MEDICAL ETHICS ADVISOR®

YOUR PRACTICAL GUIDE TO ETHICS DECISION-MAKING

JANUARY 2019 Vol. 35, No. 1; p. 1-12

INSIDE

RELIAS MEDIA

Geneticist: Rogue Scientist's Gene-Editing Procedure Violated Bedrock Ethical Principles

Immediate public, scientific, and ethics outcry

Clinical trials using heritable genome editing might be ethically permissible in the future — but only within a "robust and effective regulatory framework" including maximum transparency and a reliable oversight mechanism, concluded a 2017 report from the National Academy of Sciences (NAS) and the National Academy of Medicine (NAM).[1]

Editing the DNA of a human embryo could be morally permissible, according to a 2018 independent inquiry by the Nuffield Council on Bioethics — but only after a number of measures were put into place to ensure it proceeds in ethically acceptable ways.[2] Canada, Germany, France, Switzerland, Sweden, and Italy have all passed laws prohibiting germline intervention on human embryos for implantation.

> EDITING THE DNA OF A HUMAN EMBRYO COULD BE MORALLY PERMISSIBLE — BUT ONLY AFTER A NUMBER OF MEASURES WERE PUT INTO PLACE TO ENSURE IT PROCEEDS IN ETHICALLY ACCEPTABLE WAYS.

Despite this international consensus, a Chinese scientist recently took responsibility for the world's first gene-edited babies. He Jiankui, an associate professor at the Southern University of Science and Technology in Shenzhen, stated that the procedure was done specifically to

Financial Disclosure: Consulting Editor **Arthur R. Derse**, MD, JD, Nurse Planner **Susan Solverson**, RN, BSN, CMSRN, Editor **Jill Drachenberg,** Editor **Jesse Saffron,** Editorial Group Manager **Terrey L. Hatcher,** and Author **Stacey Kusterbeck** report no consultant, stockholder, speakers' bureau, research, or other financial relationships with companies having ties to this field of study.

MEDICAL ETHICS ADVISOR®

Medical Ethics Advisor®, ISSN 0886-0653, is published monthly by Relias Learning, 111 Corning Road, Suite 250, Cary, NC 27518-9238. Periodicals postage paid at Cary, NC, and additional mailing offices. POSTMASTER: Send address changes to Medical Ethics Advisor, Relias Learning, 111 Corning Road, Suite 250, Cary, NC 27518-9238.
GST Registration Number: R128870672.

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protect the children from HIV. This revelation only compounded the issues troubling many ethicists.

"Having listened to Dr. He, I can only conclude that this was misguided, premature, unnecessary, and largely useless," says **R. Alta Charo**, PhD, co-chair of the NAS/NAM committee. Charo is Sheldon B. Lubar distinguished chair and Warren P. Knowles professor of law and bioethics at the University of Wisconsin-Madison.

The shocking announcement served as a reminder that there probably is very little any nation, professional society, or institution can do to prevent "rogue" actors from breaking the rules, says **Carolyn P. Neuhaus**, PhD, a research scholar at the Garrison, NY-based Hastings Center. This is the case whether those rules are codified in law or institutional policy or scientific societies. "But we always knew that. The question is, 'What does it look like to do our very best to prevent it?'" asks Neuhaus.

A "renewed sense of urgency about transparency" is needed, says Neuhaus. This means fostering a culture, especially among young scientists, that rewards raising questions, whistleblowing, and sharing works in progress. "Included in this should be lab technicians, postdocs, students, and also IVF providers or nurses who might be involved in future studies that would seek to implant edited embryos," says Neuhaus.

Ethical Principles Violated

Instead of a peer-reviewed journal, the research was publicized via YouTube. "There was an immediate public, scientific, and ethics outcry," says **Charis Eng**, MD, PhD, FACP, chair of the Genomic Medicine Institute and director of the Center for Personalized Genetic Healthcare at the Cleveland (OH) Clinic.

A previous attempt at gene editing, though controversial, was performed in the setting of a clinical trial. It was vetted by a multi-institutional IRB and addressed a life-threatening medical problem that would result in death shortly after birth.[1] In contrast, says Eng, "From what I understand of this current situation, this researcher did not vet his protocol through any IRB."

Kiran Musunuru, MD, PhD, MPH, associate professor of cardiovascular medicine and genetics at University of Pennsylvania, says the experimental procedure that resulted in gene-edited twins violated "bedrock principles of ethical medical research," including the following:

EXECUTIVE SUMMARY

A Chinese scientist's recent announcement of a genome-editing procedure performed to protect children from HIV has significant implications for the bioethics and genomics fields.

- Multiple ethical principles were violated, such as the need for informed consent and transparency.
- More stringent requirements are expected.
- Researchers are concerned that legitimate work in this area may be hindered.

• **Beneficence.** Although the procedure was reportedly intended to confer resistance to HIV infection, only one of the embryos received sufficient editing to possibly gain HIV resistance. "The other did not but was permitted to proceed through pregnancy anyway," says Musunuru.

Additionally, the chance of either twin becoming infected with HIV and progressing to full-blown AIDS in their lifetimes was negligible. "There was little good to be gained," says Musunuru.

• **Nonmaleficence.** "The gene editing was imperfect and incomplete across the cells in the embryos," explains Musunuru. There is evidence of undesired, potentially harmful mutations. These could raise the risk of cancer or other diseases — not just for the twins but also their descendants. Even if the gene editing had been perfect, says Musunuru, "the edits to confer HIV infection also increase the likelihood of having serious illnesses or dying from infections with other viruses, such as flu."

• **Autonomy.** As the twins had no opportunity to consent for procedures performed on them as embryos, this responsibility fell to the parents. Yet, says Musunuru, "it was clear that the 'informed consent' procedure was not truly informed." One reason is that the potential benefits and harms were misrepresented.

"Indeed, the full extent of potential harms with gene editing is still a big unknown to scientists," says Musunuru.

The consent claimed the infants were likely to benefit from the procedure. This conflated research with therapy, says Charo: "In fact, there is not only very little chance these babies would be in need of a benefit, given their low risk, but there is no way to evaluate if this indeed conferred any benefit." Additionally, if the twins do remain HIV-negative, there is no way to show it has anything to do with the editing.

The consent form focused largely on risks of participating in in vitro fertilization (IVF), with minimal information on gene editing. **Kelly E. Ormond**, MS, CGC, LGC, acknowledges it is possible it was conveyed verbally. However, consent forms are meant to document what was in the conversation. "It did not make it clear that there are a lot of unknowns and that this is experimental," says Ormond, co-director of Stanford (CA) University's master's program in human genetics and genetic counseling and faculty at the Stanford Center for Biomedical Ethics.

Dr. He revealed that there is a second, early pregnancy, and 16 more embryos from other couples — all frozen while his work is paused. "What will happen to those embryos, or even who decides what happens, is unknown," says Charo.

Opportunity to Educate

The worrisome event has important implications for healthcare ethics. "When something so serious has occurred, one opportunity is to educate the public on ethical issues," says Eng.

Musunuru predicts that the episode will end up being required reading for future generations of scientists, as "a textbook case of all the different ways one can violate the ethical principles of medical research."

As for future rogue scientists, the international outcry from the scientific community is likely to discourage at least some of them. "The backlash is turning out to be so immense that scientists will be deterred from similar ethical violations in the future, although there will always be bad actors," says Musunuru.

Recent surveys suggest most Americans would like to see gene editing move forward. "It will be interesting to see if this affects the degree of public's acceptance of this as being OK," says Ormond. One of the challenges in this regard, says Ormond, is "You have no idea what the people responding actually know about it."

Respondents may be completely uninformed, or misinformed. While survey respondents tend to differentiate between therapeutic use and enhancement, they do not see the distinction between somatic cell gene therapies that affect only the treated individual and germline editing that affects future offspring. "Certainly, bioethicists, scientists, and clinicians see a stark difference between somatic and germline therapies," says Ormond.

More discussion around somatic gene editing is sorely needed, says Ormond. Potential treatments are a realistic possibility in the near future. In contrast, she says, "Germline editing is more ethically sticky, and that's why people gravitate to it. But it's not going to be the majority of what gets done."

Various policy boards are seeking to engage the public in discussion on ethics of genomics. The highly publicized gene-edited babies could open the door to vigorous debate. "It's gotten people talking about it, which could lead to deliberative democracy conversations," says Ormond.

Neuhaus says there is an opportunity here "to reflect on the role of gene editing in our lives." She says reflection is needed on these questions in particular:

• Does the need to edit out certain

diseases and disabilities express that existing people with those diseases or disabilities are less than able-bodied persons?

• How, if at all, does gene editing differ from other ways in which we intervene in or exert power over future humans' lives?

• How much control should parents have over their child's traits? Does a "good" parent use gene editing?

• What level of risk should parents be allowed to assume on behalf of their future children?

There's a tendency to think that if the benefits of new medical technologies outweigh the risks, then the ethical conversation is over, says Neuhaus.

Recent discussions on gene editing have been held at various museums and high schools. "I hope that more public-facing discussions, whether in print or online or in classrooms, take up these complex and nuanced and messy discussions," says Neuhaus.

Researchers Fear Shutdown

Many ethicists now see stricter regulations as inevitable, since the episode is a stark reminder of the limitations of self-regulation in the scientific community.

External legislation and regulation will be needed, says Musunuru, "to ensure that egregious ethical violations of this kind do not happen again going forward."

Some fear that too much regulation will stifle scientific innovation. "It's always going to be a tradeoff," says Ormond. "That's what the conversation needs to be about."

Regardless of how much restraint is urged by the scientific community or the general public, the reality is that no global body can actually enforce any of it. "Without laws that have actual consequences in any particular country, it's going to be very hard to prevent this," says Ormond.

As for the ethical challenges of moving from in vitro research to clinical translation, Ormond says there is no need to reinvent the wheel. The field of assisted reproduction has already been through it, with the first IVF, first preimplantation genetic diagnosis, and first mitochondrial transfer cases. "Those were very controversial when first done, as well," says Ormond.

Likewise, the clinical genetics field can share insights as to whether a given condition meets criteria for gene editing. "I hope that this one case doesn't make all of this research shut down," says Ormond. "We would really lose out on some great potential treatments if that happens." ■

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Too Few Ethics Consults for Children With Chronic Critical Illness: Less Than 1%

Ethics 'most underutilized resource'

Palliative care and ethics consultations for children with chronic critical illness are surprisingly uncommon, found a recent study.[1] Researchers looked at 385 hospitalized children at six academic centers and found that 12% received palliative care consults. Less than 1% received an ethics consultation.

This was despite the availability of pediatric palliative care teams at five out of six centers and ethics committees at all centers. "Ethics represented the most significantly underutilized resource," says **Alison J. Falck**, MD, one of the study's authors and assistant professor of pediatrics at University of Maryland School of Medicine.

Increasing numbers of children are living with chronic critical illness. "Often, these children are living with complex medical conditions that require ethically challenging decision-making," says Falck.

Many families face difficult choices regarding life-sustaining treatments, which often have unclear benefits and burdens. "It is important for hospital ethicists and ethics committee members to understand the complexities of this small but growing number of pediatric patients," says Falck.

Barriers to Consults

Poor previous experiences with ethics consults make some clinicians reluctant to call for help. Others fear being chastised for unethical practices, while some do not even realize ethicists are available. "Despite our having an ethics consult service for over a decade, we still encounter people who are pleasantly surprised that there is an ethics service available to them," says **Jennifer K. Walter**, MD, PhD, MS, an attending physician for the pediatric advanced care team at Children's Hospital of Philadelphia.

ICU staff may perceive that they already know what is ethical. "People are perhaps less aware of ways in which their own value system may be in conflict with the family," says Walter. The ICU staff does not always see this as something that calls for mediation by a third party.

"There are many myths about ethics consultations that still plague institutions and may be a barrier to requesting consults," says **Erica K. Salter**, PhD, program director of healthcare ethics at Saint Louis (MO) University.

Some clinicians see an ethics consult as a challenge to their integrity. "Ninety-nine percent of the time we are dealing with only well-intentioned, conscientious providers who truly wish to do their best by the patient," says Salter.

Fear of reception or retribution is another deterrent. Nurses occasionally admit that they wanted to call ethics sooner but were afraid of the attending physician's reaction. "This is challenging and unfortunate," says Salter.

More Than One Answer

At times, the ICU team's idea of what they want for the patient conflicts with what the family expects in terms of aggressiveness of care. Multiple family meetings are held, concerns are expressed, and a rift develops. "The perception arises that the family is being judged by the clinical team," explains Walter.

In this tough situation, ethicists can point out that there are a range of ethically acceptable choices.

"There is usually not just one answer that people have to follow," says Walter. When there is a values disagreement in the care of a child, parental preferences are honored unless the team has evidence of harm or neglect, which is almost never the case.

Clinicians themselves may disagree. Nurses providing day-to-

EXECUTIVE SUMMARY

Very few hospitalized children with chronic critical illness get ethics or palliative care consultations, found a recent study.

- Clinicians may be unaware of ethics, or fear judgment or retribution.
- Ethicists must understand the complexities of this pediatric population.
- Many families face difficult choices regarding life-sustaining treatments, which often have unclear benefits and burdens.

day care may perceive significant suffering. In contrast, says Walter, "Physicians who are not at the bedside all day are working with different information."

Ethics bring the clinical team together for an open discussion. "The goal is to create a shared mental model for the whole team in terms of what we might be able to achieve in terms of the patient's recovery," says Walter.

Unlike other units with formal reporting mechanisms, communication amongst the time-pressured, frequently rotating ICU team is sometimes fractured. "The information that the whole team carries is sometimes held by only one or two members," says Walter.

If the person who knows the big picture is not available, patients and family may get mixed messages. Walter suggests having someone, such as a primary attending or palliative care physician, serve as a repository of information.

Increased awareness of ethics has resulted in more consults being called. This is because clinicians are more comfortable and familiar with what ethics has to offer. "They come to us with incredibly challenging cases they've been struggling with, they see we take a collaborative approach, they realize it's valuable — and they call us again," says Walter.

Establish Rapport in Advance

At Saint Louis University Hospital, clinicians find ethics particularly helpful in these two types of cases involving children with chronic critical illness:

• Cases where there is a disagreement between the parents/family and providers on what constitutes an acceptable quality of life to initiate or continue aggressive medical intervention.

"These can be tough cases for providers," says Salter. For example, a patient with severe neurological injury and limited conscious awareness may require a tracheostomy and feeding tube. For clinicians, it can be helpful to hear directly from the parents. They might hear words such as:

> ETHICISTS OBVIOUSLY HAVE A DUTY TO SERVE PATIENTS' AND FAMILIES' INTERESTS. "BUT AT THE HEART OF MOST EFFECTIVE ETHICS CONSULTS IS A RELATIONSHIP BETWEEN THE CONSULTANT AND TEAM."

"We understand this sort of life wouldn't be meaningful to you, but it's meaningful to us. We have a relationship with this child; she's a part of the family, no matter how disabled."

"Ethics consults are opportunities for stakeholders to sit down and really hear from each other about what specifically concerns them about the child's experience," says Salter.

• Cases where there are disposition concerns.

It can be very distressing for providers to initiate aggressive interventions on a child for whom there is no obvious place of safe discharge with adequate, skilled caregiving assistance. "In these situations, we have to get creative about identifying and piecing together the right resources for families," says Salter.

To encourage consults on challenging pediatric cases, ethicists need to "be around, listen, and be helpful," says Salter. This does not mean serving only the needs of providers; ethicists obviously have a duty to serve patients' and families' interests. "But at the heart of most effective ethics consults is a relationship between the consultant and team," says Salter.

To demonstrate they understand clinical realities and can offer helpful advice, Salter says, ethicists at Saint Louis University Hospital make regular rounds in the pediatric and neonatal ICUs and oncology.

"This builds the rapport needed to be invited back during the crisis or conflict situations," says Salter. ■

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Surprising Ethics Knowledge Gaps in Emergency Medicine Residents

Trainees' knowledge is 'generally poor'

Gaps in clinical ethics knowledge appear prevalent among emergency medicine trainees, and few programs feature dedicated ethics modules, found a recent study.[1]

"We are hoping that program directors take note of this gap in knowledge," says **Aasim I. Padela**, MD, MSc, the study's lead author. The researchers wanted to know the baseline level of ethics knowledge that trainees have currently. Their conclusion: "Their knowledge is generally poor," says Padela.

The researchers asked these questions:

- Are emergency medicine residents prepared to deal with common ethical challenges?
- Do they perceive themselves to be prepared when they actually are not?
- Does having an ethics module in place really improve knowledge, or just the perception of how much the resident knows?

"The residents didn't score well in terms of identifying the correct issue or the correct action," says Padela. However well-prepared the residents felt they were to handle ethical challenges, it had little bearing on their knowledge.

"The main finding is that residents' knowledge is not very good in terms of identifying what the ethical issue is or how to deal with it," says Padela.

The researchers assessed knowledge and perceived preparedness for 302 residents for five ethics areas: informed consent and decisional-capacity assessment, surrogate decision-making, interpretation of advanced directives, withdrawing and/or withholding life support, and presumed consent for emergency treatment. Two significant findings:

- About one-third reported having a dedicated ethics module within their residency curriculum.

These residents perceived themselves as better prepared, but this was not borne out in the findings. There was no link between a dedicated ethics module and knowledge scores.

This suggests that residents became somewhat familiar with the topics but not enough to handle the issue in actual practice. "This is a significant challenge, and we wanted to draw attention to it," says Padela.

- Assessing decisional capacity was the most difficult topic for respondents.

Just 1% correctly addressed the general issue and identified the correct plan of action. This finding was particularly concerning to Padela. In the ED setting, the issue comes up frequently when patients leave against medical advice, or an inebriated patient is consenting to treatment.

"Every clinical case we have has an ethical wrinkle in it," says Padela. "This is part and parcel of emergency medicine. It is germane to our practice."

Techniques Vary Widely

For more than a decade, the Society for Academic Emergency Medicine (SAEM) has produced a case-based ethics curriculum for trainees. "We had hoped that residency program directors incorporate those into their teaching," says Padela, who chairs SAEM's ethics committee. Padela would like to see more focus on didactics and case-based discussions.

"Ten years ago, it was a PowerPoint presentation and description of learning points," says Padela. "Maybe we need something more interactive."

The Accreditation Council for Graduate Medical Education and the American Board of Emergency Medicine (ABEM) both require clinical ethics education in residency training. Although most programs do include ethics in the curriculum, "teaching techniques vary widely," says **Catherine A. Marco**, MD, FACEP, professor in the department of emergency medicine at Wright State University in Dayton, OH.

Ethics is included in the Model of the Clinical Practice of Emergency Medicine, which serves as the basis for the content specifications for

EXECUTIVE SUMMARY

Emergency medicine trainees lack ethics knowledge, found a recent study.

- Residents had the most trouble with assessing decision-making capacity.
- Residents with knowledge gaps perceived themselves to be prepared.
- Having an ethics module in place was not linked to higher scores.

ABEM exams. This includes areas such as professionalism, conflicts of interest, diversity awareness, electronic communications, medical ethics, end-of-life and palliative care, regulatory and legal issues, and stewardship of resources.

"Personally, I advocate for case-based discussions to highlight the importance of the practical application of principles of bioethics to the bedside," says Marco.

Padela says just as residents learn clinical pathways through actual cases, "that's how we should also treat ethics, so it sticks in people's heads and [they] can respond to it when they see it in real life."

If trainees want to supplement their clinical expertise, such as cardiovascular knowledge, there are appropriate courses to provide it. The same cannot be said of ethics. "There are no dedicated emergency medicine ethics conferences or training programs," notes Padela. Residents find themselves overwhelmed with coursework focused on patient care and clinical sciences.

"They don't appreciate the ethical challenges, sometimes, until in clinical practice — when they are the person who has to deal with these issues," says Padela. ■

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Case-Based Approach to Ethics Education: Consistency Is Goal

Ethicists have another resource to turn to for challenging dilemmas: *A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care*. "We wanted to contribute to where we thought there was a huge learning gap, where a lot of consultants could really enhance their skills," says co-author **Courtenay R. Bruce**, JD, MA.

Authored by the American Society for Bioethics and Humanities (ASBH) Clinical Ethics Consultation Affairs Committee, the book is one of the resources recommended for individuals preparing to take the ASBH's Healthcare Ethics Consultant-Certified exam. In a recent paper, the authors described how and why the book was developed.[1]

Existing resources do a good job of covering bioethics topics. "But where they fall short is, they cannot provide the experiential learning — what it's like to actually do ethics consultation," says Bruce, an associate professor at Houston Methodist's Institute for Academic Medicine

Some teaching materials do provide case studies. Typically, the case is presented, then the reader is asked to analyze it. This gives the impression that cases unfold in a linear fashion and that the facts remain as they are at the onset of the case.

"The reality is cases rarely, if ever, unfold neatly. New facts are introduced all the time as the case evolves," says Bruce.

To reflect the real-life experience of addressing an ethical dilemma, the authors introduced new facts to the 12 featured cases — nine involving adult patients, three involving minors. "We present part of the case, then embed a question and change the facts up. You are making decisions all along the way," says Bruce.

One case begins with two family members at the same hierarchical level and asks which one should be the surrogate. Further along, another person enters the picture when end-of-life care decisions need to be made. A patient interview is conducted, but the ethical issue remains unresolved. Thus, another family meeting should be called.

Co-author **Jane Jankowski**, DPS, explains, "To mimic the real process, you have to stop and think before you take another step. We are asking people to apply their knowledge of ethics at various points in the case."

Less Variation Is Goal

Ethics resources typically do not include procedural elements

or specify the types of consultative activities that are used to manage cases such as patient interviews or family meetings. "All those activities that we do are rarely discussed," says Bruce.

Ethicists may wonder what they should be looking for when determining whether a family meeting was productive, for example. "To do consultation well, and to really be accepted in the hospital, we think the clinical ethicist really must master those procedural elements," says Bruce.

Although the book is aimed toward clinical ethicists, much of the material is applicable to clinicians. How to conduct a family meeting, or how to elicit patient understanding, says Bruce, "should be a core skill."

Expertise of clinical ethicists varies even within the same institution. "To try to reduce that variation, we thought it was important to lay out some standards," says Jankowski, an associate staff ethicist at the Cleveland (OH) Clinic's Center for Bioethics.

A consistent procedural approach is necessary to ensure quality. "It's OK to have different styles. But if you're approaching cases very differently — such that it affects your analysis — I don't think that is appropriate," says Bruce.

Reducing variation is an overarching goal in healthcare to improve patient safety and the overall quality of care. "We see that all over the place, in core measures and performance measures," says Bruce. "This is definitely a step in that direction." ■

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Up to 20% of Patients Excluded From Transplant Due to Lack of Social Support

Social support is one of the factors providers use to determine whether a patient is a candidate for transplant. Recent research suggests this longstanding practice is ethically problematic and should be reconsidered.

"In studying transplant disparities for over a decade, it became clear that vulnerable populations have a much harder time being listed for transplantation," says **Keren Ladin**, PhD, MSc, director of research at Tufts University's Research on Ethics, Aging, and Community Health Lab in Medford, MA.

Providers often cite lack of social support as a reason for excluding a patient. "This struck me as odd given the lack of evidence demonstrating the importance of social support," says Ladin.

In no other area of healthcare are patients excluded from life-saving treatment merely because they do not have friends or family available. "Conditioning a person's ability to pursue life-saving treatment on social factors is ethically problematic," says Ladin.

Ladin set out to learn more about how social support factored into the decision-making process. In one study, 584 transplant providers compared two hypothetical patient profiles and selected one for transplantation. Social support was the second most influential factor they used.[1]

In another study, 551 transplant providers from 202 centers estimated that on average, 9.6% of patients evaluated in the prior year were excluded due to inadequate support.[2]

While the researchers suspected social support was important, they were a bit surprised to see just how determinative it really was.

"I could not have guessed that 10% of all patients evaluated would be turned away due to social support considerations, nor that at some centers, up to 20% of patients are excluded," says Ladin, lead author of both studies.

Although social support is widely considered by providers, there is no clear-cut definition. "This subjective criterion may be vulnerable to bias and used to exclude patients who seem 'risky,'" says Ladin.

About 67% of providers felt patients of low socioeconomic status were disproportionately impacted. Most providers felt Centers for Medicare & Medicaid Services guidelines related to social support evaluations are unclear. "Many providers thought their own center's

social support evaluations were not neutral or impartial," adds Ladin.

Nearly 25% of respondents believed that using social support in listing determinations was unfair, or were unsure. Providers were less likely to think the practice is fair if:

- they believed that social support disproportionately disadvantages low-income persons.
- they do not always inform patients that they were not listed due to social support.

In contrast, providers who thought their centers did have clear and consistent guidelines for social support evaluations were more likely to think the social support criteria are fair.

Much of the literature on transplant disparities has examined disparities that occur after the listing decision. "However, there are reasons to believe that disparities prior to waitlisting are perhaps more significant, underreported, and understudied," says Ladin.

In other health contexts, subjective criteria such as social support are known to be challenging for vulnerable populations to meet.

"These have been shown to be susceptible to implicit bias. However, our study is one of the first to study it in the transplantation context," says Ladin.

The degree to which implicit bias affects providers' perception of how much social support a patient has is not well-understood.

"We need to understand how showing up with friends and family affects providers' perceptions of patient deservingness and potential to succeed with transplant," says Ladin.

Data also are scarce on effectiveness of interventions that could bolster social support and help patients in the important post-transplant period.

"Our studies demonstrate that providers overwhelmingly rely on this criteria and want this criteria to be reformed and that approaches to evaluating social support [should] be standardized," says Ladin.

The studies' findings suggest that transplant centers should not rely exclusively on social support to exclude patients. Instead, says Ladin, "They could use social support to identify patients who could benefit from additional support and care coordination."

"SUCH POLICIES RUN THE RISK OF FURTHER MARGINALIZING THE DISENFRANCHISED, INCLUDING THE POOR AND THE MENTALLY ILL, AMONG OTHERS."

The application of medical criteria to vet patients for organ transplantation is standard practice since transplants are a scarce resource, says **Leslie M. Whetstine**, PhD, chair of the IRB at Walsh University in North Canton, OH. "Success for those in critical need must be optimized," says Whetstine. While guidelines vary, some medical contraindications for transplant include active substance abuse, current malignancy, or morbid obesity.

"On the face of it, listing decisions based on such metrics ostensibly limits bias," says Whetstine. It ensures that organs are allocated fairly, based on the assumption that medical criteria are purely objective and can be applied across populations broadly.

"But screening on the basis of medical criteria is not as straightforward as we would like to believe," says Whetstine. For example, chronic illness is more prevalent in people with lower economic status. This speaks to the added caution needed if patients are going to be excluded based on non-medical factors.

"Such policies run the risk of further marginalizing the disenfranchised, including the poor and the mentally ill, among others," says Whetstine.

Denying candidates based on judgments of social worth, such as someone's occupation, is a clear violation of the ethical principles of justice and respect for persons.

"Allocation based on life expectancy or previous transplant, where the outcomes are less clear, raise a complex of issues for analysis," says Whetstine.

As for the practice of excluding patients on the basis of inadequate social support, "this has been recently challenged due to a lack of evidence and variation in application," says Whetstine.

Policies directing organ allocation must consider how medical and nonmedical factors are weighed in a society where wealth and health disparities are significant.

"These discussions must be informed by an interdisciplinary approach that involves medicine, the social sciences, and the humanities in order to develop and implement sound, just policies," says Whetstine. ■

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SOURCE

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Burnout Intervention Dramatically Reduced ICU Turnover

As awareness of burnout in ICU providers continues to increase, data on effective solutions are beginning to emerge. A recent study paints a clear picture of the financial impact on hospitals if burnout goes unaddressed.

The participants were 198 ICU nurses at eight adult ICUs in France. One group of nurses that took part in a five-day program including education, role play exercises, and debriefing experienced a lower prevalence of job strain at six months compared to nurses who did not receive the intervention.[1] Absenteeism was 1% in the intervention group, compared with 8% in the control group. Four nurses from the intervention group left the ICU during the six-month follow-up period, compared with 12 from the control group.

"The study showed some really impressive effects. As someone with a background in ICU nursing, this is an exciting finding," says **Jennifer Seaman**, PhD, RN, an assistant professor in the University of Pittsburgh School of Nursing's department of acute and tertiary care who co-authored a recent paper on this topic.[2]

The National Academy of Medicine recently launched a two-year collaborative to promote clinician resilience and well-being. "This is such a pressing and alarming problem in the U.S., for both ICU nurses and physicians," says Seaman. "It is encouraging to see this issue moved to the forefront."

Institutions are increasingly acting to address burnout, but lack of data on effective interventions remains a barrier for many. "It's unclear if the French study's outcomes would be duplicated in the U.S. setting," says Seaman. One reason is that the participants had fewer years experience in the ICU than nurses typically have in the U.S., with a somewhat different role.

"It's not clear if this would generalize to a more experienced workforce. But the findings give us food for thought," says Seaman.

Nurses' ability to participate in interventions is another obstacle, as most work 12-hour shifts. Whether individual interventions, shared activities, or a combination of both is best is not well-studied. "So much work needs to be done to better understand what works," says Seaman.

For institutions weighing whether to commit time and resources, the promise of reduced turnover and absenteeism is a strong motivator. "When experienced people leave, there is a knowledge vacuum that affects others in the workplace, as well as patient care," explains Seaman. "It's a deleterious cycle."

Hospital leaders, of course, are more comfortable implementing options that already have demonstrated effectiveness. "We are at the point now where we are looking to find those interventions that will be feasible and effective and sustainable," says Seaman.

The mere fact that job strain — and resulting burnout — is now widely acknowledged and openly discussed is notable. "We are in a great place right now," says Seaman. "There's recognition that there's a lot at stake if workplace stress is not addressed — beyond just that one clinician." ■

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SOURCE

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CME/CE QUESTIONS

1. **Which is true regarding hospitalized children with chronic critical illness, according to a recent study?**

   a. Few received palliative care or ethics consultations.
   b. Many who received palliative care consultations felt providers' expertise was lacking.
   c. Palliative care consultations were linked to increased stress for families.
   d. Providers' views on what constitutes an acceptable quality of life was more heavily weighed than parents' wishes.

2. **Which did a recent study find regarding emergency medicine residents' knowledge of ethics?**

   a. Most programs used dedicated ethics modules.
   b. Trainees in programs with dedicated ethics modules showed adequate knowledge.
   c. Gaps in clinical ethics knowledge appear to be prevalent.
   d. Residents who perceived themselves as better prepared had higher scores.

3. **Which is true regarding patients excluded from transplant due to lack of social support?**

   a. Most transplant centers no longer use this criterion due to compelling evidence of implicit bias affecting providers' judgment.
   b. There is clear evidence linking social support to outcomes.
   c. Current guidelines require providers to cite multiple factors in addition to inadequate social support in order to exclude a patient.
   d. Providers exclude about 10% of patients on average due to inadequate support.

4. **Which did a study find regarding an intervention to prevent burnout in the ICU setting?**

   a. Absenteeism and vacancy rates decreased significantly.
   b. The program was not cost-effective for hospitals.
   c. Role play exercises were linked to increased job strain for many nurses.
   d. Only more experienced ICU nurses benefited.