



# MEDICAL ETHICS ADVISOR®

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## Data: Opioids Rising Cause of Ethics Consults

Ethicists at Massachusetts General Hospital noticed opioid use disorder was the reason for many consults. “Our hunch was that there was a great deal of emotion in decision-making in these clinical-ethical tragedies,” says **Ellen M. Robinson**, PhD, RN, HEC-C, nurse ethicist.

Most cases involved one of two scenarios: patients with infected heart valves, where the ethical question was about decision-making for cardiac surgery, or patients with severe anoxic brain damage due to drug overdose who were unlikely to regain cognitive or physical function.

“This presented tremendous complexity for families, who found themselves in a decision-making quandary,” Robinson explains. Some families had been estranged from the patient with addiction, adding to the emotional complexity.

To learn more about the cases, ethicists analyzed 1,061 ethics consults that occurred between 1993 and 2017 at Massachusetts General Hospital.<sup>1</sup> Opioid use disorder (OUD) played a central role in 43 of these cases. Consult requests involving opioids increased from 1.4% in 2009 to 6.8% by 2017. Data from

2018 and 2019 have not been analyzed yet, but the upward trend appears to be continuing.

“Conducting this retrospective review was quite helpful,” Robinson reports. “We affirmed our hunches, yet also identified more themes in the cases.”

Patients in consults where OUD was a factor were much younger than those in other cases. About one-third were homeless, compared to about 2% in non-OUD cases. Most (73%) were either underinsured or uninsured, compared to 22% of non-OUD cases. In the 43 consults where OUD played a central role, these scenarios arose repeatedly:

- **Decisions had to be made regarding continuation of life-sustaining treatment for overdose patients with neurological injury or severe infection.**

- **Clinicians were unsure if surgical intervention, such as repeat valve replacement or organ transplant, was appropriate.** The concern is that ongoing drug use would adversely affect the patient’s outcome. “We aim for all patients to receive high-quality care — if the surgeon believes it is indicated, and the patient can benefit from it,” Robinson explains. No patients would

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be denied surgery because they are addicted to drugs if the procedure would be beneficial. However, poor general health, stubborn infection, pneumonia, and other conditions are considered. “Longstanding addiction is not kind to the body,” Robinson notes. “Each and every case must be given a 360-degree evaluation laced with compassion but also with realism.”

• **Discharge planning became complicated.** “Concerns about relapse were central in clinical-ethical decision-making,” says **Julia Bandini**, PhD, the study’s lead author and an associate behavioral and social scientist at the RAND Corporation.

Patients struggling with addiction may frustrate easily. Providers aim to set them up with care that is as hassle-free as possible. Sometimes, this means setting up daily transportation to the methadone clinic or for outpatient antibiotics.

• **There were some patients who were unrepresented.** Social workers and nurses immediately begin trying to locate any family member who could come to the patient’s bedside, or at least be available by phone. Once they are found, “physicians, social workers, nurses, and ethics consultants aim to support the family in understanding the patient’s prognosis,” Robinson says.

• **Some patients asked to be discharged against medical advice (AMA).** These patients are ambivalent about receiving any medical care at all. “Presumably, this is due to an impulsive desire to return to illicit drugs,” Robinson observes. In these tough cases, the team uses a consultation service that specializes in working with patients with addictions. Ethics often intervene if a patient wants to leave AMA. Psychiatry also is called to assess decision-making capacity. “We frequently aim to

de-escalate the patient and persuade them to stay,” Robinson reports.

• **Some patients with infectious endocarditis were at high risk for relapse.** This made decision-making more ethically complex. “Ethics consultants worked with multidisciplinary teams,” Robinson says.

Psychiatry, social work, and outpatient substance abuse treatment facilities crafted the best possible plan for successful long-term outcomes. It was not always possible. “In some cases, such a strategy did not seem feasible due to poor health from long-standing disease and poor self-care,” Robinson says. Ethics consultants worked with patients and surrogates to move to a palliative care approach. Overall, the findings demonstrate how much ethics can help with these highly emotional cases. “An ethics consult offers a kind of objectivity that can be challenging for both clinicians and families to maintain in these complex and tragic cases,” Robinson adds.

**Edward Dunn**, MD, has seen a recent surge of ethical consults involving opioids in some way. He shares some issues that come up in these cases:

• **Overdose patients were resuscitated, but are now in a vegetative state due to anoxic brain injury.** At some point, the decision on whether to withdraw life support needs to be made. This may call for an ethics consult.

• **Physicians prescribe opioids appropriately, but patients cannot obtain the medications.** “We have an ethical responsibility of beneficence, but we have difficulty getting the medication to the people who need it,” says Dunn, medical director, palliative medicine service at Norton Healthcare in Louisville, KY.

As a palliative medicine physician, Dunn administers opioids to people with intractable pain due to cancer,

end-stage chronic disease, or heart failure, often at the end of life. “They need opioids just to have some kind of quality of life for whatever amount of time they have remaining,” Dunn explains.

Clinicians want to give patients enough relief to live in less discomfort, but there are obstacles in their way. Insurance companies may refuse to cover the drugs unless authorization is obtained first. Sometimes, hospital pharmacies cannot fill the prescription regardless. “Because of the backlash against opioids, we have trouble getting the drugs to people who need them,” Dunn laments. “Pharmacies don’t have the drugs. That’s an ethical dilemma for me as a physician.”

Further complicating the situation are strict caps on prescribing imposed by many state laws. “These limits may curb misuse, but they also create access barriers to those to who have legitimate needs,” says **Thaddeus Mason Pope**, JD, PhD, director of the Health Law Institute and professor of law at Mitchell Hamline School of Law in St. Paul, MN.

Clinicians feel forced to choose between helping their patient and following the law. Some experience moral distress. “The physician is seeing a patient who needs their services, but they can’t meet the patient’s needs,” Dunn notes.

• **Sometimes, the backlash against opioids affects physicians’ prescribing practices.** “The medical

community doesn’t want to be scrutinized for giving opioids,” Dunn says. That is true even when there are no actual legal constraints.

Certain clinicians, afraid of legal oversight by the Drug Enforcement Administration or their state medical board, underprescribe to avoid raising red flags.

“It is unfortunate that legal incentives appear to misalign with the standard of care,” Pope laments. “But clinicians should not allow ill-founded fears to corrupt their professional judgment.” In reality, says Pope, careful documentation of the basis for dosing is nearly always an adequate response to regulators’ inquiries. Still, he says, “some clinicians are avoiding patients with opioid needs — or even worse, firing current patients with high opioid needs.”

Physicians can terminate the treatment relationship, but they must give the patient adequate notice and opportunity to obtain another physician. “Otherwise, the physician commits patient abandonment, which is medical malpractice, a licensing violation, and a breach of standards in most professional codes of ethics,” Pope cautions.

• **Some patients present with a history of OUD, but their need for the drugs is valid.** It is unethical to send people who are addicted to street drugs home with a bottle of pain pills. “They don’t take them as directed or prescribed. It’s unsafe,” Dunn says.

What options are appropriate for these challenging patients? “We still have a responsibility to see them, and we’ve got to be able to manage their pain,” Dunn says. One option is to use buprenorphine, a semisynthetic opioid that is much safer than any other opioids. “It is very effective in treating pain and preventing withdrawal symptoms,” Dunn explains. “Overdose death from respiratory depression is rare, regardless of how high the dose.”

Another is to ask patients to agree to periodic urine checks. “We do that with the understanding that opioid addiction is a chronically relapsing disease,” Dunn notes. This means that, inevitably, some patients are going to violate their agreements. “But we can’t punish them for the disease they have. We don’t treat any other disease that way,” Dunn stresses.

If someone misses all appointments and refuses drug screens, the patient/physician relationship may have to end. But that happens only in extreme cases. “Nobody else is going to take care of these people,” Dunn adds. “That is an ethical dilemma.” ■

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# Ethics Education in High Demand for Palliative Care Clinicians

Palliative care fellows at the University of Washington are asked routinely for feedback at the end of their fellowship. Many said they did not receive enough ethics education.

At that point, palliative care fellows received some lectures on ethics topics, but did not receive any other formal ethics education. **Elizabeth K. Vig**, MD, MPH, developed a one-month ethics rotation. “Fellows were given the chance to do independent study work on a topic of their choice,” says Vig, chair of the ethics consultation service at VA Puget Sound Health Care System. For example, one fellow wrote about a case for publication involving a patient with dementia; another led an advance directive workshop with small groups.

Vig led a quality improvement project on the ethics rotation. Of 28 recent fellowship graduates who completed a survey, half reported encountering ethical dilemmas on a daily or weekly basis.<sup>1</sup> “I was surprised that so many of them encounter ethics issues often in their current jobs,” Vig reports.

Respondents offered suggestions on how to improve ethics education for future fellows. Some identified topics they wish they had learned more about during fellowship, including feeding tube use in dementia. Several recommended future fellows spend more time with ethics consultants on active cases and attend more ethics committee meetings.

Interestingly, 86% of palliative care fellows reported their colleagues asked them questions about ethics because of their palliative medicine training. In light of this, says Vig,

“palliative care fellowships should make sure fellows are equipped to handle the frequent ethics issues they’ll encounter.”

The variety and number of ethical challenges palliative care clinicians face “is very large, indeed,” notes **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center in Hempstead, NY. Some ethical questions relevant to palliative care include who should make decisions and how to manage pain appropriately at the end of life.

An increasing number of Hofstra’s palliative care clinicians (physicians, nurses, and social workers) choose to attend a two-semester clinical bioethics program. “Students engaged in palliative care work bring important insights to our classes,” Dolgin says.

In practice, palliative care clinicians see how patients, family members, friends, and clinicians respond to a patient’s discomfort, to pain, and to the dying process. Ethicists are trained to mediate disputes among stakeholders.

“In turn, ethicists benefit by observing palliative care clinicians provide hands-on medical care to very ill and/or dying patients,” Dolgin observes.

Ethics consultants and palliative care clinicians are “obvious partners in the task of caring for patients in pain,” Dolgin adds. These patients confront important questions about medical care, sometimes without decision-making capacity.

“The skills of each group, when combined, are of great potential benefit to patients and their families,” Dolgin explains.

Palliative care specialists are asked to help in many of the same situations

as ethicists. Family members who want “everything” done are a common example.

“We are often embroiled in the care of patients asking for potentially nonbeneficial treatments,” says **Rebecca A. Aslakson**, MD, PhD, division chief of critical care anesthesia at Stanford University Medical Center.

Palliative care providers often are unaware of relevant ethical principles, such as nonmaleficence in the case of treatment offering no benefit to patients. An extremely in-depth explanation probably is unnecessary.

“Palliative care providers don’t need the ‘31 Flavors’ of these ethical principles, but rather need the ‘vanilla and chocolate’ of what the principle is, where it came from, and why we use it,” Aslakson explains.

When palliative care was introduced into hospitals, some ethicists worried providers would no longer see the need for ethics consults. “We haven’t found that to be the case. Our clinical ethics consultation workload has continued to grow,” reports **Evan G. DeRenzo**, PhD, assistant director of the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center in Washington, DC.

Today, ethicists handle about 450 consults per year. “Our ethics center has been advancing our education mission as it applies to palliative care,” DeRenzo says.

For several years now, palliative care fellows, including physicians, nurses, and social workers, have been offered a credited ethics elective. “Having the palliative care fellows rotating with us is an eye-opener for them, and is a big help to us,” DeRenzo says.

By the time ethics is called, palliative care fellows usually are involved with the patient already. “They provide us insights into where the intrafamily conflicts are,” DeRenzo says.

This allows ethicists to build trust and relationships faster. Meanwhile, palliative care fellows gain ethics expertise.

“They learn to pick up brewing ethics problems sooner than they ordinarily might,” DeRenzo observes. “The special aspect of our program is that we teach at the bedside.”<sup>2</sup>

Palliative care observes how ethicists gather facts, both from conversations and the medical record. “Palliative care fellows learn how to sort the relevant clinical ethics facts from the mass of data available,” DeRenzo notes.

In the 2020-21 academic year, the ethics rotation will become a requirement for palliative care fellows. So far, four palliative care fellows have participated. Two to four will be participating each year. DeRenzo says this is a “wonderful expansion of the ethics center’s reach into patient care, and

produces ethically advanced clinicians throughout the hospital.” ■

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# Clinicians Struggle With Ethical Decision-Making if There Is No Surrogate

At least twice a month, an ethics consult is called at Mercy Hospital Fort Smith (AR) because a patient has no surrogate, says **Brian Paul Fetsko**, MDiv, BCC, vice president of mission.

Relatively new state legislation comes into play with these cases. “There is no question that this has helped, especially in cases where we’ve heard there is family but we can’t contact them,” Fetsko says.

Arkansas’ 2017 Healthcare Decisions Act allows physicians to identify a surrogate if the patient lacks capacity and has not designated anyone. “This presumes a number of things — namely, that the surrogate has provided special care and concern, is knowledgeable about patient wishes, and is reasonably available,” Fetsko observes.

If there is no one who meets those requirements, the Arkansas act allows for the supervising healthcare provider to make decisions. This happens only after obtaining concurrence from a second physician. The act also directs physicians to consult the ethics

officer or ethics committee. “It offers protection to the physician and the hospital, and avoids the need to go to court except in the most extreme cases,” Fetsko notes.

Ethics discusses the patient’s current medical condition and long-term prognosis. “The probability of success, previously stated patient wishes, the patient’s best interest, the weighing of benefits vs. burdens, the use of extraordinary care, excessive risks, and pain control all weigh into the decision-making process,” Fetsko explains. If there is no surrogate or family available, decision-making becomes more of a collaborative effort. The entire interdisciplinary care team weighs in on the situation, including nurses, case managers, social workers, chaplains, and respiratory therapists. “We have dealt with these situations proactively,” Fetsko reports.

This happens through interdisciplinary ICU rounds and huddles with hospitalists and case managers.

“Ethics asks probing questions on the patient’s decision-making capacity and who is available to

make decisions when we hear about potential obstacles to treatment decisions or placement post-discharge,” Fetsko says.

Ethicists are present daily during ICU rounds and attend the unit “huddles” about once a week. These focus more on discharge planning, but are a good way to learn about all patients on a unit. “Embedding ethics in the interdisciplinary care team has been effective,” Fetsko says.

Ethics representatives attend a weekly complex care meeting, also attended by the chief medical officer, chief nursing officer, case management, quality, and the attending physician. “This focuses on the most difficult patient cases and situations,” Fetsko says.

Efforts to promote advance directives have been underway for decades. “Yet we are still struggling to inspire patients to designate surrogates and execute living wills,” says **Kenneth W. Goodman**, PhD, FACMI, FACE, director of the Institute for Bioethics and Health Policy at University of Miami Miller School of Medicine.

The federal Patient Self-Determination Act has required hospitals to inform patients of the need to choose a surrogate for 30 years.

“Many institutions continue to do a mediocre job of it,” Goodman laments. “There are not enough policies, not enough training, and not enough support for proxies and surrogates.”

There are a few ways ethics can help:

- Draft policies on the healthcare team’s need to elicit informed consent from someone other than the patient;

- Remind proxies that their job is to communicate the patient’s — not their own — wishes;

- Help develop processes that support decision-makers;

- Give proxies a brochure or direct them to a website with a checklist of their duties and some case examples.

This is a simple way to give proxies a basic explanation of their ethical obligations. “We just might discover that for all the training required of employees, we’d solve many more problems by educating decision-makers for incapacitated patients,” Goodman offers.

Some jurisdictions recognize a “best interest” standard when making decisions for others. Even institutions in other jurisdictions can use the standard. “This is a good example of the difference between law and ethics,” Goodman observes. “We all should strive to do what’s right for patients, even if a legislature is silent on the question.”

Although it is imperfect, Goodman explains the best interest standard is a “rough-and-ready way to move forward in support of most ordinary people who become incapacitated.” ■

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## Fresh Approaches for Quality Assurance Hot Topic in Ethics Field

Quality assurance (QA) in clinical ethics work comes with some unique challenges, and many in the field desire to do it better.

“Right now, I see a lot of interest in QA in clinical ethics. There are lots of people trying to figure out how to do QA at their own institutions,” says **Thomas V. Cunningham**, PhD, MA, MS, medical bioethics program director at Kaiser Permanente West Los Angeles Medical Center.

Approaches to QA in clinical ethics “are only beginning to be discovered and pioneered,” says Cunningham, lead author of a recent paper proposing that ethics move toward comprehensive quality assessment.<sup>1</sup>

One challenge is continued disagreement on how clinical ethics work should be evaluated. This makes data irrelevant outside a given institution. “There is no shared understanding of what ‘quality’ means with respect to the activities associated with clinical ethics,” explains **Joshua Crites**, PhD, a regional bioethicist and co-director of the Cleveland

Fellowship in Advanced Bioethics at Cleveland Clinic.

Even published research on clinical ethics consults is inconsistent on this point.

“When we really dug into the literature, we found that different authors seemed to mean different things when referring to quality in clinical ethics work,” says Crites, another of the paper’s authors. There are other obstacles to effective QA in ethics:

- **Ethicists often rely on case narratives instead of metrics that can be tracked and compared easily.** “Detailed case narratives are crucial, but my view is that they aren’t sufficient alone,” Cunningham offers.

The main issue is that it is too difficult to analyze case narratives. To do so requires correlating case features with other data points, such as length of consults or patient satisfaction. “Historically, clinical ethics has been resistant to reductionist approaches to measurement using variables and mathematical analysis,” Cunningham observes.

This is changing, at least somewhat. “The field is now embracing a mixed methods approach, where narrative methods complement and co-inform reductive methods,” Cunningham adds.

- **When handling QA, most ethics services operate with limited resources — or none at all.** “Institutions rarely resource clinical ethics work adequately,” Cunningham laments. There is no funding for the time and expertise needed for ethics QA.

One way to address this is by collaborating with the hospital’s QA department on issues that involve ethics. “Reach out to those people, learn about their work, and seek opportunities for collaboration,” Cunningham suggests.

At Kaiser Permanente West Los Angeles Medical Center, the quality department tracks “discordant events.” These are cases in which a patient receives care that does not concord with their stated preferences in an advance directive or POLST.

“When the quality department is informed about a case with a potential discordant event, we work together to review the case,” Cunningham explains.

- **There is no standardization for ethics QA.** Ethics QA is handled in many different ways, with widely varying methods and resources.

“Different institutions track different measures of quality across different domains of work,” Cunningham notes.

This is problematic for an obvious reason: QA is all about making valid comparisons. “Since we lack standards of measurement, we lack the foundation for fair comparisons

across time, across persons or groups, or across institutions,” Cunningham says. ■

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# Ethical Concerns When Committing Psychiatric Patients Involuntarily

Hospitals continue to see a surge of psychiatric patients coming to their EDs. Some end up admitted involuntarily — and not always appropriately.

The underlying ethical issue is that mental healthcare is “terribly under-resourced. We have not valued or prioritized that type of care,” says **Mark McClelland**, DNP, RN, CPHQ, project manager of international operations at Cleveland Clinic Health System.

Lack of resources for mental healthcare results in multiple ethical concerns. “Most of the problems associated with the care of mental health patients are systemic and knowable,” McClelland observes.

Many patients need intensive outpatient therapy. However, for whatever reason, they cannot access it.

“This may lead some clinicians to admit a patient, due more to a lack of service availability than a patient’s clinical needs,” McClelland explains.

**Michael Allen**, MD, sees certain patterns involving involuntary commitment of people with psychiatric complaints as ethically troubling:

- **Health plan authorization requirements are interfering with medical decision-making.** To secure inpatient psychiatric treatment

approval, some insurers require the patient to be committed involuntarily. “Civil commitment has come to be used as a proxy for insurance company medical necessity,” explains Allen, professor of psychiatry at the University of Colorado Anschutz Medical Campus.

The reasoning is that if the patient truly is dangerous, the evidence would be civil commitment. If not, then the patient must not be dangerous from an insurer’s point of view.

“Of course, this is completely false,” Allen says. “Dangerous people can and should be encouraged to seek voluntary treatment. The misapplication of involuntary procedures may discourage that.”

- **Individuals who evaluate patients with psychiatric complaints often lack expertise.** “Given the shortage of qualified individuals and the fact that assessments of this type occur around the clock, the minimum qualifications have slipped,” Allen laments.

Individuals responsible for making this determination may have no more than a bachelor’s degree, or may have only a medical background with no mental health training.

Lack of competent assessors means poor and even unsafe decisions. “There is a tendency for anyone who

says they are suicidal to get admitted, while more disturbed but not overtly dangerous people who should qualify for involuntary admission are neglected,” Allen says.

- **Patients are undergoing screening and diagnostic tests they do not really need.** Once the decision to involuntarily commit is made, the receiving facility typically requires a long list of diagnostic tests before agreeing to accept the patient. For example, medical screening is required for anyone suicidal, usually including a urine drug screen, blood tests, and a head CT.

“None of this is usually medically necessary, and can be quite traumatic,” Allen says. For instance, if a patient is combative or uncooperative, a catheter might be necessary to obtain a urine sample.

- **Some patients present voluntarily with a psychiatric complaint, but decide at some point to leave without being seen.** Often, it takes many hours for a psychiatric evaluation to occur. If someone wants to leave the ED before it happens, it is highly possible they will be prevented from doing so.

“Some places will hold the patient against their will for the purpose of assessment, even though the yield on this is low and may actually discourage help-seeking,” Allen says. ■

# Research on Nurses' Suicide Risk Reveals Ethical Concerns

After three nurses took their lives in one year at her institution, **Judy Davidson**, RN, DNP, and colleagues set out to learn more about the prevalence of nurse suicide.

"We went to the literature and found nothing recent from the United States," says Davidson, a nurse scientist at University of California, San Diego (UCSD) Health. All they found were a few research articles from other countries and some decades-old data from the United States, all of which suggested nurses were, in fact, at higher risk for suicide.

Compelling anecdotal evidence drove Davidson and colleagues to investigate further. "There were no data to guide us," Davidson recalls. "But everyone we talked to said that they had experienced a loss in their career or their organization."

Davidson and colleagues embarked on two large projects. First, they started a nurse suicide prevention program. There was a suicide prevention program in place at UCSD Health for physicians. "They never thought we were at risk, so didn't think to expand it to us," says Davidson.

In 2018, the program expanded to include nurses.<sup>1</sup> The chief nurse officer and chief executive officer send an email once a year to all

clinicians with a request to undergo a screening. "No one will ever know if you took the screening or what your results were," Davidson notes. "You may remain anonymous all the way through treatment and/or referral for mental health issues."

Approximately 40 nurses are identified each year who are high risk for suicide. "They accept help and treatment," Davidson says.

It is something the nurses, who all had health insurance, could have handled on their own but did not. "Reactive programs aren't enough," Davidson stresses. "We have found that a proactive approach like this one is essential."

Attitudes about asking for help are changing. Therapists used to approach often-reluctant nurses to offer assistance after difficult cases. Now, nurses ask for the debriefings routinely. "This is a signal that we have hit a tipping point," Davidson offers. "We have changed the culture to accept the fact that we need help to process our feelings about what we witness at work."

After establishing the suicide prevention program, Davidson and colleagues researched nurse suicides further. The group conducted a longitudinal study, which indicated nurses were at higher risk. "It was surprising that no one had thought

of asking the question before," says Davidson, who co-chairs an American Nurses Association committee on nurse suicide prevention.

Next, investigators analyzed data from the CDC's National Violent Death Reporting System.<sup>2</sup> At the time, the data set included only 18 states. It also was difficult to figure out how many male vs. female nurses there were in each state. "There is a movement toward building a better nursing workforce data set," Davidson says. "But that was a difficult hurdle."

Suicide rates were higher in both male and female nurses. In female nurses, opioids and benzodiazepines were the most commonly used method of suicide. Notably, the medications used by nurses in suicide were ones commonly found in the home, not drugs diverted from work. "This may indicate that knowledge to use drugs in a lethal manner is more of an issue than access to medications at work," Davidson suggests.

Nurses who died by suicide were more likely than the general population to have experienced a job problem before taking their lives. "Incivility in the workplace puts nurses at risk for burnout, turnover, depression, compassion fatigue, and even suicide," Davidson notes.

There are many modifiable work-related stressors that contribute

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to “putting nurses over the edge,” according to Davidson. Moral distress over providing treatment viewed by nurses as inappropriate is one common example. So are conflicts with colleagues, problems with managers, and constant demands for nurses to work overtime due to understaffing.

“Nurses are subject to bullying and violence from patients, families, supervisors, physicians, and, unfortunately, even peers,” Davidson laments.

Feeling unprepared for new or expanded roles also is a major stressor. “This leaves the nurse constantly worried about making a mistake that

could harm someone,” Davidson says. Loss of autonomy and completing too many tasks in one shift also contribute to anxiety and depression. “There are ethical implications to all of these workplace stressors,” Davidson notes.

Stigma makes some nurses reluctant to seek mental health treatment. For some, this results in self-medicating, leading to substance use disorder. “Then, when this becomes apparent, in many states the licensure board is more punitive than helpful,” Davidson reports.

Currently, there is no standardized national response to substance use in nursing. “The intent should be

to preserve the nurse within the profession, rather than punish and remove nurses who have unresolved, yet treatable, mental health disorders,” Davidson says. ■

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# ‘Formerly Burned Out’ Study Respondents Offer Valuable Insights

There is a great deal of research on burnout in the literature, but little of it is specific to advanced practice registered nurses (APRNs) and physician assistants (PAs).

“We felt that our roles and responsibilities hold unique characteristics that warranted a separate study,” says **April N. Kapu**, DNP, APRN, ACNP-BC, FAANP, associate chief nursing officer at Vanderbilt University Medical Center.

Researchers sent a survey to every APRN and PA in the health system. This categorized respondents into three groups: currently burned out, never burned out, and formerly burned out. Of the 433 APRNs and PAs who completed the survey, 26% reported they were currently burned out.<sup>1</sup> This group was in worse mental and physical health, and experienced more pain and fatigue than those in the “formerly” or “never” groups.

“We also found that regardless of burnout status, nurses maintained

their empathy for their patients,” says **Elizabeth Card**, MSN, RN, APRN, FNP-BC, one of the study’s authors and a nursing research consultant at Vanderbilt University Medical Center.

The researchers’ previous work started with an examination of the prevalence of burnout, but now focuses on resiliency.<sup>2</sup> “That is where we want to go in our understanding,” Card says. The reasoning is that simply knowing the prevalence of burnout is just the first step. “Just identifying burnout alone will not help us improve the situation. Finding [burnout] and nursing resiliency will,” Card offers.

One-third of respondents fell into the “formerly burned out group.” This group interested the researchers. “We were fascinated by the ‘formerly burned out’ group and their responses related to recovery and resilience,” says Kapu, the study’s lead author.

Many formerly burned-out nurses shared insights on how they

successfully coped. One theme came up repeatedly: the need to make some type of change. This took many forms — switching jobs, caring for different types of patients, joining a social group, or starting a hobby. “But the point was to ‘make a change,’” Kapu adds.

For Vanderbilt’s ethicists, the study helped evaluate how to help APRNs and PAs prevent and cope with burnout. “We were really excited when this study came out because the data tell us how we can be helpful,” says **Kate Payne**, JD, RN, NC-BC, an associate professor of nursing at the Vanderbilt Center for Biomedical Ethics and Society.

The ethics department already offered plenty of support to APRNs and PAs. “We are always looking for ways to help support their ethical decision-making, which helps build resilience,” Payne reports.

One way ethicists do this is by making regular rounds at scheduled

times in various units. They walk through the department and help with whatever is going on at the time. “We bring it to them. That way they don’t have to drop what they are doing and go to a conference room,” Payne explains.

Ethicists can offer some “sound bite” education, such as a quick review of ethical principles involved in decision-making for pediatric patients. Targeted education for APRNs is important.

“Sometimes, we think it would be nice to have joint education sessions for all clinical caregivers. But bedside nurses, physicians, and APRNs each have their own set of ethical commitments,” Payne notes.

Certain APRNs are part of clinical teams that round throughout the hospital, and others are located on units such as trauma or the ICU. Their needs differ somewhat.

“It’s like anything in healthcare. We try to tailor it to the needs of the patient, the family, or, in this case, the APRNs and PAs,” Payne says.

Sometimes, an APRN needs a debriefing after a devastating case, but has not called ethics. The regular rounds give them a chance to talk to

the ethicist informally. Recently, a young nurse was distressed after her first time working on a cardiac death case that led to a donation.

“There was no ethical dilemma, but the nurse wanted to talk about the case,” Payne recalls. Ethicists listened, affirmed that everything was handled ethically, and reinforced that they are available 24 hours a day.

The study’s findings suggest Vanderbilt’s ethicists are on the right track. About one-quarter of formerly burned out nurses said they changed jobs because of burnout. Yet only about 8% of that group said they would recommend that to someone else.

“Not everybody advocated for leaving a job. They were trying to figure out ways to change within their job,” Payne observes.

Limited opportunities for professional growth and development was a variable that correlated with burnout. Payne says the key is to offer APRNs growth without leaving their jobs to find it. Various skill-building workshops are offered, and APRNs are encouraged to become members of the ethics committee. Gaining ethics expertise offers two ways to

foster resiliency: it is something new, and it is a way to grow professionally.

On the other hand, taking on an ethics role means less time for self-care. “The hardest thing about it is people don’t have the time to do it,” Payne laments. “It’s a constant balancing act.”

Burnout cannot always be prevented, of course, regardless of how many resources are available. “The nature of the work is difficult,” Payne notes. “But we keep trying to look for little ways to insert resiliency-building.” ■

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## Ethical Obligations to Study Participants if Findings Are of Unknown Significance

The average person carries more than 500,000 rare or novel genetic variants, thousands of which might be identified during a genomics research study. The question is whether, and how, people should be told about any of these findings.

“The vast majority would be variants of uncertain significance [VUS] and would not cause health problems,” explains **Gail Jarvik**, MD, PhD, professor of medicine

and genome sciences and head of the division of medical genetics at the University of Washington. In clinical testing, only a small number of VUS relevant to a condition for which patient is under evaluation are returned.

“Even in that case, most VUS will prove to not be associated with disease,” Jarvik reports. “We do not use VUS to determine a patient’s treatment for that reason.”

Of course, additional studies might give more clarity on the significance, or lack thereof, of VUS. “With further research, VUS can rise to being called pathogenics or be downgraded to completely benign,” says **Charis Eng**, MD, PhD, FACP, chair of the Genomic Medicine Institute and director of the Center for Personalized Genetic Healthcare at the Cleveland Clinic. A researcher informing individual research subjects

about all VUS is not realistic — and it is unethical, too, Eng says. In exome and genome sequencing research, there typically are thousands of variants of unknown significance. “It’s also very impractical. It’s not very beneficent to tell research subjects something like ‘You have thousands of VUS,’” Eng explains.

Eng says best practice in research is for a genetic counselor or research coordinator to make two things clear to study participants: only clinically actionable findings will be returned, and results will be confirmed in a clinical-grade lab in the setting of pre- and post-test genetic counseling.

“This is exactly why genomics research should be performed with appropriate informed consent given by knowledgeable people,” Eng stresses.

Attitudes about sharing information with study participants is changing. Historically, subjects did not even find out aggregate results of research to which they had contributed.

“People have started to advocate that individual research results should be returned to participants, to honor their participation, so we are not just using them as a means to an end,” says **Liza-Marie Johnson, MD, MPH, MSB**, a pediatric oncologist and vice chair of the ethics committee at St. Jude Children’s Research Hospital in Memphis, TN.

As for findings of unknown clinical significance, “the landscape is mixed about whether or not information should be returned,” says Johnson, who co-authored a recently published paper on this topic.<sup>1</sup> This ethical dilemma is a hot topic in genomics, but can come up in any kind of study.

Ethicists recently studied the question of whether research participants should be told if they carried gadolinium deposits in the

liver or brain from contrast agents used during previous MRIs. The deposits are of unknown clinical significance, but could influence future decision-making if that changes.

If someone was not told about the finding, “in the event that later we find it wasn’t safe, you may be upset,” Johnson notes.

The children’s oncology group directed a committee to work specifically on return of results for an ongoing research study called Genomes for Kids. Investigators will reanalyze results over a period.

“As it gets into the public sector, we are ramping up the return of results plan for our study participants,” Johnson reports.

Returning results requires considerable resources. Many studies take years to complete, and researchers must stay in contact with participants the entire time. Exactly how long is something to consider, since more information about VUS is coming to light.

“If you are going to return results, there needs to be a time limit set,” Johnson suggests. “Is it until the grant ends, indefinitely, or until the participants asks you to stop?”

The ability to adequately educate participants about the meaning of all these findings is another consideration.

“If you can’t do adequate pretest counseling or follow-up, it could be harmful if people don’t understand the significance of the results returned,” Johnson explains.

Generally, people want more information about their health rather than less. That does not mean it is in their best interest to hear about every single finding.

For instance, a study participant may want to know if they carry a gene for a cardiac condition for which

there is an intervention to prevent sudden death. However, that same study participant might not want to know if they carry a gene for early onset Alzheimer’s disease.

For researchers, “it’s all about having a plan and managing expectations, and communicating from the beginning,” Johnson stresses.

At the time of informed consent, investigators should be clear on what will, and will not, be returned to study participants.

“If you enroll in a study on migraine headaches and got an MRI, you would hope if they thought you had a brain tumor that they would share that information to you,” Johnson says.

While ethical obligations in that case seem pretty clear, there can be additional complexities. For one thing, MRI images are not always viewed in real time. Instead, data are collected and reviewed months later. Perhaps the person reviewing the MRI is not a board-certified radiologist; therefore, this person is not qualified to interpret results on behalf of an individual.

“It’s not just about one discussion when you are getting participants to sign a form,” Johnson explains. “There should be ongoing discussions over the course of a study, if appropriate.”

To meet ethical obligations, more than one conversation may be necessary. “What it comes down to is recognizing that most participants would want to receive information that’s important for their future health,” Johnson adds. ■

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## CME/CE QUESTIONS

- 1. What is recommended for decisions for incapacitated patients?**
  - a. Hospital policies must state clearly that the healthcare team should obtain informed consent only from the patient.
  - b. Ethicists should remind proxies that their job is to communicate the patient's — not their own — wishes.
  - c. When there is no proxy, ethics consultations are required.
  - d. When there is no proxy, physicians should make their best estimate about what the patient would have wanted, and act accordingly.
- 2. Which is an ethical response if findings during a clinical study are of unknown significance?**
  - a. Variants of uncertain significance must be shared with participants because these are used to determine treatment.
  - b. At the time of informed consent, investigators should provide specifics on what kind of findings will be shared with study participants.
  - c. Researchers are ethically obligated to inform individual research subjects directly of all findings.
  - d. Researchers should operate under the assumption that study participants do not want to know variants of uncertain significance because the information is not helpful for medical decision-making.
- 3. In a recent study, what did researchers learn about ethics consults involving opioids and discharge planning?**
  - a. Concerns about relapse came up often during clinical-ethical decision-making.
  - b. Fewer patients were homeless compared to cases not involving opioids.
  - c. Insurance companies routinely denied claims for outpatient substance abuse treatment.
  - d. Patients with infectious endocarditis were judged to be at lower risk for relapse.
- 4. Which did Evan G. DeRenzo, PhD, find regarding ethics education provided to palliative care fellows?**
  - a. Palliative care fellows opposed mandatory ethics education.
  - b. Palliative care fellows retained more information learned in a classroom than at bedside.
  - c. Palliative care fellows conflicted frequently with ethicists over end-of-life care decisions.
  - d. Palliative care fellows gained ethics expertise and picked up ethics issues sooner than they might have otherwise.