MEDICAL ETHICS ADVISOR®

YOUR PRACTICAL GUIDE TO ETHICS DECISION-MAKING

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INSIDE

Ethical obligation to encourage optimism in patients 100

Even minimal training promotes ethical research practices 101

Creative approaches to avoid the "ethics police" tag 101

Simulating better end-of-life care 104

Group tackles complex ethics of psychiatric genetics 105

Unique ethical concerns with end-of-life care for disabled adults 105

Developments on certification for those who perform ethics consultations 107

Are High-Dose Painkillers Ordered? Ethics Can Prevent Harm, Conflicts, Legal Disasters

A recent highly publicized case involved a physician who allegedly ordered high-dose painkillers, which killed many hospitalized patients.[1]

Thankfully, most ethicists will not encounter a case like this in their careers, but they still can learn much from it, says **Bojan N. Paunovic**, MD, FRCPC, president of the Canadian Critical Care Society.

The case, says Paunovic, "will most likely be looked at as a one-off. Something more formal needs to occur in institutions to highlight it." Ethicists can use the case as a teaching tool and opportunity to think through other problematic issues involving high-dose painkillers. Ethicists should be ready for these scenarios:

• There could be a rogue clinician euthanizing patients.

"Euthanasia is illegal in every state, even when carried out to reduce patient suffering," notes **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center. Dolgin also is director of the Hofstra University Gitenstein Institute for Health Law and Policy.

To prevent this worst-case scenario, "ethicists could add an important voice on a team aimed at crafting institutional responses to emerging problems," Dolgin offers.

Upon investigation, documentation should show dosages were appropriate for the patient's condition. "It's not legal to provide a dose that you know will kill a patient, though sometimes patients do ask for this," underscores **Sharona Hoffman**, JD, professor of law and bioethics at Case Western Reserve University.

If a clinician is harming patients intentionally, one may hope systems would trigger an immediate investigation. However, this does not always happen.

"This is true not just in medicine but all industries," Paunovic explains, adding that wrongdoers might explain away incidents separately without anyone realizing the big picture.

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"Smaller incidents occur in real time. It's hard to appreciate the magnitude of the issue overall."

The movement toward multidisciplinary models of care is helpful in this regard. With more people involved in a case from different disciplines, it is more likely wrongdoing will be detected. This includes ethicists.

"The ethicist is well-entrenched in the system," Paunovic says. "If there are legal issues that need to be followed up on, the ethicist can be an objective sounding board."

A policy that automatically escalates certain kinds of cases (such as a physician ordering atypical doses of pain medication) can protect both patients and the institution. The specifics on how it happens will vary somewhat depending on the hospital.

"But it should essentially be an expectation for a more rapid response/assessment of a concern," Paunovic says. "In most ICU settings, there's usually a rounding pharmacist."

This person also could be a physician, trainee, bedside nurse, charge nurse, or someone else who reports possible wrongdoing. Regardless, the process starts.

"Escalation sometimes gets to be synonymous with a complaint. Not everything that gets escalated is bad medicine," Paunovic cautions.

A cultural shift is needed to make people understand that the escalation process is not meant to be punitive. "This is a system to make sure we are on the same page. It's similar to how the QI movement has progressed," Paunovic says.

• Someone on the clinical team is uncomfortable with administering a high dosage that a physician ordered.

It is not uncommon for clinicians to disagree on the best plan of care for a patient. Sometimes, opioids are at issue (the dosage, or whether they should be administered at all).

"Ethicists might fruitfully take part in resolving disputes among clinicians about appropriate doses of opioids for hospital patients," Dolgin says.

Ethics can help if this kind of conflict cannot be resolved. Notably, clinicians' discomfort does not always stem from a dose that is too high.

"There certainly are cases when opioids are not prescribed but should be," Dolgin notes. For instance, sickle cell anemia patients who arrive at an ED may receive inadequate pain relief.

"Bias may account for some of the refusals to provide adequate pain control," Dolgin adds.

On the other hand, nurses might express discomfort giving a high dose of pain medication. In that case, ethicists can explore the ordering clinician's reasoning.

"As an ethicist, you don't have a role in determining the correct dose. You *do* have a role if the dose ordered is making someone on the

EXECUTIVE SUMMARY

Ethicists can help resolve issues in cases involving high-dose painkillers by:
- using highly publicized cases as a teaching tool;
- determining which cases should be escalated automatically;
- helping resolve conflicts among clinicians.

team uncomfortable," Paunovic observes.

Simply airing the concern can help in this situation.

"You can always have atypical doses for valid reasons," Paunovic says. "There may be a very valid reason that's not being properly explained."

An extremely high dose could be appropriate. Regardless, says Paunovic, "there may be a negative dynamic here that needs to be explored. People may be concerned about their liability."

Clinicians are not always comfortable voicing these kinds of concerns to physicians. "The ethicist can be the go-to person," Paunovic offers.

The ethicist might approach the ordering physician by saying, *"Doctor, the team is not comfortable with this dosage. Can we get another opinion?"* The idea is to start a group discussion.

"It's an atmosphere of, *'Let's talk this through more before I give the dose,'"* Paunovic adds.

• Various hospitalists may use inconsistent approaches for pain relief.

On a given day, one hospitalist may recommend comfort care only; the next day, a different hospitalist disagrees.

"It can get difficult for the patient and families if different people are in charge at different times, taking different approaches," Hoffman notes.

With so many changes and no single physician in charge, the patient's wish for comfort care may be lost.

"Information doesn't get fully conveyed, or nobody knows what the patient's wishes are, because the person who talked to them is no longer on shift," Hoffman explains.

• The clinician believes a high dose is necessary but is concerned about potential liability risks.

"If it ends up killing the patient, even if not intentionally, there could be allegations of criminal negligence," Hoffman warns.

The state could criminally prosecute the physician or seek to make an example of the hospital. "There is a fine line [when it comes to] treating patients adequately for pain. Surgery and cancer procedures can cause intense pain, and we want people to get adequate pain relief," Hoffman says.

But the clinician has to make sure he or she is not doing anything that could lead to criminal charges "At some point, there's a risk that a patient will die from too much medication. You have to worry about your own liability," Hoffman says.

Clinical justification for high-dose painkillers should be well-documented in the medical record. "If the family is on board with switching to palliative care and waiting for a natural process to take place, they are not as likely to sue," Hoffman explains.

Even so, law enforcement could still look into a case that appears suspicious. "You could have state prosecutors who get very aggressive about this and look into the cause of death and whether the patient was given medication that hastened death," Hoffman says.

Paunovic says this documentation makes successful litigation unlikely: Clinical indications (such as ongoing unrelieved pain) and a second opinion or consultation that agrees with the plan to administer high doses.

Even with solid clinical decision-making, family members who disagree with the decision to switch to comfort care may come forward. "Some may want to take the hospice approach, and others [may] want to keep treating," Hoffman says.

Physicians may face a threatened lawsuit from either side. "Some people may say, *'You are just torturing my loved one needlessly.'* These are highly emotional situations," Hoffman notes.

When things become this heated, ethics involvement is necessary. Consulting the hospital attorney is another option.

"Although the legal department is going to focus on how to avoid liability, that can be in conflict with what's best for the patient in terms of the patient's comfort," Hoffman says.

If the physician is confident that further care is futile or that the patient really needs pain relief, "with adequate documentation they should be able to trust their medical judgment," Hoffman notes.

Lawsuits always are possible, even with the best documentation. If the physician is sued, the case might end up dismissed, or the physician may prevail if the case goes to trial.

"But that's small comfort to clinicians. Even if you win, you can be in misery for years if you get sued," Hoffman says.

The situation is much less likely to progress to legal action if concerns are seen to have been addressed promptly and explained thoroughly.

"People get angry when they feel they are being ignored or brushed aside. They feel they have no option other than legal recourse," Paunovic says. ■

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Optimism Linked With Better Outcomes: Physicians Can Promote It

Optimistic people with chronic angina pectoris experienced better health status outcomes than their less optimistic counterparts, according to the results of a recent study.[1]

"A large and growing body of evidence suggests that patients' experience of illness is important for chronic disease outcomes," says **Alexander Fanaroff**, MD, the study's lead author and an assistant professor of medicine at the University of Pennsylvania.

Patients' beliefs about their illness and overall mood are strongly associated with angina severity.

"For patients with coronary artery disease, angina is correlated only weakly with anatomic disease burden," Fanaroff reports.

Fanaroff and colleagues studied 2,389 patients with chronic angina who had recently undergone coronary revascularization with percutaneous coronary intervention. Researchers wanted to know if patient attitudes were associated with ischemia-driven healthcare use and angina symptoms.

"If less optimistic patients with chronic angina were more likely to undergo ischemia-driven hospitalization or revascularization, then interventions to change patients' beliefs about their likelihood of returning to normal function may be useful," Fanaroff says.

Most patients with chronic angina will recover normal physical function through some combination of medication, revascularization, and time. "This is a particularly ripe area to try such an intervention," says Fanaroff.

The researchers found that higher levels of baseline optimism were, in fact, associated with lower rates of ischemia-driven hospitalization and revascularization. This group of patients showed greater improvements in angina severity compared with lower levels of baseline optimism.

> "A LARGE AND GROWING BODY OF EVIDENCE SUGGESTS THAT PATIENTS' EXPERIENCE OF ILLNESS IS IMPORTANT FOR CHRONIC DISEASE OUTCOMES."

"These findings are surprising on one level because they demonstrate that patients' mental state may affect 'hard' healthcare outcomes," Fanaroff explains.

Conversely, the findings confirm what many cardiologists have known for a long time.

"Instilling a sense of optimism following revascularization is something that we routinely do," Fanaroff says.

Cardiologists know that stable angina is a chronic disease characterized by exertional angina attacks that do not cause heart damage, which can be managed effectively with medicine. In contrast, says Fanaroff, "patients may think that each exertional angina attack is a heart attack and may cause them to die."

Talking about the pathophysiology of stable angina and what makes it different from heart attack can help patients understand their relatively benign prognosis.

In the study, Fanaroff and colleagues asked patients how much they agreed with the phrase *"I am optimistic about my future and about returning to a normal lifestyle."*

"This is not a question most physicians normally ask patients. Nor is it even the type of question most physicians normally ask patients," Fanaroff observes.

In clinical practice, in addition to asking about a patient's optimism level, physicians can add another question: *"What do you think it will be like to live with angina?"*

"This can be a great way to understand patients' state of mind and level of optimism to see if it matches with their prognosis," Fanaroff offers.

Ethicists can encourage physicians, advanced practice providers, and nurses to identify patients who seem less optimistic than they should be.

"This may improve patients' outlook and outcomes," Fanaroff adds. ■

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Interventions Aim to Promote Ethical Research Practices

Researchers tested the efficacy of a one-hour training session on psychology graduate students' attitudes toward ethically questionable research practices. Students who rated the training more favorably demonstrated greater attitude change toward detrimental research practices.[1]

Previously, these researchers studied techniques to reduce scientists' endorsement and use of questionable research practices.

"Previous findings have linked such practices to unreliable and less valid scientific results," notes **Donald Sacco**, PhD, chair of the institutional review board and assistant professor of social psychology at the University of Southern Mississippi. The work by Sacco and Brown was the first attempt to use prior findings in the context of a formal intervention to promote ethical practices.

At one-month follow-up, the effect of the intervention seemed to fade somewhat. Perceptions of questionable research practices were at a level in between before the intervention and one week after. Still, the researchers were encouraged that such a minimal intervention (a one-hour training session) produced results.

"We are more confident now that a more in-depth intervention, perhaps containing multiple training sessions, would be capable of fostering long-term changes," Sacco reports.

Graduate students in their first semester of training seemed to already understand what is ethically questionable. "Nonetheless, our training was able to enhance their perceptions of questionable research practices as unethical."

The next step is to conduct additional research to determine if a more in-depth intervention results in long-term attitude changes.

If so, Sacco says he believes "it suggests providing education and training to early career graduate students may be a proactive opportunity to shape ethical research values in scientists." ■

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Be on Your Best Behavior: The Ethics Police Are on the Way

During his training as a clinical ethicist, **Craig M. Klugman**, PhD, rotated in a genetic medicine service with a physician who was generous with his time.

"He introduced me to each patient and would describe everything he was doing to and for them and why," Klugman recalls.

One day, the physician casually asked to borrow a stethoscope. Klugman reminded him that as an ethics student, he did not carry one.

"From then on, he was curt, rude, and basically ignored me, even allowing doors to slam in my face," says Klugman, now a health sciences professor at DePaul University.

From that point forward, Klugman had to ask permission to enter rooms, ask the families to consent to his presence, and figure out what was going on in the case, all on his own.

"At the end of that particular day, I thanked the doctor for his time. He turned to me with anger and said, *'So, was I ethical?'"* Klugman says. "Early in my training, I learned about the fear that clinical ethicists are the ethics police."

During the first consult of **Margie Atkinson**'s career, she heard this statement from an ICU physician: *"I don't know why we consult ethics. You don't do anything anyway."* For Atkinson, DMin, BCC, now the director of pastoral care, ethics, and palliative care at Morton Plant Mease Hospitals/BayCare Health System in Clearwater, FL, that remark was a powerful motivator.

"This set me on a mission to improve our services, enhance our communication, and always investigate requests so that the consulting provider feels heard," she says, adding that ethicists receive a "bad rap" from clinicians, family, and patients.

Family members or patients sometimes become upset right away if someone on the healthcare team

calls in ethics. "They sometimes see ethics as the bad guys," Atkinson says.

A provider might ask for a consult because an incapacitated patient's family demands an intervention against the patient's previously stated wishes. How the ethicist starts out in this type of case can mitigate tension.

"The ethics team can explain to the family on the front end that the goal of the consult is to listen to all concerned," Atkinson offers.

Some clinicians bristle at the mere mention of ethics. "They often feel like an ethics consult means they have gotten their hands slapped," says Atkinson, noting that the solution is to involve everyone in the consult. "Providers begin to see the benefits of consulting ethics to resolve issues. It's up to the ethics service to make this happen."

Hospital signs that inform of an "ethics and compliance hotline" contribute to the problem. People receive the message that ethicists are enforcers, called if somebody's doing something wrong. "I would like to see these signs changed to read strictly 'compliance hotline,'" Klugman says. "The problem is that ethics is being used in two different ways in the hospital environment."

In the realm of law and compliance, "ethics" pertains to whether someone is following the rules and regulations. If not, then the individual needs to be reported and possibly reprimanded. In clinical ethics, "ethics" means something different — an exploration of ideas and values.

"We are present to help and lack any authority to report, to spy, or to demand," Klugman explains. "We exist to help deal with the moral dilemmas of medicine and healthcare." Understandably, clinicians call ethics sometimes to report wrongdoing. "When we get a consult and when we send students onto the wards, we need to be sure to explain carefully what our role is, on the phone and again in person," Klugman says. There are a few common scenarios involving ethics misconceptions:

• Clinicians report a problem that is not related to ethics.

Ethicists are tempted to "lend an ear" if someone has some type of professional problem and does not know where to turn.

"While a very human response, it contributes to misunderstanding of what a clinical ethics service can do," Klugman observes.

"WE ARE PRESENT TO HELP AND LACK ANY AUTHORITY TO REPORT, TO SPY, OR TO DEMAND."

People have complained to ethics about everything from a supervisor's negative attitude toward a patient who wants a second medical opinion. Some turn to ethicists with these troubles mainly because they have nowhere else to turn.

"Ethics is often viewed as the problem-solver. They bring any problems that do not have a clear home," Klugman says.

Good familiarity with all hospital units and departments helps ethicists connect people to the right expertise. "At times, when there is not a fixable or reportable problem or an ethics issue, I have listened to a person's frustration," Klugman adds. "That is often enough to help."

• Clinicians ask ethics to convince someone to continue treatment.

Olubukunola Mary Dwyer, JD, MA, a clinical ethicist at University Hospitals Cleveland, once received a call from an angry surgeon. He explained that a patient had just received a left ventricular assist device (LVAD); the family demanded its discontinuation. Upset that he had "wasted his time in the OR," the surgeon wanted to convince the family to continue. He asked, *"Can you make the family get on board with continuing treatment?"*

A flabbergasted Dwyer asked the surgeon to tell her more about the informed consent conversation with the family before the patient was taken to the OR. It turned out such a conversation never happened; there had not been enough time. Dwyer explained that ethicists do not convince people to continue with care. In this case, it became apparent that the family never wanted the LVAD in the first place. During a meeting shortly afterward, the family explained this, offering clear reasons why they wanted to discontinue treatment.

"The surgeon understood the family's reasoning, but wished that this had been expressed before taking the patient to the OR," Dwyer recalls. The surgeon left the consult with a better understanding of the ethics role. Ultimately, the LVAD was deactivated.

After this troubling case, the hospital changed the practice standard for nonemergent LVAD placement. Anyone considering this intervention now goes through a palliative care consult. This ensures that patients and caregivers receive a thorough, realistic view of what things might be like postoperatively. "Afterward, palliative care closes

the loop with the surgeon," Dwyer notes.

Other times, clinicians are more subtle but still make it clear they do not believe family members are making good decisions. Some are not shy about asking ethicists to tell the family.

"As far as having a conversation to be sure people are making decisions appropriately, we are perfectly fine with that," says Dwyer, a clinical assistant professor of bioethics at Case Western Reserve University.

The ethicist explains clearly to clinicians that the role of an ethicist is not to convince a family of something. "Rather, we explore what they understand about the clinical situation and what options have been presented to them," Dwyer adds.

• Clinicians become defensive if they believe they are the subject of an ethics consult.

Occasionally, requests for ethics consults are anonymous.

"Other team members don't feel comfortable letting the team know they are calling ethics," Dwyer explains. In this kind of case, no one knows who contacted ethics. Not surprisingly, the surgeon or attending in charge of the case becomes defensive.

Dwyer starts the conversation this way: *"I'm not calling because someone did anything wrong. We just happened to hear about this patient. We wanted to have a discussion with you so we can all get on the same page with a treatment plan that's best for the patient."*

Clinicians who work with ethicists usually are fine with this neutral, nonthreatening approach. "It's the ones we have gone years without contact with who react negatively," Dwyer observes. Some clinicians respond angrily: *"Who are you to get involved with my patient?"* Almost always, the situation can be handled without involving administrators.

To avoid mistrust of ethics, it is helpful to be present in clinical areas on an ongoing basis. "We don't have a huge staff, so we can't go everywhere. But we do as much as we possibly can," Dwyer says.

• Clinicians call ethics only because a hospital policy says they should.

Generally, ethicists come into a case "by invitation only. We don't go swooping in somewhere we have not been invited," says **Martha Jurchak**, PhD, RN, HEC-C, executive director of the ethics service at Brigham and Women's Hospital in Boston.

One exception is when written policies specify that ethics must be involved. Fifteen years ago, when donation of organs after cardiac death was a new practice, an addition was made to the hospital policy requiring clinicians to consult with ethics.

"It was an entirely new endeavor that needed fair and balanced discussion," Jurchak explains. After a few years, there was less controversy, and the requirement to involve ethics was removed from the policy.

• Clinicians hold strong beliefs — and think others should, too.

Such a clinician calls ethics to be an "enforcer."

"In my experience, sometimes people want the ethics police," Jurchak says. "It's for the same reason you want the regular police — to come and protect you." Clinicians sometimes make requests of ethicists along the lines of: *"Go get the DNR order because we can't get it from the family."*

"We are happy to do an ethics consult and manage the discussion," Jurchak says. "First, we have to educate [clinicians] on the role of ethics."

The first question she asks is *"How are you hoping ethics can be helpful in this situation?"* Jurchak says it is helpful to discuss not only the recommendation but why an ethicist makes that recommendation.

Next, Jurchak explains that both sides can express concerns. The ethicist explores the benefits and harms of each point of view. Ultimately, the goal is to help all stakeholders come to some kind of consensus.

After this explanation, the caller usually has a better understanding of what ethics can do for them — but not always. "Sometimes, the response is to hang up," Jurchak says. "You have to have a model and stand by the model. Sometimes, you disappoint people."

Some clinicians seem to believe *"You're either with me or against me."* Ethicists operate in sharp contrast to this attitude because a more open-minded view promotes respectful communication that could lead all parties to find some common ground. "That idea [open-mindedness] has become so foreign," Jurchak says. "We need to hold onto it." ■

COMING IN FUTURE MONTHS

- Responses if someone accuses ethicist of incompetence
- Ethics training gaps in the field of plastic surgery
- Proactively marketing ethics services to clinicians
- Meeting demand for consults *without* any full-time ethicists

Simulation Improved Pharmacy Students' End-of-Life Expertise

Faculty members at the University of Florida Colleges of Pharmacy and Nursing were interested in incorporating simulation into their programs. Teachers also wanted to integrate an end-of-life activity into the curriculum. The two programs ended up doing both.

"This dual focus evolved into us comparing paper-based end-of-life case studies with those same scenarios brought to life through simulation on students' perceived end-of-life care learning needs," says **Carol Motycka**, PharmD, BCACP, assistant dean in the College of Pharmacy.

Groups of nursing and pharmacy students were exposed to either a case study approach in a classroom setting or simulated versions of the same cases.[1] Four end-of-life scenarios were used. The cases involved a patient with muscular dystrophy, now on a ventilator; an infant dying from various birth anomalies; a 68-year-old with diminished mental capacity dying from pneumonia; and a retired chemist in severe pain who believes in physician-assisted suicide.

The simulation scenarios were conducted at the university's Center for Simulation Education and Safety Research in bays designed like relevant units, such as a neonatal ICU or medical/surgical unit, using realistic-appearing, computer-controlled mannequins. "Patient situations focused on ethical dilemmas in the transition from curative to comfort care," Motycka says.

Only the simulation group's scores improved. Interestingly, the most significant changes occurred in items related to patient care, not those related to ethics.

"Given that the course in which the activity took place was one focused on ethics, we anticipated that student responses would reflect greater understanding," says Motycka, noting that the difference in ethics learning needs was only slight. "That said, we were pleased to see the patient care domain positively impacted."

The findings underscore the important role pharmacists play in medication management at the end of life. This often happens in the midst of ethical dilemmas. "Medication plays an important role in comfort at end of life," Motycka observes. "The role of the pharmacists in both palliative and hospice care is gaining visibility."

Ethicists do not always obtain input from pharmacists to help resolve ethical dilemmas.

"This continues to be a growing field for pharmacists, but they continue to be underutilized in this form of care," Motycka says. This is especially important if cases involve medication-based decisions. There is growing awareness of pharmacists' importance in this regard.

The American Society of Health-System Pharmacists (ASHP) guidelines state that pharmacists play an important role in palliative and hospice care through symptom management, medication use and counseling, and care transitions.[2] Additionally, the ASHP Council on Pharmacy Practice advocates for an active pharmacist role on ethics committees. "There is a growing recognition of the need to utilize resources more effectively and appropriately at the end of life," Motycka adds. End-of-life care often is aggressive, expensive, and aimed at preserving life as long as possible. "All healthcare providers, including pharmacists, need to be versed in communication skills in order to bring up other end-of-life care options," Motycka says. Hospice and palliative care services must be considered.

Education on this "should be integrated throughout the pharmacy curriculum," Motycka says. "A dearth of expertise can lead to inappropriate patient care."

Patients in palliative care often require symptom management rather than long-term disease state management. "Thus, unnecessary medications that may be helpful in patients to extend life, such as statins, may be unnecessary," Motycka observes. Such medications also could harm patients since they can contribute to adverse events or drug interactions.

Pharmacists also need substantial knowledge of opioids, more than just basic pharmacology. Also important: "Assessing the risk of drug diversion if the patient has a family member or caretaker with a history of substance abuse," Motycka adds. ■

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Committee Tackles Ethical Issues in Psychiatric Genetics Field

The newly formed International Society of Psychiatric Genetics (ISPG) Ethics Committee will examine many ethical issues raised by emerging knowledge and technologies.[1]

"There is a severe lack of guidance about the responsible use of psychiatric genetics in clinical and nonclinical settings," says **Maya Sabatello**, LLB, PhD, a committee member and assistant professor of clinical bioethics at Columbia University.

The ISPG Ethics Committee aims to close some of this gap. The group consists of psychiatric genetics researchers, clinicians, bioethicists, lawyers, and others. The overarching goal, says Sabatello, is "to promote the responsible use of psychiatric genetics in society through education and published guidelines."

Central ethical issues include return of results, social justice, racial diversity, and possible use of psychiatric genetics in nonclinical settings such as courts and schools. "Questions about prediction of genomic risks are likely to increase," Sabatello says.

To answer these questions, certain ethical issues need to be addressed first, including:

- how to return such results;
- whether it is possible to accurately assess risk across racial/ethnic groups;
- what the implications of risk will be.

Who should be involved in this process also is important. "Ethicists can help by requiring that results are returned by a genetic counselor and that there are supports in place to ensure that those who receive results are not harmed by them," Sabatello says. ■

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Ethical Concerns if Patient at End of Life Is Intellectually and Developmentally Disabled

Adults with severe intellectual and developmental disabilities (IDD) often present to EDs with complex medical needs. Their advance care directives are complex, too. "This is an often-overlooked situation," says **Gavin Enck**, PhD, director of clinical ethics for Oklahoma-based INTEGRIS.

The advance directive may indicate that full resuscitation measures are desired. However, because of the patient's disabilities and conditions, the directive may not call for artificial nutrition and hydration measures. This can confuse the clinical team. "It is important to remember that from lacking the ability to make one's own healthcare decisions, it does not follow that a person has no activities, events, and/or interactions that cause pleasure or discomfort," Enck explains. For example, a patient with IDD may not want artificial hydration and nutrition because he or she found pleasure in eating. Another IDD patient might only tolerate interactions with certain caregivers and otherwise becomes agitated. "Adult IDD patients are often marginalized and have no surrogate decision-maker or advance care

planning," Enck adds. Physicians are put in the uncomfortable situation of determining whether the harms or burdens of interventions outweigh the benefits for this particular patient. Other challenges include the following:

• The process of stabilizing a patient may result in greater discomfort and harm to the patient.

For example, the advance care directive indicates the patient would want CPR, but she is frightened by strangers. "CPR is an invasive measure performed by strangers, heightening her fear and agitation," Enck notes.

• If the IDD patient is stabilized and admitted to the hospital, caregivers may feel conflicted in honoring the advance care directive.

This is because to caregivers, it is not always evident why it is appropriate to provide CPR and other invasive interventions to save the patient's life, yet the use of artificial hydration and nutrition to sustain that patient's life is inappropriate, Enck observes.

"Each of these challenges raises an ethical dilemma," he says. Clinicians must balance ethical obligations to respect a patient's documented preferences and avoid causing undue harm to patients.

The complexity of this situation makes real-time responses difficult. A formal ethics consult is not always realistic in an emergent situation. Enck says ethicists can help by "proactively developing policies, implementing clear processes, and reaching out to resources in the community for assistance." It is not enough for caregivers to understand and recognize the importance of advance care planning. They need to consider IDD patients specifically.

• Even when IDD patients present with advance care directives, the information is not always easily accessible.

"Depending on the electronic medical record program, there are ways for advance care directives or IDD patients to be flagged upon admission," Enck notes.

The authors of a recent white paper focused on end-of-life planning for people with IDD.[1]

"The hope is to provide more resources for folks earlier in their care trajectory as a way of respecting and honoring their personhood, their goals, values, and preferences," says **Virginia L. Bartlett**, PhD, an advisory committee member for the group that authored the paper. "Ethicists do get requests to support patients, their families, and/or legal guardians and the clinicians caring for them."

Regional centers, long-term care facilities, hospitals, and families all come into play. "All serve as interconnected points of care, each with a different focus, resources, and commitments," says Bartlett, an assistant director of the Center for Healthcare Ethics at Cedars-Sinai Medical Center in Los Angeles.

Some patients within this population never had capacity to form values.

"We are obliged to bring our 'best interest' assessment to medical decision-making for them," argues **Kathy Johnson Neely**, MD, MA, medical director of the medical ethics program at Northwestern Memorial Hospital in Chicago.

Others with IDD could establish values, but this is not always included in the decision-making process.

"We often give up too readily on patients who do not have capacity yet protest the plan of care. We must work diligently to bring their voice to the table," Neely offers.

There are many patients whose cognitive impairment confounds the goals and plan of care clinicians plan for them. Careful attempts at persuasion from clinicians or cajoling from loved ones does not always suffice.

"It might be inhumane to continue dialysis for an inconsolably terrified patient or impose a stem cell transplant on a confused patient," Neely cautions.

At Northwestern Memorial, a cadre of volunteers trained to become advance directive experts. They are pageable during business hours and help patients name and document their choice of decision-maker as healthcare power of attorney. This, along with a Physician Orders for Life-Sustaining Treatment form, is scanned into the EMR. A patient without representation also can make their specific wishes known.

"Our medical ethics program has enlisted social work to consult us on every patient for whom our institution is seeking guardianship," says Neely, adding that ethics coaches both the primary care team and the new guardian in shared decision-making. "We are tracking this effort to see whether this intervention will promote more timely, patient-centered decisions."

One of the more common ethical issues that disabled patients face at the end of life is healthcare providers honoring their advance care wishes, says **Kevin Rodrigues**, BA, MTS, PhD(c), a clinical ethicist at University Health Network's Toronto Rehabilitation Institute.

Patients with cognitive impairments may not have engaged in advance care planning discussions because of communication issues

or assumed incapacity. "The latter assumption is ethically significant," Rodrigues says.

Cognitive impairments, developmental disabilities, and communication barriers do not mean a person is incapable of making medical decisions. "Thus, otherwise autonomous people may not have their end-of-life wishes honored due to incorrect assumptions," Rodrigues offers.

Disabled patients may struggle with access to palliative care and pain management, more so than the general population. "Disabled persons often face general accessibility issues societally, and this is no different at end of life," Rodrigues observes.

Even if a substitute decision-maker provides consent on the patient's behalf, clinicians "still ought to probe to gain an understanding of the patient's applicable values and beliefs," Rodrigues says.

A good process for documentation, "including how to have wishes accessible in the medical chart, help prevent wishes from being overlooked," Rodrigues adds. ■

REFERENCE

1. Coalition for Compassionate Care of California. Thinking ahead matters: Supporting and improving healthcare decision-making and end-of-life planning for people with intellectual and developmental disabilities. Updated January 2015. Available at: http://bit.ly/2TeXyXQ. Accessed Aug. 6, 2019.

Update on National Certification for Individuals Who Perform Ethics Consults

The Healthcare Ethics Consultant-Certified (HEC-C) program is a national standard that recognizes a consultant's proficiency in identifying, counseling, and resolving ethical issues.

The program's content is based on a role delineation study conducted by the American Society for Bioethics and Humanities (ASBH) in 2017.

"It is not based on any institution's process, course of study, or program," explains **Felicia Cohn**, PhD, bioethics director for Kaiser Permanente, Orange County, CA.

Institutions are using the HEC-C program in these ways:

- to recognize the consultant's specialized knowledge;
- as part of a clinical ladder;
- to set a desired minimum standard.

"To date, we have received 225 applications and have certified 209 [healthcare ethics consultants]. We anticipate this number will continue to grow," says Cohn chair of the HCEC Certification Commission. Candidates were asked to complete a survey after the examination. Seventy percent said the examination met their expectations, 29% believed the exam was more difficult than expected, and only 1% believed the exam was easier than expected.

There were a few reasons candidates gave for taking the exam, including:

- to contribute to the professionalization of clinical ethics consultation sessions;
- to validate their experience;
- to earn a credential that would help them market themselves.

As for how the credential may affect their careers, candidates expected more validation from peers and supervisors and more trust from patients and families.

"The commission has already accomplished a great deal," Cohn says.

Recently, the group contracted with a testing company, Scantron, which led to additional progress.

Volunteers were enlisted to develop "psychometrically sound, reliable, and defensible test questions," Cohn reports. Multiple exam types and renewal requirements were developed, and a passing point was established based on testing industry best practices.

"Behind the scenes, the commission has been busy establishing a governance structure to codify its work and provide oversight to every step of the process," Cohn says. ■

CME/CE OBJECTIVES

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

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

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CME/CE QUESTIONS

1. **The authors of a recent study on psychology graduate students' attitudes on ethically questionable research practices found that:**
   a. a one-hour training session was more effective than multiple sessions.
   b. students who rated the training more favorably demonstrated greater attitude change.
   c. the effect of the intervention was most pronounced after one month.
   d. more in-depth training had less of a long-term effect than a single short session.

2. **What did a recent study reveal about improving pharmacy students' end-of-life care expertise?**
   a. Simulation was a more effective approach than case studies.
   b. Most students preferred classroom interventions.
   c. Students believed pharmacists should play a smaller role in palliative care cases.
   d. Hospital policies should be clear that pharmacists should not be involved in decision-making regarding medications from an ethical standpoint.

3. **Which is true regarding high-dose painkillers?**
   a. Ethicists should educate clinicians that euthanasia is legal in some states.
   b. Hospital policies should state clearly that ethicists should not be involved in cases involving legal issues.
   c. Hospitals should create an escalation policy to set an expectation for a more rapid response and assessment of a concern.
   d. State prosecutors cannot take legal action against the hospital unless a family member comes forward.

4. **A recent study showed that compared to less-optimistic patients, chronic angina patients with higher levels of optimism:**
   a. recovered normal physical function slower.
   b. required higher levels of medication.
   c. experienced greater improvements in angina severity.
   d. were more likely to undergo ischemia-driven hospitalization.