to participate in the clinical ethics program;
- clinical ethics consultants are required to write chart notes and send them to be peer-reviewed.

“By critiquing the documentation, you critique the consult,” says Dubler.

Trends also are identified. As part of the peer review process, it was noted that these three scenarios came up regularly in consults:

- the “unbefriended” patient making decisions alone;
- the patient without capacity, or with fluctuating capacity;
- the discharge planning process, in which the patient wants to assume greater risk contrary to what others think is in his or her best interest.

The group wrote algorithms outlining the steps for ethicists to take in addressing these particular scenarios. “We identified issues that should be considered, and in what sort of order,” says Dubler. These guidelines recently became institutional policy. “There is no question in my mind that this sort of rigorous systematic evaluation is in the interest of patients and the institution,” says Dubler.

There is a need for a medical record that speaks to the entire team not just about physiology, but about normative issues related to patient care, says

**Joseph J. Fins**, MD, MACP, FRCP, chief of the division of medical ethics and the E. William Davis, Jr., MD professor of medical ethics at Weill Cornell Medical College. Fins also is director of medical ethics at New York-Presbyterian Hospital/Weill Cornell Medical Center in New York City.

“Ethics should not be balkanized. Certainly, the kind of things that end up in an ethics consult can be as dispositive as anything else,” says Fins, one of the paper’s co-authors. These include issues such as whether the patient has capacity, whether aggressive measures will be pursued, and whether palliative care is an option.

“These are at least, if not more, important than the technical details of care,” says Fins. A good template reminds ethicists that there are certain elements that go into a good ethics note. In this fashion, says Fins, “the template might also help to bring standard of consultation up in an organizational, institutional way.”

For instance, if a question comes up about decision-making, others can see at a glance that the patient’s capacity was assessed, who assessed it, and what criteria were used. “The idea is that there needs to be a place for the consultant’s work to be reflected and understood by the entire clinical team,” says Fins.

The work of ethicists is somewhat different from other clinical work, notes Fins. All clinicians face challenges with EMRs being overly templated, and the need to avoid a “check box” mentality may be particularly relevant to ethics, says Fins. Ethicists may need more free text to explain their rationale.

“The goal is not to shed the normative aspects of the work and become reductionistic or overly medicalized, but for our work to be incorporated into the discourse in a way that is compatible with how

clinicians communicate with each other,” says Fins.

Ethics documentation that differs from other types of clinical documentation is less likely to be read. “If it’s presented in a way that looks unlike any other medical record note, clinicians won’t understand it, or won’t pay attention to it. And that’s counter to the intent,” says Fins.

Overtly philosophical charting that reads more like a short story is unlikely to be reviewed by the clinical team, for instance. “We’re in a clinical community. The chart is not a place for good narrative nonfiction,” says Fins. “It has to be accessible to other clinicians.” ■

## REFERENCES

1. Sanelli-Russo S, Folkers KM, Sakolsky W, et al. Meaningful use of electronic health records for quality assessment and review of clinical ethics consultation. *J Clin Ethics* 2018; 29(1):52-61.
2. Dubler NN, Webber MP, Swiderski DM and the National Working Group for the Clinical Credentialing Project. Charting the future: Credentialing, privileging, quality, and evaluation in clinical ethics consultation. *Hastings Cent Rep* 2009; 39(6):23-33.

## SOURCES

- **Nancy N. Dubler**, Adjunct Professor, Division of Medical Ethics, NYU Langone Medical Center, New York City. Email: nancy.dubler@nyumc.org.
- **Joseph J. Fins**, MD, MACP, FRCP, The E. William Davis, Jr., MD Professor of Medical Ethics/Chief, Division of Medical Ethics, Weill Cornell Medical College/Director of Medical Ethics, New York-Presbyterian Hospital/Weill Cornell Medical Center, New York City. Phone: (212) 746-4246. Email: jfins@med.cornell.edu.

# Policy Takes Neutral Stance on Physician-assisted Suicide

In a new position statement, the American Academy of Neurology (AAN) leaves the decision of whether to practice lawful physician-hastened death to “the conscientious judgment of its members acting on behalf of their adult patients dying of neurologic illness.”<sup>1</sup> This replaces a 1998 position statement that vigorously opposed participation in either physician-assisted suicide or euthanasia.

“The recognition that AAN members who reside in states where physician-assisted suicide was lawful might be conflicted by their willingness to aid their terminally ill patients seeking lawful hastened death assistance, and the historical

AAN position precluding their participation,” were the motivation behind the new policy, according to **James A. Russell**, DO, FAAN, chairman of the AAN’s Ethics, Law, and Humanities Committee.

In a 2014 survey, a significant percentage of AAN members stated that they might feel bound by conscience to comply with the wishes of dying patients for assistance in hastening death. The Ethics, Law, and Humanities Committee deliberated the issues for two years before unanimously recommending that the 1998 position be retired and issuing the new position.

“The purpose was to remove any potential conflict in guidance by

allowing AAN members to lawfully exercise their conscience on behalf of their dying patients without fear of an AAN grievance action,” says Russell. ■

## REFERENCE

1. Russell JA, Epstein LG, Bonnie RJ, et al. Lawful physician-hastened death: AAN position statement. *Neurology* 2018; 90(9):420-422.

## SOURCE

- **James A. Russell**, DO, FAAN, Department of Neurology, Lahey Hospital and Medical Center, Burlington, MA. Phone: (781) 744-5124. Email: james.a.russell@lahey.org.

---

# Companion Presence Affects Presurgical Conversations

After being present during preoperative visits for two surgeries that her father recently underwent, **Sarina Isenberg**, PhD, began wondering what effect she was having on the conversation.

Isenberg, currently a scientist at the Temmy Latner Centre for Palliative Care in Toronto, made this the focus of her dissertation. Researchers analyzed 46 visits in which companions were present, and 15 in which companions were absent.<sup>1</sup>

“I was intrigued by whether there may be fundamental differences between patients that are and are not accompanied, and whether having a family member present in the visit might impact the nature of the conversation that occurs between

the patient and surgeon during the preoperative visit,” says Isenberg.

Companions’ presence during pre-surgical visits was associated with patient-surgeon communication. However, there was no difference in patient or surgeon satisfaction.

Previous research demonstrated various ways in which family companions affect the nature of the conversation during routine medical visits.<sup>2</sup> “I wanted to test whether their findings might be translatable to the preoperative setting,” says Isenberg.

Researchers expected that the visit would be more patient-centered due to companions acting as patient advocates. They found the opposite was true: Companions’ presence was associated with lower levels of patient-centeredness.

“This change was largely driven by the companion asking biomedical questions, the surgeon providing more biomedical information, and the patient disclosing less lifestyle and psychosocial information,” says Isenberg.

Given the study’s small sample size, Isenberg is hesitant to draw ethical implications. “Our results suggested that companions altered the nature of communication. However, we cannot ascertain whether this change is ethically good or bad,” she says.

At first glance, one might intuit that companions should not be present during the preoperative exchange, since it results in a less patient-centered conversation. “However, the companions’ presence

might very well be beneficial to the patient,” says Isenberg.

Companions might perceive patients as too anxious to effectively participate in the visit. “Consequently, companions may feel compelled to advocate for the patient by asking technical questions about the surgery, thereby providing informational social support,” suggests Isenberg.

Similarly, surgeons may refrain from providing too much technical information to unaccompanied patients to avoid overwhelming them. “Conversely, the presence of a companion may prompt the surgeon to provide information

that the companion can document or remember for the patient,” says Isenberg.

Companions have another important reason for wanting technical information. They’re often tasked with caring for the patient at home post-surgery, which requires wound management, medication administration, and symptom monitoring. “This may lead them to have more informational needs during the preoperative visit,” says Isenberg. ■

## REFERENCES

1. Isenberg SR, Aslakson RA, Dionne-Odom JN, et al. Family companions’

involvement during pre-surgical consent visits for major cancer surgery and its relationship to visit communication and satisfaction. *Patient Educ Couns* 2018; 101(6):1066-1074.

2. Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review. *Social Science and Medicine* 2011; 72:823-831.

## SOURCE

- Sarina Isenberg, PhD, Scientist, Temmy Latner Centre for Palliative Care/Assistant Professor, Department of Family and Community Medicine, University of Toronto. Email: sarina.isenberg@sinahealthsystem.ca.

---

# Nurses Issue Call to Action on Moral Distress

The American Nurses Association (ANA) has released “A Call to Action: Exploring Moral Resilience Toward a Culture of Ethical Practice,” which offers specific, practical guidance for nurses, leaders, and organizations.<sup>1</sup>

“There is increasing recognition that nurses are truly suffering — and some are even leaving their profession — due to negative psychological consequences,” says Liz Stokes, JD, MA, RN, director for the ANA’s Center for Ethics and Human Rights. Those include burnout, post-traumatic stress disorder, and compassion fatigue.

For nurses, the call to action speaks to the ethical obligation for self-care. For organizations, it emphasizes the need for a culture of ethical practice. “There is a need for assessment to make sure you have a healthy work environment, and to incorporate ethics into educational programs,” says Stokes.

More evidence is needed

on the effectiveness of various known interventions. “We want organizations to research this to add to the body of knowledge,” says Stokes.

## Moral Distress Not High Priority

Many promising practices are anecdotally believed to reduce the psychological consequences of moral distress in nursing. “But we want to have the hard evidence because that’s what changes policy and gets funding,” says Stokes.

Addressing moral distress remains a distant priority at many hospitals. That’s in part because it’s difficult to put a dollar amount on what it costs the organization. “The psychological consequences can’t be visually seen,” adds Stokes. “But we do know that nurses who are experiencing negative consequences are more prone to patient errors.”

Even if there is an intervention in place, nurses can’t always use it. “Nurses are so incredibly busy. They may not have time to step away for 15 minutes in order to reflect on a difficult situation,” says Stokes.

Bioethicists can help at the institutional level by helping to develop policies, and on the individual level by assisting nurses experiencing moral distress, says Stokes. “Their role and significance is tremendous.” ■

## REFERENCE

1. American Nurses Association. A call to action: Cultivating moral resilience and a culture of ethical practice. Available at: <https://bit.ly/2J7B34w>. Accessed June 10, 2018.

## SOURCE

- Liz Stokes, JD, MA, RN, Director, Center for Ethics and Human Rights, American Nurses Association, Washington, DC. Phone: (301) 628-5384. Email: liz.stokes@ana.org.

# Preference for Aggressive Treatment Isn't Linked to Inpatient or ED Care

Preferences for more aggressive medical treatment are not significantly associated with inpatient or ED treatment, according to a recent study.<sup>1</sup>

“Declines in hospitalization and increasing use of hospice may indicate greater concern by older adults to avoid aggressive care,” notes **Steven M. Albert**, PhD, MS, FGSA, the study’s lead author. Albert is the Philip B. Hallen Endowed Chair in Community Health and Social Justice at University of Pittsburgh.

Researchers analyzed preferences for treatment at the end of life, and reported hospital and ED use for 1,118 patients over a six-month period, 1,021 patients over a 12-month period, and 945 patients over an 18-month period.

“In this study, we did not see lower hospitalization or emergency

department use in people reporting a preference for less aggressive care,” says Albert.

Likewise, a hospital admission or ED visit did not reduce patients’ interest in electing aggressive care in the future. This suggests that hospitalization or ED use in old age often is intermittent, unclear, or unplanned and not always in the hands of the older person.

“The person who falls, experiences syncope, or seems unresponsive may end up in the hospital, despite preferences to avoid aggressive medical care,” says Albert.

It’s possible that attitudes toward routine care, rather than end-of-life treatment preferences, may be more highly associated with healthcare utilization, the researchers concluded. “A useful approach, recommended by palliative care proponents, is more options for

non-hospital care,” says Albert. This might include medical home visits or simply a phone consult.

“These alternatives seem reasonable in the case of the very old, in light of the harm hospitalization may cause,” says Albert. ■

## REFERENCE

1. Albert SM, Lunney JR, Ye L, et al. Are preferences for aggressive medical treatment associated with healthcare utilization in the very old? *J Palliat Med* 2017 Mar 23. doi: 10.1089/jpm.2016.0284. [Epub ahead of print]

## SOURCE

- **Steven M. Albert**, PhD, MS, FGSA, Philip B. Hallen Endowed Chair in Community Health and Social Justice, University of Pittsburgh. Phone: (412) 624-3102. Email: [smallbert@pitt.edu](mailto:smallbert@pitt.edu).

# New Guidance Helps Clinicians Navigate Demands for Nonbeneficial Care

Any form of life-sustaining treatment should be considered a trial that should continue as long as it is desired by the patient and involves a reasonable prospect of recovery to a meaningful quality of life, according to a new guidance from the Canadian Critical Care Society.<sup>1</sup>

Two recent Canadian court cases highlight the need for the guidance. Both involved young people who were declared neurologically dead, which was challenged by their families in court.

“It’s a hugely different dynamic from 30 years ago when it was

unheard of to go to court. Now it’s happening frequently,” says **Alison Fox-Robichaud**, BSc, MSc, MD, president of the Canadian Critical Care Society. There are multiple brain death cases working their way through the courts in the United States and United Kingdom, and now in Canada as well.

“It is common for critical care to be misunderstood, and how technological support can delay death,” says **Bojan N. Paunovic**, MD, FRCPC, one of the position statement’s authors.

Misperceptions regarding brain

activity and other functions that are needed for survival are common. “It is often difficult for families to separate what they are seeing to what the doctors are saying, so they struggle with that,” says Paunovic, medical director of the critical care program at Winnipeg Regional Health Authority. The Canadian Critical Care Society recently put out an education tool on this topic.<sup>2</sup>

Fox-Robichaud says, “We’ve got to show families that when you stop the ventilator, the breathing stops — and that’s what’s keeping things going.”

## Acquiescing to Demands

Criteria for death vary across U.S. states and Canadian provinces. Some do not have legislation that refers to neurological death. “The lack of a concise legal definition is one area where we have been struggling,” says Paunovic.

A recent case occurred in Ontario, which has its own provincial statutes regarding consent and capacity. Because of the court’s ruling, some intensivists in Ontario feel they have no option but to offer ongoing inappropriate care, says Fox-Robichaud, but this is a misinterpretation of the court’s ruling. “Some clinicians may interpret this as a need to acquiesce to family demands. But this respect for patient autonomy should be balanced with our duty to educate about death, dying, and the concept of nonbeneficial care,” she says.

By providing nonbeneficial care, clinicians are potentially violating their own ethical beliefs and delaying the grieving process for families.

“We have swung the pendulum of patient autonomy so far to one side that we’ve forgotten about the balancing act in that,” says Paunovic. “We wanted to make a statement of support to clinicians in these situations, that we are behind you.”

Controversy persists as to whether neurological death is equivalent to

cardiac death. “What I would like to see is some harmony across the country in trusting the rigor with which critical care physicians make a determination of neurological death,” says Paunovic. “Unfortunately, I don’t think that we are going to get that.”

More likely, says Paunovic, “what is unfortunately going to happen is we are going to end up with a case down the road going all the way to the Supreme Court.”

## Education Needed

If the family has made a clear decision that it doesn’t believe in neurological death, then the proposed care plan should not offer interventions that would support the ongoing organ support of that person, according to the guidelines. “That’s where ethicists can come in, to set boundaries that we are not going to offer things that will perpetuate the idea that we are supporting the life of someone,” says Fox-Robichaud, a professor in the division of critical care at McMaster University.

Families may request help in transferring the patient to another facility that will provide the interventions they’re seeking. Ethicists can help the clinical team with moral distress, if it occurs, by acknowledging their ethical dilemma. “They are being asked to do this because the courts have told them

to do it, as opposed to it’s the right thing to do,” says Fox-Robichaud.

Ethicists in the hospital setting can use the Canadian Critical Care Society’s statement in these ways:

- **As a jumping-off point for conversations on how to handle similar cases in the future.**

“The more people involved in the discussion, the better,” says Fox-Robichaud. With ample education on clinicians’ ethical and legal obligations, future conflicts hopefully can be prevented.

Only a small minority of cases involve litigation. “But there are many cases involving this scenario that cause angst for the clinicians and families,” says Fox-Robichaud.

- **As a tool to navigate difficult cases.**

The guidance can support clinicians in talking with families about limiting the care that is provided. “Sometimes inadvertent communications get taken the wrong way, and now people are feeling entrenched,” says Fox-Robichaud.

Statements such as “the doctors are trying to play God and kill my loved one” are sometimes made by distraught family members. “That can be pretty demoralizing,” says Fox-Robichaud. “The healthcare team feels on more solid footing if they know they’ve followed guidelines of a national society.”

- **As a reference to develop hospital policies.**

Policies should be framed as doing what’s in the patient’s best interest. “Given the scenario, there are certain things that are reasonable to proceed with, and certain things that aren’t,” says Fox-Robichaud.

Unfortunately, clinicians sometimes begin the discussion by bluntly telling the family what they won’t do. This can result in the family feeling abandoned by the care team. “It’s

## EXECUTIVE SUMMARY

New guidance from the Canadian Critical Care Society aims to help clinicians respond to families’ demands for life-sustaining treatment.

- Some families struggle with accepting their loved ones’ deaths based on neurological criteria.
- Clinicians may wrongly believe they are obliged to acquiesce to family demands.
- Provision of non-beneficial care can delay the grieving process.

important not to approach the family that way, even when things are grossly obvious to the clinical team,” says Fox-Robichaud. ■

## REFERENCES

1. Bandrauk N, Downar J, Paunovic B. Withholding and withdrawing life-sustaining treatment: The Canadian Critical Care Society position paper.

*Can J Anaesth* 2018; 65(1):105-122.

2. Canadian Critical Care Society. Statement on misperceptions of brain death and organ donation. Oct. 30, 2017. Available at: <https://bit.ly/2JunGYS>.

## SOURCES

- Alison Fox-Robichaud, BSc, MSc, MD, Professor, Department of

Medicine, McMaster University, Hamilton, Ontario, Canada. Phone: (905) 521-2100 ext. 40742. Email: [afoxrob@mcmaster.ca](mailto:afoxrob@mcmaster.ca).

- Bojan N. Paunovic, MD, FRCPC, Medical Director, Winnipeg Regional Health Authority/Assistant Professor, University of Manitoba, Winnipeg. Phone: (204) 787-1634. Email: [bpaunovic@exchange.hsc.mb.ca](mailto:bpaunovic@exchange.hsc.mb.ca).

# Study: Older Adults Living Alone With Cognitive Impairment Lack Support

There is a dearth of programs to support older adults living alone with cognitive impairment, creating a need for novel programs and interventions, found a recent study.<sup>1</sup>

“We did the study because we felt the needs of those living alone was a missing piece of Alzheimer’s disease research,” says **Kenneth Covinsky**, MD, MPH, one of the study’s authors.

Previous research suggests that older adults living alone often experience a sense of precarity. The researchers were interested in exploring this in older adults living alone with a diagnosis of cognitive impairment.

“We felt it was important to better understand the needs of these persons from their own perspective,” says Covinsky, a

clinician-researcher in the division of geriatrics at University of California, San Francisco.

The qualitative study of 12 adults aged 65 and older identified these three themes:

- the distress stemming from the uncertainty of living with cognitive impairment that has an unpredictable course;
- the tendency of participants to feel responsible for managing their cognitive impairment;
- the pressures stemming from the lack of appropriate services to support independent living for persons with cognitive impairment.

“I think many will be surprised at the depth of insight those with cognitive impairment are often capable of,” says Covinsky.

Despite the large medical costs incurred by persons with dementia,

society is failing to provide basic social service needs to this population, notes Covinsky.

“This is ironic,” says Covinsky. “Many medical treatments and services that are provided to these patients do more harm than good, while more social services could be of tremendous benefit.” ■

## REFERENCE

1. Portacolone E, Rubinstein RL, Covinsky, KE, et al. The precarity of older adults living alone with cognitive impairment. *Gerontologist* 2018 Jan 24. doi: 10.1093/geront/gnx193. [Epub ahead of print]

## SOURCE

- Kenneth Covinsky, MD, MPH, Division of Geriatrics, University of California, San Francisco. Email: [ken.covinsky@ucsf.edu](mailto:ken.covinsky@ucsf.edu).



## Conquering the Opioid Epidemic

### Policies, Treatments, Alternatives

Gain the tools you need to join the fight against this fast-growing epidemic. Includes 3 CME/CE.

Visit [AHCMedia.com/opioid2018](http://AHCMedia.com/opioid2018)

# Ethical Response Needed if Patient Revokes Consent Due to Complications

A liver transplant recipient at University of Minnesota Medical Center returned a month later with signs of infection and brain damage. His family wished to withdraw aggressive treatments in light of a grave and uncertain prognosis. The transplantation team made several emphatic statements about the obligations they and the patient had to protect the longevity of the transplanted liver — and, therefore, to aggressively treat the patient.

“We were surprised by the intense emotional reactions from all participants in the case,” says **Nathan Scheiner**, MD, who co-authored an analysis of the case.<sup>1</sup>

## Strong Emotional Reactions

Some family members expressed near certainty the patient would not want treatment. “They had a very strong emotional reaction to repeated conversations about switching from full-code status to Do Not Resuscitate/Do Not Intubate,” recalls Scheiner.

The paper explores ethical considerations if patients consent to a treatment plan with the understanding that it carries risks of complications, then revoke consent when complications arise. “We wanted to better understand both the reason for the intense reactions we saw, and what was ethically at stake,” says Scheiner.

Some interesting insights came out of the case analysis. “There is a small but significant body of literature on surgical buy-in,” says Scheiner. This is

a contract surgeons believe they make with patients when entering into a surgical relationship. This literature helped the ethicists to understand the transplant team’s reactions. “However, we were surprised that there has been a lack of examination of the patient and family perspective,” says Scheiner. “Our analysis helps to fill that gap.”

The authors called the family’s reaction in this case “cashing out,” which is the reciprocal of “buying in.” “This helped us make sense of the intense emotional reactions and seemingly irrational refusals that patients or families occasionally express in response to new complications or perceived intolerable treatments,” says Scheiner.

## Resources Are Concern

It should be possible for a patient to withdraw consent at almost any time, even after a treatment has commenced, says **Tyler S. Gibb**, JD, PhD, co-chief of the program in medical ethics, humanities, and law at Western Michigan University in Kalamazoo.

However, it also is possible that a subsequent withdrawal of consent places the patient at greater risk of harm by interrupting the treatment than if the treatment was completed. “There is also some concern about

the squandering of resources that would result if a treatment is begun but not completed,” says Gibb. This is particularly true of scarce or precious resources such as transplantable tissue or organs.

“There is some discussion about a ‘Ulysses contract’ type of discussion between providers and patients,” notes Gibb. In essence, these agreements require some degree of perseverance by the patient even if there are subsequent complications or setbacks. “These are interesting proposals that would be difficult to enforce, but may be helpful in guiding pre-treatment informed consent discussions,” says Gibb. ■

## REFERENCE

1. Scheiner N, Liaschenko J. “Buying-in” and “cashing-out”: Patients’ experience and the refusal of life-prolonging treatment. *J Clin Ethics* 2018; 29(1):15-19.

## SOURCES

- **Tyler S. Gibb**, JD, PhD, Co-chief, Program in Medical Ethics, Humanities, and Law, Western Michigan University, Kalamazoo. Phone: (269) 337-4400. Email: tyler.gibb@med.wmich.edu.
- **Nathan Scheiner**, MD, MA, Emory University School of Medicine, Atlanta, GA. Email: scheiner.n@gmail.com.

## COMING IN FUTURE MONTHS

- Novel training program pairs chaplains and clinicians
- Why bundled payments are raising ethical concerns
- Nurses report barriers to involving family caregivers
- Ethics services facing unprecedented surge in demand

**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

**NURSE PLANNER:**

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

**EDITORIAL BOARD:**

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

**J. Vincent Guss, Jr., DMin, BCC**  
Clinical Ethicist/Bioethics Professor  
Georgetown University School of  
Medicine  
Washington, DC

**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

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

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/CE QUESTIONS**

- 1. Which is true regarding clinical ethics consultations?**
  - a. Evidence indicates the majority of consultants have had formal supervised training in ethics consultation.
  - b. Advocating for patients to have surgery if the benefits clearly outweigh the risks is an important part of the ethicist's role.
  - c. Regulatory agencies require hospitals to demonstrate that consultants have the appropriate expertise in knowledge and skills.
  - d. Certification through written examination may signify that individuals have the appropriate content expertise in ethics consultation.
- 2. Which is true regarding the American Academy of Neurology's position statement on lawful physician-hastened death?**
  - a. It leaves the decision of whether to practice lawful physician-hastened death to the conscientious judgment of its members acting on behalf of their adult patients dying of neurologic illness.
  - b. It opposes participation in either physician-assisted suicide or euthanasia.
  - c. It recommends using the term "physician-assisted suicide" instead of "lawful physician-hastened death."
  - d. It has two versions depending on state laws.
- 3. Companion presence during pre-surgical conversations is associated with which of the following, according to a recent study?**
  - a. Patients disclosing less lifestyle and psychosocial information
  - b. Patient satisfaction
  - c. Surgeon satisfaction
  - d. Increased levels of patient-centeredness
- 4. Which is recommended by new guidance from the Canadian Critical Care Society?**
  - a. Clinicians are now legally obligated to acquiesce to family demands for life-sustaining treatment.
  - b. Recognition of neurological death should be left up to individual states and provinces.
  - c. Any form of life-sustaining treatment should be considered a trial that should continue as long as it's desired by the patient and involves a reasonable prospect of recovery to a meaningful quality of life.
  - d. Requested non-beneficial care should generally be provided because it helps families with the grieving process.