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Ethicists Play 'Vitaly Important Role' in Addressing Widespread Clinician Burnout

Between one-third and one-half of U.S. clinicians are experiencing burnout, according to a report from the National Academies of Sciences, Engineering, and Medicine.¹

“As an occupational hazard, burnout occurs when work demands exceed resources. It is not a personal failing or a mental health diagnosis,” says committee member **Cynda H. Rushton**, PhD, RN, FAAN, professor of clinical ethics at Johns Hopkins University.

The report confirms that burnout among U.S. clinicians is occurring at alarming rates, says Rushton, and makes recommendations for system reforms and human factors redesign.

“Clinical ethicists are ideally situated to recognize patterns that undermine the integrity and well-being of clinicians and negatively impact patient care,” Rushton says.

Systemic problems include ineffective communication about goals of care at the end of life, lack of clinician teamwork, throughput pressures that undermine relationships and threaten

safe discharge, and inadequate staffing levels.

“The ethics piece really comes down to moral distress,” says **Christine Cassel**, MD, co-chair of the committee that wrote the report.

Sometimes, moral distress involves conflict about the treatment plan, such as nurses believing a family’s request that “everything” be done is harming a patient. But ethicists also are seeing moral distress coming up because physicians know what the patient needs, but cannot do it because of time constraints, Cassel says. For example, physicians are seeing complicated patients with just 10 minutes allotted for the visit.

“You are not able to really do what you know the patient really needs, and it eats at you,” Cassel laments.

Ethicists can encourage clinicians to call them for help with sorting out the moral distress they feel, Cassel offers. Some may need to express their discomfort about being unable to meet the needs of a particular patient because of time constraints. “People in the

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hospital ethics consultancy world have the trust and the knowledge base to contribute to that set of problems," says Cassel, senior advisor on strategy and policy and professor of medicine at the University of California, San Francisco.

Often, no one takes the time to talk though moral distress arising from all the systems issues blocking patient care. "People feel they can't be heard, and that nobody really cares about these tough issues," Cassel notes. "That's where ethicists play such a vitally important role."

Some clinicians may share that system issues are standing in the way of patient care in a pervasive way. "If you add lots of these episodes to an already busy and overworked clinician, that's a contributing factor to burnout," Cassel adds.

Help does not always need to arrive in the form of a formal ethics consult. Not many clinicians will reach out in that way. Instead, while rounding in clinical areas, ethicists can ask this direct question: Do you feel frustrated about not being able to do what is right for patients?

"It doesn't have to take hours," Cassel says. "It just takes a skilled ethicist to let people talk and be heard."

Most existing data on burnout focus on nurses and doctors.

"But the same thing is happening with many other healthcare professionals as well," Cassel observes.

The report emphasizes the need for everyone in healthcare to be involved. "Everybody's got a role in thinking about how the decisions we make, and the way we organize the work, contribute to burnout," Cassel says.

Pressures of documentation requirements, payment requirements, treating too many patients with not enough members of a team, and inadequate support from pharmacy or other departments all are contributing factors. "That can lead to ethicists being drawn in to discussions on system redesign. I would certainly hope that would be the case," Cassel says.

The report authors did not give specific recommendations for ethicists. "But [the report] does look at how healthcare organizations can create and maintain safe, healthy, and supportive work environments that foster ethical practice," says **Neil A. Busis**, MD. Clinicians and healthcare leaders may be unaware of conditions that are gradually eroding the organization's ethical climate. "How clinicians experience the organization may not match the realities of the work environment," Busis adds.

Here are two examples:

- Hospitals may espouse a patient-centered mission, but then limit the number of Medicare or Medicaid patients that can be scheduled for nonurgent outpatient visits;
- Hiring or promotion practices do not necessarily reflect the

EXECUTIVE SUMMARY

Burnout is widespread among U.S. clinicians, according to the authors of a new report. Ethicists can:

- address moral distress due to inability to provide good patient care;
- ask clinicians if they feel frustrated about not being able to do what is right for patients;
- encourage clinicians to ask for help.

organization's claim that they value diversity. "Aligning structures and processes with organizational and workforce values requires a sustained intentional focus on collective values," Busis says.

A previous review of the literature concerned whether burnout affected the quality of care.² "This would be important to know if we are to build a case for the healthcare system to take measures to prevent burnout," says **Carolyn S. Dewa**, MPH, PhD, the study's lead author and professor in the department of psychiatry and behavioral sciences at University of California, Davis.

Dewa and colleagues did find evidence of a link between burnout and quality of care, but the studies were not consistent in how quality of care was measured. Therefore, says Dewa, "it was difficult to come to conclusions about the magnitude of the effects and the dimensions of quality affected."

Better understanding is needed on exactly how burnout negatively affects quality of care, whether it causes medical errors, poor communication, lower satisfaction, or other problems. "Healthcare systems are constantly changing and seeking ways to decrease costs while introducing innovation," Dewa notes.

This raises the question of whether anyone is considering how the changes are affecting providers. "Neglecting to do so seems like a missed

opportunity for good stewardship of their most important resource: their clinicians," Dewa offers.

Frequently, professional burnout is associated with poor quality of care in the published literature. "However, reporting biases are common in many fields of literature. These biases typically result in exaggerated effects being published," explains **Daniel Tawfik**, MD, MS, an instructor of pediatric critical care medicine at Stanford (CA) University School of Medicine.

The authors of a recent study examined whether published studies provide exaggerated estimates of the link between burnout and quality of care.³ "Research on burnout and quality of care appears especially vulnerable, because many studies are not prespecified or have several potential methods of analysis," Tawfik notes. If studies with more impressive results are more likely to be published, this would give a skewed picture. "We wanted to summarize what is currently reported regarding this relationship between burnout and quality of care, and to look for evidence that these reported relationships might be larger than the true relationship," Tawfik explains.

The researchers expected to find a variety of burnout measures and quality of care outcomes reported in the literature. "However, the sheer number of different combinations of burnout and quality of care

assessments was a little surprising," Tawfik reports. The authors found a moderately strong relationship between burnout and quality of care, despite the finding of some excess significant findings. "Burnout is associated with several adverse outcomes, not just related to quality of care but also related to other aspects of physician well-being and patient satisfaction," Tawfik says.

For organizations, says Tawfik, "our findings highlight the growing ethical and moral imperative to focus on provider well-being as a crucial aspect of their mission." ■

REFERENCES

1. The National Academies of Sciences, Engineering, and Medicine. *Taking action against clinician burnout: A systems approach to professional well-being*. Washington, DC: The National Academies Press; 2019. Available at: <http://bit.ly/2NIWcJb>. Accessed Nov. 6, 2019.
2. Dewa CS, Loong D, Bonato S, Trojanowski L. The relationship between physician burnout and quality of healthcare in terms of safety and acceptability: A systematic review. *BMJ Open* 2017;7:e015141.
3. Tawfik DS, Scheid A, Profit J, et al. Evidence relating health care provider burnout and quality of care: A systematic review and meta-analysis. *Ann Intern Med* 2019; Oct 8. doi: 10.7326/M19-1152. [Epub ahead of print].

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Social Media Effective Tool to Recruit Youth for Research Studies

Researchers are turning to social media to recruit participants, with a recent study revealing that Instagram and Snapchat are effective ways to reach youth.¹

“Given the near-universal use of social media by youth, using these platforms to reach them is quite effective, and can greatly facilitate their participation in research,” says **Sheana Bull**, PhD, MPH, one of the study’s authors and professor of community and behavioral health at Colorado School of Public Health.

Researchers used social media to recruit youth age 13 to 20 years in Colorado for a study to evaluate familiarity about age restrictions for recreational marijuana. “We wanted to share our experience in using social media to recruit for public health research,” Bull says.

Ads were placed in three social media platforms, encouraging the completion of a web-based survey. Over two months, 828 eligible youth completed the survey. “We were surprised at our success in reaching youth through Snapchat,” Bull reports. The researchers anticipated the variable success with Facebook and Instagram, since youth are not using these platforms consistently.

Considering the success of the social media approach, Bull sees

ethical implications. “It is imperative to have diverse voices represented in health-related research,” she says.

Some researchers have a preconceived notion that youth will not talk to adults or engage in research.

“When we work to include their perspective by reaching out to them where they are — online — we are better able to adhere to high-quality standards for participant engagement in research,” Bull offers.

Another group of researchers interviewed 44 physicians on their attitudes toward using social media for cancer therapeutic trials.² “The motivation of the study was to understand how physicians understand social media use in the service of improved enrollment in clinical trials,” says **William Dale**, MD, PhD, one of the study’s authors and a clinical professor in the department of supportive care medicine at City of Hope in Duarte, CA.

Dale and colleagues wanted to know how physicians viewed the advantages of recruiting via social media, and also what concerns they expressed. Key findings:

- Physicians recognized the benefits of using social media for clinical trial recruitment;

- Physicians noted multiple barriers. These include more time and administrative burden, and the risk of misinformation.

“These barriers may lead to a lack of access for certain patients as we are increasingly dependent on social media for our information sources,” Dale suggests.

Physicians reported a need for institutional-level interventions, such as:

- restructuring of clinical trial offices to include personnel with social media expertise;
- increased evidence-based approaches to social media use;
- more physician training on the use of social media.

Community-based and academic-based physicians made similar observations and expressed similar reservations about social media use. This came as somewhat of a surprise, according to Dale: “We assumed the academic physicians would be more familiar with social media, more likely to endorse it and less likely to see barriers.”

Social media should not be assumed to be a “loose zone” in terms of research methods or participant welfare, says **Katrina A. Bramstedt**, PhD, secretary general at the Luxembourg Agency for Research Integrity. “Researchers must still adhere to the principles of research ethics and integrity,” Bramstedt cautions.

Many social media forums are used by vulnerable populations, such as children, students, and the terminally ill. Sensitive topics are discussed: mental health, sexuality, health status, and financial status. “Researchers should not assume that social media data, even when public,

EXECUTIVE SUMMARY

Social media is an effective tool for recruiting youth participants for research studies, according to the authors of a recent study. Physicians express mixed attitudes about this practice, according to another study. Ethical considerations:

- Effectively recruiting youth means diverse participation;
- Personnel with social media expertise are needed;
- Researchers should not fake their identity or collect data without consent.

is permitted for their use,” Bramstedt adds. Researchers should follow these practices:

- **Review each website’s terms and conditions to understand and honor the data restrictions.** Social media platforms need to “sharpen their moral compass” regarding data security and transparency, Bramstedt says. For instance, terms and conditions need to be written in lay language.

“Also, they need to be presented in a manner such that users are encouraged to actually read them, rather than simply check the box to access the site,” Bramstedt adds.

- **Access private web spaces only with the express consent of the owner.** Be sure to secure their permission to perform institutional review board (IRB)-approved research, too.

- **Take care to avoid disclosing the identity of social media participants.** “Privacy is a complex topic due to the ease at which social media narratives can be searched and potentially traced to their author,” Bramstedt observes.³

“Researchers should not hide or fake their identity to lurk in private web spaces and collect data without consent. This is unethical,” she says.

There is guidance researchers can consult regarding ethical use of social media for clinical trial recruitment:

- The Association of Internet Researchers offers guidance on ethical research practices (Read more at: <http://bit.ly/33pfsLs>);

- The British Psychological Society has produced Ethics Guidelines for Internet-Mediated Research (Read more at: <http://bit.ly/32nCZLq>).

Some academic libraries also have produced general guides. Bramstedt suggests university librarians and ethicists co-teach seminars on social media research. Also, she says ethicists

should provide research ethics trainings in hospital and academic settings.

“Researchers may find this to be a research landscape that is unfamiliar to them, or they are not fully aware of the hazards,” Bramstedt adds.

Researchers who use social media for recruitment must follow the same rules and policies that are required with flyers, handouts, radio, or television, says **Thomas J. George, Jr.**, MD, FACP, associate director for clinical research at University of Florida Health Cancer Center.

This includes the IRB preapproving any information given to potential subjects to ensure it is not misleading, inaccurate, or biased.

“Most researchers who use social media to recruit subjects do so through general awareness-raising of the research, the need for the question being asked by the study to be answered, or where more information can be found,” George notes.

The safest way to use social media in this regard is to simply share preapproved information about the trial, without making any false claims about the research.

“In other words, using social media as a digital venue for distributing the IRB-approved educational or promotional materials will prevent researchers from unintentionally overstepping ethical or regulatory boundaries,” George explains. Consider these other clearly unethical practices:

- Providing incorrect or false information to entice potential

subjects to contact research staff, or offering enticements, payment, or favor for participation if the IRB did not approve those already;

- Falsifying social media endorsements from patient advocacy, foundation not-for-profit groups, or expert testimonials as a way to make the research appear more acceptable to the lay public;

- Overemphasizing the benefits while minimizing the risks of potential participation in the research.

On the other hand, asking “influential” social media users to share, like, or retweet the post is more of a gray area.

“Some of this can be mitigated by referencing the account holder’s profile disclaimer that ‘retweets or likes do not constitute an endorsement,’” George says. ■

REFERENCES

1. Ford KL, Albritton T, Dunn TA, et al. Youth study recruitment using paid advertising on Instagram, Snapchat, and Facebook: Cross-sectional survey study. *JMIR Public Health Surveill* 2019;5:e14080.
2. Sedrak MS, Sun V, Liu J, et al. Physician perceptions of the use of social media for recruitment of patients in cancer clinical trials. *JAMA Netw Open* 2019;2:e1911528.
3. Williams ML, Burnap P, Sloan L. Towards an ethical framework for publishing Twitter data in social research: Taking into account users’ views, online context and algorithmic estimation. *Sociology* 2017;51: 1149-1168.

COMING IN FUTURE MONTHS

- Ethics of organ procurement from unrepresented patients
- Nursing students unprepared to address ethics violations
- Ethics training in palliative medicine fellowships
- Ethics education in obstetrics and gynecology

Ethical Issues for Individuals Providing Unproven Stem Cell Treatments

There are well-established, significant ethical concerns regarding the safety and efficacy of treatments offered by stem cell clinics. Much less is known about those actually providing these unproven interventions. The authors of a recent study examined their background and training.¹

“We were interested in the extent to which it matched, or did not match, the marketing claims being made by these businesses,” says **Leigh Turner**, PhD, one of the study’s authors and associate professor at University of Minnesota Center for Bioethics.

Turner and colleagues investigated the three states with the most stem cell clinics (California, Texas, and Florida), using the database from a 2016 paper.² Of 183 identified companies in those states, 166 continued to advertise unproven stem cell procedures in 2018, with 608 identified clinicians. The authors scrutinized what claims those clinicians made about themselves and their training that was posted on company websites. They confirmed these qualifications using state medical board-licensing databases.

For example, many cosmetic surgery clinics have started marketing stem cell treatments for people with neurological or respiratory diseases or spinal cord injuries. “This raises questions about whether people are operating in their scope of practice or far outside that,” Turner says.

More than half the clinicians were physicians. The most common nonphysicians associated with the clinics were physician assistants, nurses, and alternative medicine practitioners. Five clinics were staffed only with podiatrists, two with naturopaths, one with dentists, and

one with practitioners with unclear qualifications.

Turner and colleagues did not evaluate clinical practices. They only looked at the extent to which the clinicians’ training and background matched, or did not match, the marketing claims the clinics made. “If you have someone with no relevant background and training, it raises a whole different set of questions about safety,” Turner says. For instance, someone who lacks training in performing bone marrow aspiration still may be injecting this into people with neurological conditions.

Seventy-seven percent of orthopedic clinics offering stem cell treatments were, in fact, staffed by individuals with a background in orthopedics. “When that subset of the marketplace made claims about stem cell treatments, they usually restricted these claims to orthopedic injuries and diseases,” Turner reports.

Some clinics offered stem cell treatments for ligament tears. “At least they had relevant training for the injuries they were claiming to treat,” Turner notes. However, he emphasizes that does not mean there is good evidence supporting the treatment in the first place. “There are still serious questions about the efficacy of the product that is going into people,” Turner cautions.

In the rest of the marketplace, fewer than 20% of clinicians have received relevant training for the diseases and injuries that they claimed to treat. “That is pretty unnerving,” Turner offers. “And we had a pretty low bar.”

If the researchers could find just one person with relevant training in orthopedics, they classified that clinic as equipped with relevant training in

orthopedics. “It’s still possible that other individuals were providing treatment who did not have relevant training,” Turner notes.

The findings make it clear that stem cell treatments are offered by people with no relevant expertise, who are self-representing as experts. One ethical concern is that patients seeking treatment are unlikely to be able to protect themselves from misleading advertising produced by businesses making persuasive-sounding claims. “They don’t have ‘scam’ written all over them. They are doing everything they can to seem credible and legitimate and trustworthy,” Turner explains.

Even if potential clients do want to find out more about the background of those providing the treatments, they might not know where to look. Turner and colleagues called for state medical boards to consider conducting more investigations in this area. “It’s pretty clear: The problem is not so much regulatory gray zones; it’s that businesses are not complying with the law,” Turner says.

Disciplinary consequences might include imposition of emergency restrictions or license revocations, depending on the gravity of the violation. “But there first needs to be an investigation. Oftentimes, that’s not happening,” says Turner, adding that that boards could do a better job of curtailing misleading advertising. Boards may not take action without a persistent citizen demanding an investigation of a particularly egregious case. “It raises the question: If we think of medicine as a self-regulating profession, how well is that being done?” Turner asks. “Does the bar need to be lower in terms of triggering enforcement activity?”

The sheer number of stem cell clinics proliferating in certain markets makes it harder to find resources to police them all. “You’re left with regulators picking off the extreme outliers, the most outrageous businesses that attract critical news

media coverage,” Turner observes. “The rest go unnoticed.” ■

REFERENCES

1. Fu W, Smith C, Turner L, et al. Characteristics and scope of training of clinicians participating in the US

direct-to-consumer marketplace for unproven stem cell interventions. *JAMA* 2019;321:2463-2464.

2. Turner L, Knoepfler P. Selling stem cells in the USA: Assessing the direct-to-consumer industry. *Cell Stem Cell* 2016;19:154-157.

Ethics Consult Can Go Undocumented — to the Detriment of Ethics Department

Many times, **Trevor M. Bibler**, PhD, has read these words “Ethics said” in a clinical colleague’s notes, followed by some inaccurate statements.

One bedside nurse documented that “Ethics said it is OK to restrain the patient until morning.” The opposite was true: The ethicist had stated that the team was not justified in restraining the patient. “But I wanted to talk with the attending for additional information before moving further,” Bibler recalls. “Somewhere, the message was lost.”

In other case, a cardiologist documented that a patient was “cleared from an ethics perspective.”

“We do not ‘clear’ patients,” Bibler notes. In that case, the ethicist had been told that the patient was going back and forth on her decision to move forward with a left ventricular assist device (LVAD) evaluation. During a conversation with the ethicist, the patient explained that she wanted to complete the evaluation but was not committed to accepting or rejecting the LVAD. The ethicist confirmed with the team that they were justified in continuing an evaluation, but said nothing whatsoever about the patient being “cleared.”

“Without my own note documenting my actions, there could be confusion about nearly every aspect of the consultation,” says Bibler, assistant professor of medicine at the

Center for Medical Ethics and Health Policy at Baylor College of Medicine, Houston.

When Bibler sees false or misleading statements on what ethics said or did, he usually calls the person who documented it. “I tell them that my analysis or plan isn’t what they have documented,” Bibler explains. “I ask that the next time they are at the computer that they amend the note.”

Many problems can occur if ethics consults are documented sparsely or not at all, says **Ariel Clatty**, PhD, a clinical ethicist at UPMC Presbyterian Shadyside Hospital. One issue is that there is no documented resolution to an ethical concern. “It could cause liability to medical staff with no ethics consultation documented if the case were to proceed to court,” Clatty offers.

Lack of documentation hinders the ethics service from knowing how it is performing. Clatty says this information, if consistently documented, helps with quality improvement efforts: Which service line is requesting consults, what the consultations are for, discharge rates before and after a consult is placed, and length of stay.

Documentation of the ethicist’s actions, assessments, analysis, plan, and recommendations allows anyone reviewing the chart at any point to “have some sense of the ethicist’s involvement, in their own words,” Bibler says.

Notably, every other clinical consultation service documents their actions in the patient’s chart. The same is not true of hospital administrators in risk management, operations, or the legal department, all of whom occasionally give input on specific patients. “The ethicist risks being seen as an administrator rather than clinical consultant, if they do not document their involvement in the way other clinical healthcare professionals do,” Bibler explains.

Ethics notes differ somewhat from clinical documentation, since they focus on ethics issues and recommendations. “But if we are going to call ourselves clinical ethicists, then we are relevantly similar to other clinical consultation services,” Bibler offers.

According to Bibler, measuring the quality of an ethics service depends mainly on two determinations:

- whether recommendations are in line with ethical standards;
- whether clinicians follow those recommendations.

“Without proper documentation, these two essential aspects of the ethicist’s work would have to rely on word-of-mouth or internal documentation,” Bibler adds. Some ethicists actively avoid documentation of their involvement. The concern is that it will expose the institution legally because some may perceive ethics involvement as a signal that something went terribly wrong with a case.

This concern is unfounded, Bibler says. It is based on a misunderstanding of the ethics role as someone who ensures the hospital is meeting compliance-related requirements: “But this is an inadequate and mistaken understanding of how ethicists operate.” Bibler says that if anything, ethics involvement should be a posi-

tive thing from a risk management perspective. “It makes more sense for the institution to want to show that when ethical conflicts or questions arise, they have a team who can address these issues,” Bibler shares.

At Houston Methodist Hospital, ethicists treat every consultation as a formal request. All requests are

documented. The only exception is general questions about policies, such as the state surrogate decision-making hierarchy, that do not involve patient specifics.

“Our default is to leave at least one note,” Bibler says. “I can’t recall the last time I didn’t leave at least one note in the patient’s chart.” ■

Evolving Ethics of Anonymous Sperm and Egg Donors

Traditionally, the identity of sperm and egg donors were kept strictly anonymous, but this is changing. A recent position statement from the American Society for Reproductive Medicine concerns this ethical issue.¹

According to the report, “The expectation of absolute anonymity has evolved into an expectation that recipients will have more information about donors, and vice versa, and even a possibility of future contact between parties.”

When donors are kept anonymous, “there are a lot of ethical issues that come up,” says **Robert Klitzman**, MD, director of the online and in-person master of bioethics program and a professor of psychiatry at Columbia University.

In vitro fertilization (IVF) use and, therefore, sperm and egg donors continues to increase. “The kids usually never find out they were created by a donor. If they do, they have no easy way to find out who the person is,” Klitzman notes.

Many parents do not even tell their friends or the child’s pediatrician, afraid the child will find out. “Ethically, that creates a lot of problems. Whether they have a right to meet the person has to be mutually agreed on. But people have a right to medical information,” Klitzman says. For many years, there was a similar

situation with adoption records. “In the 1970s, there was a realization that, ethically, people have a right to know about their biologic and genetic origin,” Klitzman recalls.

At the time, adoption agencies opposed this. Similarly, says Klitzman, “some IVF providers are very wary of ending anonymous donation.”

Lack of records is a significant ethical concern. “The fact that you have no record anywhere is a problem,” Klitzman observes. “The need to address anonymity is part of a larger need to oversee and monitor, and perhaps regulate, egg banks and sperm banks.”

Disclosing donors’ identity could mean the IVF industry passes those costs on to prospective parents. “Given the high costs that are already associated with assisted reproductive technologies, this may create a challenge, as not everyone may be able to pay,” says **Maya Sabatello**, LLB, PhD, assistant professor of clinical bioethics at Columbia University.

Some people may be reluctant to donate if privacy cannot be assured. Prospective parents may express their own concerns about privacy. “They may prefer anonymity because of concerns about involvement of a third party in the family,” Sabatello suggests. A couple who chooses to use donated gametes against cultural

or religious norms may be vilified. “Keeping it quiet allows the couple to stay a part of the community while having a child that they cannot otherwise have,” Sabatello explains.

Traditional practices of anonymity in gamete and embryo donation have gone through important transformations already.

“Historically, these practices were carried out in secrecy. The medical recommendation was to keep them a secret, even from the resulting child,” Sabatello reports.

Today, donors are recruited in public places. Prospective parents often can choose from a list of possible donors, as well as decide whether they would like to keep the donor anonymous. “The rise of nontraditional families also impacted this practice,” Sabatello adds.

Growing children are asking for explanations about their conception. Parents who used gamete donation and delivered a child with disabilities advocated for more medical information about the donor, sometimes to find a diagnosis. “Changes and practices vary significantly across countries,” Sabatello notes.

Some countries still uphold donors’ anonymity. “On the other hand, there is a growing trend among European countries to reverse the policy of anonymity,” Sabatello says.

Some laws require donors' information to be recorded in a national registry. Donors have to agree to be contacted in the future by the resulting child. "Under this approach, parents maintain the power as to whether to share with the child the story of conception," Sabatello says.

It is the child who needs to trigger the disclosure process. "Exact conditions for contact differ. Some require that this child reaches age 16 or above, others just require sufficient child maturity," Sabatello says.

In some countries, an addendum is added to the birth certificate of children born as a result of gamete donations. "The idea is that children should know their story of origin and be able to connect with biological parents," Sabatello adds.

Direct-to-consumer testing has "changed the rules of the game," Sabatello observes. There are anecdotal accounts of people who decided to conduct ancestry testing and found

they had no biological relatedness to the people they thought of as their parents. "In some cases, they were able to track down the biological parent. We are likely to hear of more such cases in the future," Sabatello predicts. Some consumers have found many half-siblings through direct-to-consumer genetic testing, and realized that they must be related through a sperm donor. "They then feel betrayed by their parents, who never told them," Klitzman says.

Technology is, in part, driving the changing attitudes about anonymity, since people are finding the information on their own. "As that becomes more of the norm ... attitudes and practices are going to change," Klitzman predicts.

It remains an ethical balancing act between the rights of children and their parents — and also the third party involved in reproduction. "Donors who donated many years ago under the veil of anonymity may

have not imagined the technological possibilities that we have today," Sabatello offers.

Others still may oppose disclosing their identity. Certain individuals may change their minds, but there is little recourse for them at this point. "People who donate today and want anonymity should be aware that it may not be possible to guarantee that," Sabatello cautions.

Considering the rise of genomic consumers and increased awareness of the rights of children, Sabatello says it is "a hard sell that donors can be, or should be, anonymous. Their act has implications and the child's interests should be considered." ■

REFERENCE

1. Ethics Committee of the American Society for Reproductive Medicine. Interests, obligations and rights in gamete and embryo donation: An ethics committee opinion. *Fertil Steril* 2019;111:664-670.

One-Size-Fits-All Limits on Opioids Are Ethically Problematic

Elect officials and other health agencies and advocacy groups are enacting many new requirements to combat the opioid epidemic.

"We can all agree that decreasing the use of opioids is the right thing to do for patients," says **Joseph Bosco**, MD, professor in the department of orthopedic surgery at NYU Langone Health.

Physicians are morally obligated to lead the way in opioid reduction, Bosco adds. He and other research colleagues recently reviewed various interventions with an ethical lens.¹

"The current opioid crisis generated immediate actions at many levels," says **Claudette Lajam**, MD, the study's lead author and an associate

professor at NYU Langone Health, also in the department of orthopedic surgery. Regulatory requirements were implemented quickly. These placed seemingly arbitrary limits on prescribing, even for painful surgical procedures. "We wanted to examine the ethical implications of regulatory changes and physician-led changes," Lajam says.

According to the analysis, these regulatory interventions are ethically sound:

- requirements for educational programs for prescribers and patients;
- robust prescription monitoring programs that cross state lines;
- more prescriptions of naloxone for at-risk patients;

- development of condition-specific pain management guidelines;
- improvement of opioid disposal programs;

elimination of pain control questions from patient satisfaction surveys. "Arbitrary, one-size-fits-all limits on opioid prescribing were less ethically sound due to interfering with autonomy and nonmaleficence," Lajam says. ■

REFERENCE

1. Lajam CM, Cennamo J, Hutzler LH, Bosco JA 3rd. Ethics of opioid prescriber regulations: Physicians, patients, and pain. *J Bone Joint Surg Am* 2019; Oct 9. doi: 10.2106/JBJS.19.00437. [Epub ahead of print].

Challenges to Transplant Allocation Carry Ethical Implications

An insurance company's denial of coverage for a liver transplant sometimes is perceived as discriminatory. The authors of a recent paper analyzed judicial review of these controversial cases.¹

"Transplant decisions, although they are made locally, have the potential for sweeping consequences," says **Elliot B. Tapper**, MD, the study's lead author and an assistant professor in the division of gastroenterology and hepatology at the University of Michigan.

Tapper and colleagues reviewed all published court opinions that involved a denial of liver transplant candidacy in violation of constitutional rights.

Of 1,562 cases, 290 transplants were denied due to a patient's failure to abstain from drinking, 273 cases involved incarcerated inmates, two involved patients requesting a bloodless transplant for religious reasons, and two cases involved age discrimination.

Court cases decided on constitutional grounds are consequential for every transplant program across the country.

"With that in mind, we wanted to survey the landscape of legal cases that invoked constitutional clauses so that centers and payers could avoid pitfalls," Tapper explains.

If objective data do not clearly support a transplant decision, it could be seen as arbitrary.

"Because of the way transplants are funded and organs are allocated, people are protected from capricious rulings as a function of the 14th Amendment," Tapper says.

Researchers recommended that payers avoid rules denying transplants on the basis of a prespecified period of

sobriety. This is no longer supported by the literature.

"Centers should be allowed the flexibility to determine, on a case-by-case basis, who is the best possible candidate," Tapper says.

Despite high-profile cases in which people were denied transplants because of their undocumented status, Tapper and colleagues found no such cases.

"It is possible that is because people lack resources or agency to bring cases," Tapper suggests.

Two cases alleged discrimination based on age. Investigators recommended using objective, data-driven measures for transplant selection, including evaluation for frailty. These criteria are associated with outcomes before and after transplant.

"These evidence-based metrics can be used to determine if somebody is too sick for transplant, irrespective of their age," Tapper says.

Decisions to list (or not list) a patient as a transplant candidate based on nonmedical criteria can be "concerning, because they can lead to discrimination based on disability," says **Alexandra K. Glazier**, Esq., president and CEO of New England Donor Services in Waltham, MA.

For instance, centers might consider a patient's existing social support or ability to adhere to post-transplant care. These are important factors in evaluating the potential for a successful transplant outcome. However, they are subjective. If not carefully considered, it can lead to conclusions made based on a patient's disability rather than individual circumstance, Glazier cautions. "The ethical implications are significant," she says.

Access to transplantation should be as equitable as possible, based on sound medical judgment, not subjective considerations that can lead to discrimination.

"As a scarce resource, however, the system must maximize the life-saving benefit of organ transplantation and minimize any organ wastage," Glazier offers.

The balance of these principles requires appropriate consideration of expected patient outcomes.

"But this assessment should not form the basis for discrimination," Glazier adds.

Organs are allocated only to candidates listed for transplantation. Once a patient is listed as a candidate for transplant, the national allocation policies are based on objective medical criteria and other objective factors (e.g., acuity of the patient and time waiting for an organ). To ensure a system that provides access to transplantation without discrimination, Glazier says there should be national standards regarding patient selection criteria.

"Disability should neither be a relative or contraindication to listing a patient as a candidate for transplantation," she says.

Further, patients should be evaluated individually based on transparent, consistent criteria.

"Patients should not be excluded from consideration for transplantation solely on the basis of a disability," Glazier adds. ■

REFERENCE

1. Tapper EB, Wexler R, Goldman E, Volk M. Constitutional challenges to liver transplant policy. *Transplantation* 2019;103:e378-e381.

Fresh Data on Medical Student, Nurse Attitudes on Medical Assistance in Dying

Nurses play a central role in the process of medical assistance in dying (MAID), even if they bear no responsibility for the act itself, according to the authors of a recent study.¹

Researchers interviewed 59 Canadian nurses who had participated in a MAID experience or who chose to not participate. “We felt this study was important for two reasons,” says **Barbara Pesut**, PhD, RN, Canada research chair in health, ethics, and diversity and a professor in the school of nursing at the University of British Columbia.

First, Canada is the first country to allow nurse practitioners to act as MAID assessors and providers. “As such, it was important to understand their initial experiences with this new role,” Pesut says. Second, researchers suspected that registered nurses were essential to the care provision surrounding MAID. “To date, much of the literature surrounding assisted death has centered around physicians,” Pesut says. Some findings:

- **There was wide variation in practice supports (policies, procedures, or collegial mentorship) for nurses.** “For many nurses, their initial experiences with MAID happened within a practice support void,” Pesut reports. This was most concerning for nurses who had to work alone and who had participated in multiple MAID deaths.

- **Nurses experienced a wide range of emotional reactions.** For some nurses, MAID was one of the most meaningful experiences of their entire careers. For others, it was so emotionally distressing that they felt compelled to leave their jobs — even the profession of nursing altogether, in some cases. “Some nurses described an emotional overload after providing

MAID that was difficult to understand,” Pesut says. For others, it faded over time. Certain nurses reported an overload recurrence after each MAID death.

- **It was not always easy for nurses to conscientiously object to participation in MAID.** “Some felt that it might jeopardize their employment if MAID responsibilities were embedded within specialized positions, such as palliative care clinicians, in which there was typically only one nurse in the role,” Pesut says.

- **Patients request MAID from nurses for a variety of reasons.** These requests do not always lead to a MAID death. For some patients, just the option of knowing MAID is available is enough. For others, talking about their suffering brings a degree of resolution so that MAID is no longer required. “However, these are complex conversations that require a high degree of nursing skill and time,” Pesut notes.

Another group of investigators recently examined Canadian medical students’ attitudes toward MAID.² “There was a lack of empirical, national-level data about the perspectives and intentions of Canada’s next generation of physicians toward MAID,” says **James Falconer**, the study’s lead author.

This was particularly important to know due to significant changes to Canada’s medical and legal landscape around this issue. MAID was legalized in Canada in 2016. “What existed was a lot of opinion, rhetoric, and policy recommendations in the media and among medical-professional associations,” says Falconer, a PhD candidate in the department of sociology at McGill University at the time of the study.

However, none of this was based on solid evidence. “Our study sought to fill the knowledge gap in the Canadian conversation on this issue, at precisely the time when the law was undergoing a significant change,” Falconer explains.

Researchers surveyed 1,210 Canadian medical students. Notably, there was no statistically significant difference between medical students with rural vs. urban upbringings. “We were aware from the literature review that some individual factors, such as religion and frequency of religious attendance, were associated with opinions on MAID,” Falconer says.

Researchers discovered that despite the range in willingness to provide MAID across regions, there did not appear to be enough of a regional disparity to cause concern about the availability of the service for those who choose it.

Even in Alberta, the region where medical students showed the lowest willingness to provide MAID, 63% of medical students were willing to fulfill a patient’s request for MAID. This, compared to 71% nationwide. “This is an important finding, with implications for the availability of physician-assisted dying across regions,” Falconer suggests. ■

REFERENCES

1. Pesut B, Thorne S, Greig M, et al. Ethical, policy, and practice implications of nurses’ experiences with assisted death. *ANS Adv Nurs Sci* 2019;42:216-230.
2. Falconer J, Couture F, Demir KK, et al. Perceptions and intentions toward medical assistance in dying among Canadian medical students. *BMC Med Ethics* 2019;20:22.

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CME/CE QUESTIONS

- 1. Which did the authors of a recent report recommend regarding clinician burnout?**
 - a. Burnout should be viewed as a mental health diagnosis, with a focus on alleviation tactics for individual clinicians.
 - b. Generally, ethicists should not become involved in addressing underlying systems issues because it detracts from their primary role.
 - c. Hospitals should prioritize efforts for nurses specifically, because efforts to combat burnout thus far have yielded results only for physicians.
 - d. Everyone in healthcare can play a role in creating healthy work environments that foster ethical practice.
- 2. Which is true regarding using social media to recruit participants for research studies?**
 - a. While youth responded to social media posts, few followed through to actual participation.
 - b. Social media effectively reached youth, helping researchers to adhere to high-quality standards for diversity.
 - c. Youth were highly suspicious about the intent of researchers, making the social media strategy ethically problematic.
 - d. Concerns about privacy ended the study prematurely, forcing researchers to use traditional methods to contact participants.
- 3. Which is true regarding anonymity of sperm and egg donors?**
 - a. Direct-to-consumer genetic testing should have no bearing on clinics' continued responsibility to safeguard future donors' anonymity.
 - b. Attitudes are changing in part due to children requesting explanations about how they were conceived.
 - c. European countries are moving toward more stringent protections of donor anonymity.
 - d. Prospective parents report fewer concerns about involvement of a third party in the family.
- 4. Which intervention to limit opioid prescribing did providers find ethically problematic?**
 - a. Requirements for educational programs for prescribers and patients
 - b. Robust prescription monitoring programs that cross state lines
 - c. One-size-fits-all limits on opioid prescribing
 - d. Elimination of pain control questions from patient satisfaction surveys