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INSIDE

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Ethicists Have More Evidence That Consults Are Effective, But Outcomes Inconsistent

'We haven't captured the right process measures yet'

Several years ago, **Selena Au**, MD, attended a presentation on conflict resolution that recommended referral to clinical ethics consultation. A colleague respectfully asked the presenter what "hard evidence" exists that an ethics consult was effective.

"Although I was part of a hospital ethics committee, I could not silently answer the question in my head. Even more so, I realized there was no consensus definition for a consult that works," says Au, a clinical assistant professor and critical care physician at University of Calgary's department of critical care medicine in Alberta.

> "OUR PAPER IS A CALLING THAT ETHICS SERVICES MUST DEFINE THE PROCESSES THAT MAKE A 'QUALITY CONSULT' IN A WAY THAT'S MEASURABLE."

Au and colleagues set out to answer this important question by conducting a review of the literature. They found that ethics consults in adult ICUs are linked to high satisfaction and higher likelihood of coming to a consensus on a clinical decision.[1]

The review also revealed a lack of standardization in what outcomes are looked at and how they're reported, says Au, "despite ethics services being ubiquitous across many hospitals."

Based on these findings, Au would answer her colleague's original question thusly: "I would say that when an ethical conflict arises, a clinical ethics consult is an appropriate step. The

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evidence says there may be benefit, and there is low signal for harm."

More likely, there are benefits to the patient, family, and provider that aren't being measured. "We haven't captured the right process measures yet," says Au. "Our paper is a calling that ethics services must define the processes that make a 'quality consult' in a way that's measurable."

The effect of ethics consults is inherently difficult to measure. "Not everything that counts can be counted. This has been an ongoing conversation at our institution," says **Tim Lahey**, MD, MMSc, chair of the clinical ethics committee at Dartmouth-Hitchcock Medical Center in Lebanon, NH. Hospital administrators typically rely on metrics to justify resource allocation. "This poses a challenge for ethicists wanting to justify FTE support as institutions tighten purse strings," says Lahey. He suggests the following approaches to justify ethics resources:

• Refer to existing data.

"There are some data that ethics consultation benefits patients and institutions," notes Lahey. A 2003 study showed that clinical ethics consultation reduced hospital and ICU length of stay, and reduced use of life-sustaining therapies in patients who did not survive to discharge.[2]

"These results were confirmed in a 2014 study,[3] which also showed ethics consultation resulted in improved achievement of goals of care," says Lahey.

• Create new metrics to assess the real-world effect of ethics consults.

Some examples: The number of patients with advance directives, ICU length of stay, staff burnout rates, and metrics from the shared decision-making field measuring decisional anxiety in patients and family members.

"Stories about times when ethics consultants helped hospital staff make the best out of a challenging clinical situation can be one way institutional leadership promotes improved employee morale," adds Lahey.

• Build relationships with hospital leaders.

"Most hospital administrators can come to understand that ethics consultants help defuse challenging communications, which aids good patient care and may even avert lawsuits," says Lahey. A good relationship between hospital leadership and ethics leadership facilitates that understanding. One key mechanism is to have an organizational ethics group that connects ethicists with hospital leaders.

EXECUTIVE SUMMARY

Ethics consults are linked to high satisfaction and more likelihood of consensus, but outcomes used are inconsistent, found a recent study. To justify ethics resources:

- refer to previous studies showing benefits of consults;
- make hospital leaders aware that ethics consults can defuse problems causing dissatisfaction;
- ask risk managers for case examples where ethics involvement averted a possible lawsuit.

"Having a risk manager say ethics consultation helped defuse a potentially litigious situation is another nice story-based approach," says Lahey.

Many organizations struggle with how best to evaluate their ethics consultation activities. "Unfortunately, there's no one-size-fits all solution that is right for all organizations," says **Ellen Fox**, MD, president of Fox Ethics Consulting and director of the Altarum Institute's Center for Ethics in Health Care in Washington, DC.

Ethics consultation evaluation requires thoughtful planning. It must be tailored to each organization's unique circumstances. "It's essential to start by determining what the evaluation is designed to accomplish," says Fox. The following are some examples:

• to demonstrate the value of the consultation service to leadership;

• to ensure that the service is meeting established quality standards;

• to identify and improve specific ethics quality gaps;

• to develop new knowledge that can be published and generalized to other settings.

"For many organizations I work with, a major purpose of evaluation is to demonstrate the value of ethics consultation to leadership in order to get more resources and other types of support," says Fox. Organizations often assume that it's essential to evaluate effectiveness — in other words, the effect of ethics consultation on specific desired outcomes.

"But outcomes may not be the best thing to evaluate," says Fox. Evaluating effectiveness can be very costly and requires a high level of expertise to do well.

"Focusing too much on outcomes that are easy to measure, such as requester satisfaction, can create perverse incentives that tend to compromise quality in other areas," adds Fox.

Outcomes evaluations may be appropriate for well-funded and highly sophisticated ethics consultation services, or for research settings. "But for most programs, there are better ways to demonstrate value," says Fox. The following are some possible approaches:

• Demonstrate that there is a perceived need for an ethics consultation service in the organization, and that the service is meeting the need.

"In my experience, very low consultation volume is often a red flag for quality problems," says Fox. The solution is not to increase awareness of ethical issues or the availability of the service to address them, but to improve the quality of the service to ensure it is consistently adding value.

"Once demand is high, the service can then demonstrate that resources are inadequate to meet the need," says Fox.

• Demonstrate that ethics consultation is contributing to other organizational priorities.

Some examples: Improving the efficiency of care delivery, reducing organizational risk, enhancing the organization's reputation, and improving employee morale. "Such contributions can be described qualitatively, without rigorous outcomes studies," Fox explains.

• Demonstrate that high-quality ethics consultation is an expected part of healthcare delivery, and that the service is meeting quality standards.

"In many organizations, at least some individuals who perform ethics consultations lack the core competencies required to do it well," says Fox. Ethics consultations don't always meet accepted quality standards promulgated by the American Society for Bioethics and Humanities, such as appropriate documentation.

"Ethics consultation services can demonstrate tangible results by identifying ethics-related 'best practices' they are not meeting, then measuring improvement over time," says Fox. ■

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Nurses, Physicians Consider Different Factors to Decide on Family Presence During Resuscitation

Patient's survival is doctors' priority

Nurses and acute care physicians consider different factors when making decisions on family presence during resuscitation, found a recent study.[1]

"Much research has explored the overall perceptions of healthcare professionals related to family presence during resuscitation. But little research has explored decision-making processes," says **K. Renee Twibell**, PhD, RN, CNE, associate professor at Ball State University's School of Nursing. Twibell also is a nurse researcher at Indiana University Health Ball Memorial Hospital in Muncie.

Previous research has shown that nurses and physicians have different perceptions about family presence.[2] "We wanted to explore those interprofessional differences specifically in factors related to decision-making," says Twibell.

Researchers surveyed 325 nurses and 193 acute care physicians on decision-making factors about family presence. "From our own clinical experiences and existing published evidence, we suspected there would be differences between physicians and nurses," says Twibell.

Physicians focused primarily on the patient. Nurses balanced the needs of multiple stakeholders: the patient, family, and resuscitation team.

"We were surprised at how strongly the physicians spoke about not inviting family presence due to the potential for family disruption," says Twibell. Also important to physicians is the family's lack of knowledge about resuscitation events. In analyzing the data, it became clear that the physicians prioritized their patients' survival. "They had little tolerance for anything that would compromise that," says Twibell.

Better Collaboration

Most families believe it is their right to be present with loved ones when situations are life-threatening. "Not inviting families to witness the resuscitation of a loved one may appear unethical to families," notes Twibell. However, physicians perceive a clear ethical call to save a patient's life; they do not want anything to deter from their efforts to do so, including family presence.

Ariane Lewis, MD, assistant professor at New York City-based NYU Langone Medical Center's department of neurology, says it can be beneficial for families to directly witness the immense efforts being made to save a person's life. This can help them come to terms with the severity of the situation. "However, families can become overwrought with emotions and interfere with a resuscitation," says Lewis.

Developing policies on this issue can allow institutions to take an organized, systematic approach. Lewis suggests this wording: "If families are interested in remaining in the room during resuscitation attempts, they should be given the opportunity to do so, provided that their presence will not interfere with patient care."

Cheyn Onarecker, MD, MA, chair of the healthcare ethics council at Trinity International University's Center for Bioethics & Human Dignity in Deerfield, IL, says the fact that families benefit from being present during resuscitation efforts on their loved ones has been recognized for some time. "The families say they experienced more meaningful closure by being present," says Onarecker. "They feel as if they had a chance to say goodbye." Families can see for themselves how far the medical team was willing to go to save the person rather than wondering later if the team had made a serious effort.

"Interestingly, the families do not appear to suffer serious psychological consequences from the experience," says Onarecker. Some studies indicate that families actually experience less psychological trauma by being present.[3]

EXECUTIVE SUMMARY

Nurses and acute care physicians consider different factors for decision-making on family presence during resuscitation, found a recent study.

- Physicians focus primarily on the patient.
- Nurses consider the patient, family, and resuscitation team.
- A designated "family facilitator" can minimize disruption.

"Hospital leaders might worry that legal issues might arise more frequently as a result of having families present," says Onarecker. "But that has not occurred."

Minimize Disruption

Twibell says the ethical question is: "Whose needs, priorities, and wishes are most important?" Some hospitals appoint a member of the healthcare team as a "family facilitator" during a resuscitation, to coach and support individuals who choose to be present. This minimizes the threat of disruptions caused by families. "Such a solution allows family members to be there for a loved one in crisis, and allows physicians to focus on the patient without fear of interruption," says Lewis.

The researchers hope to design and test a decision-making process for family presence during resuscitation so clinicians can consistently manage this aspect of end-of-life, family-centered care.

"Our hope is that nurses and physicians can collaborate better if they understand differences and similarities in decision-making preferences related to family presence," says Twibell. ■

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Early DNR Status Adversely Affects Hospitals' Quality Metrics

Hospitals wrongly classified as performance outliers

Higher "do not resuscitate" (DNR) rates resulted in some hospitals being classified as performance "outliers," found a recent study.[1]

"[The Centers for Medicare & Medicaid Services] and a lot of other organizations spend a lot of time trying to develop outcome measures to help hospitals deliver higher-quality care, mostly based on administrative claims data," notes **Jeffrey T. Bruckel**, MD, MPH, the study's lead author and a cardiovascular fellow at University of Rochester (NY) Medical Center.

The researchers used the California State Inpatient Database because it captures the "early DNR variable." "We decided to see if it varied between hospitals, and if it would impact hospital outlier status for heart failure," says Bruckel.

Researchers found that DNR status did affect hospital risk-adjusted heart failure mortality metrics. "I don't think it surprised any of us that patients at different hospitals had different DNR rates," says Bruckel. Patients with DNR orders have increased in-hospital mortality, which can skew the hospital's quality metrics. "If you don't account for it in your risk models, then you might classify hospitals as outliers which might not be," says Bruckel. Some key findings include the following:

• among 55,865 patients from 290 hospitals, 12% had a DNR order;

• hospitals with higher DNR rates had higher mortality;

• including DNR in risk models resulted in reclassification of 9.3% of "outlier" hospitals.

Some predictors, such as the presence of early DNR status, that could have potentially been included in the model were excluded, either

because they weren't available or are difficult to measure. "They have had to make some decisions, just by virtue of the way the outcomes are created," says Bruckel. "And it turns out that those things can actually be pretty important indicators of patients who carry risk."

If the excluded predictors are spread unevenly throughout hospitals, this can skew results further. "Some hospitals might take care of patients that have higher rates of one thing or another, that aren't necessarily captured in the models," explains Bruckel.

Bruckel says important questions for CMS, in light of the study's findings, include: "Are models performing adequately? Are they really measuring what we want to measure? Or are we penalizing hospitals arbitrarily?"

"The bottom line is, if you take care of patients who elect to be DNR for whatever reason, you shouldn't be indiscriminately penalized," says Bruckel.

Unintended Consequences

Generally speaking, the goal of reporting quality metrics to hold hospitals accountable is laudable, says **Kenneth Covinsky**, MD, MPH, a clinician-researcher in the division of geriatrics at University of California, San Francisco.

"But as a community, we do have an obligation to make sure that our quality measures are accurate and actually do lead to better care for patients," says Covinsky.

> "BUT AS A COMMUNITY, WE DO HAVE AN OBLIGATION TO MAKE SURE THAT OUR QUALITY MEASURES ARE ACCURATE AND ACTUALLY DO LEAD TO BETTER CARE FOR PATIENTS."

One issue is that metrics on in-hospital deaths don't take into account that not all deaths can be prevented with high-quality care. Some patients are admitted to hospitals at the end of life, when the ability of medical intervention to impact mortality is limited. "In these cases, an equally important goal is to provide care that enhances the well-being of the patient, controls symptoms, and respects the patient or family," says Covinsky.

The finding that the inclusion or exclusion of DNR orders in hospital mortality quality metrics strongly influences hospital quality rankings "warns us about potential unintended consequences of hospital mortality metrics," says Covinsky.

The issue is the inclusion of patients whose deaths are not driven by quality of care, but rather, are dying because they are at the end of life. Thus, a hospital that recognizes when patients are at the end of life and delivers good palliative care can be classified as a performance outlier because of a higher death rate. By the same token, a hospital that provides ineffective care and discharges patients to a skilled nursing facility, with the deaths occurring at the skilled nursing facility, can be wrongly deemed as delivering high-quality care.

One reason quality metrics focus on mortality rates is because they're easy to measure. "We may need to focus on measures that better represent quality, such as functional status and symptom control — even though they are more difficult to measure," concludes Covinsky. ■

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EXECUTIVE SUMMARY

Higher mortality due to DNR rates results in classification of some hospitals as performance outliers, researchers found. Some ethical concerns include the following:

- hospital reimbursement and reputation can be adversely affected due to higher DNR rates;
- not all deaths can be prevented with high-quality care;
- important metrics such as functional status and symptom control are difficult to measure.

Medical Students Engaged by Advance Care Planning Training, but Few Act

An educational session successfully engaged medical students in learning about advance care planning conversations, both professionally and personally, found a recent study.[1]

"We conducted this study with the goal of improving advance care planning education for medical students, so that these future doctors can help patients with advance care planning," says **Hillary Lum**, MD, PhD, assistant professor of medicine in the division of geriatric medicine at University of Colorado School of Medicine in Aurora.

Groups of 127 third-year medical students participated in a 75-minute session, framed by The Conversation Starter Kit. Students were evaluated immediately after the session and one month later. "Since advance care planning may not seem like a priority to students who are young and busy, we used conversational, interactive methods to improve engagement and buy-in," says Lum.

After the session, 73% of students reported plans to discuss advance care planning, 91% had thought about their own preferences for future medical care, and 39% had chosen a medical decision-maker.

Using a small-group, discussion-based format and asking students to think about their own advance care planning were effective teaching methods. "Reflecting on their own preferences made students more comfortable with the concept of discussing advance care planning with patients," says Lum.

However, just the educational session was not enough to cause students to take any concrete actions with regard to their own future medical care. Only a minority had completed an advance directive (14%) or talked with their healthcare provider (1%). One month later, there was no evidence that the session increased students' actions regarding these steps.

"The more buy-in from medical students and other healthcare professionals for advance care planning, the more often patient wishes will be followed in clinical practice," says Lum. ■

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Ethics of Unilateral 'Do Not Attempt Resuscitation' Orders in Pediatric Care

Jeopardizing parent/provider relationship 'not ethically defensible'

A unilateral "do not attempt resuscitation" (DNAR) order only is appropriate in very limited circumstances in pediatric care, according to a recent paper.[1]

"It is always challenging when patients and the medical team disagree about care plans, particularly so at or near the end of life," says lead author **Jonathan M. Marron**, MD, MPH, a clinical ethicist at Boston Children's Hospital. Marron also is a postdoctoral research scholar at Harvard Medical School's Center for Bioethics.

Shared decision-making encourages the medical team and patient or surrogate to work collaboratively to decide on an appropriate treatment plan, in light of the medical facts and the patient's preferences and values. "But what happens when there is disagreement about what is 'appropriate?'" asks Marron. "And how does the added layer of complexity of a parent making choices for her child change this decision-making calculus?"

The researchers became acutely aware of these challenges when caring for a patient with end-stage liver disease for whom liver transplant was not possible. The mother wished to provide CPR if her infant son were to have a

cardiopulmonary arrest. The medical team was unsure if performing CPR was medically appropriate, given that there were no curative options. "We wanted to explore the role of the unilateral DNAR order in pediatrics, using this case as a jumping-off point," says Marron.

The fact that everyone involved in the care for children is "incredibly emotionally invested" can lead to disagreements that can be particularly entrenched and even contentious, says Marron.

Parents wish to do what is best for their children. The medical team wishes to do the same: They feel it is their professional responsibility and moral obligation. "The challenge lies in these rare cases in which stakeholders view 'what is best' to be different, sometimes diametrically so," says Marron.

There is an increasing focus on how to ethically manage requests for futile or potentially harmful interventions. "We have begun to recognize that providing care that is believed to be inappropriate can cause medical providers great moral distress, and the feeling of not meeting one's professional responsibilities," says Marron.

Several societies have put forth professional guidelines as a process-based means to address such challenges.[2,3] "But parents are not like other surrogates. Their role, and their relationship with their children, is unique and quite hallowed," says Marron.

A previous study showed that a majority of neonatologists (76%) believed unilateral DNAR decisions are ethically permissible if survival is felt to be impossible. A minority (25%) responded that the unilateral DNAR order would be permissible based solely on poor neurological prognosis.[4]

"IN PEDIATRICS, WE HAVE GREAT DEFERENCE TO PARENTS' PREFERENCES REGARDING THE MEDICAL CARE FOR THEIR CHILDREN. SHOULD CARE AT THE END OF LIFE BE ANY DIFFERENT?"

"In pediatrics, we have great deference to parents' preferences regarding the medical care for their children. Should care at the end of life be any different?" asks Marron.

Ultimately, the authors concluded that with very few exceptions, maintaining an open dialogue is preferable to unilaterally placing a DNAR order for a child.

"This strategy is not without its own challenges," notes Marron. "But we feel it to be ethically preferable to the potentially great harm to the parent-provider alliance that could be caused by placing a unilateral DNAR order."

Instead, the authors say, focus should be placed on open discussion between parents and members of the clinical team, shared decision-making, and maintenance of the clinician-parent relationship while simultaneously supporting members of the clinical team who express discomfort with parental decisions.

The parent-provider relationship is "incredibly important, particularly so at the end of life," says Marron. "It is not ethically defensible to put that relationship in jeopardy when other options are available." ■

EXECUTIVE SUMMARY

A unilateral do not attempt resuscitation order only is appropriate in very limited circumstances in pediatric care, concludes a recent paper. Some ethical approaches include the following:

- holding an open discussion between parents and members of the clinical team;
- using a shared decision-making process;
- supporting clinicians who express discomfort with parental decisions.

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Is Surrogate Acting in Own Self-Interest, the Patient's, or Both?

Start by assuming surrogate is 'trying to do the right thing'

Possible conflicts of interest should be on a clinical team's radar if surrogates make decisions that appear to conflict with patients' known preferences. However, there are many more likely explanations.

"It's fascinating to me that we encourage people to appoint healthcare agents that are close to them, and know them the best — when, of course, these are the people that are almost guaranteed to have conflicts of interest," says **Timothy W. Kirk**, PhD, associate professor of philosophy at York College of the City University of New York in New York City.

Conflicts between the surrogate and the clinical team can arise, some intractable. In some cases, nursing home staff have seen the patient on a daily basis for years, yet estranged family members are the ones making decisions. "The nurse manager and social worker may be thinking, 'Nothing's been written down, but we know she wouldn't want this,'" says Kirk.

Kirk says there are two ways to approach this. One is going to court to challenge the surrogate's fitness because he or she is making decisions contrary to the patient's preferences. State laws vary as to the extent that clinicians can choose not to honor a care decision made by a surrogate decision-maker.

Before things get to that point, ethicists can help to explore the surrogate's reasoning. Kirk starts with the assumption that a surrogate is "trying to do the right thing. Trying to understand what someone else would have wanted is a hard thing to do."

A clinical ethicist isn't always needed in these situations. "Many clinicians have the skills to do this without seeking help outside of the care team," says Kirk.

It might be that the surrogate misunderstands the proposed clinical intervention, or envisions different outcomes than the team. "The surrogate may be applying some of the patient's known values, while the team is applying other of the patient's known values," adds Kirk.

Explore Reasoning

Even if the surrogate's decision is somewhat self-serving, it doesn't necessarily conflict with the patient's values. "While ethical theory likes to presume that patient preferences are independent and self-interested, the empirical literature does not support this presumption," says Kirk.

In fact, patients often choose to put family members' needs above their own. "I can't tell you how many times I've learned that patients are deliberately and thoughtfully making decisions motivated by what is best for their families, not for themselves," says Kirk.

The issue of housing is one example. A common scenario: The surrogate is a family member who lives with the patient in subsidized housing, but the patient is the one who qualifies to live in that housing. If the patient has to go to a nursing home or dies, the surrogate no longer has a place to live.

"In a situation like that, there can be a strong incentive to make decisions that align with keeping the patient eligible for housing, so the surrogate also has a place to live," says Kirk. While this is a contributing factor in the decision-making, the

EXECUTIVE SUMMARY

If surrogates' decisions appear to conflict with patients' known preferences, further exploration is needed. Ethicists may learn that:

- surrogates misunderstand the proposed clinical intervention;
- a patient is choosing to put the surrogate's needs first;
- the patients' stated wishes don't fit the relevant clinical scenario.

surrogate may also know the patient would prefer to go back home. "The patient may indeed make the same decision with the same motivation: so that the surrogate has a place to live," says Kirk. Thus, the surrogate's "self-serving" decision still reflects the patient's values.

The patient may have asked the surrogate to give up a job, move into the home, and become a full-time caregiver. In this situation, both parties are relying on housing remaining available for the surrogate. "That may support an inference that the patient would make the same decision for the same reason as the surrogate is, which is consistent with substituted judgment," says **Margot Eves**, JD, a staff bioethicist and director of the Clinical Ethics Immersion Program at Cleveland (OH) Clinic.

Eves says clinicians should "take a step back" if a surrogate's decision appears self-serving. "The primary reason that surrogates may place, or appear to place, their own wishes over patient preferences is the overwhelming emotional burden of the situation," says Eves.

Some surrogates lack social support themselves and fear being alone. Many have never tried to make decisions for another adult before. "Surrogates may have difficulty processing the 'if/thens' in complex medical scenarios," says Eves. Many feel rushed to make a decision, confronted with new information. "Trying to understand it, its implications, and then consider various pathways may require time," says Eves.

Surrogates often fear making the wrong decision, especially in end-of-life care. "Often, there is a significant amount of uncertainty," says Eves. Even when patients have spoken to their families about their wishes, these often are not specific enough to be applicable to the current situation.

Ethical responses include "compassion, patience, and sincere inquiry," says Eves. Ethicists should make ongoing efforts to redirect the surrogate's focus back to the patient by taking the time to learn about the patient as a person. "Understanding the patient's values informs the decision-making process, and increases our ability to guide or support the surrogate in thinking about medical decisions," says Eves.

Eves offers this example of a nonjudgmental, transparent approach: "I understand that it is terribly upsetting to see your wife doing so poorly and that you want to make sure she has every opportunity to get better. However, my understanding is that before she became so confused, she told the doctor that she did not want to be intubated or have CPR. You also mentioned earlier that your wife has not seen a doctor the whole time you have known her; 38 years is a very long time to not see a doctor. It does not surprise me that someone who has not seen a doctor in so long also has indicated that she does not desire aggressive life-saving measures. We have an obligation to honor the patient's wishes and values. However, you are requesting that we provide these interventions should she need them. I am sure you can appreciate that this creates a challenging situation. We just met her, and you are her husband; we know that you know your wife better than we ever will. Please, help us learn more about her, and why it is that you believe she would want these interventions even though she told us she would not."

"The most important thing is to acknowledge the surrogate's emotions, and not simply move on to 'information-giving' mode," says Eves. Ethicists can:

- offer ideas on solutions or alternatives that were not yet identified;
- ask similar questions differently in a way that might be better understood by the surrogate.

Another way of asking, "What would Mrs. Smith want?" is "If Mrs. Smith could see what we see, and hear all the information from the doctors, what do you think she might say? What concerns might she have? What do you think she might want to know?"

"Ethics involvement can provide 'fresh eyes' to a situation," says Eves. ■

SOURCES

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Study: Clergy May View End-of-Life Decision-making Differently From Clinical Team

Most U.S. clergy reject the legalization of physician-aided dying (PAD), found a recent study.[1]

"There have been no adequate surveys of clergy that describe their ethical views on end-of-life issues," says lead author **Michael Balboni**, PhD, ThM, MDiv, a researcher in the department of psychosocial oncology and palliative care at the Dana-Farber Cancer Institute in Boston.

The researchers surveyed 1,005 clergy on controversial end-of-life ethical issues, including whether the terminally ill should ever be "allowed to die" and moral/legal opinions concerning PAD/physician-assisted suicide (PAS).

In debates on PAS, there often are clergy representing both sides of the issue. "They therefore seem to cancel each other out in the debate: The pope is against it; Bishop Tutu is for it," says Balboni. The researchers wanted to provide actual percentages as to how many clergy are for or against PAS. "The findings held a few surprises," says Balboni. Findings include the following:

• The majority (80%) agreed that there are circumstances in which the terminally ill should be "allowed to die."

• A minority agreed that PAD/PAS was morally (28%) or legally (22%) acceptable.

• Those reporting distrust in healthcare were less likely to oppose legalization of PAD/PAS.

• Religious beliefs associated with disapproval of PAD/PAS included "life's value is not tied to the patient's quality of life" and "only God numbers our days."

• Clergy who had stronger medical knowledge of end-of-life care were more likely to be opposed to PAS.

"These clergy have a better sense of how palliative care can adequately treat pain and other physical symptoms," says Balboni.

• Clergy were more likely to accept PAS if they thought that pain could not be addressed near the end of life.

"Clergy who understand that medicine has made considerable advancement in pain management in life-threatening illness were less likely to worry about unremitting and unaddressed pain," says Balboni.

• Most clergy understand a moral difference between "allowing to die" and PAS.

Most reject the idea that the patient should hasten his or her own dying by introducing an outside agent intended to end the patient's life. On the other hand, says Balboni, "Large majorities believe that patients should be allowed to die when overmastered by their disease."

Distrust Is Concern

Policymakers should recognize that the vast majority of clergy in the U.S. are opposed to the legalization of PAS for moral reasons, says Balboni. There continues to be considerable religious resistance to PAS among Christians, Muslims, Buddhists, and Hindus. "There is a relatively significant voice of agreement that from religious viewpoints, PAS is deeply problematic," says Balboni.

Another important factor is the distrust some clergy have in the healthcare system. "This is based on a variety of reasons, including medical hubris and disregard of religious rationales within serious illness," says Balboni.

Distrust in healthcare may also play a role in the increased likelihood of black and Hispanic minorities receiving aggressive care at the end of life. "These minority groups are far more religious than whites, and religion is intertwined with other associated reasons leading to distrust," says Balboni.

If PAS grows in legalization in the U.S., one potential unintended consequence is acceleration of healthcare distrust among racial and ethnic minorities, says Balboni. This, in turn, could lead to less hospice use and more aggressive care at the end of life. "Trust is likely a key problem in why many religious persons receive more expensive, aggressive care near death," says Balboni.

State health policymakers need to carefully consider this possibility, says Balboni: "There are likely invisible and surprising connections where further loss of trust among certain at-risk health populations will almost certainly increase, not decrease, medical costs." ■

REFERENCE

1. Balboni MJ, Sullivan A, Smith PT, et al. The views of clergy regarding ethical controversies in care at the end of life. *J Pain Symptom Manage* 2018; 55(1):65-74.

SOURCE

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CME/CE QUESTIONS

1. **Which is true regarding ethics evaluation, according to Ellen Fox, MD?**

   a. All organizations should use the same approach for evaluation.
   b. Measuring effectiveness on specific desired outcomes is the single best option if organizations lack expertise and resources.
   c. Requester satisfaction is the only metric that has been linked to increased quality in other areas.
   d. Some individuals who perform ethics consultations lack the core competencies required to do it well.

2. **Which did a study find on decision-making regarding family presence during resuscitation?**

   a. Physicians focused primarily on the resuscitation team's needs.
   b. Nurses were mainly concerned about the family's lack of knowledge about resuscitation events.
   c. Physicians had strong concerns about the potential for family disruption.
   d. "Family facilitators" increase the risk of disruption.

3. **Which is true regarding surrogate decision-makers, according to Timothy W. Kirk, PhD?**

   a. Surrogates experience increased stress if patients have a DNR order.
   b. If concerns exist about conflict of interest, the surrogate's reasoning should be explored.
   c. Early court involvement is best as soon as surrogates make decisions that appear to conflict with patients' known preferences.
   d. Surrogates' acknowledgement that their own housing is a factor in their decision-making is a clear indication that the patient's values are being disregarded.

4. **Which is true regarding clergy and end-of-life decision-making, according to a recent study?**

   a. Most clergy support legalization of physician-aided dying.
   b. Most clergy do not agree there are circumstances in which the terminally ill should be "allowed to die."
   c. Clergy who had stronger medical knowledge of end-of-life care were more likely to be opposed to physician-assisted suicide.
   d. Most clergy make no distinction between "allowing to die" and physician-assisted suicide.