



# MEDICAL ETHICS ADVISOR®

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## Ethical controversy erupts over minors' autonomy

*Ethical issues are "difficult and complicated"*

In the controversial "Cassandra C" case, a 17-year old Connecticut girl diagnosed with Hodgkin's lymphoma was ordered by the state Supreme Court to undergo chemotherapy against her will. The girl refused further treatment after undergoing surgery to remove a lymph node, but as of press time is being kept in a hospital room under court order.

"It's a very difficult and complicated topic; in this case, especially so because

of the age of the patient," says **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center in Hempstead, NY. Dolgin is also director of Hofstra University's Gitenstein Institute for Health Law and Policy.

The court decided that the girl's mother was in violation of her duty to the child by refusing potentially lifesaving care, and gave Connecticut's Department of Children and Families authority to make all of the girl's

### EXECUTIVE SUMMARY

The Connecticut case of Cassandra C, a 17-year old girl ordered by the state Supreme Court to undergo chemotherapy against her will, spotlights conflict between respecting minors' autonomy and obligations to promote their best interests.

- This case could set a precedent for requiring minors to prove sufficient maturity to make medical decisions.
- Previous court cases involving adolescents' refusal of cancer treatment have had mixed results.
- Physicians have the legal right to question a patient's capacity if he or she refuses potentially life-saving care, experts say.

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**EXECUTIVE EDITOR:** Russ Underwood  
(russ.underwood@ahcmedia.com).

**MANAGING EDITOR:** Jill Drachenberg  
(jill.drachenberg@ahcmedia.com)

**DIRECTOR OF CONTINUING EDUCATION AND  
EDITORIAL:** Lee Landenberger.

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medical decisions. “If the patient was six months older, in theory, there would be no conflict at all,” says Dolgin. In reality, if an 18-year-old refused life-saving care with the likelihood of certain death, his or her capacity probably would be questioned, she says.

“It’s very compelling to save a child; who can let a child die who might live?” asks Dolgin. “On the other hand, it’s certainly a tough call when a child, almost an adult, and her mother are both refusing care.”

The case has put a national spotlight on the tension that can exist between the autonomy of minors and their right to make decisions about their care, and the obligations of both the law and medicine to promote the best interests of the child.

“It is worth noting that the pendulum has swung from an almost absolute insistence on autonomy, to recognition that autonomy must also be balanced with ethical principles such as nonmaleficence and beneficence,” says **Matthew R. Kenney**, PhD, vice president of mission and ethics at Saint Francis Hospital and Medical Center in Hartford, CT.

This is especially true in the case of minors. “This case will set a precedent by which the burden of proof could rest on the minor to prove sufficient maturity to make medical decisions,” says Kenney.

“Law and ethics do not always coincide — they are two different things,” says **Dennis M. Sullivan**, MD, director of Cedarville (OH) University’s Center for Bioethics.

The fact that the girl is so close to the legal age of maturity means that she may have more of an ability to understand the risks and benefits of intervention and non-intervention. “On the other hand, the medical stakes couldn’t

be higher,” says Kenney.

With chemotherapeutic treatment, her current chances of survival are estimated by physicians at 80% to 85%; without treatment, the likelihood of surviving more than two years is poor. “Based on this, ethically speaking, this treatment is ordinary — medically beneficial — and ought to be provided,” says Kenney.

Kenney sees the primary ethical concern as the conflict between Cassandra’s autonomy and her best interest. “Ethically, there is precedent for violating a patient’s autonomy — particularly one who may not have full capacity for informed consent — in the short term, in order to maximize autonomy in the long term,” he says. For instance, in some circumstances it may be permissible to force a patient in an acute schizophrenic episode to take his or her psychiatric medication, since the medication would enable the patient to regain greater autonomy.

“Applied to this case, compelling Cassandra to receive chemotherapy now — which many contend violates her autonomy — preserves her future autonomy,” says Kenney. “One cannot have autonomy if one does not have life.”

“This situation cries out for an ethics consultation,” says Sullivan. “The majority of ethics consults are resolved by facilitating better communication between the healthcare team and the patient and family.” A medical ethics professional could explore Cassandra’s fears about the chemo, and could make sure she is not reacting to misinformation, for instance.

“If she is worrying about having a family someday, has anyone discussed the idea of cryopreserving her eggs before beginning the therapy?” asks Sullivan. “We may never know, since

Family Services was called early on because of fears about neglect.”

Ideally, similar refusal-of-care cases would be addressed by hospital ethics committees; in this case, the patient was not hospitalized when the dispute arose. “It raises a fascinating question: Is there any institutional capacity for ethics consults outside the hospital setting?” asks Dolgin.

While the legal system results in one side prevailing, ethics consults are based on a collaborative approach. “Ethics consults are grounded in the notion that everyone should win, and reaching a resolution that will serve all of us,” says Dolgin. “Very often, it gets people to consider the situation in ways they haven’t previously.”

Physicians have the legal right to question a patient’s capacity if he or she refuses potentially life-saving care; often, psychiatry is called in, she says. “Clinicians are upset when competent adults refuse care that could save them,” says Dolgin. “Patients are often found not competent, even though those calls are exceedingly difficult to make, and there are no hard and fast rules about what they mean.”

An ethics consult, had one occurred, could have helped clarify issues around decision-making for minors including autonomy, beneficence and nonmaleficence, and provided insight into existing state law on the issue as well as hospital policy. “Perhaps most importantly, an ethics consultation would have opened up an avenue of communication which might not have been present before,” says Kenney.

Provider response to a family’s refusal of treatment depends in part on the probability of success of the treatment. “However, cases such as this, which include a complex treatment plan, a highly emotional situation, and a sick adolescent

making decisions, should be determined on an individual basis,” says **Mary A. Ott**, MD, associate professor of pediatrics/adjunct associate professor of philosophy and bioethics at Indiana University School of Medicine in Indianapolis.

A small number of cases involving adolescents’ refusal of cancer treatment have gone to court. “Two high-profile cases resulted in a long bioethics dialogue,” says Ott. One was the 2007 case of a 14-year-old Jehovah’s Witness with leukemia who refused blood transfusions and died as a result, after being determined to be competent to make the decision by bioethicists and the court, Ott says. Another case involved a 15-year old with Hodgkin’s lymphoma who refused conventional therapy in favor of prayer and herbal treatment. He was not judged competent to make the decision, and the family compromised on a combination of therapy and herbal treatments, she says.

“All children’s hospitals with large cancer programs periodically have a case where an adolescent refuses treatment,” notes Ott. Usually, the oncologist, the adolescent, the family and the ethicist are able to agree on an acceptable plan of care. “We try and anticipate conflicts; when they occur, we use a mediation-based approach and identify common goals of care,” says Ott.

Seventeen states have a “mature minor” doctrine.<sup>1</sup> This allows minors to present evidence of their maturity to a court so that they are legally allowed to make decisions, including medical decisions, as an adult. “Ethics will often follow the law on this issue, and in cases like this, is required to,” says Kenney. “Ethically, in the case of minors there is a recognition that autonomy must be balanced with the best interest of the child.”

The mature minor doctrine requires that the adolescent understand the nature and consequence of the medical treatment. “It is not clear that these criteria had been met in this case,” says Ott. “It is my hope that this will not be viewed as a failure of the mature minor doctrine.”

The mature minor doctrine, says Ott, “is a powerful tool that can support an adolescent’s emerging autonomy and capacity to make their own straightforward medical decisions.” Examples include adolescents seeking urgent care for a minor injury or seeking contraception. “Both are examples where the minor demonstrates good judgment and responsibility in seeking care,” says Ott.

If parents or other surrogate decision-makers are refusing beneficial or life-saving treatment on behalf of a minor, hospitals sometimes ask the court to appoint a guardian to make decisions in the child’s best interest. “Of course, this is more easily applied to the case of a 3-year-old or 7-year-old. It is much less clear when the case involves a 17-year-old,” says Kenney. Often, medical professionals seek assent to treatments from minors who are approaching the age of maturity but not yet able to legally give consent.

“One could contend that refusing to provide life-saving medical treatment to a minor is tantamount to assisting them with suicide,” says Kenney. “Indeed, there may be a legal and ethical requirement to provide life-sustaining treatment to patients who are incapacitated.”

Minors should not be given a false sense of autonomy, he says. “If Cassandra did not actually have the freedom and power to make decisions about her care, it should not have been presented to her that she did

have this power,” says Kenney.

When having informed consent conversations, providers should be clear on the difference between assent and consent. “We want to preserve as much autonomy as possible,” says Kenney. “But the medical community and the law also have an obligation to preserve life and protect patients from harm.”

## REFERENCE

1. Coleman DL, Rosoff PM. The legal authority of mature minors

to consent to general medical treatment. *Pediatrics* 2013; 131(4):786-793.

## SOURCES

- Janet L. Dolgin, PhD, JD, Co-director, Hofstra Bioethics Center; Director, Gitenstein Institute for Health Law and Policy, Hofstra University, Hempstead, NY. Phone: (516) 463-5873. Fax: (516) 463-4800. Email: Janet.L.Dolgin@hofstra.edu.
- Matthew R. Kenney, PhD, Vice President, Mission and Ethics, Saint Francis Hospital and Medical Center, Hartford, CT. Phone: (860) 714-4880. Email: MKenney@stfranciscare.org.
- Mary A. Ott, MD, Associate Professor of Pediatrics/Adjunct Associate Professor of Philosophy & Bioethics, Indiana University School of Medicine, Indianapolis. Phone: (317) 274-8812. Fax: (317) 274-0013. Email: maott@iu.edu.
- Dennis M. Sullivan, MD, Director, Center for Bioethics, Professor of Pharmacy Practice, Cedarville (OH) University. Phone: (937) 766-7573. Email: sullivan@cedarville.edu. ■

# “Don’t worry about the cost” doesn’t reflect patients’ reality

*High cost of care poses potential harm to patients*

**D**on’t worry about the cost. All that matters is getting you well.” Well-meaning physicians frequently say this, but in fact, patients have good reason for wanting to know what care will cost them.

“Providers may say that good care shouldn’t be contingent on cost, but the costs are real for the patient,” says **Paul T. Menzel**, PhD, professor of philosophy emeritus at Pacific Lutheran University in Tacoma, WA.

Physicians have an ethical obligation to learn what healthcare costs and to communicate this to patients as part of the informed consent process, says **Rosie Tong**, PhD, emeritus professor of philosophy at University of North Carolina, Charlotte, and former director of its Center for Professional and Applied Ethics. “I value my health, but I do not value it at all and any costs,” she says. “I think a reasonable person can make a good choice about foregoing medical treatment deemed ‘necessary.’”

New online medical pricing tools

are becoming available, but these are of limited value to patients. “The question patients are asking is not how much the drug costs, but how much the drug will cost them,” says **Laura Tenner**, MD, assistant professor in the Cancer Therapy and Research Center at UT Health Science Center San Antonio. Given the complexity of the healthcare system, the average patient would have difficulty determining from an online tool what he or she will truly end up paying for a given treatment or procedure.

“As our population ages, more and more people are going to see their dollars flying out the door for healthcare,” says Tong.

## Providers unaware of costs

Providers typically don’t inform patients of out-of-pocket costs in advance. “Hospitals aren’t used to doing that. Doctors don’t even know what their patients are being billed for

a given surgery,” says Menzel.

Some ethicists argue that providing estimates to patients simply isn’t enough. “For any free market exchange system to work, the consumer has to know the price of the product in order to make an informed decision,” says Tenner. “Working with estimates still puts patients at risk for significant financial toxicities.”

Previously, neither insured patients nor their providers had much reason to take costs into account. The increase in high-deductible plans has changed that. “I don’t think healthcare providers should wait for people to ask what it will cost. It should just be part of the information that’s given to people,” Menzel says.

Receiving exorbitant bills in the mail for healthcare diminishes patients’ trust in the healthcare system and in their physician. “This can strain the patient/physician relationship,” says Tenner.

Any business that didn’t inform its customers of what a service will

cost them, in any area other than healthcare, “would be censured by our society,” says Menzel. “This is just basic morals and common sense. But it is a wrenching change for the culture of our provider institutions.”

Here are some ethical principles that come into play with price transparency:

- **Non-maleficence.**

“The cost of care can have profound effects on the patient’s financial stability, and therefore, well-being,” says Tenner. “Potential harms include loss of savings, loss of property, and bankruptcy.” A growing pool of data shows patients are incurring significant financial burden due to out-of-pocket expenses of costly prescription drugs.<sup>1,2,3</sup>

Tenner argues that physicians have an ethical obligation to include cost as part of the shared decision-making process. Unfortunately, physicians are often unaware of their patients’ exact out-of-pocket costs.

“However, physicians do have an obligation to work with their patients and connect them to resources that can help patients navigate through the healthcare system,” says Tenner. This allows the physician and patient to make informed decisions together.

A range of costs for a given procedure isn’t helpful to an individual patient; he or she needs an exact dollar amount. “So much depends on the

‘deals’ a healthcare provider has made with insurers,” says Tong, noting that costs vary widely by geographical location. “The market tolerates high prices in one area of the country but not another.”

Understandably, physicians don’t want to misinform their patients about the cost of care. “Of course, this brings up the issue of whether physicians should make it their responsibility to know the costs,” says Tong. “Should medical schools require students to take a course labelled something like ‘Health Care Ethics and Economics?’”

- **Autonomy and informed decision-making.**

“Some patients are spending their life savings or the funds for their child’s college education on prescription drugs,” Tenner notes. Patients are unable to decide whether the price of taking the drug outweighs the benefits if they are unaware of the medication’s cost.

- **Equality.**

Without price transparency, consumers cannot make informed decisions. This diminishes competition and allows prices to climb. “As costs become too high, the divide between those who can afford the medication and those who cannot becomes wider,” says Tenner. “This causes increasing healthcare disparities.”

A culture change is needed in healthcare, argues Menzel, in which comparative effectiveness and even cost-effectiveness are taken into consideration by providers. “This should not be considered unethical, but should instead be considered vigorously ethical,” he says.

Where there is good evidence that a less expensive treatment is as effective as a more expensive one, insurers may refuse to pay for the more costly treatment. “But it isn’t just insurance companies that should be making the first step here. This is a medical expertise matter,” Menzel says.

To ensure sustainability of the healthcare system, providers need to know if a cheaper treatment is just as effective as more expensive alternatives. If so, says Menzel, “it’s immoral to prescribe the more expensive treatment — unless the provider justifiably believes the patient is more likely to benefit from it. You have to allow room for that.”

## REFERENCES

1. Kaiser Family Foundation, “Medical debt among people with health insurance,” January 2014, at <http://kff.org/report-section/medical-debt-among-people-with-health-insurance-incidence-of-medical-debt>.
2. Ramsey S, Blough D, Kirchoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Affairs* 2013; 32(6):1143-1152.
3. Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient’s experience. *The Oncologist* 2013; 18(4):381-390.

## SOURCES

- Paul T. Menzel, PhD, Professor

## EXECUTIVE SUMMARY

There is a growing movement toward more transparency of healthcare costs and new online pricing tools available to patients. However, significant obstacles remain, making it difficult for physicians to meet their ethical obligations to inform patients.

- Out-of-pocket costs can adversely affect the patient’s well-being.
- Physicians are often unaware of the cost of care.
- Patients are unable to make informed decisions if they’re unaware of the cost.

# Report: Bioethics programs' reproductive education doesn't reflect needs of practicing OB/GYNs

*Physicians often encounter "ethics of the mundane"*

There is a mismatch between the reproductive issues that bioethics educators consider most important and the ethical dilemmas that physicians actually face in daily practice, according to a recent Hastings Center report.<sup>1</sup>

Researchers conducted parallel surveys of directors of graduate bioethics training programs and obstetrician-gynecologists (OB/GYNs) in order to learn whether reproductive health education in bioethics programs reflected real-life concerns for practicing physicians. They found a mismatch between what was covered in bioethicist training programs and the realities of clinical practice.

"In many ways it wasn't surprising. But it gave specificity to a problem we had discussed amongst ourselves

as scholars of reproductive ethics," says **Michelle L. McGowan**, PhD, associate professor of women's studies and bioethics at the Pennsylvania State University in University Park.

The bioethics graduate program directors reported prioritizing these topics: assisted reproductive technology, theories of reproductive ethics, prenatal genetic testing, and abortion ethics.

The physician sample, which was drawn from the American Medical Association's database of practicing OB/GYNs, had a different set of priorities. "They focused on abortion and prenatal testing, and also topics such as sexuality and contraception, which are very rarely covered in standard bioethics curriculum," says

McGowan.

Bioethics programs typically spend a lot of time on controversial cases that make headlines. "But most of medicine is not practiced in those cutting-edge areas. We need to be more aware of the routine concerns that face practicing physicians" says **Jessica Berg**, JD, MPH, one of the study's authors. Berg is a professor of law and bioethics at Case Western Reserve University in Cleveland.

Practicing physicians are mainly focused on fundamental areas such as pregnancy termination, contraception, infectious disease, and sexuality, says Berg. These topics aren't prioritized in bioethics programs; in some cases, they're not covered at all. "Even where there was agreement, in most areas the priority assigned by bioethics programs was at odds with the priority assigned by physicians," says Berg.

The researchers recommend that:

- Bioethics programs gather additional data on areas of relevance to practicing physicians.
- Specialty groups review course coverage. For instance, the American College of Gynecology might create priority lists of reproductive topics based on

## EXECUTIVE SUMMARY

There is a mismatch between the reproductive issues that bioethics educators consider most important and the ethical dilemmas that physicians actually face in daily practice, according to a recent Hastings Center report. The authors recommend the following:

- that the bioethics and medical communities work together to develop appropriate content in bioethics curricula;
- that clinical consultation be more fully integrated into the practice of reproductive medicine;
- that bioethics programs gather additional data on areas of relevance to practicing physicians.

members' experiences.

"Bioethics training directors should be more cognizant of problems facing practicing clinicians," says McGowan. "And there should be more cross-talk between these entities."

Bioethics programs might invite more clinicians to give guest lectures, in order to give students a sense of the real-world problems practitioners are facing. Bioethics students could also do clinical shadowing to understand how reproductive medicine and ethics

come up in everyday practice.

Rather than focusing solely on the exceptional cases, bioethics programs should also cover "the ethics of the mundane," says McGowan. "Things like contraception and post-menopausal health get very scant attention in bioethics curriculum now, but often arise in the clinical context."

## REFERENCE

1. Farrell RM, Metcalfe JS, McGowan, ML, et al. Emerging ethical issues in reproductive medicine: Are

bioethics educators ready? Hastings Center Report, 2014; 44: 21–29.

## SOURCES

- Jessica Berg, JD, MPH, Professor of Law and Bioethics, Case Western Reserve University, Cleveland, OH. Phone: (216) 368-6363. Fax: (216) 368-2086. Email: jessica.berg@case.edu.
- Michelle L. McGowan, PhD, Associate Professor, Women's Studies and Bioethics, The Pennsylvania State University, University Park, PA. Phone: (814) 865-5480. Email: mml73@psu.edu. ■

# Are consultants called the "ethics police?" What's behind clinicians' attitudes

*Role includes supporting providers*

At times, providers react negatively to the involvement of ethics; "ethics police" is an often-used derogatory term reflecting this attitude. "The key to avoid being perceived as the 'ethics police' is to emphasize that final decisions on how to proceed are primarily between the healthcare provider and the patient," says **Michael A. Rubin**, MD, MA, chair of the ethics committee at UT Southwestern Medical Center in Dallas.

Rubin always introduces himself as an advisor, not as a representative of the hospital administration or a judicial board. He tells both the patient and the person requesting the consult that he's a third party outside of the patient-physician relationship.

"Furthermore, if I have my white coat on, I remove it to indicate that I'm assuming a different role in this particular interaction," says Rubin. "While some people might perceive this as weakening the role of the ethics consultant, I believe it is a source of

influence." This is because it makes it clear that the roles of provider and advisor are separate.

People who react negatively to ethics consults are often uninformed about what services are actually provided. "The skeptics will call risk management, and often find that the risk managers want us to get involved," says Rubin. "I usually tell them that our legal folks define the black and white, and the ethicist helps the physician and patient explore the gray."

How the consultant reacts to the term "ethics police" or other negative

comments colors the rest of the encounter. "If the consultant's tone indicates preparation for a conflict, there will be a conflict," says Rubin.

If an ethics consultant hears the term, "ethics police," he or she should be able to explain why such a characterization isn't accurate. "This means being able to say what the role of 'ethics consultant' is charged to do in the institution," says **Stuart G. Finder**, PhD, director of the Center for Healthcare Ethics at Cedars-Sinai Medical Center in Los Angeles.

Some physicians worry that the Health Care Ethics Committee

## EXECUTIVE SUMMARY

Clinicians occasionally refer to consult services as the "ethics police;" misconceptions are typically behind this negative perception. Experts suggest the following approaches:

- Emphasize that final decisions are primarily between the provider and patient.
- Explain that the consultant is outside of the patient/physician relationship.
- Speak directly to clinicians opposing the involvement of ethics.

(HEC) will interfere with the patient's care or challenge the physician's authority. "A physician's explicit opposition to an ethics consult should be a rare event at a hospital that fosters a moral and just community; however, it certainly does occur," says Rubin.

At times, consults are called because members of the care team disagree about the direction of care. "As there is a power differential — or at least a perception of one — between these various stakeholders, the HEC may be involved to facilitate resolution of a disagreement," says Rubin. Rubin recommends that bioethicists consider the following practices if they encounter resistance to ethics consults:

- Refer to the hospital ethics consultation policy.

"A well-written policy will indicate that it is appropriate for an ethics consult to be called even in the opposition to a treating physician," says Rubin.

- Insist that conflicting parties first make an attempt to resolve their disagreement through their usual hierarchies.

For example, in the case of a nurse-physician conflict, the nurse manager and medical director should be involved. Rubin first asks if the usual pathways have been attempted. "This will decrease the likelihood of the perception that the HEC is being used

as a 'punitive' consult, or perceived as being intrusive," says Rubin.

- Attempt to speak personally with the clinician opposing the involvement of the HEC.

"If they absolutely refuse, at least they have been given a chance to privately indicate their objection," says Rubin. "They may be less resistant when given the chance to speak freely outside of earshot of the other stakeholders."

If individuals insist a personal conflict is the real reason why a colleague called an ethics consult, Rubin simply proceeds with the process. In other situations, providers may have had previous experiences with ethics consultants that were not helpful. "Establishing the specific goals of the consult will often allow better cooperation," says Rubin.

## Supporting providers is part of role

An important role for ethics consultants is to allow patients and families to articulate their goals, values, and preferences, but they are also there on behalf of providers. "Ethics consultants help and support healthcare providers in articulating the values embedded within their professional and institutional roles and associated

responsibilities," says Finder.

Although the role of the ethics consultant is typically advisory, those who provide ethics consultation must be attentive to the potential influence their participation can play in a situation.

"Having the role 'ethics' associated with one's activities often causes others to grant the ethics consultant a kind of moral authority that may well be unwarranted," Finder explains. "This can shut down others from seeing their own moral experiences as having legitimacy and being worthy of attention."

Involved parties aren't likely to speak freely about their concerns if they fear being judged or disrespected. "This is especially so if the individual — be they patient, family member, or staff — holds values that may not be common or mainstream," says Finder.

## SOURCES

- Stuart G. Finder, PhD, Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center, Los Angeles, CA. Phone: (310) 423-9636. Fax: (310) 423-9638. Email: Stuart.Finder@cshs.org.
- Michael A. Rubin, MD, MA, Chair, Ethics Committee, UT Southwestern Medical Center, Dallas, TX. Phone: (214) 648-8513. Fax: (214) 648-0341. Email: Michael.Rubin@UTSouthwestern.edu. ■

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# Use proven strategies when conflicts arise over withdrawing futile treatments

*Uncover underlying reasons for resistance*

**C**onflict surrounding withdrawal of futile treatments is one of the most common reasons for ethics consults being called. "Reported frequency of ethics consultations

involving futile care range from 10 to 65%. But futility isn't a modern construct," says **Blair Henry**, BSc, MTS, an ethicist at Sunnybrook Health Sciences Centre in Toronto.

In fact, he notes, Hippocrates stated that physicians should "refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless."<sup>1</sup>

Nonetheless, discontinuation of futile treatments is a continuing source of conflict and controversy in both bioethics and acute care medicine. “One issue involves the use of the word ‘futile’ and how this is defined by the healthcare team and the family,” says Henry. “Sometimes it’s best not to focus on the issue of futility.” Instead, establish the goals of care. Then, redirect the conversation toward how the goals can be achieved.

“Medical futility can be defined as an action that serves no useful purpose in attaining a specified goal for a given patient,” says Henry. Determining that an action is medically futile can involve decisions to either withhold treatment, or to withdraw treatments that were previously started.

“Physicians are not obliged to offer treatments that they believe would be medically futile,” says Henry. “However, the withdrawal of futile medical treatment is a different matter.” In 2013, a Canadian court ruled that withdrawal of life-supportive care requires the consent of the substitute decision-maker.<sup>2</sup> “With the exception of the provision under the Texas Advance Directives Act, most states have similar requirements,” says Henry.

Henry adds that the premise of good medicine always involves two elements: a proposed treatment plan that represents standard of care and

one the clinician believes provides more benefit than harm, and consent from the patient or surrogate that signifies their acceptance to undertake the treatment based on knowledge of the risks, benefits and alternatives, and consideration of its congruence with their values and beliefs.

“Frequently, families feel like they are being asked to decide to allow death to occur and that this is their responsibility,” says Henry. “These can be challenging clinical encounters.” Withdrawal of futile treatments typically involves stopping life-supportive treatment such as ventilator support, blood pressure support, or dialysis, in an intensive care unit (ICU) setting and allowing for death to occur. Thus, strong emotions of guilt and grief are commingled with attempts to make a treatment decision. Henry suggests bioethicists utilize the following strategies when dealing with decision-making related to the withdrawal of futile medical care:

- Use goals of care as the basis for medical decision-making.

This takes the focus off specific medical treatments and places it on the goals that the patient, family, and team want to achieve. “This can help reframe difficult conversations by acknowledging the impossibility of achieving the outcome desired as being the reason for changes in the plan of care,” says Henry.

- Consider the legal requirements

of the jurisdiction.

“Withholding treatment is a clinical decision; however, withdrawal of treatment typically requires the consent of the substitute decision-maker as stated by law,” says Henry.

- Engage the interprofessional care team.

Chaplains can provide much-needed spiritual care; nurses can support the family struggling to accept a new reality. A consistent message from all healthcare providers is key. “Hearing different messages from various healthcare providers will cause family members to lack trust in the medical team’s judgment,” he says.

- Determine if the family’s hesitancy is related to lack of trust in the medical opinion.

If so, the use of second medical opinions is often helpful. “This shows the family that the plan to withdraw is confirmed by medical professionals not directly involved in the care,” says Henry.

- Consider a trial of continued therapy.

Educate the family on what would be needed from the patient’s clinical presentation to allow for a change of mind to occur. “Staff can stipulate that in the event of further deterioration or organ failure, that no escalation of treatment would be provided,” adds Henry.

## Conflict management skills needed

The patient may have made his or her wishes perfectly clear in an advance directive — for example, stating a wish not to be supported by life-sustaining treatments if permanently unconscious. “But if some or all of the family members do not want to limit life support, the providers may feel compelled

### EXECUTIVE SUMMARY

Withdrawal of futile treatment often results in conflicts between providers and family members, necessitating an ethics consultation. Some expert strategies for bioethicists include:

- Redirect the conversation toward achievement of goals of care.
- Determine if hesitancy stems from lack of trust in the medical opinion.
- Ask open-ended questions such as “Why?”

to continue treatment as a practical matter,” says **Charity Scott, JD, MSCM**, Catherine C. Henson Professor of Law at Georgia State University College of Law in Atlanta.

Advance directive laws can provide immunity from civil and criminal liability for carrying out patient wishes expressed in an advance directive that meets the legal requirements in the state.

“Nevertheless, even though providers may understand that the law provides for such immunity, they may still be reluctant to follow the patient’s written requests when family members are onsite and vociferously protesting against following them,” says Scott. By the time an ethics consult is called, communication among the parties has often deteriorated. Scott recommends that bioethicists utilize the following conflict management tools for addressing an apparent impasse in these situations:

- Active listening.

“This is probably the most important skill to exercise, in seeking to understand the underlying reasons for the parties’ differing positions,” says Scott. This allows bioethicists

to determine what interests, needs, desires, fears, or emotions are underlying someone’s insistence on getting “their way” in a conflict.

“With patience, a bioethicist may learn that a father who staunchly insists on aggressive treatment for his daughter may be feeling guilt or remorse about having moved away from his family during her early childhood,” says Scott.

- Ask open-ended questions.

“Don’t assume that you understand a person’s perspectives and desires from the positions they may take,” says Scott. “‘Why?’ is the classic open-ended question that doesn’t invite a simple yes or no response.”

- Rephrase what you have heard to ensure that you have understood, by stating “Let me see if I understand...”

People often need to feel heard before they will listen to someone else. “That can go a long way to lowering the temperature in a high-conflict situation and creating openness to hearing another person’s perspectives and concerns,” says Scott.

If a bioethicist has not been trained in mediation or conflict management skills, he or she may inadvertently worsen the situation

by assuming that legal or ethical principles will prevail and resolve a thorny issue.

“Rarely does either law or ethics mandate a single medical treatment outcome,” says Scott. “Even then, coming to agreement about that outcome is preferable to having someone feel coerced into accepting it.”

## REFERENCES

1. Kasman, D. When is medical treatment futile? A guide for students, residents, and physicians. *J Gen Intern Med* 2004; 19(10): 1053-1056.
2. Cuthbertson v. Rasouli, 2013 SCC 53, [2013] 3 S.C.R. 341

## SOURCES

- Blair Henry, Ethicist, Sunnybrook Health Sciences Centre, University of Toronto, Ontario, Canada. Phone: (416) 480-6100 ext. 7178. Email: Blair.henry@sunnybrook.ca.
- Charity Scott, JD, MSCM, Catherine C. Henson Professor of Law, Georgia State University College of Law, Atlanta, GA. Phone: (404) 413-9183. Fax: (404) 413-9225. Email: cscott@gsu.edu. ■

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# ED setting poses unique challenges in palliative care delivery

*Time, quiet spaces are both scarce resources*

It is very easy for emergency department (ED) providers to “err on the side of caution” when deciding whether to institute life-sustaining therapies. “But this, in fact, may not be the best course of care,” says **Tammie E. Quest, MD**, director of Emory Palliative Care Center and associate professor in the Department of Emergency Medicine at Emory

University School of Medicine in Atlanta.

ED providers are challenged with managing pain and other symptoms faced by patients with serious illnesses, and helping them decide about the use of invasive medical interventions.

“Emotions are high, and severe illness is often sudden and unanticipated,” says **Ashley Shreves,**

MD, assistant professor in the Department of Emergency Medicine and the Brookdale Department of Geriatrics and Palliative Medicine at Icahn School of Medicine at Mount Sinai in New York City. Here are other unique challenges involving palliative care in the ED setting, says Shreves:

- Limited background

information is available to help physicians, patients, and caregivers make the decisions about the best path forward.

- Time and space are limited. “Discussions about the risks and benefits of proceeding with treatment that focuses on prolonging life, versus comfort and quality of life, take time,” says Shreves. “This is best done in a quiet space — a scarce resource in the ED.”

- ED providers have no established relationship with patients and families coming to them at their most vulnerable time. “Creating a therapeutic bond and gaining the trust of such patients and families can be challenging in the limited time available in the ED encounter,” adds Shreves.

- EDs are often loud, chaotic, and uncomfortable, with limited privacy. “This can be a particularly stressful environment for patients with advanced illnesses, and even worse for those at the end of life,” says Shreves.

In 2013, the American College of Emergency Physicians recommended, as part of the Choosing Wisely campaign, that emergency physicians not delay hospice and palliative care services for patients who might benefit from these in the ED setting.

“With this recommendation as a best practice in the field, we need the education and implementation tools necessary to deliver on this recommendation,” says Quest.

The Education in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) and the Center to Advance Palliative Care’s Improving Palliative Care in Emergency Medicine (IPAL-EM) projects provide education and tools to improve the provision of palliative care in the ED. Quest is director of both projects.

“Increasingly, the evidence is building in the field to identify the

most effective strategies,” says Quest. Still, a standardized approach is lacking.

In a 2014 study, 11 program leaders were interviewed on ED and palliative care integration. Researchers found that few collect outcomes-based metrics.<sup>1</sup> When tracking does occur, there is a lack of standardization as to what metrics are used.

The IPAL-EM project, with expert consensus, provides guidelines on metrics that EDs can use to track outcomes. “While these have not yet become standard in the field, we have begun to see many programs throughout the country report metrics that may not yet have made it to the literature,” says Quest.

Both the culture of emergency medicine and financial reimbursement models push physicians to prioritize the use of invasive, life-sustaining treatments for their patients, says Shreves. This occurs regardless of the underlying illness and/or prognosis.

“Physicians should be rewarded for having the lengthy, challenging conversations that patients and families so desperately need and want, rather than discouraged from doing so as a result of time and financial pressures,” she adds.

Shreves recommends the following changes:

- Emphasizing palliative care skills in residency training.

“This would give physicians the basic knowledge to meet the symptom and psychosocial needs of patients with advanced illnesses,” says Shreves.

- Correcting providers’ misconceptions about legal requirements.

Fear about taking a misstep on this high-stakes terrain can dissuade physicians from even talking to patients and families about important end-of-life issues. “There is a considerable mythology concerning the ethical and legal boundaries that govern end-of-life decision-making,” explains Shreves.

- Involving bioethicists in developing policies for palliative care in the ED setting.

“Bioethicists could help create institutional policies and educational interventions that empower physicians to engage in the process more,” says Shreves.

## REFERENCE

1. Quest T, Herr S, Lamba S, et al. Demonstrations of clinical initiatives to improve palliative care in the emergency department: A report from the IPAL-EM initiative. *Ann Emerg Med* 2013; 61(6):661-667.

## SOURCE

- Ashley Shreves, MD, Assistant Professor, Department of Emergency Medicine, Icahn School of Medicine at Mount Sinai, New York City. Email: ashley.shreves@mssm.edu.
- Tammie E. Quest, MD, Director, Emory Palliative Care Center/Associate Professor, Department of Emergency Medicine, Emory University School of Medicine, Atlanta. Email: tquest@emory.edu. ■

## COMING IN FUTURE MONTHS

- Ethical concerns with genomic testing of newborns
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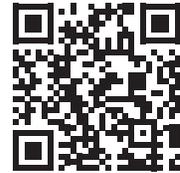
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## CME QUESTIONS

- 1. Which is true regarding a minor's right to refuse treatment, according to Matthew R. Kenney, PhD?**
  - A. Physicians may not violate a patient's autonomy in the short term.
  - B. Physicians do not have the legal right to question capacity if a patient refuses life-saving care.
  - C. All states have a "mature minor" doctrine.
  - D. Providers should be clear on the difference between assent and consent during informed consent conversations.
- 2. Which is true regarding reproductive health education in bioethics programs, according to a recent Hastings Center report?**
  - A. There is a mismatch between what is covered in training programs and clinical practice.
  - B. Practicing clinicians want more help with assisted reproductive technology.
  - C. Bioethics graduate program directors adequately cover everyday issues such as contraception.
  - D. Clinicians want less information on prenatal testing.
- 3. Which is recommended involving ethics consults, according to Michael A. Rubin, MD, MA?**
  - A. Bioethicists should not present themselves as advisors.
  - B. Consults should not be called without the treating physician's consent.
  - C. Policies should specify that it is not appropriate for a consult to be called if the treating physician is opposed.
  - D. Conflicting parties should first attempt to resolve their disagreement through their usual hierarchies.
- 4. Which is true regarding palliative care provision in the emergency department, according to Ashley Shreves, MD?**
  - A. All EDs currently collect outcomes-based metrics on palliative care.
  - B. Emergency physicians should not delay hospice and palliative care services.
  - C. There is a disincentive for emergency physicians to prioritize invasive, life-sustaining treatments.
  - D. Palliative care skills are currently over-emphasized in residency training.