MEDICAL ETHICS ADVISOR®

YOUR PRACTICAL GUIDE TO ETHICS DECISION-MAKING

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INSIDE

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Patients, Families Viewing Ethics Consult Notes in Real Time

Like all other healthcare providers who document in the medical record, ethicists will need to write their notes while keeping in mind who might read them as a result of the Cures Act, which requires hospitals to provide immediate access to electronic medical records.[1]

"It's likely to give most ethicists pause to give patients access to all of their notes," acknowledges **Tim Lahey**, MD, MMSc, director of clinical ethics at University of Vermont Medical Center.

Ethics notes include evaluations of patient decision-making capacity, surrogate decision-maker motivations, and other similarly delicate issues. "Yet if our multidisciplinary conversations have been robust and open, there should be no surprises in our notes," Lahey says.

The Cures Act allows healthcare institutions to blind patients to some aspects of the electronic health record. "But it seems paradoxical to be less transparent about ethics consultation notes compared to other aspects of the medical record," Lahey observes.

It may make sense to preserve the privacy of such deliberations in rare circumstances. "But we should not define the routine process around edge cases," Lahey says.

In complex cases, the best ethics notes are teaching tools as well as consultation notes, says **Kenneth W. Goodman**, PhD, FACMI, director of the University of Miami (FL) Miller School of Medicine's Institute for Bioethics and Health Policy. In reading the ethics notes, clinicians often glean insights on how the ethics service contributes to patient care. Patients, along with their surrogates and proxies, will be able to learn from such consultations. "Though it will be unsettling at first, we now must join our colleagues in medicine, nursing, social work, and other clinical practices in writing better, clearer, and more informative notes," Goodman offers.

For some ethicists, this may be a good time to reassess the goals of ethics notes. "We have a rare opportunity to reimagine the ethics consult note and ensure it helps make clear the essential role of ethics in clinical care," Goodman explains. Ideally, ethics notes describe conflict without judgment

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and state facts without prejudice, with recommendations explained in simple terms. "This can educate and inform those who read them why we reach the conclusions we do," Goodman says.

Sharing ethics notes electronically could help patients to comprehend clinical ethics concepts.[2] "Most patients and families are not familiar with ethics consultation services and would benefit from being aware that such services exist and might be of useful assistance to them," says **Marion Danis**, MD, head of the section on ethics and health policy in the department of bioethics at the National Institutes of Health Clinical Center. Ethicists will need to "find a way to be candid and honest while also being sensitive to the way that patients may perceive their notes," Danis adds.

Patients gaining access to ethics notes is "part of a broader conversation on how much access, in general, patients should have to their charts," says **Lydia Dugdale**, MD, MAR (ethics), associate director of clinical ethics at NewYork-Presbyterian Hospital/Columbia University Irving Medical Center. Most healthcare providers support a certain amount of transparency, but problems can arise.

Dugdale says the two main issues are when patients identify errors in documentation, and when patients do not understand medical jargon and want an explanation. Dugdale's patients sometimes bring medical records to office visits and ask that mistakes be fixed, without realizing doctors are not authorized to correct someone else's documentation errors. Also, a 20-minute appointment hardly provides enough time to address the patient's medical concerns, let alone questions on previous documentation.

"It's easy to see how the ideal of transparency and open access becomes difficult to make reality," says Dugdale, director of the Columbia Center for Clinical Medical Ethics.

There are additional concerns when it comes to ethics notes that describe familial discord or complicated social situations.

"I have consulted on the question of unsafe hospital discharges for patients whose home environments might be intolerable for most, whether it's hoarding, filth, or poor sanitation," Dugdale reports.

Patients might be upset this information (or descriptions of substance use disorder, prison time, or harmful relationships) is in their medical record. Ethicists will want to keep this in mind when documenting.

"I don't believe they need to write their notes for a non-medical audience, but they should attend to sensitive issues with prudence and compassion," Dugdale suggests.

Not all ethicists are aware of the new requirements. "It's unclear to me whether clinicians understand just how much of the medical record is available to patients under the Cures Act," Dugdale says. "Most of us are so busy with the pandemic that we aren't putting much thought into tailoring notes differently because patients have access to them."

Ethicists may not place any formal consult note into the patient chart.

"They likely take notes, but don't place either the notes or a summary in the chart. I have heard of some keeping a 'shadow' chart separate from the main medical record," says **Charles E. Binkley**, MD, director of bioethics at Markkula Center for Applied Ethics at Santa Clara University. With patients accessing medical records, it is a good time

for ethics to change those outdated practices. "Ethics consult notes absolutely need to go in the chart," Binkley stresses.

Some ethicists may be concerned about legal liability with particularly contentious cases if the family can view the notes. However, says Binkley, "accurate and soundly reasoned documentation is actually protective."

Just as with any other note in the medical record, the potential vulnerability is if there are recommendations made that are not based on solid ethical reasoning.

"This really speaks to the need for solid training for everyone who is involved both in conducting and in documenting clinical ethics consults," Binkley says.

Ethics notes provide a summary of the encounter and the rationale for recommendations. It is the same kind of information the family can review on the clinical side, but ethicists typically use more of a narrative approach. Sometimes, it turns into several pages of text.

"A more succinct note is more likely to be read and understood," Binkley suggests. "Ethicists probably need to write notes like clinicians write notes."

If ethics notes mirror the way clinicians chart, it gives a consistent picture of the care provided. "As professional ethicists move into the clinical realm, they need to understand that they have to chart according to medical standards," Binkley explains.

The ethics notes will not include a physical exam or lab results, but should contain a good history, assessment of religious and social needs, family dynamics, decision-making capacity, the ethical question, and options for resolving it. "It's important to give the reasoning behind the recommendation and how it takes into account the patient's values," Binkley says.

A good clinical note reflects the fact shared decision-making took place. "In the same way, the ethics note should reflect some level of shared decision-making with the team, and also with the patient," Binkley says. "It's not, 'This is what you should do,' it's 'Here are some ethical options.'" ■

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Court Ruling on Life Support Withdrawal Affects Ethics Committees

A recent court ruling allows a family to keep a patient on life support over the objections of the clinical team and the hospital ethics committee.[1] This carries important implications for ethics committees in general, says **Thaddeus Mason Pope**, JD, PhD, HEC-C, professor of law at Mitchell Hamline School of Law in St. Paul, MN.

"Inappropriate treatment cases have received significant attention in both the legislature and courts over the past few years," Pope notes.

The most notable recent case involved an infant whose family disagreed with doctors about withdrawing life-sustaining treatment.[1] The case centered around the Texas Advance Directives Act, which gives doctors the right to stop treatment if they believe treatments are futile and are causing harm, after a review by the hospital's ethics committee.

In January 2020, a court ruled the baby could be removed from life support, but the Texas 4th District Court of Appeals reversed that decision in July 2020. The parties appealed back and forth all the way to the Supreme Court, which declined to review the case on Jan. 11, 2021, which leaves the baby on life support.[2] "Technically, the case goes back to district court for a trial on the merits," Pope notes.

But since the appellate court already provided an exhaustive analysis, it seems unlikely the district court will reach a different result. This means the hospital must continue life support during litigation before the district court, which could be many months. "Even if the district court rules for the hospital, the family will appeal and probably win since they already won before the same court of appeals," Pope explains. "Of course, a baby this catastrophically ill may die before all this litigation is complete."

The Texas case carries broader implications for ethics committees nationwide. "Hospitals may need to afford more procedural due process when deciding on whether to withhold or withdraw life-sustaining treatment without consent," Pope observes.

Courts in other states might rule similarly. "Therefore, ethicists and ethics committees should assess the fairness of their nonbeneficial treatment policies," says Pope,

adding hospitals should look to model guidelines provided by multiple critical care societies, which recommend multidisciplinary review.[3]

Many hospitals' nonbeneficial treatment policies were informed by the Texas law. For example, some policies offer only 48-hour notice of the committee meeting to determine appropriateness. That period may be too short for the family to adequately prepare and meaningfully participate. "Hospitals should look at how much notice other state agencies or private organizations give individuals before depriving them of life, liberty, or property," Pope offers.

Clinicians might not completely understand their legal obligations in these cases, says **Carl Coleman**, JD, a professor of health law at Seton Hall University. Some clinicians believe that, from a liability perspective, it is always riskier to withhold or withdraw life-sustaining treatment than to continue providing it, on the theory that physicians would never be held liable for keeping a patient alive. "But courts have been increasingly willing to impose damages when providers prolong the process of dying in violation of a patient's advance directive or the instructions of a legally authorized surrogate," Coleman notes.[4,5]

Ethicists can help educate clinicians about these issues by paying close attention to legal developments and supplying clinicians with examples of relevant court decisions. "Ethicists can also organize training programs featuring lawyers knowledgeable about legal issues in medical care," Coleman suggests. This might include hospital attorneys, law professors, or healthcare compliance or risk management professionals.

Serious disagreements about withdrawal of care are inevitable. "Cases of perceived inappropriate care seem to be on the rise," reports **Joelle Robertson-Preidler**, PhD, a clinical ethics fellow at Baylor College of Medicine's Center for Medical Ethics and Health Policy. Clinicians in those cases feel conflicted about their obligations to nonmaleficence and autonomy. "In such cases, ethicists can foster communication on both sides of the disagreement by reorienting discussions around what the patient would want for him or herself," Robertson-Preidler says.

A typical situation is a patient with a poor prognosis who is unlikely to live without life-sustaining technologies. Nevertheless, the family wants "everything" done. "The healthcare team often thinks in terms of medical indications and best interest standards for decision-making, while the family often thinks in terms of important patient and family values," Robertson-Preidler explains.

Ethicists' job is to bridge these gaps and redirect conversations around the patient's best interest. "That is where I believe ethics committees can be most helpful," Robertson-Preidler offers.

It is not always clear to clinicians what their legal obligations are in inappropriate care cases. "There are often many ways to resolve a particular issue ethically, but these alternatives may be narrowed by state law, and further by hospital policies," says **Olivia Schuman**, PhD, a clinical ethics fellow at Baylor College of Medicine and a clinical ethicist at Houston Methodist Hospital.

As liaisons between the family, the clinical team, and hospital administration, ethicists can clarify what a particular hospital is willing to support. For example, some hospitals might prefer to perform a time-limited trial of a treatment before involving an ethics committee. "Likewise, they can help hospital administration understand what kinds of ethical issues clinicians are facing that require additional hospital policy guidance," Schuman says.

Depending on state laws, an ethics committee could be in a situation to approve removal of life-sustaining treatment over the objections of family members. "But nobody wants that kind of resolution," Schuman adds. "It is better to prevent such a situation from happening in the first place with good communication." ■

COMING IN FUTURE MONTHS

- What "wrongful life" lawsuits mean for ethics
- Data on discrimination in healthcare
- Ethical concerns on nonessential drugs at end of life
- Integrating palliative care in critical care settings

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Ethics Services Want to Know How Consult Data Compare to Other Hospitals

Ethics services often struggle to obtain data to improve the quality of consults even at their own hospitals, let alone outside institutions. Yet some ethicists are forging ahead with this challenging proposition. "We are trying to move the bar on what we can assess, and move from the qualitative to the quantitative," says **Thomas V. Cunningham**, PhD, MA, MS, bioethics director of Kaiser Permanente's Southern California region.

Quantifiable data usually are limited in scope (e.g., the number of consults performed annually). Unlike clinical areas, ethics documentation leans heavily on a narrative approach. "What we are trying to do is take that same approach, but then quantify things," Cunningham explains.

Many ethics services are seeing a sustained growth in volume. "It then becomes harder to measure and assess the way we used to," Cunningham notes.

If a service conducts about a dozen consults a year, with roughly half of those highly complex cases, it is feasible to try to glean some insights on trends from narrative charting. "But when you are doing 120 consults, you have to create new ways of measuring to capture the quality, and assess the quality, and improve. We need some new methods for that," Cunningham explains.

Kelly Armstrong, PhD, director of clinical and organizational ethics at Inova Health System, developed the Armstrong Clinical Ethics Coding System (ACECS) tool, a standardized approach to data-gathering on ethics consults. The challenge was to sufficiently differentiate between different types of cases that involve the same theme. "Not all informed consent cases are the same," Armstrong observes.

Informed consent cases range from an adolescent partnering in her own medical decision-making about a birth plan, to a person with questionable capacity because of a mental illness, to a substitute decision-maker making questionable choices for a dying patient. "The coding system uses common definitions and avoids bioethics-specific language or specific medical technology or procedures. It can be used in any healthcare setting," Armstrong reports.

Armstrong hoped that when the codes were paired with other metrics, it would allow ethicists to observe institutional and cross-institutional trends. To find out, ethicists analyzed data on 703 cases over a two-year period at two academic medical centers, both of which used the ACECS tool.[1] Comparing ethics consults across institutions could be handled effectively as a way to improve quality, the researchers concluded. "The approach uses some advanced statistical methods that usually aren't applied to ethics consultation," Cunningham notes.

Researchers wanted to go beyond just comparing individual ethicists; instead, they compared ethics services at two different health systems. "That has not been done before," Cunningham says.

The same approach could be used to compare ethics services in hospitals nationwide.

"Once you can do two hospitals, maybe you can do the whole region. Or maybe you can do all major academic medical centers with a similar population," Cunningham offers. "We are trying to lay the groundwork for doing that in the future."

Currently, there is no standard way of collecting ethics consult data. "There's a lot of provincialism. They count different things because that's the way they started doing it," Cunningham reports.[2]

Armstrong wanted to create a shared language that was relevant not only to ethicists, but also to providers and administration. "Some hospitals may see only one case in years, but could look at the database and see that Hospital X sees multiple cases every year," Armstrong says.

To compare data, though, ethics services have to document in the same way. "Once we know we are using the same method, we can compare how we are doing, whether we are seeing different things, or whether we are seeing the same things," Cunningham explains. "It gives you a yardstick to assess yourself against external [data]."

This gives ethics consult services more insight into how they can improve, whether in terms of quality, volume, or both. It also allows them to advocate for more resources if they learn another hospital has higher volume or better quality. Then, once ethics services obtain additional resources (e.g., another full-time ethicist), the comparison data can show whether it paid off. "You invest in some personnel resources, and see if you grow the way you anticipated," Cunningham says. "Now, you can look outside of yourself, at another institution, to ask those questions."

Ethicists have relied on methods such as Excel spreadsheets to track consults. "You can do it that way, but it's inefficient," Cunningham notes. "It limits your ability to compare

yourself to other institutions because they are not doing it the same way."

Kaiser Permanente is adopting the ACECS tool in its Southern California region's 13 hospitals, which conduct around 1,200 consults a year. The tool was piloted at the West Los Angeles Medical Center for two years before it was adopted across the region. Ethicists will use the data to compare different hospitals within the system.

For instance, one hospital might conduct two consults every year for a patient who is unrepresented. However, another facility with similar volume might perform eight consults. "You can use comparison data to find the reason for the discrepancy," Cunningham explains. It could be that ethicists are coding consults differently, that some ethicists round in the ICU more often, that one of the hospitals sees more homeless patients who are more likely to be unrepresented, or another reason.

Data collected on ethics consults also can be used to support efforts to improve quality of clinical care. "The goal is to say, 'our metrics align with yours. You are looking at stroke, or length of stay; we can look at it, too,'" Cunningham says.

For example, clinical areas often track time frames from ED admission to inpatient beds for stroke patients. Ethicists can offer more nuanced insights on this quality metric. There might be a connection between a long length of stay and the chances of conflict between the family and the clinical team. "That is the kind of thing our coding system can do," Cunningham says. "We are hoping to align our data with clinical measures and use that to create conversations with the clinical team." ■

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Routine Ethics Consults Helpful if ECMO Is Considered

Early, routine use of ethics consults is helpful if extracorporeal membrane oxygenation (ECMO) is considered for a patient, according to a recent study.[1]

Researchers analyzed 20 ethically complex cases from 2018 and 2019, identifying four key ethical domains: Limits of prognostication, treatment burden, system-level concerns, and the intervention becoming a "bridge to nowhere."

"We undertook this study after leadership in critical care observed heightened moral distress among the care team with increased use of ECMO," reports **M. Jeanne Wirpsa**, MA, BCC, HEC-C, a clinical ethicist and research chaplain for spiritual care and education at Northwestern Memorial Hospital in Chicago.

At that time, ECMO was an emerging advanced medical technology for adults. The hospital's ECMO program had just started. "Ethics had been consulted on a couple of challenging cases, but only when conflict between the family and clinical teams had reached an intractable stage," Wirpsa reports.

The department decided to initiate a protocol for early, automatic ethics consultation for every patient placed on ECMO.

"This presented an opportunity to fill a gap in the research literature," Wirpsa says.

Thoracic surgery, lung transplant, cardiology, critical care anesthesiology, and nursing all were involved. The researchers were aware that caring for patients with limb ischemia, dyspnea, and other side effects of prolonged ECMO was challenging for the teams.

"But we underestimated the degree of distress experienced, especially by bedside nurses. It was enough to make them question their vocational path in some cases," Wirpsa says.

The researchers also knew there were uncertain indicators for initiating ECMO, but failed to recognize the moral weight of serving as the physician in charge of making that decision. "Our involvement facilitated a deeper appreciation of the unique challenges faced by each discipline," Wirpsa says.

Managing the expectations of family decision-makers was particularly challenging. "Patients come to our institution because we offer advanced medical interventions not available elsewhere," Wirpsa notes.

When a patient is placed on ECMO, usually emergently, families have begun to face the gravity of the situation. Suddenly, ECMO offers new hope. Even though the primary team explains ECMO will

be a time-limited trial and a bridge to recovery, transplant, or device, many families remained focused only on the possibility of hope. The many services involved further complicated the issue. "Ethics initiated regular care conferences among the various treating teams and with family decision-makers to reduce mixed messages," Wirpsa says.

By the end of the study, researchers had a much better sense of which patients and families would benefit most from ethics involvement. "The evidence, however, is not as definitive nor robust as we hoped," says Wirpsa, adding that more research is needed to measure the impact of ethics consultation on ECMO patients.

"There are generally two approaches to ethics consults for ECMO or potential ECMO patients. At some hospitals, ethics consults are reserved only for ECMO patients if a specific ethical issue is identified," says **Andrew Courtwright**, MD, PhD, external faculty scientist in the Yvonne L. Munn Center for Nursing Research at Massachusetts General Hospital. "Based on our institutional experience, this is typically when there is disagreement between healthcare surrogates and medical teams about whether it is appropriate to continue ECMO in a patient with a perceived poor prognosis."

In some cases, surrogates want to continue ECMO, but the medical team disagrees. In other cases, surrogates want ECMO discontinued, but the medical team believes it is premature because the patient could recover. "Ethics consultants in these cases play a relatively 'standard' role in terms of identifying stakeholders, discussing values, and mediating conflict," says Courtwright, an assistant professor of clinical medicine at University of Pennsylvania's Perelman School of Medicine.

An alternative model is to engage in routine ethics consultation for all patients on ECMO, even if a specific ethical issue has not been identified. "The advantage of this approach is that ethics consultants are exposed to a range of outcomes for ECMO patients, not just circumstances in which there is significant disagreement about continuing ECMO therapy," Courtwright says.

This gives ethicists the chance to find problems that have not become apparent. One study revealed consultants described an ethical issue in about one-fourth of cases when consults were conducted routinely for all ECMO patients.[2] In an "as-needed" ethics consult model, it is possible clinicians eventually may have requested an ethics consult.

"In our experience, however, early ethics involvement can help mitigate some of the moral distress associated with the care of critically ill patients on ECMO," says Courtwright, the study's lead author. This is particularly apparent for patients with unclear prognosis and significant treatment burdens.

The drawback of a routine ethics consult model is the amount of time and resources necessary to staff such a service. It is especially challenging for hospitals with many ECMO cases. If ethics consults are going to be conducted for all ECMO patients, ethics "should be prepared for a step-wise rollout in volume," Courtwright suggests.

After Massachusetts General Hospital started a routine ECMO ethics consult program, it took almost a year for the ethics service to build the capacity to see all ECMO patients within 48 hours. It was necessary to increase the number of full-time ethicists, develop interdisciplinary collaborations, and create a culture in which ethics always was consulted early.

"Ethics committees considering this approach should request financial and/or administrative support from their institution before embarking on this commitment," Courtwright offers. ■

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Frail Older Patients Receiving Higher-Intensity End-of-Life Care

Frail older adults undergoing emergency general surgery receive more aggressive end-of-life care than older adults without frailty, according to the authors of a recent study.[1]

"Older emergency surgery patients have very high rates of mortality in the six months after surgery," notes **Zara Cooper**, MD, MSc, FACS, one of the study's authors and Kessler Director of the Center for Surgery

and Public Health at Brigham and Women's Hospital in Boston. "The end-of-life care that these patients receive is of interest to surgical clinicians and policymakers who seek to improve patient and family outcomes and experience."

There were little data describing end-of-life care in older patients who die after emergency general surgery. "We sought to describe end-of-life trajectories for older emergency general surgery patients and, specifically, to compare patients with frailty to those who are not frail," Cooper reports.

Cooper and colleagues retrospectively analyzed data of 138,916 adults older than age 66 years who underwent partial colectomy, small bowel resection, laparotomy, adhesiolysis, or peptic ulcer disease repair between 2008 and 2014 who died within one year. Of this group, patients with any degree of frailty went to hospice less often, spent fewer days at home, and needed higher-intensity care at the end of life. "We were surprised to see that frail patients received higher-intensity end-of-life care, and had higher healthcare utilization," Cooper offers.

Frailty is well-recognized as a harbinger of adverse outcomes after surgery. Patients with more accurate prognostic understanding are less likely to choose high-intensity treatment at the end of life.

"Our findings suggest that the most vulnerable patients are potentially being subjected to the most burdensome treatment, have fewer days at home, and are not receiving hospice care," Cooper explains. Of individuals who survived hospitalization but died within one year, those with moderate-to-severe frailty were most likely to be hospitalized again, to visit an ED, or be admitted to the ICU vs. individuals who were not frail.

Overall, says Cooper, the study's findings "highlight opportunity for targeted interventions for all older patients, especially frail older adults, undergoing emergency general surgery to establish better prognostic understanding and discuss advance care planning before hospital discharge." ■

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Ongoing Ethical Concerns with Misleading Advertising by Cancer Centers

Recent guidance outlines ethical concerns when cancer centers advertise directly to the public.[1] The authors recommend these centers ensure fair and balanced promotion of cancer services, avoid exaggeration of claims, and provide data and statistics to support direct and implied assertions of treatment success.

Ongoing ethical concerns have been raised about cancer center marketing. A Truth in Advertising investigation focused on cancer centers using atypical patient testimonials in advertisements.[2,3]

"Before cancer center marketing is published, it should be reviewed by those familiar with medical ethical requirements and applicable advertising laws, which are meant to protect consumers," says **Laura Smith**, JD, Truth in Advertising's legal director. The authors of one paper studied how to ensure advertisements do not take advantage of vulnerable patients.[4]

"Hospital ethicists should work with administrators, clinicians, and the communications office to encourage and enforce a commitment to responsible advertising," says **Steven Woloshin**, MD, the paper's co-author and co-director of the Center for Medicine and Media at The Dartmouth Institute.

Woloshin says ethicists at cancer centers can help ensure ethical advertising by encouraging inclusion of balanced information about benefits and harms of tests and treatments. Cancer centers should establish explicit guidance for responsible marketing and prohibit the advertising of unproven or experimental therapies. Finally, Woloshin suggests formally testing marketing messages and submitting them for independent review.

"Just like the IRB reviews ads to recruit patients into trials, an entity could review ads targeting prospective patients for treatment at the center," Woloshin notes. The goal is to "ensure they are not misleading and do not generate false hope." ■

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Surrogates' Authority Varies on Mental Health Treatment Decision-Making

If a patient without decision-making capacity needs mental health treatment, clinicians will turn to the surrogate decision-maker. However, state statutes vary widely on the scope of authority given to surrogates in this particular situation.[1]

"For mental health treatments for incapacitated patients, some states allow default surrogates unrestricted decision-making, some allow limited decision-making, some allow no decision-making, and some do not address the matter at all," says **Paul S. Mueller**, MD, MPH, professor of medicine and biomedical ethics at Mayo Clinic College of Medicine and Science. Mueller and colleagues found eight states delegated broad authority to surrogates, 25 states prohibit surrogates from giving consent for specific therapies, and 13 states are silent on whether surrogates can make decisions.

"Advance directives can be very helpful in these situations. Again, this can depend on state law, but knowing patients' expressed wishes is always helpful," Mueller says.

Previous research of state statutes delineating the powers of default surrogates making decisions for patients who lack decision-making capacity revealed similar variation.[2] "Ethicists should be familiar with their respective jurisdictions' statutes and case law, especially those whose health systems cross state borders," Mueller says. ■

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Altruism Is Factor in Perceived Ethical Obligation to Share Health Data

Research participation often is viewed as a selfless act, with participants enrolling in studies with little expectation of reward or benefit in return. The assumption is most participate with the anticipation findings from research will help others. Investigators explored if this perception also was true in terms of allowing one's health information to be used.

"We wanted to understand the extent to which altruism, the sacrifice of one's well-being without expectation of reward to oneself, is associated with the belief that people have an ethical obligation to allow their health information to be used for research," says **Minakshi Raj**, PhD, MPH, an assistant professor in the department of kinesiology and community health at the University of Illinois at Urbana-Champaign.

Raj and colleagues surveyed 2,069 adults to learn how altruism contributes to the belief in an ethical obligation to share health information for research.[1] "Sharing health information can be a relatively passive act and an easy way for people to contribute altruistically to research," Raj says.

The study's findings suggest this belief is shaped by altruism, by one's experience with healthcare, and by general concerns on the use of personal information. The authors explored the relationship between feeling obligated to share health information and altruism, along with the conditions under which participants might not believe they have to share their health information, according to Raj.

Raj and colleagues found a person's belief in an obligation to share health information for research is complex. Altruism is associated with this belief, but so are notions of trust and privacy. They were surprised to find perceiving that discrimination based on ethnicity or race occurs in the health system was associated with a greater likelihood of believing there is an ethical obligation to share health information for research, according

to Raj. It is possible that perceiving discrimination makes people believe that allowing their health information to be shared could improve well-being and healthcare for communities that have been affected by discrimination.

Jodyn Platt, PhD, MPH, another study author, says these findings should "prompt ethicists in the clinical setting to challenge assumptions about risks and benefits." Ethicists can do this by engaging in deeper dialogue with research participants, says Platt, an assistant professor in the division of learning and knowledge systems at the University of Michigan. Researchers could ask direct questions such as: "What are your expectations about participating in research?" or "What are your hopes and concerns?"

As for ethical implications on the findings, Raj says assumptions about willingness to participate (or not participate) in research should be questioned. Just because people are generous and selfless, one cannot assume they are comfortable or willing to share their health information.

"Similarly, just because people have had negative experiences of discrimination does not mean they are reluctant to help others," Raj says.

The findings underscore the importance of good informed consent. Participants should understand how their health information will be used and, ideally, have a say in it.

"Ethicists might think about new ways to show participants appreciation for their contribution to science and society," Raj offers.

The study's findings suggest general altruism is different from the obligation to allow sharing of health information. "If we want to make an argument that people are obligated to participate in research, including research that uses only their health information, we need to find ways to recognize that participants are handing over their personal information for a cause that they may never benefit from personally," Raj says. ■

REFERENCE

1. Raj M, De Vries R, Nong P, et al. Do people have an ethical obligation to share their health information? Comparing narratives of altruism and health information sharing in a nationally representative sample. *PLoS One* 2020;15:e0244767.

Nurse Leaders Report Ethical Dilemmas Related to Patient Care, Work Environment

As part of a nursing leadership course, students at the University of North Carolina Wilmington interview nurse leaders from acute care and outpatient settings. One of the interview questions is, "What ethical dilemmas have you faced?" The students submitted in-depth, thoughtful responses from their interviews.

"As we began to review the answers, we realized we were getting high-value feedback that had the potential to impact how we educate nurse leaders," says **Melissa Scott**, PhD, RN, an assistant professor at the School of Nursing.

The nurse leaders discussed ethical dilemmas involving patient care issues, including end-of-life care, care planning, and responses to child and elder abuse. They also described ethical difficulties in cases of disciplinary issues, such as drug diversion or staff not following hospital policies. One nurse leader talked about an employee who was consistently late for work.

"She was a single mother who had very little help, and the school would not accept her child earlier enough for her to make it to work on time," Scott recalls. Despite feeling empathy for this employee, the nurse leader had to follow hospital policy, which required disciplinary action.

Another nurse leader described disciplining an employee who went against hospital policy. However, in this case, following the policy likely would have resulted in patient harm. "Both of these situations created ethical dilemmas," Scott says. "The employees were doing the best they could, yet the leader had the obligation to follow organizational policy."

The faculty decided to use these insights to develop content to add to nurse leader curricula and professional development courses. *(http://bit.ly/3rBVkBz)*

"Patient care issues and work environment issues require critical reasoning. Nurse leaders need help with both of these issues," Scott notes.

Ethicists could offer this help by taking a more active role in developing educational content for nurse leaders. "I think it would also be helpful for the ethicist to deliver the education as well," Scott says.

Formally, the ethicist could deliver content in a classroom in collaboration with the organization's professional development team. "Informally, in-services, email blasts, and joining in-unit huddles are a possibility," Scott adds. The ethicist

can make sure nurses know the easiest way to contact ethicists. Some nurses do not realize what ethics can offer them or think it is too time-consuming to involve the ethics team. "Ensuring the leaders of an efficient process for asking for a consult might encourage leaders and staff to reach out for assistance," Scott says. ■

Nurse 'Ambassador' Programs Pose Significant Ethical Concerns

Some pharmaceutical companies offer "nurse ambassadors" to assist patients on complicated medication regimens. The authors of a recent paper examined ethical issues posed by these programs.[1] "Nurses, including nurse practitioners, need to pay attention to the fact that they are becoming targets of pharmaceutical marketing," says **Diana J. Mason**, PhD, RN, FAAN, the paper's co-author and a senior policy service professor at the George Washington University's Center for Health Policy and Media Engagement.

Nurses who are approached by a drug company for this kind of position should think twice about becoming involved in this new role. "Consider the ethical challenges that may present. Discuss with the company how to handle these," Mason says.

The goal is to define ahead of time the ethical lines that will not be crossed. "Be mindful that you must always act in the best interests of the patient," Mason offers.

There is evidence indicating doctors who received payments related to specific drugs prescribe that drug to patients more often than doctors without those financial ties.[2,3] Mason says the same ethical concerns hold true for nurses. However, since nurses previously were not prescribers, they were seldom targeted by pharmaceutical companies.

"Discussion of the ethical issues related to pharmaceutical marketing has seldom been included in nursing curriculums," Mason notes.

This changed after nurse practitioners gained prescriptive authority. It is particularly relevant in states that provide nurse practitioners with full practice authority, meaning nurses can prescribe with no physician supervision or mandated collaboration.

"Nurse ambassador programs are an example of the way pharmaceutical companies are using nurses, who may not be aware that the practice really has them straddling a line in terms of unethical behavior," Mason observes.

One of Mason's colleagues took a position with a major pharmaceutical company and became a top seller. "Physicians trusted her because she was a nurse, smart, and knowledgeable. She also knew how to talk with physicians," Mason says.

When Mason noted the nurse was promoting a medication that was quite controversial, the nurse replied, "I'm a sales rep, not a nurse."

"But she was still a licensed RN, and used her knowledge, skills, and reputation to be successful at her job," Mason says.

Another colleague was making a lot of money working for pharmaceutical companies as a consultant. "She spoke for them and noted that they prepared her slides and drafted papers for her, making it easy work. She hadn't thought that this was wrong," Mason recalls. After reflecting on this marketing strategy that pharmaceutical companies used, the nurse quit speaking for the companies. One issue is the nurse ambassador programs are largely unregulated at the federal level. "It may be up to the nursing profession itself, and state licensing boards, to convey to nurses that the programs may violate professional ethics," Mason says.

Ideally, Mason says the National Council of State Boards of Nursing would issue some guidelines to answer the question: What constitutes unethical practice as a nurse ambassador? "Perhaps they could partner with some nurse ethicists to develop guidelines," Mason suggests.

Nurse ambassador programs have been successful for pharmaceutical companies. "But there is a dearth of discussion within the nursing community about them," Mason reports.

The overarching issue is nurses sometimes are used wittingly or unwittingly by pharmaceutical companies to increase their profits. "And it's not always in the best interest of patients," Mason adds. ■

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1. Yang YT, Mason DJ. Problematic promotion of medications by nurse ambassadors: Legal and ethical issues. *JAMA* 2021;325:345-346.
2. DeJong C, Aguilar T, Tseng C, et al. Pharmaceutical industry-sponsored meals and physician prescribing patterns for Medicare beneficiaries. *JAMA Intern Med* 2016;176:1114-1122.
3. ProPublica. Dollars for doctors: How industry money reaches physicians. http://bit.ly/2MNB1T3

MEDICAL ETHICS ADVISOR®

CME/CE QUESTIONS

1. **Which is true regarding a recent court ruling on life support withdrawal without consent?**
   a. Review by the hospital's ethics committee is no longer required if doctors agree treatment is futile.
   b. Hospitals have instituted less stringent requirements for providing procedural due process when deciding on whether to withhold or withdraw life-sustaining treatment without consent.
   c. In assessing non-beneficial treatment policies, hospitals should look to model guidelines provided by leading critical care societies, including multidisciplinary review.
   d. Policies should make it clear that it is always riskier to withhold or withdraw life-sustaining treatment than to continue providing it.

2. **Which did the authors of a recent study find regarding data for quality improvement on ethics consults?**
   a. Ethics services should place more emphasis on a narrative approach to improvement rather than using quantifiable data as ethics is narrative rather than quantitative.
   b. Comparing ethics consults across institutions could be an effective approach to improve quality.
   c. Narrative approaches to charting are more effective for quality improvement at institutions with high consult volume.
   d. Ethics services should focus on metrics unique to ethics instead of attempting to align with clinical metrics.

3. **Which did the authors of a recent study find regarding frail older patients and end-of-life care?**
   a. Frail older adults undergoing emergency general surgery receive more aggressive end-of-life care than older adults who are not frail.
   b. Lower-than-expected rates of mortality in the six months after surgery.
   c. Frail patients went to hospice often.
   d. Patients with more accurate prognostic understanding are far more likely to choose high-intensity treatment.

4. **Which did a study reveal regarding surrogates' authority for decisions on mental health treatment?**
   a. Federal statutes address this specifically, overriding state statutes.
   b. States allow default surrogates unrestricted decision-making.
   c. States prohibit surrogates from giving consent for specific therapies.
   d. State statutes vary widely on the scope of authority given to surrogates in this situation.