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INSIDE

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Are Ethics Committees Effective? Some Are Being Replaced with Alternative Model

The vast majority of hospitals have ethics committees. Yet these committees vary in terms of their effectiveness, leading some ethicists to conclude it is time for a new approach.

"The field has matured and professionalized so much since the inception of ethics committees. It's reasonable to experiment and try new things. We can have thriving ethics programs using new approaches," says **Hilary Mabel**, JD, HEC-C, core faculty and healthcare ethicist at Emory University Center for Ethics.

Mabel has worked with multiple ethics committees, some high-functioning, and others less so. "We started to question, 'Should we be doing clinical ethics this way? Are we doing it this way just because this is the way it's always been done? Would another way be better?'" says Mabel.

One approach is the professional clinical ethicist (PCE)-primary model, which Mabel and co-authors describe in a recent paper.[1] The model dissolves the traditional ethics committee and places primary responsibility for ethics work on PCEs. "In place of ethics committees, new structures can be created to allow former ethics committee members and other hospital staff to collaborate with ethicists and engage in meaningful ethics work," says Mabel.

One form of this model was implemented at Wellstar, Mabel's previous institution, in 2022. At Wellstar, ethics committees were discontinued. In their place, the ethics program initiated these approaches:

- a regular ethics grand rounds series for systemwide education;
- an ethics liaison network for highly engaged staff seeking advanced education and camaraderie;
- an ethics advisory group to weigh in on strategic directions and other goals.

Mabel expects that more ethics programs will consider the PCE-primary model as time goes on. "Talking about the PCE-primary model helps soften the taboo of deviating from the traditional ethics model," says Mabel. "If first movers find success with it, other programs may

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increasingly consider innovating their programs as well."

Implementing the PCE-primary model poses multiple challenges, however. It is likely to result in significant pushback from longstanding members of the ethics committee. "You have to develop a thoughtful plan for what you are going to replace ethics committees with — for what comes next," advises Mabel. "Patience, adaptability, and creativity are important." Since everyone in healthcare is familiar with ethics committees, it's necessary to get people comfortable with the idea of a different model. "You have to be clear in your vision. Getting buy-in from hospital leadership is essential for a transition process, as well," says Mabel.

There is a risk of losing valued, experienced ethics committee members. Some will choose to discontinue collaborating with the ethics program under the new model. "For folks who see the ethics committee as part of their professional identity, there may be hurt feelings," says Mabel. "There is a need to retain these folks in the next iteration of your ethics program and maintain those strong relationships."

Healthcare providers with an interest in ethics sometimes want to know, "What does the ethics committee do?" "The purpose was hard to define," recalls **Joshua Crites**, PhD, a staff ethicist, regional ethicist, and co-director of the Cleveland Fellowship in Advanced Bioethics at Cleveland Clinic.

Crites and colleagues were concerned that the ethics committee was not as productive as it could be, even though there were many invested members. "You've got a group of interested people. They come to the meeting, and they hear about cases and get some self-education. But the output from that is sometimes limited, because they may not have the time or expertise to deliver that education outside of the committee itself," explains Crites.

Some healthcare providers wanted to become ethics committee members, but their schedule would not permit them to attend meetings. Typically, ethics committee meetings were held at 7 a.m. or 12 p.m. "Clinical nurses, in particular, have difficulty getting to those meetings and getting coverage for their patients. They sometimes have work restrictions where they can't do things on days when they are not working," says Crites. The same issue came up with members of the community, many of whom were at work during the committee meeting times.

To address these issues, and make the ethics program overall more effective, Crites and colleagues made some changes. Professional clinical ethicists still are the ones who do the actual bedside consultation work. However, ethicists dissolved ethics committees at Cleveland Clinic Ohio hospitals and replaced those with a new model. "A structured, tiered network allows healthcare professionals to incorporate a passion for, and commitment to, ethics into their professional development. With the new model, we provide a clearer set of expectations, and we teach those expectations in ways that we couldn't as a committee," reports Crites.

The network for healthcare professionals also has a community-based counterpart. "We have a parallel group of people from the community who function alongside us," explains Crites. Without some of the structural limitations of a committee model, greater representation of communities and higher community member engagement is possible.

The new ethics model also is more efficient. Previously, Crites and colleagues had to go to 13 different ethics committees within the health system to obtain input if a policy needed updating. Some of the committees met only quarterly, delaying review and input.

Many policies, such as the system's do-not-resuscitate policy, required specialized knowledge rather than input from all committee members. "Relatively few members had expertise in policy work," explains Crites. Similarly, contributing to ethics initiatives (such as quality improvement of the Ethics Consultation Service) was limited by the committee structure. "You've got only a couple people with the time and interest to engage in those kinds of things," explains Crites.

Now, PCEs can draw on a group of people throughout the healthcare system and the community to form goal-driven and time-limited task groups. When a policy comes up for review, or an organizational issue would benefit from ethics guidance, ethicists query the network for volunteers.

The new model provides standardized core education for members, known as "ethics ambassadors." Members obtain professional growth and development, as opposed to just being an attendee at a committee. "That's really the idea here — to create a network of people who are more fulfilled in their jobs because they understand some of the ethics issues that are at play. They are able to help their colleagues in a way they were not previously," says Crites.

All participants are expected to be able to identify ethics issues on their units. For example, an ethics ambassador may hear a colleague say that the family is struggling to identify what is important to the patient. If so, the ethics ambassador would identify the need to clarify patient values and ensure goal-concordant care. "That's something that we can empower all healthcare professionals to do directly," says Crites. In other cases, the issue is a clinical problem, not an ethics problem. "It helps orient everyone involved to come to a solution, if you know what framework to apply to solve the problem," says Crites.

Ethics ambassadors also are expected to recognize when they need support from a professional clinical ethicist. "We are not asking people to become ethicists or do ethics work. We are endeavoring to empower them to do the work that they know how to do a little better. They are able to more confidently approach some of the ethical aspects of their care that they see every day," explains Crites.

An ethics ambassador might say, "It sounds like not everybody is on board with the plan of care. Let's talk about that." "Sometimes it comes as a surprise when you are moving forward and one person is not OK," says Crites. Ethics ambassadors routinely ask questions such as: "Have we talked to all the right people? Do they know what the plan is? Do they support the plan? How can we support them?"

"If we can get 10 more people in every hospital asking those kinds of questions, that is the benefit of having a more diverse group of healthcare professionals involved in ethics work," says Crites.

Ethics is interwoven into everyday patient care, as opposed to being restricted to monthly or quarterly meetings. "This makes ethics hyper-local at the bedside and accessible to caregivers in a way that an ethics committee can't," concludes Crites. ■

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Timing of Ethics Consults Varies by Diagnosis, Language, and Ethnicity

Farshid Dayyani, MD, PhD, joined the ethics committee at University of California Irvine (UCI) Medical Center in 2020. Then, the pandemic hit. "We were getting really busy at the medical center with consults, five or six a week. These were very difficult consults," recalls Dayyani, a medical oncologist at UCI Health and professor of clinical medicine for hematology/oncology at UCI School of Medicine. The hospital is located in Orange County, CA, which has significant Hispanic and Asian populations. "The diversity made it important to look for disparities in what we are seeing with ethics consults," says Dayyani.

Dayyani and colleagues wanted to know if patient characteristics (language, diagnosis, and race/ethnicity) affected the timing of ethics consult requests or the ethics team's recommendations. There were limited data showing some racial and gender disparities in delays to obtaining ethics consults.[1] The researchers saw the need for a more comprehensive analysis of ethics consults and reviewed charts of all patients seen by the Ethics Consult Service from 2017-2021.[2] Overall, the study demonstrated some clear differences and disparities for diagnoses, ethnicity, and language barriers. Some key findings:

• Patients admitted for COVID-19 had longer median times to ethics consults (19 days) from the time of

admission, compared to patients with other primary diagnoses (eight days).

• Both COVID-related illness and cancer diagnoses were associated with prolonged time from admission to ethics consult.

• The majority of consults (80%) involving cancer or COVID-related illness involved end-of-life recommendations.

In these cases, ethicists' recommendations usually involved changing the patient's code status to "do-not-escalate" care because it was not medically indicated or beneficial, withdrawal of life-sustaining interventions, or switching to comfort care only. "COVID has passed, but cancer has not. The implication here is to preemptively start goals-of-care discussions, before the patient is admitted with a complication from a terminal diagnosis," says Dayyani.

Conflicts at the end of life are one possible reason for the disparities in timeframes to ethics consults, suggests Dayyani. A common scenario: For a patient with a terminal condition, the clinical team feels continued treatment would be more harmful than beneficial. One patient's family might be receptive to the idea of a do-not-resuscitate order and hospice. Another family might demand that everything possible be done to sustain the person's life.

"That might reflect that, culturally, there is less willingness to speak until it's unavoidable. As a result of failed communication, the ethics consult is delayed," says Dayyani.

If a patient is getting unwanted, inappropriate care, but waits 20 days for an ethics consult, that patient is potentially being harmed as a result of the delay, adds Dayyani.

In such cases, identifying conflict earlier could facilitate ethics consults. "An ethics consult can be requested by any member of the team — the nurse, the physician, specialists, or hospitalists. Teaching the team to recognize the conflict and escalating it quickly to an ethics consult might shorten these delays," says Dayyani.

• Ethics recommendations did not differ based on whether the patient had decision-making capacity or not.

"That was reassuring that [individuals who perform ethics consults] are a highly objective group who are really trying to look at the best outcome for the patient from an ethical standpoint," says Dayyani.

• Spanish-speaking patients had longer median times to ethics consults (20 days) from the time of admission than English-speaking patients (seven days).

This indicates that language barriers could result in delayed ethics consultations. Possibly, clinicians are less likely to initiate prolonged discussions with the family if there is a language barrier because of the need to bring in an interpreter. "So, you try to manage things and delay the difficult discussions, until it comes to a point where you really can't avoid it anymore. That certainly might be an explanation for these delays," says Dayyani. ■

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Intervention Reduces Distress of Surrogates

Being a surrogate decisionmaker in the intensive care unit (ICU) can have long-term psychological consequences, including post-traumatic stress.[1,2]

"These individuals are charged with making life-and-death decisions on behalf of someone who may be beloved and central in their world, grieving because of the prospect of losing them — all the while contending with the unpredictable circumstances in the ICU. This can be a recipe for regret, guilt, and traumatic stress responses, among other poor psychological outcomes," says **Wendy Lichtenthal**, PhD, FT, FAPOS, founding director of the Center for the Advancement of Bereavement Care at Sylvester Comprehensive Cancer Center.

To support surrogates, Lichtenthal and colleagues created a brief intervention called Enhancing and Mobilizing the Potential for Wellness and Resilience (EMPOWER). The approach uses evidence-based mental health interventions to meet the needs of individuals who are unlikely to have time to engage in regular psychotherapy during an acutely stressful situation. Clinicians begin by identifying what the surrogate is struggling with the most. For some, it is the prospect of losing someone they care about deeply. Others have difficulty coping with other stressors in their lives. Next, surrogates are taught breathing, grounding, and mindfulness exercises to reduce their stress response. "We explain that these same tools can be used when communicating with the medical team or to help them tolerate difficult feelings," says Lichtenthal. Finally, the surrogates engage in a "coping rehearsal." This gives the surrogates an opportunity to think through how they would make decisions aligned with the patient's values, or how they would cope with other stressors. "The intervention gives space for surrogates to reflect on their own personal values as well as the patient's

values. An ethical challenge is that these are not always one and the same," adds Lichtenthal.

The researchers conducted a study to evaluate how feasible it was for surrogates to complete the intervention, how acceptable they found it, and whether it showed any promise in addressing the known struggles surrogates face.[3]

Sixty surrogates who reported an emotionally close relationship with the patient and/or significant anxiety, were randomized into two groups. One-half of the surrogates received the EMPOWER intervention and half received enhanced usual care. Three months post-intervention, researchers surveyed both groups. Surrogates in the EMPOWER group reported less grief intensity and less post-traumatic stress and depression. The group also was more satisfied overall with the care provided.

"The intervention empowers surrogates with tools to cope with and tolerate their distress rather than try to get rid of it," observes Lichtenthal.

For clinicians, it is important to remember that the surrogate's ability to take in information can be compromised. This is true even for clinicians who are excellent communicators. "In the surrogate's state of stress, they may not have the capacity to process what they are being told: Think of a deer in headlights," says Lichtenthal. "The ethical responsibility may therefore be to attend to the surrogate's psychological needs during these times."

Surrogates may feel pressured to make certain decisions or grapple with uncertainty over what the patient would want. Surrogates may feel conflicted in not wanting the patient to suffer, yet also wanting to do everything possible to extend their life. The study's findings suggest that clinicians can alleviate these burdens with a fairly simple intervention. "It would be wonderful to have evidence-based psychological care of surrogate decision-makers as the standard of comprehensive care in the ICU, wherever possible," concludes Lichtenthal.

Recognizing that family surrogates are not only acutely upset but also are confused — in part because of their strong emotions, is "a novel insight into the challenges of critical care," according to **Holly Prigerson**, PhD, one of the creators of the EMPOWER intervention and director of the Cornell Center for Research on End-of-Life Care. In Prigerson's view, the pertinent question is: How can someone be prepared for making life-and-death decisions for their loved one when they are in a state of shock and disbelief? "EMPOWER addresses the need to attend to the surrogate's emotions -- to empower them to confront the realities of the patient's situation, and thereby make better decisions on the patient's behalf," says Prigerson. ■

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Some Surrogate Decision-Makers Are Unprepared — or Unaware — of Role

One of the most important goals of advance care planning is to prepare surrogate decision-makers for their role, according to **Lingsheng Li**, MD, MHS, a research fellow in geriatrics and palliative care at UCSF. Yet Li and colleagues often heard the opposite from surrogates. Many admitted being entirely unprepared for the decision-making process.

"In particular, given disparities in advance care planning engagement and healthcare access, we wanted to better understand the experiences of surrogates from historically marginalized communities," says Li. The researchers combined data from two randomized controlled trials to look at a large dataset of 422 surrogate participants from diverse backgrounds.[1] Most (73%) of the surrogates were from minoritized groups, 15% had limited health literacy, and 38% were Spanish-speaking. Some key findings:

• Almost half (46%) of the surrogates reported that the patient had never discussed end-of-life medical wishes with the surrogate.

• Fifty-one percent of surrogates said that there was no formal documentation of the surrogate's role.

• All the surrogate participants in the study were identified by the patient participant as their medical decision-maker. However, 13% of surrogates reported that they had never been formally asked by the patient to play this role. Some surrogates only become aware of their role when clinicians

contact them after patients lose decision-making capacity. "One of our roles as palliative care physicians is to help surrogates navigate this process," says Li.

• The surrogate participants reported higher confidence for decision-making in the future than actual readiness for decision-making.

This reflects previous research suggesting that surrogates overestimate their confidence in advance of facing an actual decision.[2] "It is incredibly important for clinicians to help facilitate and encourage conversations regarding the patient's goals and wishes," underscores Li.

• Among historically marginalized participants, confidence and readiness scores were lower.

"There are a lot of barriers to advance care planning access for historically marginalized communities," observes Li. Disadvantaged socioeconomic status, language or cultural discordance, and mistrust of the healthcare system all contribute to lack of advance care planning. "We need more language-concordant and culturally aligned interventions and community outreach programs," says Li.

Overall, the study findings demonstrate that surrogates often are in a difficult position. Many are called on to make difficult medical decisions for others in urgent or emergent situations that leave them feeling unprepared and highly distressed. "Clinicians can encourage and remind patients to include their potential surrogates in conversations about medical planning and preferences for end-of-life care," offers Li. The Prepare for their Care program (https://prepareforthecare.org) is one resource that can prepare surrogates to start those conversations. More than 60% of surrogate participants had accompanied the patient to a doctor's appointment or hospital visits. "These visits are important opportunities for clinicians to talk with both the patient and the surrogate about care planning, and provide resources that help improve surrogate preparedness," says Li.

Even with preparation, many surrogates still find it difficult to make choices about withholding or withdrawal of life-sustaining therapies. Some family members were very clear that they would not want to be intubated or remain intubated and on mechanical ventilation, "Even so, there can be a sense of extreme guilt where surrogates feel they are responsible for the patient's death," says **Ann L. Jennerich**, MD, an assistant professor of medicine at University of Washington.

Some surrogates feel pressured to make decisions about code status or withdrawal of life-sustaining therapies when they are not ready to make those decisions.

"Often, we need to give people space and time," says Jennerich. Clinicians may have very conclusive evidence that a patient's outcome is not going to be acceptable based on the patient's previously expressed values. However, it might take time for a surrogate to feel comfortable moving forward with a plan that reflects those values.

"Repeatedly asking about code status or having multiple providers bombard surrogates with negative news can generate distress," warns Jennerich. This can prevent clinicians from reaching consensus on the next best steps for the patient's care. Jennerich tries to emphasize that even though surrogates are the ones making decisions, "we are a team." The ethicist's job is to help elicit information about the patient, allowing the surrogate to make the decision the patient would have wanted given the circumstances. In some cases, that means discontinuing life-sustaining therapies. The surrogate, ideally, is guided to the ethical decision in a thoughtful way. "I emphasize the importance of honoring what the patient would have wanted," says Jennerich. "In essence, the patient is making the decision through the surrogate decision-maker." ■

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Long-Term Care Providers Frequently Face Ethical Dilemmas

Ethical conflicts are common in long-term care facilities, but access to ethics resources often is lacking in these settings. "Access to ethics consultation can reassure everyone involved that the medical director, nurse, or administrator isn't missing something," says **David N. Hoffman**, JD, assistant professor of bioethics at Columbia University.

Many long-term care facilities lack access to ethics consultants, however. Hoffman and colleagues wanted to learn more about care conflict dilemmas in long-term care, and what ethics resources providers used to assist with dispute resolutions. The researchers surveyed 138 medical directors,

administrators, chief medical officers, and clinical practitioners at long-term care facilities.[1] Some key findings:

- Two-thirds of participants stated that they had to reject surrogate instructions because they were inconsistent with the patient's wishes.
- Most (71%) participants reported managing a family conflict.
- Respondents reported a wide range of ethical conflicts between staff, patients, family, and surrogate decision-makers. The two most common issues involving end-of-life care were interpreting advance directives and surrogate conflicts over treatment decisions.
- Many respondents conveyed the need to clarify on care wishes in advance, to avoid issues with end-of-life care for patients with dementia.
- More than half (55%) of participants worked at facilities with an official dispute mediation policy for cases where surrogate decisions conflict with a patient's previously expressed wishes. About one-third of those policies included an ethics consultation or an ethics committee.
- Eighty percent of respondents at facilities with an official dispute policy reported having to use it in the last few years.
- Only 10% of providers requested an ethics consult when managing patient-surrogate conflicts or disputes. More commonly, staff had a goals-of-care discussion with the family, staff, and patient (if possible) present.
- Just five respondents reported obtaining an ethics consult for help managing a conflict.

The research draws on a previous study about attitudes and practices of nursing home medical directors toward advance directives to voluntarily stop eating and drinking (VSED).[2] In that study, most (79.6%) long-term care facility medical directors indicated some degree of familiarity with VSED. However, about one-quarter (23.9%) were not sure if their facility could accommodate a request for VSED. One-fifth of respondents stated that they were personally uncomfortable caring for a patient who requests VSED. Notably, most respondents reported that they personally would be "somewhat" or "very" willing, in the event of terminal illness or late-stage dementia, to consider VSED for themselves. "What was fascinating is the number of medical directors who said, 'If I were in this kind of situation, I would want my advance directive respected' — who would want to be without assisted oral feeding. Yet they said their institutions couldn't do that, because of a misunderstanding of federal regulations," observes Hoffman.

The study was inspired by Hoffman's work with a resident of a long-term care facility in New York. The resident's advance directive stated that when she got to a certain level of functional assessment, she wanted no artificial feeding and no assisted oral feeding. The facility refused to honor the advance directive.[3] "The facility wouldn't even discuss another interpretation of the regulations that they were worried they would run afoul of. And that's where we are today. We have a lot of work to do," says Hoffman.

Long-term care facilities have the same ethical obligations to patients/residents as hospitals do, "and then some extra ones," says Hoffman.

Unlike a hospital setting when the patient is discharged, the long-term care facility "is the patient's home. They are not going anywhere, so if they are not able to access services that they need, that would normally be given to someone if they were in a private home, that would be a problem," says Hoffman.

An estimated 6.9 million Americans 65 years of age or older are living with Alzheimer's disease in 2024.[4] "As the baby boomer generation gets closer to the point where there are growing numbers of people suffering from Alzheimer's and other dementias, and are more frequently ending up in facilities rather than remaining in private homes, we have a problem of those institutions — the long-term care facilities — having an enormous amount of legal power over these individuals," says Hoffman.

Even if a patient has an advance directive stating they want VSED when they get to a certain level of functioning, long-term care providers may be over-cautious and not comply with the directive. "Long-term care facilities are treated with such suspicion that they are somewhat understandably paranoid about doing anything that could be considered allowing patient harm," Hoffman explains. "There is so much of a risk management/risk avoidance mindset in long-term care facilities."

To overcome this, Hoffman recommends that providers instruct patients on the importance of creating a clear, enforceable, legally binding advance directive. It is also necessary to train nurses, administrators, and directors at long-term care facilities about their obligations to respect the patient's wishes. "We are hoping that, with the findings of this study, we can start a dialogue about respect for patient's wishes in a way that doesn't create risk management concerns," says Hoffman.

Long-term care providers may not know what to say when family members insist on care that the patient explicitly said they did not want. Ethicists can help staff to understand that they have the moral authority — and, in fact, a moral obligation — to push back if family members insist on artificial feeding against the patient's stated wishes. Hoffman says that staff could state something like, "We understand that you are upset and that doing what your loved one said we were supposed to do in this particular circumstance is upsetting. But this is something we are

morally and legally obligated to do. It's also medically the right thing to do."

Attending to ethical issues in long-term care facilities has important implications for residents, their family members and friends, and staff, and for improving care experiences and outcomes, according to **Candace L. Kemp**, PhD, a professor at The Gerontology Institute at Georgia State University. Kemp's research has focused on ethical issues in assisted living communities.[5,6] Offering training to staff that promotes awareness and identification of ethical issues, as well as key ethical principles and factors is an important first step. "In an ideal world, care communities would have resources available — including access to a trained ethicist available to consult," says Kemp.

Currently, Hoffman and colleagues are developing best practice guidelines for ethical issues at long-term care facilities. The goal is to increase the ethics expertise of a group of people at each facility, who can be called on to assist in ethically challenging cases. "This can be an additional responsibility beyond their normal day job because these issues don't come up all that often. Once you've dealt with a particular circumstance or scenario once or twice, it gets a lot easier to apply what you learned the first couple of times to the next 10 times," says Hoffman.

Hoffman also is planning to develop internships for bioethics students at long-term care facilities. Students would serve as ethics consultants on an as-needed basis, so the cost is not prohibitive. The students would become familiar with the individual facility's operations and know what rules ought to be applied in a given situation. "They will know how to mediate disputes in a manner that's both legally and ethically appropriate," says Hoffman. ■

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Goals of Care Discussion Took Place — But Was it Documented?

When clinicians discuss patient goals and preferences, the discussion needs to be added to the medical record for other healthcare providers to access the information when necessary. Yet the documentation often is missing or incomplete.

"As clinicians, we might see multiple patients at a time, and may need to document these conversations later in the day. Clinicians document as best as they can, but may inadvertently miss documenting items discussed during the visit," says **Jessica Ma**, MD, an assistant professor at Duke University School of Medicine and a physician in the Geriatric Research Education and Clinical Center at the Durham VA Health System. Ma and colleagues analyzed the content and documentation of 40 goals of care conversations led by nurses and social workers. The researchers reviewed transcripts of the conversations to see if these five key components were covered:

- goals and values;
- illness understanding;
- end-of-life planning;
- surrogates;
- advance directives.

Then, the researchers looked to see if these same components were documented in the medical record. Some key findings include:

- For most (67%) of the conversations, all the key components were discussed with patients.
- Surrogates and advance directives often were documented completely.
- Overall, most components were discussed and documented.

After patients articulate their goals and values, healthcare providers are ethically obligated to respect autonomy. "This study shows that nurses and social

workers can play a key role in this ethical obligation," says Ma.

• Goals and values and end-of-life planning were less likely to be documented in comparison to more tangible, concrete components (such as the name of a surrogate decision-maker or whether an advance directive was completed).

This could be because patients are more likely to be able to name surrogates than to articulate their core values and goals, suggests **David Bekelman**, MD, MPH, another of the study authors and professor of medicine and psychiatry at the University of Colorado School of Medicine, a core investigator at the Seattle-Denver Center of Innovation, and a physician in the VA Eastern Colorado Health Care System.

Bekelman says ethicists can help to address this issue in these ways:

• Remind clinicians of the importance of eliciting and honoring patient values and goals, and of the importance of identifying a surrogate decision maker.

• Find ways for clinicians to document goals of care conversations succinctly, such as by using templates.

• Identify how inaccuracies in documentation can occur. For instance, there may be an issue with clinician, nurse, or social worker workflows that needs to be addressed.

The ethical concern is that incomplete documentation could cause patients to receive care discordant to their preferences. Additionally, it always is possible that patient preferences have changed since the initial conversation took place. "Clinicians should verify if patient goals are consistent with what is reported in the documentation," advises Bekelman. ■

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Ethical Considerations for Patient, Family, and Staff if LVAD Is Deactivated

An estimated 2,500 heart failure patients have left ventricular assist devices (LVADs) implanted each year. In some cases, the burdens of the LVAD outweigh the benefits, so a decision is made to deactivate the device in the hospital setting.

"We see a lot of people with LVADs at our center, and I was curious if there was a difference in bereavement for people who died with an LVAD," says **Anne Kelemen**, LICSW, APHSW-C, SEP, lead author of the study and palliative care social worker at MedStar Washington Hospital Center.

Kelemen and colleagues interviewed 11 family members of patients who died following LVAD deactivation.[1] Participants talked about drawing strength from positive relationships with hospital staff.

"A lot of times, when people have LVADs, they have them for a number of years. Patients and families build more relationships with the care team than somebody who dies in the hospital maybe only after just a couple of weeks, who doesn't have the longer-term relationships that the LVAD patient has," says Kelemen.

Hope for survival was another theme that emerged. One family member reported that the patient hoped to live another 10 to 15 years. "Some families didn't expect the patient was going to be dying that soon, and were not ready for the patient's death," says Kelemen.

It was unclear if additional information could have helped the families to prepare for this possibility. Despite knowing that the device was not going to cure the patient's heart failure, the family might, nonetheless, have hoped that the patient would be among those who lived another 10 years or so. Additionally, the patient might have had discussions with healthcare providers that the family was not privy to, involving the prognosis and the possibility that LVAD would need to be deactivated in the near future. "This reflects what I've seen clinically, that when it comes to the end of life and the device needing to be deactivated, it sometimes comes as a surprise. And that brings stress not only to the patients and families, but also the staff," says Kelemen.

Many family members said that lack of physical suffering and seeing that their loved one was comfortable was important to them. Several talked about their faith and spirituality and emphasized that they appreciated support from the hospital chaplain. One commented, "People came in and prayed with us, which, you know, was wonderful."

Overall, the study findings call attention to the need for effective communication about LVADs not only at the end of life, but also at the point of decision-making and post-death.

"We recommend having those conversations not only initially, but

throughout the LVAD experience," says Kelemen.

Anthony Merlocco, MD, MSt, an ethicist and associate professor of pediatric cardiology and radiology at University of Tennessee Health Science Center, says that one primary ethical concern is to address the possibility of device withdrawal before the LVAD is implanted. "Ethics surrounding LVAD deactivation have been outlined for some time. But few patients and clinicians are acquainted with the academic discussion," notes Merlocco. Some people do not see any distinction between LVAD deactivation and active euthanasia. "At the bedside, these arguments drive concerns that turning off the LVAD is an intentional act and morally equivalent to killing," says Merlocco. Some clinicians report moral distress in such cases. Ethicists can help by educating clinicians on patient autonomy, including respecting the patient's right to refuse treatment. "Support for caregivers and healthcare workers often starts with simply having an open discussion about their experiences and the psychological effects of having a loved one or a patient with an LVAD," says Merlocco.

Although an ethics consult is not necessary every time an LVAD deactivation is considered, it is helpful in these situations, says Merlocco:

- if conflicts arise;
- if goals of care are unclear or uncommunicated;
- if there is moral distress regarding the permissibility of LVAD withdrawal.

"In such cases, an ethics consultation and palliative care involvement may be extremely helpful," offers Merlocco.

With LVAD deactivation, conflicts arise when there is a misunderstanding or miscommunication between the patient, family, clinicians, and caretakers regarding the goals of care, and/or how those goals may be addressed. "People may have different perceptions of the benefit, burden, psychological experience, and quality of life associated with LVAD. Some patients may have altered risk perceptions," says Merlocco. For example, some patients feel that with an LVAD, they are sicker or closer to death, when in fact the device is providing a needed medical support. Others may not be able to see beyond the immediate burdens of an LVAD. "When considering deactivation of an LVAD, perceptions often differ on how this fits into the goals of care — and what means are permissible to achieve those goals," says Merlocco.

> "NO FAMILY MEMBER CAN BE ADEQUATELY PREPARED FOR THE SUDDEN DEATH OF AN INDIVIDUAL THEY HAVE KNOWN FOR A LIFETIME."

As a palliative medicine physician working at the Heart Hospital of the University of Louisville Health, **Edward Dunn**, MD, has been involved in the deactivation of an LVAD for many patients and their families. "This is a rather dramatic event," says Dunn, an associate professor of palliative medicine at the University of Louisville School of medicine and medical director of palliative care and Ethics Committee chair at Jewish Hospital of Louisville.

In most cases, the patient will die in a matter of minutes to hours after deactivation. Clinicians prepare the patient by infusing anxiolytic and analgesic medication prior to deactivation, and verbally prepare the patient and family for what to expect. "However, no family member can be adequately prepared for the sudden death of an individual they have known for a lifetime. When family and friends are assembled around the bedside, they are witnessing the rapid death of their loved one," says Dunn. Despite these challenges, not all LVAD deactivations call for an ethics consult. "If there is an ethical question in LVAD deactivation, there must be conflict," explains Dunn. Here are some conflicts Dunn has seen involving an LVAD patient requesting deactivation:

- **A conflict may arise between the patient and a spouse, adult children, siblings, or parents.**

The patient often is unhappy given the limitations of life with an LVAD, which includes no bath, shower, or swimming. "Their lives are quite literally appended to a battery pack that provides the electrical energy that will drive the heart pump. They must always be thinking about battery life in everything they do," says Dunn.

At some point, an LVAD patient may decide this quality of life is no longer acceptable. Often, progressive health problems (such as chronic kidney disease requiring dialysis, peripheral vascular disease resulting in limb amputations, a debilitating stroke, a carcinoma or lymphoma, or progressive lung disease) result in the body deteriorating despite the functioning LVAD preserving heart function. To a patient in this situation, life may no longer be worth living. "But to family members, that life must continue because they cannot accept the death of their loved one. Therein lies the conflict," says Dunn.

Ultimately, deactivation is the patient's decision (assuming that the patient has decisional capacity). Yet family members sometimes challenge this decision. "When we are confronted with such challenges from family members, an ethics consultation could be very

helpful to bring stakeholders on both sides of the conflict to a resolution, if possible," says Dunn.

• A patient may be conflicted about whether to deactivate.

A recent ethics consult involved a patient who had undergone LVAD implantation three years prior. However, the patient's decline from chronic pulmonary fibrosis accelerated over a two-year period. The patient no longer could get out of bed without becoming extremely short of breath, which often triggered an acute panic attack. After several hospitalizations over a three-month period, he requested LVAD deactivation, claiming that his life was no longer of value to him. The patient's siblings supported this decision. However, the patient became very ambivalent about the request, and vacillated on a daily basis.

"Our chaplain developed a relationship with him. Together, our team helped him resolve the matter within himself," says Dunn. Ultimately, the patient finally agreed to deactivation. This occurred in the presence of his siblings, and the patient died within minutes after deactivation.

• There may be conflict between the patient and the heart failure team.

LVAD candidates are subjected to significant scrutiny in terms of overall medical condition prior to the device being implanted. The clinical team carefully assesses vital organs (such as lungs, kidneys, liver, and brain), the level of family and social support available, and the individual's track record of consistent follow-up and reliability in cooperating with healthcare plans. "With the effort and expense of implanting an LVAD and providing the necessary complex care required thereafter, a heart failure team will not take lightly a patient's request for deactivation," observes Dunn.

In some cases, the heart failure team challenges such a request. "This can be a very delicate interaction between the patient, the family, and the heart failure team," says Dunn. In this situation, an ethics consult can be very helpful. Ethicists listen to all the stakeholders on both sides of the conflict in an effort to achieve some type of resolution. An additional role for the ethics consultant is to support all the stakeholders involved. "These conversations can be emotionally charged and complex," explains Dunn. ■

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Ethical End-of-Life Care Discussions in ICUs

Intensive care unit (ICU) clinicians experience multiple barriers to quality end-of-life care conversations, a recent study found.[1] Researchers interviewed 27 ICU clinicians and advanced practice providers at three hospitals. These themes were identified that either facilitated or obstructed end-of-life care:

• Work system barriers resulted in delays in end-of-life communication among the clinical team and between clinicians and families.

• Some clinicians overrelied on palliative care, viewing them as the only clinicians who could handle end-of-life discussions.

• End-of-life discussions varied greatly depending on which clinician was having the conversation. One ICU fellow stated, "The quality of the conversation depends very highly on who is having it. There's no standardization."

• Treatment goals of clinicians, family, and patients were misaligned. For example, clinicians might feel that the family should get a do-not-resuscitate order or withdraw care, but the family is not ready to do so. An advanced practice provider stated, "We could do a better job of supporting families when their decisions or goals do not align with our own."

• Joint discussions between care teams led to fewer situations where conflicting information was provided to patients or families.

• Clinicians reported moral distress because of providing non-beneficial care.

An ICU attending stated, "There are circumstances when there's real moral angst, moral anxiety amongst the ICU providers, because they feel like they're doing things that are just unkind to patients." An ICU fellow described a family that was pushing clinicians to do "everything," which resulted in an ICU stay of several months. Throughout this, the patient was receiving care that clinicians perceived as harmful and inappropriate.

"It is important for clinicians to recognize that these are ethical dilemmas where ethicists can offer guidance," says **Anne Stey,** MD, one of the study authors and an assistant professor of surgery at Northwestern Medicine. ■

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Ethics Concerns if Patient Currently Is (or Previously Was) Incarcerated

Unique ethical issues come up with individuals who currently are (or previously were) incarcerated or whose surrogate decisionmaker is incarcerated, a recent study found.[1] "Limited empirical data were available for patients impacted by incarceration," says **Janice Firn**, PhD, MSW, HEC-C, one of the study authors and a clinical ethicist at Michigan Medicine and Center for Bioethics and Social Sciences in Medicine.

Firn and colleagues analyzed ethics consults for patients affected by incarceration from 2015-2022. The researchers compared those patients who received ethics consults with the overall population of 37,184 patients who were affected by incarceration.

Overall, 3% of ethics consults involved individuals affected by incarceration. Some key findings regarding these consultations:

- Surrogate decision-making and fiduciary duties (determining beneficence, non-maleficence, and best interest) were the most common ethical issues that were addressed.
- Intra-family communication challenges were common.
- Access to decision-makers and provision of medically necessary care were affected by the patient's incarceration status.
- Some of the ethics consults were requested because clinicians were unable to reach wardens or court-appointed legal guardians during off-hours.

In some cases, surrogates were unable to speak about the patient's values and wishes because of lack of contact with the patient. In other cases, there was no next of kin or durable power of attorney identified. "Healthcare teams had misperceptions about who could serve as a surrogate decision-maker, or the process for involving the family in decision-making," reports Firn. Clinicians sometimes wrongly assumed that the warden could serve in that role for incapacitated patients, instead of a family member or another third party.

> STAFF MAY NOT REALIZE THAT INCARCERATED INDIVIDUALS HAVE THE RIGHT TO ADVANCE CARE PLANNING.

Ethicists provided guidance for employing the "best interest" standard if a surrogate could not be identified or could not be reached for time-sensitive treatment decisions. Ethicists also collaborated with many other individuals to resolve the cases. In some cases, ethicists worked with the health system's Office of the General Counsel to pursue emergency guardianship if indicated, or to pursue a court order if necessary, to provide treatment.

The Office of the General Counsel, in turn, communicated with the state attorney general's office to advocate on behalf of the person who was incarcerated. Ethicists coordinated with social workers to communicate with the prison. Sometimes, this was necessary to arrange for surrogates who were incarcerated to participate in decision-making conversations with the healthcare team.

Ethics issues related to surrogate decision-making were common. "Incarceration is incredibly disruptive to relationships. This isolation and inability to have regular contact makes accessing the surrogate, and/or the surrogates' ability to engage in substituted judgment, challenging," explains Firn. Ethicists can help to ensure ethical care for patients affected by incarceration in these ways, offers Firn:

- **Advocating for additional education and better collaboration.**

Ethicists can reach out to healthcare system legal offices, hospital security, social work, medical record technology specialists, correctional officials, and the state attorney general. At Michigan Medicine, the Office of General Counsel has a contact with the state attorney's office that ethicists collaborate with when there are concerns. Ethicists have also met with the prison system's lead social worker. "We communicate with the prison physicians and staff to explore the patient's values and prior stated wishes. Our healthcare teams also proactively coordinate with prison healthcare teams around discharge care needs," reports Firn.

- **Facilitating completion of advance care planning documents and appointing proxy decision-makers.**

Staff may not realize that incarcerated individuals have the right to advance care planning. The presence of guards at the bedside also can hinder efforts to have detailed conversations about goals of care. "These may act as deterrents to engaging incarcerated patients in advance care planning," notes Firn. ■

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Unique Ethical Concerns with Informed Consent for Psychedelics

The use of psychedelics in psychiatric care raises multiple challenging ethical issues. "Some of these issues arise with many novel or experimental treatments. However, others are distinctive to psychedelics," asserts **Jacob M. Appel**, MD, JD, MPH, HEC-C, director of ethics education in psychiatry at Icahn School of Medicine at Mount Sinai and an attending physician at Mount Sinai Health System.

One recent issue is that some states are making psychedelics available for supervised use outside of the conventional healthcare system. Yet psychedelics remain illegal for non-research purposes under federal law. "Informed consent for the use of a product that may be decriminalized at the state or local level, but is still illegal under federal law, is complex," says Appel.

One question is to what degree patients must be informed of the risk of arrest or prosecution. At a minimum, researchers should be certain that subjects understand that participating in a research protocol does not absolve someone from the legal consequences of using an illicit substance. "Unfortunately, many potential subjects believe that admission into a clinical trial is a metaphorical 'get out of jail free' card, and it is not," according to Appel.

In addition, there are significant uncertainties about short-term and long-term clinical responses to psychedelic exposure. This makes it difficult to know how much information is sufficient.

"Achieving the right balance is not easy," says Appel. Researchers must ensure that a study participant is adequately informed while, at the same time, avoiding overwhelming the person with too much information.

Psychedelics have received substantial recent attention from the scientific, clinical, and lay communities for the treatment of psychiatric conditions, observes **Rebecca W. Brendel**, MD, JD, director of the Center for Bioethics at Harvard Medical School. "While studies continue toward FDA [Food and Drug Administration] approval, some states, such as Colorado and Oregon, have already implemented pathways for use outside the medical system," says Brendel.

Psychedelic compounds cause variable responses in different individuals and environments. "This makes informed consent both essential and challenging. Once clinically approved within the medical system, novel attributes of the compounds themselves will require clinicians to engage in informed consent processes that specifically include elements unique to psychedelic substances," argues Brendel.

Brendel and colleagues analyzed the challenges involved in designing informed consent processes for psychedelics.[1] One concern is that participants may experience short- or long-term perceptual disturbances or personality changes. There also is a need for researchers or clinicians to communicate the privacy risks involved with psychedelics. The authors recommend explaining to participants that there is a risk that data could be misused or mistakenly released. That could potentially result in negative occupational, social, or legal outcomes for patients or clinical trial participants. To convey complex information on psychedelics, the authors recommended using role playing, simulations, or open-ended consent quizzes. "We recommend interactive education and assessment of comprehension as part of the informed consent process," offers Brendel. ■

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Most Financial Conflicts of Radiology Guideline Authors Are Undisclosed

Even though the federal Physician Payments Sunshine Act was enacted more than a decade ago, misconceptions persist as to its requirements. "In talking to colleagues and friends, the impression we got is that most people are not generally aware how publicly available the data are; and most physicians think that the reporting amount has to be significantly large," reports **Ajay Malhotra**, MBBS, MD, MMM, a professor of radiology and biomedical imaging and of neurosurgery at Yale University School of Medicine.

Since the law was enacted in 2013, biotechnology, pharmaceutical, and medical device companies have been required to report all payments to physicians to the Centers for Medicare and Medicaid Services. The information then is made publicly available on the

Open Payments database. "There is an overall lack of awareness of how low the reporting amounts are," says Malhotra. The reporting threshold for 2024 is $13.07.[1]

Physicians use the American College of Radiology Appropriateness Criteria (ACR-AC) to make decisions on what diagnostic imaging to order. "It has become even more onerous on people who are writing the guidelines, which are dictating the clinical use of imaging, to be more transparent about their financial conflicts," says Malhotra.

Malhotra and colleagues wanted to know if guideline authors were disclosing all their financial conflicts. Previously, the researchers looked at authors' financial conflicts in a single radiology journal.[2] They compared the payment reports in the Open Payments database to the financial disclosures made by guideline authors. The nondisclosure rate was very high.

"We decided to extend the study and look at the five main radiology journals," says Malhotra. The researchers looked at financial disclosures that were provided by authors of all ACR-AC published in 2019, 2021, and 2023.[3] They compared those with payment reports from the Open Payments database in the previous three years. "We found high nondisclosure rates for all of the journals," says Malhotra. Of guideline authors in those journals who received industry payments, most of the payments were undisclosed. The proportion of the total value of nondisclosed payments was 86.1% in 2019, 88.6% in 2021, and 56.7% in 2023.

One issue is that many journals ask authors to report conflicts of interest that are "pertinent" to the research being submitted for publication. This is likely a reason for the undisclosed financial conflicts.

"It puts the onus on the person who is completing the form to determine what's considered 'pertinent,'" explains Malhotra. As it stands currently, guideline authors can choose not to report financial conflicts if they view those as not "pertinent." For example, a clinician may be authoring guidelines on how to image patients with intracranial aneurysms and is not being paid by the specific device makers included in the guidelines. However, the clinician is being paid by the industry overall, which is making devices to treat various types of aneurysms. "Is it a conflict? Potentially, yes. But the authors might say they don't think so. And most of those people are not disclosing it," explains Malhotra.

Some journals now are emphasizing the need for guideline authors to disclose all their financial relationships, not just those specific to the paper being presented. As a board member of the *American Journal of Neurology*, Malhotra has seen increasing attention to this issue. The journal currently is considering providing authors access to the Open Payments website and asking them to cross-check their own names with what they have reported to the journal. This way, the author cannot claim that they did not know about a financial conflict. "There's been an ongoing discussion about changing policies to have people disclose everything, and not just what they consider pertinent," reports Malhotra. ■

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Electronic Order Set Facilitates Treatment Withdrawal

At OhioHealth, an electronic order set is used to facilitate withdrawal of life-sustaining treatment.

"We hoped to increase awareness of the order set and provide guidance for nonpalliative clinicians to feel comfortable to use it," says **Samantha Grable**, Pharm D, a palliative care pharmacist at OhioHealth Grant Medical Center.

Grable and colleagues assessed the use of the order set and the time to inpatient death before and after the order set was updated.[1]

The updated order set contains the use of defaults (for example, pre-medication orders and nursing orders) to help provide the standard of care. It also implemented improved safety measures, including look-back to identify whether the patient has received neuromuscular blocking agents and guidance on medication choices based on patient renal function.

The researchers compared the time from activation of orders to patient death for 1,949 patients during a 12-month period before (2017-2018)

and after (2021-2022) the order set was updated.

For patients who had palliative care consults, palliative clinicians were the users of the order set in 47% of cases. If orders were placed by a palliative clinician, median time to death was 4.5 hours, compared with 3.9 hours for nonpalliative specialists.

"It was encouraging to see that the majority of order set users were nonpalliative providers," says Grable. Nurse practitioners were the most frequent users (39%) of the order set.

Overall, use of the tool increased 35.8% in the 2021-2022 group. "Our hope is that the withdrawal of life-sustaining treatment order set will be a practical tool to help navigate potentially highly emotional and stressful clinical situations," concludes Grable. ■

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Ethical Obligations if Patients Have Limited English Proficiency

As a nurse and clinical bioethicist, **Melissa Kurtz Uveges**, PhD, MA, RN, had a strong desire to facilitate communication with patients with Limited English Proficiency (LEP) and to provide information in their preferred language.

"Ethical issues related to cases involving LEP patients who are likely to initiate an ethics consult include insufficient informed consent and breach of confidentiality," reports Uveges. Uveges and colleagues authored a paper exploring nurses' ethical obligations for patients with LEP.[1]

"Routine assessment of patients' language preferences is imperative to optimize healthcare outcomes," underscores Uveges, an assistant professor at Boston College's Connell School of Nursing. Clinicians need an adequate understanding of the professional role obligations of the interpreter, who facilitates communication between the patient and healthcare team. "Accessing professional interpreters to facilitate communication with patients, while sometimes time-intensive, is imperative," says Uveges.

This can prevent errors in healthcare interpretation, medical errors, and hospital readmissions. "It can also promote patient comprehension, maximize care utilization and clinical outcomes, increase patient satisfaction, and ensure the patient's perspective is appropriately communicated," adds Uveges.

Clinical ethicists can help to resolve issues arising in cases where care has been suboptimal. This can happen with the use of untrained interpreters. "Clinicians' use of family or ad hoc interpreters occurs often, especially in the context of private practice healthcare visits," notes Uveges.[2]

Ethics consultants can contribute to organizational efforts aimed at ensuring access to professional interpretive services for all patients. Ethicists also can educate healthcare providers as to why the use of family or ad hoc interpreters is not ideal. "Clinical ethicists can help guide how best to navigate ethical quandaries arising in such cases," says Uveges. ■

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CME/CE QUESTIONS

1. **Which of the following did researchers find regarding ethics consults at University of California Irvine Medical Center?**
   a. Cancer diagnoses were associated with fewer delays for ethics consults.
   b. The majority of consults involving cancer or COVID-related illness involved end-of-life recommendations.
   c. Ethics recommendations differed based on whether the patient had decision-making capacity.
   d. Spanish-speaking patients had shorter median times to ethics consults than English-speaking patients.

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CME/CE QUESTIONS

2. **Which of the following did researchers find regarding surrogate decision-makers?**
   a. Surrogates had all discussed the patients' end-of-life wishes at some point in time.
   b. All surrogates recalled being asked by the patient to play this role, either verbally or in writing.
   c. About one-half of surrogates said that there was no formal documentation of their role.
   d. Among historically marginalized participants, confidence and readiness scores were higher.

3. **Which of the following did researchers find about documentation on goals of care discussions?**
   a. Documentation was more complete if it occurred after the visit, compared to during the visit.
   b. When clinicians documented items during the visit, advance directive information often was incorrect.
   c. Discussions on goals and values were missing from most charts.
   d. The names of surrogates and whether an advance directive was completed were well-documented.

4. **Which of the following did researchers find regarding family members of patients who had left ventricular assist devices deactivated?**
   a. Participants were highly distressed by negative experiences with hospital staff.
   b. Families usually declined support from hospital chaplains.
   c. Family members reported lack of readiness for the patient's death.
   d. Families were misinformed that the device was going to cure the patient's heart failure.

5. **Which of the following did researchers find regarding end-of-life care conversations in the intensive care unit?**
   a. Clinicians agreed that end-of-life discussions should be handled solely by palliative care specialists.
   b. End-of-life discussions were consistent, regardless of which clinician was having the conversation.
   c. Treatment goals of clinicians, family, and patients frequently were misaligned.
   d. Clinicians were reluctant to involve ethicists, even in cases where conflict had escalated.

6. **Which of the following did researchers find regarding financial conflicts of radiology guideline authors?**
   a. Physicians tended to report financial payments even if they did not meet criteria for reporting.
   b. For radiology guidelines published in 2019, 2021, and 2023 in the five main radiology journals, of the authors who received industry payments, most financial conflicts were undisclosed.
   c. Journals are required to ask authors to disclose all financial relationships, not just those viewed as pertinent to the paper under consideration.
   d. Authors correctly stated that financial payments are only publicly reported if the amounts are significant.