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## Nursing and Medical Students, Residents Unprepared for Ethics Violations

**N**ursing students were not too happy with how they responded to observed ethics violations, ranging from patient privacy violations to infection control issues, according a recent study of nursing students.<sup>1</sup> The findings suggest better preparation could be useful.

Also, it is not just nursing students who need more confidence in responding to ethics violations. The same is true of many medical students and residents, according to **William Nelson**, PhD, MDiv. Some suspect they have observed an ethics violation, but are not completely sure. Other times, they are certain it is a violation, but have no idea how to respond. In either scenario, ethics can be of great help, Nelson offers.

Recently, a resident asked a senior medical student to discuss details on a patient in the middle of a crowded elevator. The student suggested they talk in private to avoid disclosing identifiable patient information in a public area. “The resident was not totally content with the student’s initial response, but later commented that she appreciated

the medical student’s professionalism and action to protect confidentiality,” says Nelson, director of the ethics and human values program at Geisel School of Medicine at Dartmouth.

In this case, the student knew full well that it was a breach of patient confidentiality, but was reluctant to confront the resident. “As students, they know that residents are going to be evaluating them at the end of the clerkship, and they don’t want to undermine the relationship,” Nelson notes.

Clinicians may face similar discomfort within an organizational hierarchy, making it difficult to challenge higher-ups. “Providers might be junior, in terms of status, to a senior person who is violating an ethical standard,” Nelson suggests.

Since graduate medical education trainees and senior physicians serve as role models, the effect of ethics violations is compounded. “It not only diminishes the integrity of the individual clinical or administrator,” Nelson says. “It really undermines the professionalism of the profession.”

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Clinicians may see all kinds of transgressions, such as colleagues concealing medical errors from patients, failing to give a true informed consent, or performing nonbeneficial tests that help providers financially. “Whatever you can do to help clinicians respond to these types of challenging situations, the better off you and the organization will be,” Nelson says.

According to Nelson, clinicians need what he calls “in-the-moment skills.” This know-how can boost one’s confidence when reacting on the spot to ethics violations. Sometimes, it is necessary to skillfully discuss the situation with the violator right away. In other cases, the right course of action is to discuss the violation (whether real or perceived) with the appropriate person, such as the clerkship director or chief resident. “Just as an impaired provider must be appropriately called out, so must an ethically impaired provider,” Nelson says.

Failure to act on observed ethics violations negatively affects the quality of patient care, Nelson warns. “Healthcare professionals have a duty to patients, the public, and the profession to recognize and address ethical misconduct,” he says.

Ethicists can offer plenty of regular education sessions: on ethics principles, examples of ethics dilemmas, conflict resolution mechanisms, and decision-making, says **Andria Bianchi**, PhD, a clinician-scientist and bioethicist at University Health Network in Toronto. “Clinicians will

hopefully feel confident in providing real-time responses while also knowing that the ethics team can offer additional support,” she offers.

Case-centered ethics rounds effectively prepare clinicians for these situations, says **Rosalind Ekman Ladd**, PhD, a visiting scholar in philosophy at Brown University. Some violations, such as “forgetting” infection control measures, call for an immediate response. “Role-playing is a useful technique,” Ladd suggests.

A clinician can practice saying things like, “Did you forget to use the hand sanitizer?” or “Using the sanitizer every time is such a pain, isn’t it?” Then, such discussions come more naturally. Suspicion of impairment or medical error call for a different approach. “There should be a consensus about which violations call for immediate response, and which require reporting to someone else,” Ladd explains.

A resident may be mistaken about what he or she thought was a medical error, or mistaken that a clinician is impaired. “If it requires serious disciplinary action, that is better undertaken by the person’s superior,” Ladd says. ■

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## COMING IN FUTURE MONTHS

- Legal exposure involving surrogate decision-makers
- Demonstrate value of ethics with great documentation
- Ethical concerns of involuntary psychiatric commitment
- The most effective approaches for ethics QA

# Ethics of Warrantless Blood Draws in Hospital Setting

A recent Supreme Court ruling allows police to obtain blood draws from unconscious drunk driving suspects.<sup>1</sup>

“When a law enforcement officer requests a blood draw of a drunk driving suspect, ethical considerations include balancing the suspect’s expectation of privacy against the public’s safety,” says **Anne M. Brendel**, JD, an attorney with Buchalter Law Firm specializing in healthcare law and regulatory matters. Policies should be updated and modified regularly, particularly

in light of the Supreme Court’s recent decision, Brendel advises.

“Hospitals may wish to consult an ethicist, along with an attorney, to determine the appropriate policies and procedures based on the applicable ethical and legal concerns,” she adds.

Ethics should be proactive in this regard.

“Given that blood alcohol content steadily diminishes over time, it’s important that hospital policies and procedures are clear on the front end,” Brendel stresses. Less confusion

arises if staff are trained to act promptly in the event a police officer requests a blood draw on any patient.

“Waiting for an ethics consult until after a law enforcement officer requests a blood draw could cause a delay in action — and the loss of valuable evidence,” Brendel notes. ■

## REFERENCE

1. *Mitchell v. Wisconsin*, No. 18-6210, Supreme Court of the United States (June 27, 2019). Available at: <http://bit.ly/37Exhca>. Accessed Dec. 4, 2019.

# Ethics of Organ Procurement From Unrepresented Patients

Some states allow organ procurement from unrepresented decedents. The authors of a recent paper examined some ethical concerns with this controversial but common practice.<sup>1</sup>

“The issue arose in the context of our work in clinical ethics,” says **Joseph A. Raho**, PhD, the paper’s lead author and a clinical ethicist at UCLA Health.

The ethical question is whether the organs of unrepresented decedents should be procured for transplantation.

“We have no way of knowing what that individual would have wanted regarding organ donation,” Raho observes.

A decision not to retrieve organs means those potential organs will be lost. People who would have benefited from the organ could die as a result.

“On the other hand, if the decedent did not leave any wishes regarding donation, and no surrogate

with knowledge of the decedent’s values is available to decide, perhaps the organs should not be taken,” Raho offers.

Vigorous debate on both sides of this issue led Raho and colleagues to perform a literature search to see what had been published on the topic. Finding nothing, they decided to write their own paper.

“Our hope is that it will initiate sustained collaborative reflection among scholars, policymakers, the public, and, ultimately, clinicians,” Raho says.

Currently, U.S. transplantation policy is based on the donation model. Researchers were surprised to learn the practice of organ retrieval from the unrepresented is legally permissible in 45 states. This meant that the default policy for the unrepresented was in fact “routine retrieval,” unless there were prior evidence that the decedent did not want to donate. “The ethical

implications are significant,” Raho notes.

Procuring organs from unrepresented patients without express consent “poses significant ethical concerns, not the least of which is the specter of exploitation for hegemonic gain,” says **Leslie M. Whetstone**, PhD, professor of philosophy at Walsh University and a bioethicist at Aultman Hospital in Canton, OH.

“Saving a life is such an important ethical concern, and decedents have the potential to save multiple lives through organ recovery,” says **Richard J. Howard**, MD, PhD, former chief of the division of transplantation and emeritus professor of surgery at the University of Florida. Thus, he suggests every effort should be made to recover all possible organs for transplantation. If a dead person has no obvious next of kin who could authorize organ recovery, Howard outlines the next steps:

- Clinicians spend at least 24 hours searching for such an individual. “We then ask a friend, if there is one, what she thought the individual might have wanted,” Howard explains.

- Clinicians go to a judge, provide this information, and ask for the court’s permission to recover organs. “They almost never deny it,” Howard notes.

- The medical examiner also must be notified. “But in Florida, there have been no denials in at least five years,” Howard reports.

- Donor registries are searched to determine if the decedent already registered. “In Florida, that is sufficient to recover organs,” Howard adds.

Despite the existence of this well-traveled path, there are some ethical issues that come into play:

- **The practice raises major issues of justice.** If current transplantation policy is based on the donation model, the question is why unrepresented decedents are treated differently. “Unrepresented patients are inherently vulnerable. They come disproportionately from marginalized backgrounds,” Raho says.

Examples include the homeless, the mentally ill, substance abusers, and those estranged from their families. “Is it fair to use

unrepresented decedents as sources of organs, when many of them would have been excluded from receiving a transplant, had they needed one, for various reasons?” Raho asks.

People may well be denied transplants for lack of social support, substance dependence, or mental health conditions, or even lack of sufficient means to ensure they will be able to afford post-transplant immunosuppressive medications. “If patients will not be able to care for the organ sufficiently to maximize the opportunity for a successful transplant, then the risk of organ loss is high,” Howard notes.

Two patients are affected adversely: the one who received the transplant but was not able to care for it, and the patient who might have received the organ. “It is frequently a difficult issue of where to draw the line, so to speak,” Howard says. “Every transplant program has its own guidelines.”

- **It raises questions about whether a “presumed consent” donation model would be more ethical.** “Organ donation is a clear public good. Many adults indicate that they would want to donate,” Raho says. While the vast majority of U.S. adults support organ donation (93%), only about half (54%) are registered donors, according to

the results of a recent study.<sup>2</sup> If the presumption is that unrepresented decedents would have wanted to donate, perhaps there is a need to rethink the “donation model” in favor of a “presumed consent” model for the entire population, Raho offers. “This is a consideration that merits further discussion.”

Another recent study demonstrated the projected effect of moving toward a presumed consent model.<sup>3</sup> This model has been implemented in several countries to address the organ shortage. “An opt-out system that applies to everyone, while not without challenges, offers a far more equitable approach to the matter,” Whetstone says. ■

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## Ethics Curriculum Feasible for OB/GYN Faculty

**M**uch ethics education focuses on students and residents, but practicing physicians also need ethics expertise. An ethics and professional curriculum was piloted for faculty in obstetrics and gynecology.<sup>1</sup>

“Our motivation was the awareness that faculty model ethical knowledge, behavior, and care formally, informally, and via the

hidden curriculum,” says **Kavita Shah Arora**, MD, MBE, MS, one of the study’s authors.

The goal was to fill gaps in ethics education. Twenty-eight faculty members attended a single four-hour session. Participants reported less burnout. “We were happy to see that our curriculum was both feasible and well-received. Faculty are looking

for this information,” says Arora, an associate professor of reproductive biology and bioethics at Case Western Reserve University.

While efforts have been made to educate trainees, there has been a relative lack of ethics education focused on medical faculty. “Further work is necessary to assess whether we also raised knowledge in ethics and

impacted use of ethics consultative services,” Arora adds.

Ethicists who work alongside obstetrician-gynecologists should consider offering these routine educational opportunities, according to **David I. Shalowitz**, MD, MSHP:

- Review common ethical issues (advance care directives, informed consent for procedures, or whether sale of nonmedical products is permissible in the clinic);
- Give updates on intersections between the law and ethics;
- Discuss cases that clinicians have found particularly challenging.

“Obstetrician-gynecologists routinely encounter ethical challenges during clinical care,” notes Shalowitz, assistant professor of gynecologic oncology at Wake Forest Baptist Health.

Some of these issues are addressed by the Committee on

Ethics of the American College of Obstetricians and Gynecologists. This provides adequate guidance in most circumstances, Shalowitz says. “However, in some cases, uncertainty may remain, in which case an ethics consultant may provide much-needed clarity,” he explains.

Continuing ethics education is vital for practicing physicians, “especially in our field,” says **Ginny Ryan**, MD, MA (Bioethics), an associate professor in University of Iowa’s department of obstetrics and gynecology. “Medical students I work with consistently rank obstetrics and gynecology as the most ethically fraught experience they have on their rotations,” she reports.

Students find it challenging to consider pregnant women as separate from the fetus. “Students also struggle with issues surrounding abortion, pelvic exams on anesthetized patients,

reproductive rights, and the lack of availability of infertility care,” Ryan adds.<sup>2</sup>

Hospital leaders also can support providers by encouraging continuing ethics education and conference attendance.

“Leaders can look into hosting their own conferences or roundtables to address locally or regionally pertinent ethics issues,” Ryan suggests. ■

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## Surprising Data on Patient Preference for Informed Consent in Acute Stroke

**W**hen there is a decision to be made regarding whether to treat a stroke patient with tPA, time is limited, and it is a matter of life and death. Yet, there is no standard approach for informed consent for these high-pressure cases.

“As a practicing clinical neurologist, it became clear that the standard ethical principles of obtaining informed consent were more challenging to apply in this time-sensitive, complex situation,” says **Ann Murray**, MD, a practicing neurologist and assistant professor in the department of neurology at West Virginia University School of Medicine.

Ideally, shared decision-making in informed consent occurs in an

outpatient environment or research setting, with ample time, plenty of discussion, and a detailed exploration of the patient’s individual perspective. “In a fast-paced clinical setting, this is just not possible,” Murray laments.

Murray and colleagues examined what patients actually want in the informed consent process. They gave 184 participants a hypothetical situation: to decide whether to provide consent for a family member to receive IV-tPA.<sup>1</sup> “We wanted to at least start the conversation on informed consent in the acute care setting,” Murray explains.

Three informed consent models were presented, based on parental qualities, statistical data, and a general consent statement. Respondents were

equally likely to give consent with all three approaches. More preferred the parental approach. “Based on our experience in clinical practice, the findings were not surprising,” Murray says.

However, this does challenge the current ethical models for informed consent. “In our experience, when patients or families are faced with emergent, high-stakes decision-making, they do regularly ask what the specific provider would do if it was them,” Murray reports.

This, then turns into a much more “parental” discussion. Patients realize that the issues involved are complex, and it is a high-stakes moment in their lives. “They are truly looking for advice, not just medical facts,”

Murray observes. Asking the clinician, “What would you do?” makes it personal. It brings the provider’s own values into the discussion, as well as their expertise.

“It is important to recognize that our results suggest a more nuanced approach to consenting, not a one-size-fits-all,” Murray offers.

The paper suggests that patients view statistical discussion of outcomes and risk as less meaningful.

“Despite parental approaches being completely out of favor and regularly discouraged in medical training and practice, there are some medical situations where patients actually prefer it,” Murray says.

This is not to suggest that the provider leave the patient out entirely in decision-making. “But, it recognizes that provider expertise and personal input can, and often should, more significantly impact the decision-making process,” she adds.

When urgent decisions must be made, “you have to be flexible in the models of shared decision-making,” says **Joshua Uy**, MD, geriatric fellowship program director at Penn Medicine in Philadelphia. Paternalism, agent, collaborative, or consumer models are some options.

In an urgent situation, says Uy, “I probe a little bit about the patient. Once I get the lay of the land, I absolutely make a recommendation by saying what I think might fit them best.”

To learn what he needs to know, Uy asks open-ended questions such as “Tell me a little bit about what you’re worried about, and what you’re hoping for.” He then asks, “Tell me what you would like to know about the treatment.” Next, he uses narratives of theoretical vignettes or actual cases, and offers a recommendation. It is not just factual issues that need to be addressed.

“Often, the underlying thing to be addressed is the emotional issues,” Uy notes.

Clinicians should be able to explain outcomes in several ways, such as narrative, numerical, or pictorial.

“For patients who can’t make decisions, paternalism can be kindness,” Uy says. “When I walk into an auto mechanic shop or a clothing shop, I just need recommendations. I know very little about fashion or cars.” ■

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# Guidance on Ethics of Artificial Intelligence in Radiology

The radiology community should act right away to develop codes of ethics for artificial intelligence (AI), the authors of a consensus statement urge.<sup>1</sup>

“AI raises novel ethical challenges,” says **Raym Geis**, MD, FACR, the paper’s lead author and a clinical adjunct associate professor of radiology at National Jewish Health.

The authors of the statement were concerned that ethical guidelines are lagging behind the progress AI has made in the field of radiology.

“We wanted to start what we hope will become a rich discussion of ethics of AI in radiology. We will likely be interfacing with AI in our daily practice in the near future,” Geis

explains. Many people on the clinical side of radiology ask questions about how AI can be used in ways that put patients first.

“One concern is that benefits and potential harms are distributed equally across all populations,” Geis notes.

He gives this example: An AI tool is used to diagnose tuberculosis on chest X-rays.

“You train it for the U.S., and it works well for people here,” Geis says. However, in a developing country with more patients presenting with significant HIV and low T4 counts, many may have florid TB without typical findings on X-ray. Therefore, the AI may call it normal.

AI also could be used to predict who will not show up to undergo their CT scan. Then, clinics could send a rideshare service to pick up the patient.

“But what if instead you double-book that appointment time? Then, if the patient actually does show up, they’ll have to wait,” Geis says.

Data privacy for medical images is another example.

“There are no standards for how to de-identify medical images as much as possible,” Geis observes. “Techniques are still evolving for how to accomplish that.”

The statement is not prescriptive about regulation or codes of conduct, or how ethical practice actually will

be ensured. “It will probably be a combination of federal regulation, educating the public as well as clinical and technical participants, and placing as many barriers as possible

against unethical behavior,” Geis predicts. ■

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artificial intelligence in radiology: Summary of the Joint European and North American multisociety statement. *J Am Coll Radiol* 2019;16:1516-1521.

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# Meet Unique Challenges of Pediatric Ethics Consults

Many ethicists consult on pediatric cases only rarely. A recent paper addressed some unique considerations.<sup>1</sup>

“We wanted to highlight some features, both theoretical and practical, that those practicing in the pediatric setting should be aware of,” says **Caroline A. Buchanan**, PhD, HEC-C, an assistant professor in the program for bioethics and a member of the hospital ethics committee at University of Kentucky College of Medicine.

The authors saw a need for standardization in both education and training for pediatric ethics consultants.

“Certain features of pediatric units may differ from adult ones,” Buchanan observes. The paper covers some unique issues that arise during

pediatric consults. These include pediatric assent, theories of parental authority, and family-centered care for pediatric patients.

The process of pediatric ethics consultation also is somewhat different. Here are some examples:

- Pediatric cases involve multiple decision-makers; often a triad of the medical team, the patient, and the parents. “Communication skills, then, are especially important,” Buchanan notes.

- Pediatric units often are highly interdisciplinary. “This requires careful information-gathering by an ethicist, and sensitivity toward multiple individuals who have invested time and care toward their patient,” Buchanan explains.

- Pediatric ethicists also should be prepared to follow patients

throughout their stay, if necessary, supporting the team as treatment plans progress.

- Consultants also must be familiar with common difficulties in determining beneficent care for pediatric patients. Some treatments may carry a high variability in outcomes.

“Others may have the threat of long-term disability or chronic complications, or permanent effects on the patient’s ability to reproduce or engage in other aspects of their later life,” Buchanan adds. ■

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# How to Create a Truly Diverse Ethics Committee

Consider this recently unsolicited comment: “I really need to be on the ethics committee. I’m not shy about telling folks what is right and what is wrong.” For **F. Keith Stirewalt**, PA, MBA, MDiv, a remark like that is worrisome.

“I fear those with monocular lenses coming onto the committee, seeing the world only through their personal perspective,” says Stirewalt, chaplain for clinical engagement at Wake Forest Baptist Medical Center in Winston-Salem, NC. Ethics

committees thrive on the diverse perspectives of patient advocates, attorneys, chaplains, and hospital leaders. “Administrators are often forgotten, or seen as the ‘enemy,’” Stirewalt observes. Stirewalt provides a few examples of diversity in ethics committees:

- A university-based elder law attorney can address the legalities of a situation;

- Chaplains can emphasize the need to respect diversities of faith in patients, visitors, and staff;

- An academic philosopher may be the only one bold enough to ask, “Why?” when everyone seems to agree on a particular course;

- A neonatologist can explain why a policy for adult patients is not appropriate for pediatrics;

- Nurses can point out why a process sounds good in theory, but will not work in clinical practice.

The answer, says Stirewalt, “is to be purposeful in the recruitment of people with these various lenses. Who is missing at the table? We need to go

get them.” Recruiting individuals who would benefit the committee is not always easy. One obvious obstacle is lack of compensation. “Participation in ethics comes at the cost of time, paid for in the shifting of professional duties and by less time and energy with our families,” Stirewalt laments.

Diversity on the ethics committee “doesn’t just happen. It has to be intentional,” says **Robyn M. Axel-Adams**, M.Div, BCC, manager and senior affiliate faculty at the Charles Warren Fairbanks Center for Medical Ethics.

A respiratory therapist, music therapist, dentist, and quality control expert can add insight that a committee would never have thought of before.

“Chaplains and social workers help us to view the patient in a holistic way,” Axel-Adams adds.

In one case, a frail, elderly woman was unconscious, and slowly dying. Her daughter insisted she remain a full code, even though it was potentially inappropriate, and no one wanted to perform CPR on the woman.

“The chaplain was able to ascertain that the patient’s religious conviction was that the more she suffered, the more grace God released into the world,” Axel-Adams recalls.

This belief was a primary reason she stayed in an abusive relationship and would now remain a full code. “The staff was challenged with this theology, but respected her values and kept her a full code,” Axel-Adams reports.

Diverse ethics committee members can bring previously unexplored options to light. A recent case involved a woman who had resided at a long-term acute care hospital, and was now refusing to eat. She struggled with cognitive impairment, and could not express why she was not eating.

A dental professor, and member of the ethics committee, voiced concerns about a dental issue. She asked if the patient recently underwent a dental examination to see if there were any intraoral conditions that might be contributing to her refusal to eat. “We were all taken aback that we had not thought of the obvious,” Axel-Adams says.

Ethics-related policies affect the entire hospital community. “Thus, having representation from a variety of disciplines will help ensure many voices are heard and respected,” Axel-Adams adds.

Stirewalt favors an application process for anyone interested in joining the ethics committee. During this process, it is important to ask these three questions:

- Why do you think you would like to be on the ethics committee?
- How do you feel your experience and knowledge will assist the committee?
- What are your hesitations about joining the ethics committee?

People do not necessarily need extensive education in bioethics to participate on an ethics committee. “It is true — ethics committees need folks with formal bioethics training,” Stirewalt admits. However, he says the basics, the ethical principles of autonomy, beneficence, nonmaleficence, and justice, can be taught to newbies.

“In the end, committees need competent, reflective listeners who are not afraid to speak up when they perceive the risk of injustice,” Stirewalt offers.

Also, it is important to eliminate those who are interested for the wrong reasons. Members must be willing and able to wrestle with difficult issues, not just hear about conflicts, inappropriate surrogates, and unusual end-of-life cases.

“There is a fine line between voyeurism and contribution on an ethics committee,” Axel-Adams stresses.

Interdisciplinary composition is “what makes ethics committees so valuable,” says **Peter Clark**, PhD, professor and director of the Institute of Clinical Bioethics at Saint Joseph’s University in Philadelphia. Clark shares a few observations about the makeup of ethics committees:

- Nurses and physicians comprise about half of all members;
- Many committee members are women;
- Most committees include an administrator and a chaplain (or at least someone trained in pastoral care);
- Most committees include lawyers, board members, or risk managers;
- Most committees lack at least one person from a racial or ethnic minority. “Achieving ethnic and racial diversity remains a challenge,” Clark says. Recruiting representatives from different ethnic and racial backgrounds could help facilities identify and eliminate disparities in care, Clark adds.

• Few committees include nutritionists, occupational or physical therapists, or psychologists. Clark suggests including psychiatrists or psychologists would be helpful because an ethics committee often addresses issues surrounding a patient’s competency to make medical decisions.

For issues around wound care, Clark says occupational and physical therapists are especially beneficial. Their opinions on pain management could be valuable. Additionally, since feeding tube issues are yet another key subject for ethics committees, a nutritionist could help address those needs for elderly patients.

Clark says ethics committees should include at least representatives from social work, nursing, clinical ethics, pastoral care, respiratory care,

law, psychiatry/psychology, and dietetics and nutrition. There also should be at least one community representative.

“The committee should also try to be diverse culturally and racially, especially in the appointment of the community member,” Clark adds. ■

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## Many More Palliative Care Consults With Predictive Analytics

**P**alliative Connect, a system powered by predictive analytics, increased palliative care consultations for seriously ill patients by 74%, according to the authors of a recent study.<sup>1</sup>

“We were not so surprised that nudging physicians to consider palliative care for seriously ill patients was effective at increasing the number of consults,” reports **Katherine Courtright**, MD, MSHP, the study’s lead author and assistant professor of medicine at University of Pennsylvania’s Perelman School of Medicine.

More exciting were the apparent positive effects “downstream” from the consult. These included more referrals to home-based palliative care for continuity after discharge, and better documentation of advance care plans.

Palliative Connect uses electronic health record data and machine learning to develop a score on a patient’s likely prognosis over six

months. The researchers compared the number of palliative care consults in an eight-week period in a group of 134 admitted patients before and after Palliative Connect was used. The Palliative Connect group received far more consults (85 vs. 22 in the other group). Patients also were seen an average of a day and a half sooner.

“This approach attempts to level the playing field for all seriously ill patients in the hospital,” Courtright says. Ideally, all get the chance to discuss their values, goals, and preferences, not just the ones busy clinicians can identify. “This approach assesses all patients in the same way,” Courtright explains. Then, the system informs clinicians of the highest-risk patients who are likely to benefit from a palliative care consult. Ultimately, it leaves the decision up to their clinician.

Courtright sees two ethical concerns with machine-learning predictive models such as Palliative Connect:

- Models need to be assessed for possible unintended effects on healthcare disparities before they are implemented widely;

- The excitement about the potential of these tools could lead to hasty deployment, before researchers can fully evaluate their effectiveness and safety. “Predictive models on their own do not improve care,” Courtright notes.

The tools need to be linked to a clinical action or intervention, and then tested rigorously. “We need to be ready to say some of them just don’t move the needle on care the way we had hoped or intended, and move on,” Courtright says. ■

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## Nearly Half of Pediatric Oncology Patients Receive No Palliative Care

**O**nly about half (54.5%) of pediatric oncology patients received any palliative care service prior to death, according to a recent review of the literature.<sup>1</sup>

“With the push for early palliative care integration, it is clinically

important to understand the current epidemiology of pediatric palliative care provision,” says **Brian Cheng**, the study’s lead author and an MD candidate at Northwestern University. The analysis of 16 studies revealed palliative care discussions

do not happen until late in the illness trajectory. Further, the review revealed palliative care does not begin until close to time of death.

The American Academy of Pediatrics recommends starting palliative care at diagnosis for children

with cancer. “Providers should assess children individually and discuss with families the potential benefits of palliative care,” Cheng suggests.

A second study showed that of 10,960 hospitalizations of children with cancer and high in-hospital mortality risk, only about one in 20 received palliative care.<sup>2</sup>

That study also linked palliative care to lower costs for medical facilities.

“There is a continued need for large, high-quality studies on palliative care provision in children with cancer,” says Cheng, who also served as the lead author on the second study. ■

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## Even the Best Ethics Consults Can Result in Dissatisfaction

Despite the ethicist’s best efforts, people are not always happy with the results of a consultation.

“Sometimes, an individual is upset with a particular outcome because it seems at odds with what they believed were the facts,” says **Christine Gorka**, PhD, MS, MA, director of the Clinical Ethics Center at Memorial Medical Center in Springfield, IL. Some common examples:

- **The patient or family wants to be discharged home, but the clinical team does not think it is safe.**

Therefore, the clinical team argues the discharge should not happen.

“In those situations, the ethicist can be in the unenviable position of informing the team that we cannot automatically force patients into a nursing home or another ‘safe’ location,” Gorka says.

The ethicist’s job is to work with the team to build a discharge plan that takes both safety and the patient’s values into consideration. A recent ethics consult involved a patient with severe neurological injury necessitating 24-hour care. Her siblings were adamant she should return home. But because she had a PEG tube, the clinical team resisted the discharge plan.

“Working with the family, it was agreed that they would attend a couple of training sessions to learn

what would be required of them,” Gorka recalls.

This gave the family skills and confidence they would need to care for the patient at home, performed in the safety of a supervised setting.

“Or, conversely, if through this exercise they learned that they did not feel comfortable managing all Ms. X’s care needs, the family might come to understand why placement might be best,” Gorka offers.

In this particular case, the family performed each task without difficulty, and voiced appreciation for the training.

“This made the team feel more comfortable with the plan to discharge home,” Gorka reports.

- **Family members challenge the suitability of the identified proxy decision-maker.** This is sometimes because of a known medical or mental health condition, such as dementia, depression, or substance use disorder. In other cases, there is a long-standing interfamily conflict.

“Those individuals are less than satisfied when the proxy is not removed from the decision-making role after ethics involvement,” Gorka notes.

Sometimes, the concern is about the decision-maker being unavailable at bedside, or tough to reach by phone. “The ethicist could identify

periods of time to call or alternate contacts/individuals who are used to reach the decision-maker during times when the team is having difficulty,” Gorka suggests.

Family tension often comes to a boiling point when information has to be shared, or visitation times are established.

“It is always prudent to have considered individuals responsible for updating ‘warring’ factions, or establish visitation schedules to prevent bedside conflict,” Gorka says.

- **The clinical team and the patient or family disagree regarding the benefit of continuing treatment.**

“It has been said that futility, like beauty, is in the eye of the beholder,” Gorka says.

One possible outcome from an ethics consult is that care should continue for a defined trial period or until a particular milestone is reached — or not.

“Anyone who feels strongly that current treatments are futile is not likely to be happy with a recommendation to continue, even if only for a brief time,” Gorka explains.

Sometimes, a little education on how a decision was made, or the role of ethics, helps.

“It depends on the reasons behind the opposition,” Gorka adds. If the objection is clinical in nature, such

as a dire prognosis, an ethicist may ask the individual to consider the “certainty” of their position. On the other hand, statements like: “I would

never do this to my loved one” are an indication that the objection may be rooted in the individual’s personal or religious values. In those cases,

“the ethicist may need to remind them that it is the value system of the patient that needs to be considered,” Gorka says. ■

## Pediatric Oncology Ethics Consults Few in Number, Limited in Scope

Just 35 ethics consultations were performed for 32 patients over 10 years at a specialty cancer hospital, according to a recent analysis.<sup>1</sup>

“The ethical issues that arise in pediatric oncology are distinct, and we wanted to characterize them based on our institutional experience,” says **Meredith C. Winter, MD**, the study’s lead author, currently a pediatric critical care fellow in the department of anesthesiology and critical care medicine at Children’s Hospital Los Angeles.

Ethics was most commonly called for cases involving resuscitation preferences (26% of consults) and conflicts over clinicians’ obligation to provide treatment that was viewed as nonbeneficial (29% of consults). Two issues came up repeatedly during consults:

- **Physicians questioned their obligation to provide potentially toxic treatment for patients with a history of poor compliance.**

Clinicians were offering stem cell transplants or intensive chemotherapy to patients who had missed medical appointments and not taken prescribed antibiotics.

“Concerns were raised that potential toxicities could outweigh any potential benefit,” Winter explains. These included life-threatening infections, hemolysis, and neutropenia.

- **Clinicians wanted to know whether invasive procedures were ethically justified.** In one case, clinicians were offering a

ventriculoperitoneal shunt to improve a terminal patient’s life quality. The mortality risk was high, and the benefit was murky.

Winter notes it is common to weigh benefits and risks regarding a patient’s care goals. Obviously, she adds, this decision can be especially challenging.

Ethics consults for adults involve two parties: the healthcare team and the autonomous patient. For pediatric cases, there are three involved parties: the patient, the family, and the healthcare team.

With an extra party, Winter observes that making decisions in pediatric cases can be even more complicated.

However, research on pediatric ethics consultations is scarce. Winter reports that existing studies concern withdrawing life-sustaining treatment after traumatic events, extremely premature neonates, and children with life-limiting syndromes or congenital problems.

The authors of a previous study also studied issues prompting ethics consultations in pediatric oncology. They found most consults occurred in the outpatient setting. Few involved limitation of life-sustaining treatment.<sup>2</sup>

In contrast, in her study, Winter says nearly 90% of ethics consultations happened in inpatient settings. Three-quarters of these occurred in the ICU.

Further, Winter observes ethics consultations were called for patients

only with metastatic, recurrent, or refractory disease.

No consultations happened at diagnosis or during survivorship, periods that are heavy with ethical issues. Fertility concerns, genetic testing, clinical trials, chronic pain management, and long-term effects of toxic treatments are some examples.

These findings may suggest clinicians do not recognize ethical dilemmas other than treatment-related decision-making and care goals at life’s end.

Winter suggests offer more education to help medical teams identify important ethical issues and to call on the proper resources to address those issues when needed.

Memorial Sloan Kettering’s Ethics Committee recently implemented an annual ethics committee retreat and an ethics seminar series for those who treat pediatric patients.

“Education should increase awareness of resources that are available to support providers who face ethical dilemmas,” Winter says. ■

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## CME/CE QUESTIONS

- 1. Which is true regarding the ethics of organ procurement from unrepresented decedents?**
  - a. Most states allow organ procurement from unrepresented decedents.
  - b. There is a consensus that it is an unethical practice.
  - c. Currently, U.S. transplantation policy is based on an "opt-out" system.
  - d. The default policy for unrepresented adults is routine retrieval, even if there is evidence the decedent did not want to donate.
- 2. Which is true regarding an OB/GYN ethics curriculum?**
  - a. Participants in an ethical education session reported less burnout.
  - b. Ethics education was effective only for trainees; medical faculty disliked the format.
  - c. Moral distress worsened after ethics education.
  - d. Trainees attempted to handle complex issues without involving ethics.
- 3. Which did the authors of a recent study find regarding stroke patients and decision-making?**
  - a. Families preferred a uniform approach based on statistical data.
  - b. Patients were far more likely to give consent with a statistical data approach.
  - c. Most people preferred the "parental" approach with advice along with medical facts.
  - d. It is unethical for providers to tell patients what the providers would do in a similar situation.
- 4. Which was an effect of a predictive analytics program on palliative care consults?**
  - a. Fewer referrals to home-based palliative care after discharge
  - b. Sparser documentation of what happened during consults
  - c. Better documentation of advance care plans
  - d. Decision-making by individual clinicians no longer was a factor