



MEDICAL ETHICS ADVISOR®

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

OCTOBER 2018

Vol. 34, No. 10; p. 109-120

→ INSIDE

Ethics behind industry-neurosurgeon relationships 112

Informed consent challenges when the patient is in ICU 113

Ethical concerns with pediatric ED patients 114

Unexpected data on how ethics consultants are trained 115

Ethical guidance on fertility preservation in cancer patients 116

End-of-life care differs for language-impaired patients 118

What's behind surge of outside-the-ICU ethics consults 118



RELIAS
MEDIA

Growing Evidence That Surrogate Decision-makers Need Help

Role is 'burdensome and distressing'

Surrogates reported better-quality communication and patient- and family-centered care with a family support intervention, found a recent study.¹ “The thing that drove us to want to do this study was we think there are ways to improve how we engage families in care decisions for incapacitated patients with advanced illness,” says **Douglas B. White**, MD, MAS, the study’s lead author.

About one in four patients are admitted to an ICU within 30 days of their death.² “There are lots of problems with what happens there,” says White, chair of ethics in critical care medicine at University of Pittsburgh Medical Center (UPMC) and director

of the University of Pittsburgh Program on Ethics and Decision Making In Critical Illness.

One worry is the degree to which the care provided matches patient prefer-

ences. Another is the toll that the decision-making process takes on family. “Lots of families leave ICUs with high rates of stress, anxiety, PTSD, and depression,” says White.

ONE WORRY IS THE DEGREE TO WHICH THE CARE PROVIDED MATCHES PATIENT PREFERENCES. ANOTHER IS THE TOLL THAT THE DECISION-MAKING PROCESS TAKES ON FAMILY.

ences. Another is the toll that the decision-making process takes on family. “Lots of families leave ICUs with high rates of stress, anxiety, PTSD, and depression,” says White.

The study, which looked at 1,420 critically ill patients, found that length of stay in the ICU was shorter with the intervention than with usual care.

“This was likely due to families being able to more rapidly make patient-centered decisions about transitioning to comfort-focused care,” says White.

ReliasMedia.com

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 Relias Learning, 111 Corning Road, Suite 250, Cary, NC 27518-9238. Periodicals postage paid at Cary, NC, and additional mailing offices. **POSTMASTER: Send address changes to Medical Ethics Advisor, Relias Learning, 111 Corning Road, Suite 250, Cary, NC 27518-9238.**

GST Registration Number: R128870672.

SUBSCRIBER INFORMATION:

Customer Service: (800) 688-2421.
ReliasMediaSupport@reliasmmedia.com.
ReliasMedia.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@reliasmmedia.com or (866) 213-0844.

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

Relias 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.

Copyright © 2018 by Relias LLC. *Medical Ethics Advisor*® is a registered trademark of Relias 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 researchers did not bring in palliative care consults or add new team members. Instead, they trained the existing team in advanced communication and support skills. “We think the nursing teams in the ICUs are an underappreciated resource to deliver effective systematic support to families,” says White.

The intervention was then embedded in a care pathway for families in ICUs. “What’s nice about that is it’s potentially a much more scalable model than models that require outside resources,” says White.

Part of Clinical Culture

The goal is to provide good, basic support to all ICU families. “That is valuable for a couple of reasons,” says White. Fewer ethics consultations are requested simply because of inadequate communication. Necessary consults are less complex because there already has been good communication between the family and the team.

“Instead of cases where the caregivers and family are at loggerheads because of major disagreements and bad feelings, maybe you will instead see cases where there is just disagreement about one issue,” says White.

The approach calls for training of nurses in mediation and emotional support skills. Palliative care physicians — or ethicists — are well-positioned to take on this role.

“It would be great for the ICU team and administration to align with ethics consults, who are expert communicators, on this role,” says White.

Few ICUs have a systematic approach to support families in ICUs. “There are lots of downsides to that,” says White. If left up to individual physicians as to whether and how families are supported, it happens inconsistently. “The field is shifting to develop processes of care that make routine family support the default,” says White.

There is increasing recognition of the importance of supporting ICU families consistently. “It’s not enough for hospital administrators just to say, ‘It’s important, but we’re not going to give you any [more] infrastructure to do it than you had before,’” says White.

Just as ICUs use clinical protocols for patient care, protocols can similarly be used to support families. “What’s nice about this intervention, as potentially a model for the field, is nurses can say, ‘What’s on the list for today in terms of the plan for family support?’” says White.

Family support interventions no longer fall by the wayside during busy times. As implementation science has shown, practice changes do not just happen, says White: “You have to put structures in place to make the things you think are important part of the fabric of the clinical culture.”

EXECUTIVE SUMMARY

Surrogates reported better-quality communication with a family support intervention, found a recent study. Some strategies include:

- training nurses in advanced communication and support skills;
- including family support interventions in care pathways;
- adding nurses or social workers to the ICU team to support families.

To make life-and-death decisions for another is “one of the most difficult tasks imaginable, raising countless tricky ethical issues,” says **Kenneth W. Goodman**, PhD, FACMI, director of the University of Miami’s Institute for Bioethics and Health Policy. “Yet we too often tend to leave these family members and friends in the lurch.”

Surrogates need resources to be successful. Ideally, this includes an ethics orientation on the principle of substituted judgment. “This is no mean feat against a background of grief, hope, love, and denial,” says Goodman.

Clinicians, in turn, need guidance in order to support families. This might take the form of ethicist-led workshops or an in-service titled “How to Help Family Members Decide,” suggests Goodman.

Surrogates often worry about being ill-prepared or making the “wrong” decision. “These are often high-stakes decisions, and emotionally taxing ones,” says **Jonathan M. Marron**, MD, MPH, teaching faculty at Harvard Medical School’s Center for Bioethics and a pediatric oncologist and clinical ethicist at Boston Children’s Hospital.

Surrogates are asked to disconnect themselves from their role as the patient’s loved one and make a decision as if they were the patient and not themselves. “This inherent conflict — and conflict of interest — is challenging. It can be both burdensome and distressing,” says Marron. Ethicists can support surrogates in these ways:

- reminding surrogates that they have been entrusted with the role for a reason and that they know the patient and can use that knowledge to identify what the patient likely would have wanted;
- asking surrogates to speak about

what matters to the patient and what he or she enjoys. “Such an exploration can help surrogates to really put themselves in the patient’s shoes and feel better able to make decisions on a patient’s behalf,” says Marron;

- pointing out that for most surrogate decisions, there is not an obvious right or wrong answer. “We are all just working together to do the best we can to take care of the patient,” says Marron.

Two Key Concerns

A multicenter trial is currently underway to evaluate the effect of “a multifaceted surrogate support intervention on surrogates’ psychological distress, the quality of decisions about goals of care, and healthcare use.”³ “The study was motivated by the need for effective strategies to address two key concerns in the care of critically ill adults and their families,” says **Jennifer Seaman**, PhD, RN, the study’s lead author. These two issues are:

- incapacitated ICU patients frequently receive aggressive care that is likely not what they would choose;
- the decisional surrogates of critically ill patients have a high prevalence of anxiety and distress, which often persists well beyond the ICU episode.

“The intervention being tested seeks to address both these interrelated problems by providing surrogates with multiple types of support,” says Seaman, an assistant professor in the University of Pittsburgh School of Nursing’s department of acute and tertiary care.

A trained ICU nurse or social worker joins the ICU team as a family support specialist. This person delivers emotional, communication, decisional, and anticipatory grief

support to surrogates through daily interactions during the ICU stay.

“Effective and scalable strategies to support surrogate decision-makers are essential to ensuring that critically ill patients receive care that is consistent with their values and preferences,” says Seaman. ■

REFERENCES

1. White DB, Angus DC, Shields AM, et al. A randomized trial of a family-support intervention in intensive care units. *N Engl J Med* 2018; 378(25):2365-2375.
2. Teno JM, Gozalo P, Trivedi AN, et al. Site of death, place of care, and health care transitions among U.S. medicare beneficiaries, 2000-2015. *JAMA* 2018; 320(3):264-271.
3. Seaman JB, Arnold RM, Buddadhumaruk P, et al. Protocol and fidelity monitoring plan for Four Supports: A multicenter trial of an intervention to support surrogate decision makers in intensive care units. *Ann Am Thorac Soc* 2018; 15(9):1083-1091.

SOURCES

- **Kenneth W. Goodman**, PhD, FACMI, Director, Institute for Bioethics and Health Policy, University of Miami (FL). Phone: (305) 243-5723. Email: kgoodman@med.miami.edu.
- **Jonathan M. Marron**, MD, MPH, Center for Bioethics, Harvard Medical School, Boston. Phone: (617) 632-3453. Email: jonathan_marron@dfci.harvard.edu.
- **Jennifer Seaman**, PhD, RN, Department of Acute and Tertiary Care, School of Nursing, University of Pittsburgh. Email: jbs31@pitt.edu.
- **Douglas B. White**, MD, MAS, UPMC Endowed Chair, Ethics in Critical Care Medicine, University of Pittsburgh Medical Center. Phone: (412) 864-3757. Email: douglas.white@pitt.edu.

Ethics of Industry-Neurosurgeon Relationships

Conflicts of interest are inherent to surgical innovation and can be handled in an ethically sound manner, concluded a recent literature review.¹

“In some subspecialties, such as functional neurosurgery, allowing neurosurgeons to have collaborative relationships with industry is essential to further innovation and leading to advancements, especially in the context of shrinking NIH support,” says **Maya A. Babu**, MD, MBA, one of the study’s authors.

Previous research analyzed 4.3 million records in 2013 and 11.41 million records in 2014 in the Centers for Medicare & Medicaid Services Open Payments database.² “I was surprised by the volume of inaccuracies of attribution,” says Babu, the study’s lead author. These included incorrect locations and practice specialties.

“The payment value varied whether the transfers of value had to do with royalty payments or research dollars, which obviously do not flow to an individual’s bank account,” says Babu, director of adult neurotrauma in the department of neurological surgery at Massachusetts General Hospital.

A better system is needed for inputting the information into Open Payments, Babu says. Currently, industry compliance officers send

the information to CMS. After it is posted, physicians are given a limited time period to contest inaccuracies. Even if an inaccuracy is flagged correctly and the company agrees it is incorrect, it remains on the Open Payments site with the dispute noted.

“THERE IS A REAL OPPORTUNITY HERE FOR NEUROSURGEON COLLEAGUES TO DRAFT THE DICTATES OF WHEN INDUSTRY RELATIONSHIPS MAY CREATE UNETHICAL FINANCIAL OR DECISION-MAKING INFLUENCES.”

“It’s important to differentiate when an industry relationship crosses the line and unduly influences medical decision-making,” says Babu. A consortium of neurosurgeons representing the subspecialties could do so by developing

recommendations for industry-physician relationships.

“There is a real opportunity here for neurosurgeon colleagues to draft the dictates of when industry relationships may create unethical financial or decision-making influences,” says Babu.

External stakeholders may not understand the nuances and necessity of research innovation collaborating with industry participation, she adds. Having a closed feedback loop with industry can facilitate device improvements, for instance.

“Ensuring that patients are protected and that decision-making is not fueled by ulterior motives is best governed by colleague neurosurgeons,” says Babu.

The first step is for neurosurgeons to not put themselves in situations in which they might be vulnerable to conflicts, says **Genevieve P. Kanter**, PhD, assistant professor in the division of general internal medicine and department of medical ethics and health policy at University of Pennsylvania Perelman School of Medicine in Philadelphia.

“To ensure patient autonomy and safety, the most important thing is that patients know that they have a choice in their treatments,” says Kanter.

Kanter says neurosurgeons should:

- be comprehensive about where they get their information and appropriately skeptical about different sources of information;
- disclose to patients the existence and nature of any financial arrangements with industry;
- inform patients of the full range of treatment options, including nonsurgical options;
- clearly explain the experimental

EXECUTIVE SUMMARY

Conflicts of interest are inherent to surgical innovation and can be handled in an ethically sound manner, concluded a recent literature review. Neurologists can ensure ethical practices by:

- being comprehensive in where they get information;
- avoiding being beholden to or dependent on a single source of income;
- making patients aware of alternatives, including nonsurgical options.

or research nature of procedures when applicable and the uncertainty of the scientific evidence related to these procedures;

- encourage patients to seek second or third opinions, particularly about risky or invasive procedures;
- avoid putting themselves in situations where they may be beholden to or dependent on a single source of income. “This may involve restricting payments that they receive from device firms, or making sure that they are talking to different and competing device makers,” says Kanter.

Ideally, the physician should be able to convey this information.

“But if not, third parties — and this may involve payers or government — should work to create patient incentives to obtain information about a broad range of providers and treatments available to them,” says Kanter. ■

REFERENCES

1. DiRisio AC, Muskens IS, Cote DJ et al. Oversight and ethical regulation of conflicts of interest in neurosurgery in the United States. *Neurosurgery* 2018; May 30. doi: 10.1093/neuros/nyy227. [Epub ahead of print]
2. Babu MA, Heary RF, Nahed BV. Does the open payments database provide sunshine on neurosurgery?

Neurosurgery 2016; 79(6):933-938.

SOURCES

- **Maya A. Babu**, MD, MBA, Director of Adult Neurotrauma, Department of Neurological Surgery, Massachusetts General Hospital/Assistant Professor, Harvard Medical School, Boston. Phone: (617) 726-1002. Email: mababu@partners.org.
- **Genevieve P. Kanter**, PhD, Assistant Professor, Division of General Internal Medicine/Department of Medical Ethics and Health Policy, University of Pennsylvania Perelman School of Medicine, Philadelphia. Phone: (215) 898-2703. Email: gpkanter@pennmedicine.upenn.edu.

Informed Consent Challenges When Subject Is in ICU

ICU patients frequently lack capacity to provide informed consent for clinical research due to multiple factors. These include sedation, coma, ICU-acquired delirium, or underlying illness. However, the presence of one or more of these characteristics does not automatically designate a potential subject as lacking capacity to provide his or her own informed consent, notes a recent paper.¹

“Many can communicate but may not be able to talk due to the endotracheal tube,” says **Avelino Verceles**, MD, MS, associate professor of medicine in the division of pulmonary, critical care, and sleep medicine at University of Maryland School of Medicine in Baltimore.

Researchers who conduct trials on critically ill patients should be aware that intubation and mechanical ventilation may not always preclude a patient from providing informed consent, underscores Verceles.

Clinicians may seek the input of a legally acceptable representative (LAR) when medical decisions need to be made. “Although the LAR is someone who has the patient’s best interests in mind, there is still the possibility that the LAR’s decision may not be consistent with the patient’s wishes,” says Verceles.

Even if the ICU patient does have capacity, “that doesn’t mean you’re out of the woods,” says **Parker Crutchfield**, PhD, an associate professor of medical ethics, humanities, and law at Western Michigan University Homer Stryker MD School of Medicine in Kalamazoo.

This is because ICU patients are vulnerable to coercion. “It’s not like they can leave the ICU of their own will,” says Crutchfield. Patients may perceive that if they decline to participate in research, their care will suffer.

Coercion remains an ethical concern even if patients lack decision-

making capacity, as surrogates may also believe that receiving good care is contingent on agreeing to participate in research.

One way to mitigate this, says Crutchfield: “Make sure the attending physician is not a member of the research team. Try to get rid of any conflicts of interest.”

Both patients and surrogates need to understand they are free to choose not to participate in the research. “The biggest thing is to make them aware that whoever is treating them will treat them in the same way, whether they do the research or not,” says Crutchfield.

Prospective enrollment at a point in time when the ICU patient does have capacity to consent is sometimes used. Input from the community then becomes more important in contrast to retrospective or interventional research.

“Community engagement

enhances protections for vulnerable populations,” says Crutchfield. “It makes it easier for participation to be fully informed.” It also can help identify those who do not want to participate in research. “It takes some creative thinking about what aspect of the community you might go to,” says Crutchfield.

Research ethics consultants or clinical ethicists can be of great help. If the patient suffers from a chronic

condition, for example, ethicists may suggest the researcher seek input from a particular group. “Think carefully about the population and who might be able to speak for it,” says Crutchfield. ■

REFERENCE

1. Verceles AC, Bhatti W. The ethical concerns of seeking consent from critically ill, mechanically ventilated patients for research — A matter of

possessing capacity or surrogate insight. *Clin Ethics* 2018; 13(3):107-111.

SOURCE

- **Avelino Verceles**, MD, Associate Professor of Medicine, Division of Pulmonary and Critical Care, University of Maryland School of Medicine, Baltimore. Phone: (410) 328-8141. Email: avercele@som.umaryland.edu.

Ethics Needs of Pediatric EDs More Prevalent

Consent for treatment, confidentiality, and appropriate treatment for psychiatric problems, substance issues, pregnancy, and sexually transmitted diseases are just some of the ethical challenges involving minor patients in the ED setting. “The ethical and timely treatment of minors is an important component of emergency medical treatment,” says **Catherine A. Marco**, MD, FACEP, professor in the department of emergency medicine at Wright State University in Dayton, OH.

Ethical challenges in pediatric EDs are more prevalent than in adult EDs, found a recent study.¹ Researchers also found that nurses voice specific moral distress issues that are different than adult EDs. Of 123 nurses and physicians surveyed:

- most participants (69%) reported encountering daily or weekly ethical challenges;
- participants wanted more support for moral distress (16%), conflict management with patients or families (16%), and resource issues (15%);
- of 23 reported occurrences of moral distress, 61% were associated with pediatric mental health cases;
- education was the most common intervention clinicians wanted from the ethics consultation service.

“Working in the ED is often associated with being fast-paced and efficient,” says **April Kam**, MD, MScPH, FRCPC, one of the study’s authors. In contrast, an ethical consultation is viewed as a slow process of careful deliberation that happens on inpatient wards.

As a pediatric emergency physician at McMaster Children’s Hospital in Ontario, Canada, Kam has personally encountered many ethical dilemmas: “I was interested in what the needs were in the ED and how we could address it.” Not surprisingly, nearly two-thirds of respondents reported encountering ethical issues daily or weekly

“The ED is the point of entry for the most vulnerable patients during a stressful time in their lives,” says Kam. Clinicians are making decisions with incomplete information and limited resources. The survey responses reflected keen awareness of these ethical challenges. “The qualitative comments were so rich,” says Kam. “They reflect the challenging environment that all ED healthcare providers work in and the moral distress that they inevitably experience.”

EDs would clearly benefit from more ethics education and ethics-

based decision-making tools. “But perhaps equally importantly, there needs to be an outlet for the concerns of ED healthcare providers to be addressed,” says Kam.

At McMaster Children’s Hospital, ED providers do this by documenting any concerns, which are discussed during daily meetings. “We are also in the early stages of implementing a uniform way to debrief after resuscitations,” adds Kam. ■

REFERENCE

1. Colaco KA, Courtright A, Andreychuk S, et al. Ethics consultation in paediatric and adult emergency departments: an assessment of clinical, ethical, learning, and resource needs. *J Med Ethics* 2018; 44(1):13-20.

SOURCES

- **April Kam**, MD, MScPH, FRCPC, Associate Professor, Pediatric Emergency Medicine, McMaster University, Ontario, Canada. Phone: (905) 521-2100 ext. 73983. Email: kama@mcmaster.ca.
- **Catherine A. Marco**, MD, FACEP, Professor, Department of Emergency Medicine, Wright State University, Dayton, OH. Phone: (937) 395-8839. E-mail: catherine.marco@wright.edu.

Orientation for Ethics Consultants? Some Have None at All

Institutions should re-evaluate their orientation practices for ethics committee members that perform ethics consultations, suggests recent research.¹ The researchers considered this important question: How are individuals prepared to take on the role of serving on an ethics committee?

“As we examined the literature, it was clear that available data did not answer this important question. So we developed our study,” says **Jennifer Cohn Kesselheim, MD, EAC**, one of the study’s authors.

The researchers surveyed 116 members and 16 chairs of ethics advisory committees on how members are recruited and what orientation practices are used to educate new members.

“Our aim was to provide data to our own hospitals here at Harvard for purposes of continuous quality improvement,” says Kesselheim, co-chair and the founding director of the Harvard Medical School Master of Medical Sciences in Medical Education program.

The researchers also sought to spark dialogue outside of their institution. “We hope these data motivate ethics committee chairs and hospital ethicists to consider

more explicitly how new committee members are oriented and trained,” says Kesselheim.

The researchers hypothesized that responses would be associated with whether participants were familiar with the American Society for Bioethics and Humanities (ASBH) Core Competencies in Healthcare Ethics Consultation. Respondents with greater familiarity with the ASBH competencies did tend to have higher self-reported preparedness. They also experienced more extensive orientation.

“As ASBH continues its important work in setting standards for ethics consultation, we hope our data will be useful,” says Kesselheim. Other key findings include:

- most respondents (62%) found their orientation curricula to be helpful;
- standard educational materials such as readings (50%) and case studies (41%) were offered during orientation;
- videos on ethics consultation were offered 19% of the time;
- a significant number of respondents received no orientation at all (24%) or were unsatisfied with the orientation they did receive (14%).

“We found the data about the rather low prevalence of orientations or other training opportunities noteworthy,” says Kesselheim.

The data spotlight unmet educational needs. “Future research is needed to determine optimal training strategies,” says Kesselheim. Case-based learning, online modules, and simulation are some possible approaches.

Ideally, bioethicists will team with medical educators to devise the best interventions for orientation of ethics consultants, says Kesselheim: “This could be implemented with rigorous outcome measurement to ensure learning objectives are being met.” ■

REFERENCE

1. Zaidi D, Kesselheim JC. Assessment of orientation practices for ethics consultation at Harvard Medical School-affiliated hospitals. *J Med Ethics* 2018; 44(2):91-96.

SOURCE

- **Jennifer Cohn Kesselheim, MD**, Assistant Professor of Pediatrics, Center For Bioethics, Harvard Medical School, Boston. Phone: (617) 355-6363. Email: jennifer_kesselheim@dfci.harvard.edu.

live & on-demand **WEBINARS**

- ✓ Instructor-led Webinars
- ✓ Live & On-Demand
- ✓ New Topics Added Weekly

CONTACT US TO LEARN MORE!

Visit us online at ReliasMedia.com/Webinars or call us at (800) 688-2421.

Ethics Guidance on Reproductive Issues in Cancer Patients

Multiple ethical issues related to reproduction in the context of cancer are addressed in an updated position statement from The American Society for Reproductive Medicine's (ASRM's) Ethics Committee.¹

"The recent update of our opinion discusses a host of ethical issues that can present when a patient faces a diagnosis and treatment protocol likely to result in future infertility," says **Judith Daar**, JD, chair of ASRM's ethics committee. These updates include:

- **Distinctions and recommendations regarding established vs. experimental therapies.**

This includes experimental protocols such as ovarian and testicular tissue cryopreservation. The ethics committee advises that such emerging techniques should be offered only as part of an IRB-approved research plan, with full disclosure of risks and uncertainty of benefits to the patient.

"Elective oocyte or semen cryopreservation is well-established and now frequently offered," notes **Louise P. King**, MD, JD, an assistant

professor of obstetrics, gynecology, and reproductive biology at Boston-based Harvard Medical School.

For women, success rates are not as well-defined. "Thus, their ability to preserve a chance at fertility with their own genetic material is not as easily 'guaranteed' as for men," says King.

- **The ability of minors to give consent to fertility preservation.**

The ethics committee recognizes that most post-pubertal minors are capable of assent or objection when presented with fertility preservation options. "The committee believes that if a minor objects to any offered treatment, the procedure should not be done, despite parental wishes," says Daar.

With children facing cancer diagnosis who are old enough to set aside semen or oocytes, a larger set of ethical questions arise. "These are highly complex and require protecting children's ability to make decisions independent of their parents," says King.

- **The welfare of expected offspring.**

Patients may wish to seek preimplantation genetic testing of any embryos formed via IVF treatment

to determine the risk profile for developing a health-affecting condition at some point during the child's life. "The committee supports the use of these testing technologies in this situation as ethically justified," says Daar.

Patients should consider whether to undergo genetic testing to identify and exclude embryos that carry any genetic predisposition to cancers. "Most cancer patients may pass along a potential genetic predisposition," says King.

At the time of oocyte or semen cryopreservation, no final decisions need to be made. "For men, this is such an easy process. They can be counseled on the process and cost and will likely proceed forward," says King.

For women, the process can delay cancer treatments. "Fertility specialists typically work closely with oncologists to coordinate care," says King.

- **The need for fertility providers to counsel patients about preparing advance directives that direct the disposition of cryopreserved gametes and embryos in the event the patient dies before any or all fertility treatment is undertaken.**

"The complex legal structure surrounding posthumous reproduction is a compelling incentive for patients to specify their preferences for postmortem gamete and embryo disposition," says Daar.

Often Not Straightforward

Fertility preservation for medical reasons — primarily cancer diagnoses — is "sometimes straightforward,

EXECUTIVE SUMMARY

Reproduction options for cancer patients raise a number of ethical issues for the welfare of patients and resulting children. Some updated ethics recommendations include:

- Emerging techniques should be offered only as part of an IRB-approved research plan, with full disclosure of risks and uncertainty of benefits.
- If a minor objects to fertility preservation treatment, the procedure should not be performed, regardless of his or her parents' wishes.
- Patients may use preimplantation genetic testing of embryos to determine the risks of a child developing a health-affecting condition.

but often not,” says **Linda D. Applegarth**, EdD, clinical associate professor of psychology at the Ronald O. Perelman and Claudia Cohen Center for Reproductive Medicine at Weill Cornell Medical College in New York City.

For women of reproductive age with a poor prognosis, the process of freezing eggs or embryos can be complicated. “The medical procedures for cryopreservation can be extremely medically and emotionally taxing at a time when the patient is already under a great deal of stress,” says Applegarth. It means that cancer therapy must be postponed until after an egg retrieval. If embryos are created, then decisions must be made about disposition of those embryos were the patient to die.

A single woman might choose to use donor sperm in order to create embryos, rather than freezing eggs only. “Or sometimes a single woman will bring her boyfriend as a sperm provider. What are his rights and responsibilities, should she pass away?” asks Applegarth. Both parties need to understand the implications of creating embryos while not being in a fully committed relationship. Women typically must be in remission for three to five years before being cleared to use frozen eggs or embryos. “It would be ethically negligent on the part of fertility clinic personnel not to have a

formalized plan established with the patient and her partner regarding the future disposition of embryos,” says Applegarth.

At the same time, failing to inform cancer patients about the availability of fertility preservation options “is also negligent — and, in the minds of many patients, unethical,” says Applegarth.

Patients need to consider their own prognosis. “Children suffer greatly at the death of a parent. Yet, many studies show children in single-parent homes also do very well,” says King. All that is required ethically is that potential parents consider this ahead of proceeding forward, she explains.

Posthumous reproduction is “a very different question,” says King. Many programs require families to wait a full year after death before proceeding; many families ultimately choose not to go forward.

In short, providers should ensure that patients with cancer are considering all the “downstream” issues, says King. However, expecting individual reproductive endocrinologists to fully address all of the relevant ethical issues is unrealistic. “As with anything in medicine, it can sometimes be impossible to truly convey everything to patients,” says King.

A good example is DNR discussions. Patients have seen multiple examples of successful

CPR on TV. “Thus, it’s very hard to explain that true CPR is somewhat brutal and rarely successful,” says King. The same is true of fertility preservation in cancer patients. “No matter how forthright providers are about the low chance of success or possible drawbacks, patients may not believe they will personally have poor outcomes,” says King. ■

REFERENCE

1. Ethics Committee of the American Society for Reproductive Medicine. Fertility preservation and reproduction in patients facing gonadotoxic therapies: an Ethics Committee opinion. *Fertil Steril* 2018; 110(3):380-386.

SOURCES

- **Linda D. Applegarth**, EdD, Clinical Associate Professor of Psychology/Director of Psychological Services, The Perelman/Cohen Center for Reproductive Medicine, Weill Cornell Medical College, New York City. Phone: (646) 962-3315. Email: lia2004@med.cornell.edu.
- **Judith Daar**, JD, Visiting Professor of Law, School of Law, University of California, Irvine. Phone: (949) 824-9674. Email: jdaar@law.uci.edu.
- **Louise P. King**, MD, JD, Assistant Professor of Obstetrics, Gynecology, and Reproductive Biology, Harvard Medical School, Boston. Phone: (617) 667-4030. Email: lpling@bidmc.harvard.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 ReliasMedia.com/opioid2018

Patients With Language Barriers Less Likely to Limit Life Support and Change Code to DNR

Decisions regarding life support, code status, and advance directives are different for patients with limited English proficiency (LEP) in the ICU compared with patients whose primary language was English, found a recent study.¹

“This is the first study to show that language is an independent risk factor for differences in decision-making and care at end of life,” says **Amelia Barwise**, MB, BCh, BAO, the study’s lead author.

Previous research explored the impact of race and ethnicity on end-of-life care, use of hospice, treatment withdrawal, and intensity.

“But not much has been done on the effect of LEP on end-of-life care, particularly in the ICU,” says Barwise, a research associate in the division of pulmonary and critical care medicine at Mayo Clinic in Rochester, MN. According to the study, ICU patients with LEP:

- were not as likely to change to a do-not-resuscitate (DNR) code status while in ICU;
- took 3.8 days longer to change to DNR status;
- were less likely to receive a

comfort measures order set if they died in the ICU;

- took longer to transition to comfort measures only;
- were not as likely to prepare an advance directive;
- were more likely to receive mechanical ventilation;
- were more likely to be restrained, despite no documented increase in agitation levels;
- had an average length of stay 2.7 days longer;
- were more likely to have a family conference and as likely to get a palliative care consult.

Patients who died in the ICU were less likely to switch to comfort measures only. “This suggests treatment intensity continues until death,” says Barwise.

Taken as a whole, the study’s findings strongly suggest that patients with language barriers receive more aggressive care toward the end of life. The reasons for this are not entirely clear.

“It is difficult to know whether what we have found is secondary to poor communication from providers,” says Barwise.

It is possible that the patients made informed choices and that aggressive treatment is what they really wanted. On the other hand, language barriers may have limited their ability to make their goals and preferences understood.

If aggressive end-of-life care stemmed from uninformed decisions or inadequate communication, says Barwise, “these differences could be classified as a healthcare disparity.” ■

REFERENCE

1. Barwise A, Jaramillo C, Novotny P, et al. Differences in code status and end-of-life decision-making in patients with limited English proficiency in the intensive care unit. *Mayo Clin Proc* 2018 Aug 9. pii: S0025-6196(18)30373-2. doi: 10.1016/j.mayocp.2018.04.021. [Epub ahead of print]

SOURCE

- **Amelia Barwise**, Research Associate, Division of Pulmonary and Critical Care Medicine, Mayo Clinic, Rochester, MN. Phone: (507) 255-9007. Email: barwise.amelia@mayo.edu.

Surge in Ethics Consults Outside ICU Setting

Ethicists at Springfield, IL-based Memorial Medical Center have been seeing increased volume of consults for some time. Recently, they have noticed many are occurring outside of the ICU setting.

“The ethics service has recently seen more requests for consults involving discharge and treatment questions in mentally ill patients

who lack adequate social support,” reports **Christine Gorka**, PhD, director of the Clinical Ethics Center.

The service began in 1991 with one part-time volunteer ethicist and now has three full-time ethicists. “Even with those staffing levels, volume can become an issue,” says Gorka. While only one or two consults normally come in per day,

sometimes volume is greater. “In those circumstances, consults are triaged for urgency and responded to in that fashion,” says Gorka.

The ethics center database tracks about 40 reasons that a consult can be called. “Ethics reports annually to hospital administrators on volume of consults, the requesting professions, reasons for consults, location in the hospital, and overall

patient demographics,” says Gorka. Here are three reasons for the recent surge in outside-the-ICU consults:

- **Difficult family dynamics.**

A common question is: Under what conditions is it ethical to prevent (or allow a surrogate to prevent) a family member from visiting a patient or from receiving information about the patient?

“The solutions to these problems can be more complicated outside an ICU than inside that environment,” says Gorka. “Access is more difficult to control.”

An example of a case where one might limit visitation is when there is a clinical reason, such as a neurological injury, for why a patient is ordered to a quiet environment, free from stimuli, to promote healing. The same is true for any patient where the presence of a visitor causes agitation or distress.

“Limiting information can be trickier,” says Gorka. Decisions to disclose or limit information should be made considering what the patient would have wanted.

“That said, sometimes they are not,” says Gorka. Ethicists have encountered instances where information was being improperly used, including social media postings, for example.

- **Questions about decisional capacity.**

Consults involving a wide variety of ethical issues cannot proceed without a capacity assessment. “In an ICU, by contrast, patients are often so obviously unable to make decisions that a capacity assessment isn’t necessary,” explains Gorka.

- **Potentially unsafe discharges.**

Some consults involve patients who want to leave against medical advice. Others involve patients for whom few resources are available, being discharged to a potentially

unsafe setting. Sometimes, 24-hour supervision is recommended, but the family cannot or will not provide it.

Recently, an ethics consult was called about a wheelchair-bound patient with congenital physical disabilities who had several recent hospitalizations due to respiratory problems. Some clinical team members felt the patient, who lived in a house with help from friends and paid support staff, needed a guardian to force placement into a nursing home. The attending physician believed the patient had capacity to decide upon discharge.

Ethicists had numerous lengthy conversations with the patient. Ultimately, they agreed with the attending physician that the patient had capacity and that guardianship did not seem appropriate.

“Maintaining independence was the highest priority to this patient,” explains **Bethany Spielman**, PhD, JD, a member of Memorial’s Human Values and Ethics Committee.

Ethicists met with providers, the patient, and the outside support network consisting of friends and paid help. The group discussed ways to address care concerns and other needs, and the patient was discharged to the home setting.

Another case involved a young stroke patient left with severe cognitive and physical disabilities. The patient had a large support network of siblings, with the eldest sister identified as proxy decision-maker. “The team was pushing for discharge to a nursing home because of the feeding tube placed during the admission,” says Spielman. The family objected because they wanted the patient to return home. Ethics gathered the family and providers to discuss discharge needs and next steps. “As the family indicated they were committed to any training that

the hospital felt was needed, ethics supported their request to discharge patient home,” says Spielman.

Another case involved a morbidly obese patient who was transferred to the hospital from a nursing home for treatment of respiratory problems. “The patient had been making all healthcare decisions the entire admission,” says Spielman.

When approached about discharge options, the patient indicated a desire to return home instead of to the nursing home. Some members of the team felt this was unsafe because the patient was essentially bed-bound. “A question about capacity was raised, and ethics was consulted to assist,” says Spielman.

After meeting with the patient, it became clear that the patient had capacity. In anticipation of returning home, the patient had already started working on re-establishing a home support network to help with most activities of daily living. The patient expressed frustration with the care received in the nursing home and was willing to participate in at-home physical therapy. The attending physician agreed, and the patient was discharged home. In this case, says Spielman, “Ethics reaffirmed the patient’s right to make discharge decisions, even if some believed they might not be the ‘best’ decisions.” ■

SOURCES

- **Christine Gorka**, PhD, Clinical Ethics Center, Memorial Medical Center, Springfield, IL. Phone: (217) 757-2353. Email: gorka.christine@mhsil.com.
- **Bethany Spielman**, PhD, JD, School of Medicine, Southern Illinois University, Springfield, IL. Phone: (217) 545-4261. Email: bspielman@siu.edu.

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@reliamedia.com

To reproduce any part of Relias Media 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 INSTRUCTIONS

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

1. Read and study the activity, using the provided references for further research.
2. Log onto ReliasMedia.com and click on My Account. First-time users must register on the site. 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/CE QUESTIONS

- 1. Which did a recent study find regarding surrogates after a family support intervention?**
 - a. Quality of communication between clinicians and the surrogate decreased.
 - b. ICU length of stay decreased.
 - c. Nurses felt ill-equipped to take on the role of supporting families.
 - d. Overall volume of ethics consults increased significantly.
- 2. A recent study on orientation for ethics consultations found that:**
 - a. All respondents received some type of orientation, but it was not always adequate.
 - b. A significant portion of respondents were unsatisfied with their orientation.
 - c. All successful orientation programs used videos on ethics consultation.
 - d. Medical educators rejected the idea of collaborating with bioethicists on educational interventions.
- 3. Which is true regarding research consent and ICU patients?**
 - a. ICU-acquired delirium is a clear and permanent indication of lack of capacity to consent.
 - b. There is less potential for conflicts of interest if the attending physician is not a research team member.
 - c. Coercion is only an ethical concern for patients, since it does not apply to surrogates.
 - d. Prospective enrollment is unethical even if community input is obtained.
- 4. Which is an ethical obligation regarding reproduction in the context of cancer, according to Louise P. King, MD, JD?**
 - a. Final decisions about whether to undergo genetic testing should be made at the time of oocyte or semen cryopreservation.
 - b. Programs must require a waiting period for families before proceeding with posthumous reproduction.
 - c. With children facing cancer diagnoses who are old enough to set aside semen or oocytes, it is necessary to protect their ability to make decisions independent of their parents.
 - d. Reproductive endocrinologists must be able to fully address all relevant ethical issues with patients.