MEDICAL ETHICS ADVISOR®

YOUR PRACTICAL GUIDE TO ETHICS DECISION-MAKING

JUNE 2020 Vol. 36, No. 6; p. 61-72

INSIDE

RELIAS MEDIA

Clinical Ethicists 'Doubling Down' on Efforts as Hospitals Adjust to New Normal

There may be some ethicists asking, "What can ethics do to capitalize on this moment?"

"Every single ethics committee needs to be asking that question right now," says **Melissa M. Bottrell**, MPH, PhD, chief executive officer of Berkeley, CA-based Ethics Quality Consulting.

Hospitals are continuing to face complex ethical questions stemming from the coronavirus response.

"It's an opportunity to double down on infusing the concept of ethics throughout the organization's culture," Bottrell says.

The pandemic "made ethics committees players of central importance," says **Lydia Dugdale**, MD, MAR (ethics), associate director of clinical ethics at NewYork-Presbyterian. Ethicists were called to craft policy for allocation of scarce resources and initiation of CPR in COVID-19-positive patients.

"Ethicists will need to continue to assert their voices even after the crisis ends," says Dugdale, who also serves as director of the Columbia Center for Clinical Medical Ethics.

When COVID-19 first hit, hospital-based ethicists fell into two distinct groups, Bottrell observes. Some ethicists received calls from hospital leaders asking for their immediate help. "During policy and practice discussions, ethicists were a trusted advisor at the table," Bottrell notes. Now, this group is focused on what they can do next for the organization.

Other ethicists were left out of the decision-making process for coronavirus issues. Members of this group are asking themselves why they were not consulted. "There are definitely places that didn't get the call. They now have some soul-searching to do," Bottrell explains.

Possibly, hospital leaders saw ethics as narrowly focused on bedside consults. "Some may have thought that ethics' regular time frame for response was too long for the speed of decision-making that was happening," Bottrell offers.

Certain ethicists already were part of pandemic flu preparedness committees.

Financial Disclosure: Physician Editor **Arthur R. Derse**, MD, JD, Nurse Planner **Susan Solverson**, RN, BSN, CMSRN, Editor **Jonathan Springston**, Editor **Jill Drachenberg**, Editorial Group Manager **Leslie Coplin**, Accreditations Director **Amy M. Johnson**, MSN, RN, CPN, and Author **Stacey Kusterbeck** report no consultant, stockholder, speakers' bureau, research, or other financial relationships with companies having ties to this field of study.

MEDICAL ETHICS ADVISOR®

Medical Ethics Advisor®, ISSN 0886-0653, is published monthly by Relias LLC, 1010 Sync St., Ste. 100, Morrisville, NC 27560-5468. Periodicals postage paid at Morrisville, NC, and additional mailing offices. POSTMASTER: Send address changes to *Medical Ethics Advisor*, Relias LLC, 1010 Sync St., Ste. 100, Morrisville, NC 27560-5468.

GST Registration Number: R128870672.

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If ethicists were already planning that way, it clearly signaled their expertise was relevant. If not, says Bottrell, "maybe it wasn't clear that it was in the ethics committee scope."

Leaders also considered how well-connected ethicists were outside their own institutions. Right away, some jumped into exchanging model critical care triage policies with ethics colleagues near and far. "If they were tied into what was happening in the region or state, then ethics could be a conduit of information in this fast-moving story," Bottrell says.

Typically, ethicists consult on cases involving one patient, their family members, and a small group of treating clinicians. "In normal times, we are doing things such as ethics education and ethics consults to help make decisions in the setting of individual patients," says **Mary Devereaux**, PhD, chief of bioethics at Rady Children's Hospital-San Diego.

Those same ethicists contributed to organizationwide, statewide, or regional issues. "We've scaled up to a completely different level. We are talking about how to save the most lives in the nation or the state or a particular community," says Devereaux, who also serves as assistant director of the research ethics program at the University of California, San Diego.

At many institutions, clinical ethics expertise is not fully appreciated until a challenging case appears. "COVID has certainly been a tough case, but on a much larger scale, and with much higher stakes," says **David A. Fleming**, MD, MA, MACP, professor emeritus of medicine and senior scholar at the University of Missouri Center for Health Ethics.

Caught off guard, healthcare systems suddenly faced many urgent, complex ethical questions. "The value of ethics expertise has certainly been realized in this pandemic," Fleming notes.

Hospital leaders found themselves grappling with the reality of the COVID-19 surge with inadequate supplies. "It brought attention to the ethics question: How do you allocate resources fairly?" Devereaux says.

Ethicists asked leaders what the organization was doing, and soon found themselves crafting a triage policy. "In other cases, hospitals implemented their command center for disaster preparedness and ethics was part of that, but they didn't have to initiate their involvement," Devereaux observes.

Some ethicists helped with statewide or regional policies. "At all of those levels, people have been asking for medical ethicists to be involved," Devereaux says.

Even if ethicists lacked strong ties with hospital leaders, they forged them out of necessity. "The pandemic has certainly raised the profile nationally of public health and epidemiology. It's also true of bioethics," Devereaux explains.

This is a special opportunity for clinical ethicists to nurture their newly expanded role. "I would hope leadership would see that there's a unique kind of expertise that people trained in ethics bring to the table," Devereaux says.

If hospitals want to create an institutional ethical culture that addresses fair access to healthcare, community trust, and physician and staff well-being, they are going to need ethicists' help. "It's easy to make decisions on a budgetary basis or economic basis without thinking of ethical issues," says Devereaux, noting ethicists also are needed for future planning. "Once our current situation resolves, hospitals are going

to need to review what we've learned. We will need to prepare for not just the next pandemic, but other public health disasters."

Ethics can begin by examining larger issues behind recurrent consult requests. "The way you move into organizational thinking is to respond to these questions systematically," Bottrell suggests.

If a life-sustaining treatment withdrawal policy lacks clarity, ethicists need to revise it or provide education. "That pushes you into conversations with leadership over specific topics," Bottrell says. "You demonstrate that you can solve a problem for them — not as a one-off, but long-term."

For instance, furloughs and layoffs happening at many hospitals require transparency. "Ethics can help with how to fairly distribute the economic belt-tightening, and assure good stewardship of resources," Bottrell explains.

To accomplish this, ethics needs a presence during high-level discussions on resource allocation, protecting vulnerable patients, and caring for staff. "In the midst of this angst, as healthcare adapts to the 'new normal,' both old and new moral questions will arise," says Fleming. "Clinical ethicists still have a lot of work to do."

There are a few examples of hospital initiatives with which ethics can be involved:

• Hospitals will be restarting elective surgeries and returning to regular appointment schedules. More than just finances is at stake when such decisions are made.

"Having a voice at the table that offers a balanced and measured response as to mission and ethical implications will be important for the integrity of any healthcare institution," Fleming stresses.

• A variety of new policies will be needed. Hospitals are expanding services to underserved areas, making resource allocation decisions for highly vulnerable patients, and setting standards for telehealth.

When institutions are crafting all these policies, says Fleming, "ethics should do the heavy lifting."

• Hospitals need to respond to public concerns about transparency. For example, triage policies must be available for public viewing and engagement.

"It fosters trust that decisions will be objective and fair when the time comes for them to be made," Fleming notes.

• Hospitals need approaches to respond to the emotional and physical welfare of healthcare teams. "This should, and hopefully will, be a high priority for healthcare systems and government in the foreseeable future," Fleming says.

• Research ethics questions are arising regarding clinical trials for both treatments and vaccines. "This is increasingly important, especially in recruiting subjects from vulnerable and underrepresented populations," Fleming says.

• Critical care triage protocols may need to be revised. Changes might be needed depending on the clinical experience in hard-hit areas, or input from public engagement.

"Further refinement of triage protocols should ensure that they are just, usable, and transparent," Fleming adds. ■

Making Critical Care Triage Policies Transparent to Patients, Community

Certain hospitals are including information on their critical care triage policies in admission packets to explain how care or supplies will be allocated if rationing becomes necessary. People want to know what it means for them in particular.

"There will be big enough concepts and words used that require interpretation in the immediate situation," says **Paul T. Menzel**, PhD, professor of philosophy emeritus at Pacific Lutheran University in Tacoma, WA. Hospitals are obligated to explain how decisions would be made. "It's wrong to hide them ... but how to make them transparent, and how aggressively, is another matter," says Menzel, an affiliate professor at the University of Washington department of bioethics and humanities.

Some clinicians feel ethically obligated to inform everyone up front of the possibility. Others think it is better to do so only if and when it becomes necessary. "There are real ethical nuances there," Menzel observes. "This is a real ethical dilemma."

Menzel sees a strong parallel with another controversial practice. Clinicians struggle with how to tell patients about voluntarily stopping eating and drinking as a way to hasten death. "In certain situations, that can be a very viable and even comfortable and appropriate option," Menzel suggests.

Yet if clinicians bring it up too early, people may fear the clinician is pushing them to end their life. "This can happen if it's brought up in the wrong context, or the wrong way, to someone who hasn't asked about

it specifically," Menzel notes. In one such case, the patient was adamantly opposed when the clinician first brought it up.[1] "When problems and pain persisted, the clinician bravely decided to broach it again," Menzel explains.

This time, the patient immediately decided the option was the right choice. "It was accomplished successfully. But it wouldn't have happened if the clinician hadn't taken the risk of bringing it up again," Menzel recalls.

In other cases, clinicians have held off on raising the issue. When they finally do talk about the issue, it becomes apparent the patient would have greatly benefited from knowing about the option earlier.

Clinicians face a similar dilemma when informing people of how decisions would be made if care is rationed. In both situations, says Menzel, "there is the risk of too much information, too soon — or the risk of too little, too late."

Patients and families do have the right to the information. "People ought to know what's going on," Menzel argues.

Putting the information in an admission packet may be insufficient. This puts the burden on the patient or family to ask about the option. "A more aggressive stance would be to raise the issue, and say, 'Right now, it's not applicable to you. But if you want to talk about this at any point, please ask,'" Menzel says.

Ethicists cannot respond to every alarmed patient and family member about what critical care triage means for them. Instead, ethicists can support clinicians to confidently and capably answer tough questions. "Ethicists should communicate clearly to clinicians that this is very tough work. You are not always going to make the right decision," Menzel says.

That is a good place to begin, since none of the guidelines offer definitive answers. "They are tough to write, there are always tradeoffs, and there are dilemmas harbored in just about every priority claim stated," Menzel says.

Most people would agree that someone with the best prospect of success should go ahead of somebody with worse chances. "But even that is challengeable, not only in terms of philosophy but also in the minds of very ordinary people who do understand the dilemma," Menzel says.

It is not enough for clinicians to clearly communicate the guidelines to patients. Clinicians need more than that from ethics, Menzel stresses. He suggests ethicists give clinicians a fuller picture by saying something like: "The best thinking we've put into it at this facility has generated these guidelines. Nobody should think they are the ultimate moral truth. They are just the best we can come up with."

"There are complex dilemmas involved in this, and you can't paper them over," Menzel acknowledges.

Making triage processes transparent, an ethical obligation for providers and hospitals, has proven quite challenging. "We are obligated to educate the public about scarce resources and the principles of population-based ethics of healthcare delivery under crisis standards of care," says **Kathleen Akgün**, MD, MS, associate professor of medicine at VA Connecticut Healthcare System and Yale University School of Medicine.

These principles are contrary to ethical obligations during regular times, which prioritize patients' autonomy. This is a complicated message to convey. "We have been working on how best to telegraph these issues to the public without causing alarm," says Akgün, co-chair of the clinical ethics committee and director of the medical intensive care unit at VA Connecticut.

Ethicists are developing a frequently asked questions pamphlet to be given to patients and surrogate decision-makers at hospital admission. "We remain concerned over whether this would be enough preparation when the time comes," Akgün says.

Clinicians may struggle to comprehend all the ethical nuances of critical care triage guidelines. Many feel ill-prepared to explain all the details to distraught family members.

"Some are working 12-hour shifts for weeks on end. There are often calls to ethicists about patients who seem to be failing, and the question is what to do," says **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center in Hempstead, NY.

No matter how much guidance is in place, ethical challenges remain for everyone. "Anything you do is in an arena in which ethics are being shifted and re-examined," Dolgin explains. "The possibility of feeling satisfied and sanguine does not exist."

How the critical care triage policies are communicated publicly is an important question, among many others that organizations will need to examine through an ethical lens. "We will have to rethink some of the foundational principles of bioethics," Dolgin predicts. "It's not possible to rely on autonomy in a context where many lives are going to be lost."

Some hospitals will find it necessary to revise triage policies. If so, efforts should be made to obtain public input, Menzel says. That can be accomplished by including members of the community on policy-forming committees, or

by holding public forums with prominent people in attendance.

"This is especially important if the situation in the region is one where there really is a prospect of having to ration, or there's evident public worry about it," Menzel says. ■

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Disciplinary Action, Terminations, Gag Orders: 'Avalanche Effect'

When the COVID-19 pandemic started, hospitals suddenly had to determine how to ration scarce critical care resources, something they never had to do before.

Fortunately, multiple guidelines already existed based on mass casualties and previous epidemics. "But we really had never talked about how to ration equipment for providers," says **Charles E. Binkley**, MD, FACS, principal and founder of ProNobis Health, a San Francisco-based healthcare quality and bioethics consulting firm.

Hospitals could not change the fact they were caught without enough personal protective equipment (PPE) and could not immediately obtain more of it. However, they could control whether they responded ethically to this terrible situation. "Some hospitals have failed miserably during this crisis. The whole situation around PPE has eroded trust," says **Diana J. Mason**, RN, PHD, FAAN, senior policy service professor at the George Washington University Center for Health Policy and Media Engagement in Washington, DC. Mason has heard these firsthand accounts:

• An experienced intensive care unit nurse went through the proper channels to report concerns, and was called in the next morning and fired.

• Nurses and physicians were told they could not bring in their own N95 masks from home, even though the hospital was not providing them.

• An immunocompromised nurse was told she would have to care for COVID-19 patients, and ended up quitting her job as a result.

"The message is: 'You are expendable, and we want you to put your life on the line — and choose between your family and your job,'" Mason says.

Some hospitals imposed gag orders on staff, barring them from voicing concerns about PPE publicly. Nurses and physicians have been disciplined or threatened with termination for reporting inadequate PPE on social media.[1,2] *(Editor's Note: The American Medical Association argues, according to the organization's* Code of Medical Ethics*, that physicians are ethically obligated to address conditions that put them and patients at risk: https://bit.ly/3dFlOeI.)*

Mason says these kinds of practices are unethical, and that hospitals could have handled things differently. "If I were the head of the hospital, I would say to staff, 'If you don't have adequate PPE, you speak out. Go tell the world what you are working with, and that we are working to find it but we can't get it.'"

Instead, some hospitals doubled down on efforts to tightly control messaging. "That message, for many hospitals, was 'We're doing just fine, thank you.' That says the priority is the hospital's image, and not their workers," Mason says.

Physicians and nurses have had to choose between protecting themselves and taking care of patients. This dire situation brought underlying problems to the surface. "Nurses and physicians have been feeling they're being put in impossible situations for a long time now," says Binkley, former chief of hospital quality at Kaiser Permanente. "It's been an avalanche effect."

On one hand, the crisis could have rallied healthcare providers, with the feeling that they are fulfilling their mission. "But if there is a sense that people are being forced to do things, if there's not a transparent process, if there's any sense that administrators are making unjust decisions, that's where the moral injury comes into play," Binkley notes.

Hospital policies on PPE allocation must be transparent and equitable, with a mechanism to address grievances.[3] This raises complex ethical questions. "But it's the right process. It's the way we need to be doing things to avoid moral injury," Binkley argues.

Creating a "safety culture," where staff are encouraged to report concerns without fear of retribution, has been a major focus at many organizations. If healthcare staff perceive workplace safety culture positively, they tend to also feel positively about patient safety culture, according to the authors a 2018 study who analyzed data from 132 medical centers.[4] "Unfortunately, this is unmasking some of the superficiality of those initiatives," Binkley laments.

Many healthcare providers already distrusted hospital administrators' priorities to some extent.

"These issues have been bubbling up for a long time. Now, COVID is showing us the fault lines," Mason observes.

Hospitals appeared hypocritical by first implementing wellness programs for providers, then punishing them for reporting concerns about PPE.

"It's having it be real and not just there to protect the image of the brand," Binkley says. "I think most people can discern the difference."

That is not to suggest hospital administrators are unethical as individuals. Yet faced with prioritizing financial viability, risk management, and public relations during the pandemic, some lost sight of the hospital's mission.

"That's where ethicists can really contribute to the conversation," Binkley offers.

Ethicists have unique expertise when it comes to resolving conflicts between families and providers, or within the care team. Now, ethicists can put these skills to work in resolving disagreements between administrators and providers.

"Ethicists can come in and be objective, hear both sides, and look at it through an ethical lens," Binkley says.

Conflicts between hospitals and staff ended up playing out in the public eye. If ethicists had been involved when issues with PPE first came up, that possibly could have been prevented.

"Ethicists could have helped formulate policies that were just, transparent, equitable, and accountable," Binkley says.

Ethicists also could have mitigated myriad problems, ranging from poor morale to legal action, when staff did voice concerns publicly.

"Most ethicists would support the right of staff to speak up, without fear of retaliation, but may qualify it based on intention," Binkley explains.

The ethical intent should be to avoid harm to patients and staff, not to get back at administrators. Ethicists could have sorted out whether internal processes were followed by the staff, and whether staff complained publicly only as a last resort. This is a better option than hospitals implementing blanket gag orders and punishing anyone who violates them, Binkley says.

"The voice of ethics should be present whenever you are making difficult decisions, not just involving patients but also the medical and nursing staff and all of the ancillary staff," Binkley says.

Hospital leadership sets the tone for everyone else, namely that ethical behavior is expected.

"When hospitals do the right thing, the staff are right there with them," Mason says.

Modeling ethical leadership is particularly crucial during a crisis. Unfortunately, hospitals are not always well equipped in this regard. "Quite frankly, not all hospital CEOs were prepared, not just for the management of the situation but also the ethical context of that situation," Mason notes.

Mason says hospital leaders should ask themselves two questions: Who is paying attention to employee wellness? How am I showing I care about employees' well-being right now?

"It may be as simple as making rounds on a regular basis, saying 'How are you doing? What do you need? How can we better support you?'" Mason suggests.

The hospital CEO should be "visible, supportive, and observing how critical situations are being managed," Mason adds. Hospitals need to get serious about putting plans in place to support staff over the long term and, hopefully, restore trust. "We have a lot of deep work to do around the ethics of all this," Mason says. ■

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COMING IN FUTURE MONTHS

- Telehealth uncovers new ethical considerations
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Ethicists Offer Much-Needed Support to Clinicians with Moral Distress

The issue of moral distress is nothing new in healthcare, but the COVID-19 pandemic has amplified the problem.

"Very few people have had the time to consider what shifting standards of care will look like during a pandemic. We are by necessity doing things very differently. That does not mean it is wrong," says **Lucia D. Wocial**, PhD, RN, FAAN, HEC-C, a nurse ethicist at Fairbanks Center for Medical Ethics at Indiana University Health.

Clinicians know that good end-of-life care does not mean excluding family members from being with patients.[1] "Even if a video connection can be set up, it is a poor substitute for direct contact with a family member," Wocial says.

Visitor restrictions mean some patients are dying alone. "There have been real tragedies where people are literally brought to the emergency room by family who never see the person alive again," Wocial says.

Some clinicians found themselves working in unfamiliar locations and without enough supplies.

"You have to get up to speed really fast, and the stakes are high," Wocial notes.

In the context of all this, there may be clinicians who believe they cannot meet ethical obligations to patients. "The stress on clinicians is enormous. Everybody is working harder than they've ever had to work in the past," Wocial observes.

It is counterintuitive for healthcare providers to slow down during an emergency. "Yet we need them to do that," Wocial offers. "There are difficult ethical questions every moment of every day, and that's exhausting."

Ethicists can support clinicians with moral distress in specific ways, according to Wocial:

• Emphasize that protecting themselves is not unethical. Clinicians are choosing between patient care and their own safety. Ethicists can help clarify what is at stake.

If a clinician intubates someone without proper PPE, it might have been helpful for that one patient. But there is a bigger picture. "You put yourself at risk. If we lose you, that's one more person we've lost on the front line," Wocial says.

• Explain the ethical justification for refusing CPR. Emergency department providers have asked ethicists what they should do if an actively dying patient arrives. They ask this specific question: If the physician can make a reasonable judgment that the patient cannot recover, is it ethically permissible for him or her to not perform CPR, even if the family wants the team to try?

"With limited PPE and looming ICU [intensive care unit] shortages, that is an ethically permissible position to take," Wocial says.

Refusing to perform CPR in this situation may feel unethical.

"It doesn't mean you've done anything wrong," Wocial explains. "It means you had to make a tough choice in an ethically challenging situation."

Still, there are clinicians who may struggle with the decision. "Ethicists can say, 'What you're doing is good, and here's why, from an ethics standpoint,'" Wocial suggests.

• Give a name to what clinicians are feeling. Simply learning what "moral distress" means, and understanding that many others are suffering from it as well, is comforting. "We expect people to experience it because these are very ethically challenging times," Wocial says.

• Encourage clinicians to make self-care a priority. "Failing to take care of ourselves will not serve us or our patients well in the long run," Wocial notes.

Staff at the University of Rochester (NY) Medical Center did not have to make allocation decisions. The hospital never was overwhelmed with COVID-19 patients, reports clinical ethicist **Marianne C. Chiafery**, DNP, PNP-BC. Nurses also had enough PPE to be protected while at work, so that was not an issue. However, clinicians experienced moral distress over these specific concerns:

• Staff worried about bringing the virus home. "Our hospital supplied staff with scrubs that they can change out of before going home, which helped," says Chiafery, associate professor of clinical nursing at University of Rochester's School of Nursing.

Still, nurses were conflicted between meeting their professional obligation to not abandon patients in need and possibly harming their own family members.

"The tension between personal safety concerns and professional obligations weighs heavily," Chiafery says.

• Staff struggled with caring for critically ill patients who were isolated from loved ones. Ethicists explained that there are no "good" options in this situation. If nurses allowed visitation for COVID-19 patients, others would be put at risk. "We acknowledge that while not allowing visitors feels wrong, the least

bad option is to restrict visitors," Chiafery says.

Next, ethicists pointed out there are ways to mitigate harm, and help patients and families in this awful situation. Nurses make more frequent phone calls to family, and offer patients computer and phone access 24/7. "Staff spend more time at their bedside just being with them," Chiafery reports.

Palliative care colleagues found a way to help, too, by developing scripts to use for goals of care discussions. "These are hard even when everyone can talk face to face," Chiafery says. "Losing that in-person contact made it more challenging."

• Staff struggled with comforting patients and family. Not being able to physically comfort patients is "a painful realization" for many staff, Chiafery says.

One physician noted that in talking to a new mother about her premature baby, he normally would reach out with a comforting touch to the shoulder. Not being able to perform this simple gesture bothered him greatly. "To this physician, it violated his sense of who he is a healthcare provider, and how he demonstrates that concern to those in his care," Chiafery says.

Just hearing other colleagues express the same concern was reassuring. Ethicists also stressed the importance of eye contact as a way to connect. They also recommended that staff convey their feelings. Chiafery explained it this way to staff: "It's OK to say to a patient or family, 'I understand your frustration with this situation, because I feel the same. I wish things were different.'" ■

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Families' Surprising Opinions on End-of-Life ICU Care

Intensive care units (ICU) may be associated with poor-quality end-of-life care. A recent study's findings call that into question — at least from the family's perspective.[1]

"ICUs have traditionally been viewed as the worst place in the world to die, even worse than regular hospital wards," says **Josh Rolnick**, MD, JD, the study's lead author and a clinical scholar in the National Clinician Scholars Program at the University of Pennsylvania. "You see that assumption among clinicians, policymakers, and researchers. We wanted to understand if this assumption was correct."

Rolnick and colleagues examined the association between ICU care during terminal hospitalization and family ratings of end-of-life care for patients who died in more than 100 Veterans Affairs hospitals between 2010 and 2016. The authors created four categories: patients who received no ICU care, those who received only ICU care, those who received ICU care but died outside the unit, and patients who received ICU care and died in the unit.

Of 57,550 decedents, a family member or close contact had completed a survey for 28,062 decedents. Before looking at the survey results, Rolnick and colleagues hypothesized that ICU use would be linked to lower ratings of care. However, they discovered that the opposite was true: More ICU time was linked to higher ratings.

That was true not just for patients treated solely in ICUs, but also for patients who were treated in both levels of care (ICUs and general wards).

"Unfortunately, another surprising finding was the high level of uncontrolled pain reported across all hospital settings, even in ICUs," Rolnick says. About half of families reported "some" or "significant" pain during the patient's last month of life.

"If it is true that ICUs lead to better end-of-life care, it may be for a few reasons," Rolnick offers. For one thing, the staffing ratios are different. There are more clinical staff available per patient, and the nursing staff ratio also is lower.

"With only one or two patients rather than four or more, the nurse has more time available to devote to the needs of the patient and family," Rolnick says.

People also may sense that "everything" was handled in the ICU setting. Additionally, says Rolnick, "ICU staff are more experienced with end-of-life care than ward staff because they treat more critically ill patients."

The study's findings do not imply that people should be admitted to ICUs for end-of-life care, Rolnick stresses. ICU ratings were worse than nursing homes and hospice units. "While we don't know if this association is causal, it does suggest that we should make efforts to avoid having patients die in acute hospitals if feasible," Rolnick says.

It is not as simple as just making sure people stay out of the ICU. Doing so, says Rolnick, "may even worsen their experience. Instead, we need to find ways to get them out of acute care hospitals entirely."

The findings carry important implications for discussions on end-of-life decision-making.

"It may not be appropriate to counsel people that the end-of-life experience will be worse in the ICU than on regular hospital wards," says Rolnick. "That is not so clear."

What is clear is the complexity of improving end-of-life care.

"It may be a matter of having better staffing ratios for patients who need intensive palliative efforts," Rolnick offers. ■

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POLST Forms Not Always Used as Intended, Rarely Accessed in EDs

Physician Orders for Life-Sustaining Treatment (POLST) forms have been implemented widely to reduce unwanted, aggressive treatment for patients with serious illness at the end of life.

"However, most studies on POLST have been limited to nursing home residents or among decedents. Very few have evaluated the influence of POLST on the care of patients who are hospitalized," says **Kelly C. Vranas**, MD, assistant professor in the division of pulmonary and critical care medicine at Oregon Health & Science University.

Vranas and colleagues set out to better understand how POLST forms are used in the hospital, and whether treatment limitations on POLST influence the intensity of treatment hospital patients received.[1] Some key findings:

• Among patients presenting to the emergency department (ED) with POLST forms, most had orders for full treatment.

"This makes us wonder whether POLST forms are actually being completed inappropriately among patients who are healthier than the intended patient population," Vranas offers.

POLST is specifically for patients with chronic serious illness who are approaching the end of life. "There has been a push nationwide to include POLST completion as an indicator of high-quality care, particularly among primary care providers," Vranas notes.

When used as a marker of quality, patients who are not the intended population end up completing POLST forms. These patients are too healthy for POLST and, therefore, select full code/full treatment options.

"This leads to overuse among inappropriate patients," Vranas explains. "It has the potential to threaten patient-centered decision-making and undermine the voluntary nature of POLST completion."

• POLST forms were accessed infrequently (less than 7% of the time) by ED providers.

"This is concerning," Vranas says. The researchers could not find evidence that ED providers had accessed POLST, either by clicking on it in the electronic medical record, or by calling the Oregon POLST Registry. This suggests there is a need for standardized approaches that make it easier for ED providers to identify advance care planning documents.

"Our results highlight the need to better understand the culture and workflow of emergency providers," Vranas adds.

• Possessing a POLST form was not associated with reduced hospitalization or receipt of aggressive treatment.

There are two main reasons: POLST forms are not used as originally intended, and ED providers are not accessing them anyhow. "For these reasons, any potential benefit of POLST is diluted," Vranas observes.

• Patients with treatment limitations on POLST were less likely to be admitted to the ICU. This suggests that POLST may help align treatment received with patient preferences — but only "if POLST [forms] are completed among the intended population only, and they are accessed in a timely manner," Vranas says. ■

REFERENCE

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Is the Family Hoping for a Miracle? Ethical Responses Vary

The first ethics case discussion **Trevor M. Bibler**, PhD, was a part of was about a little boy who was a candidate for a liver transplant. His parents did not want him to receive it because they were hoping for miracle.

"When I asked the ethicist presenting the case what the family meant by miracle, he said he wasn't sure," says Bibler, an assistant professor of medicine at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston.

Bibler decided to research this topic, and found some literature on medicine and miracles. What was missing was discussion of how healthcare professionals might respond to the hope for a miracle.

It became apparent, says Bibler, "that additional theoretical discussion, but also practical recommendations, could be helpful for pediatricians who encounter parents or guardians who are hoping for a miracle of some kind."

Parents and the clinical team sometimes conflict on what they believe is best for the child. "The hope for a miracle seems to be a persistent challenge in pediatric medicine — and adult medicine as well," Bibler observes.

Clinicians give parents as much leeway as possible on what is best for their child. "But there can be a tension that arises when the healthcare professional disagrees with this plan," Bibler notes.

When parents hope for a miracle, they usually also request to start or continue specific interventions. "Ethically and professionally, the healthcare professional is put in a tough spot," Bibler says.

Clinicians have to respect the parents' beliefs while meeting their own ethical obligations to promote good consequences and minimize bad ones. "The real ethical crux of the issue is that the hope for a miracle can be a clash of worldviews," Bibler explains.

As a clinical ethics fellow, **Sophia Fantus**, PhD, was consulted on cases where families hoped for a miracle. The medical team appeared to be frustrated.

"They interpreted the family as being unable to comprehend the advice and guidance of the healthcare team, and that religion or spirituality was being used as a way to avoid or deter any sort of decision-making," says Fantus, an assistant professor at the University of Texas at Arlington School of Social Work.

Discussions stalled as both families and providers struggled to assess their own values, morals, and beliefs.

"Religion has been shown to play a positive role for loved ones, contributing to an understanding of why this painful experience has happened," says Fantus, adding that effective responses to hopes for miracles "can ultimately help bridge rapport in the patient-provider relationship."

Parents sometimes want life-sustaining technology continued because a miracle is possible, but the pediatrician believes it is harmful. The key to an ethical response in this kind of case, says Bibler, is to gain insight into what the parent means by "miracle." A recent paper offers a process-based approach to this.[1]

"We describe guardians who hope for a miracle as integrated, seeking, and adaptive," says Bibler, the paper's lead author. Where the parent falls in these categories affects the pediatric care team's response:

• Integrated. Families in this group often refer to Bible passages or stories in conversations with the healthcare team.

"Some families may have an altar in place by the bedside, and may hold onto rosaries or place crucifixes in the room at bedside," Fantus reports. These families make statements such as "Only God determines who can live or die."

"They are applying their religious worldview into their grief and loss," Fantus says. For these families, a miracle is a quick and complete

recovery of the child. One ethics consult involved with a family of a patient on extracorporeal membrane oxygenation with a dire prognosis. The family asked the team how many hours they would allow for them to pray and ask God to perform a miracle.

"The family asked for 12 hours, seeing as that was sufficient time for God to perform a complete recovery," Fantus says.

• **Seeking.** An example is a parent with a child on life-sustaining interventions who sees the healthcare professionals as the hands of God. The families may pray or cite religious texts, but they also rely on providers' expertise. "However, if the treatment plan changes or the clinical condition changes, the hope for a miracle may also change," Fantus says. The family often concludes that it is God's plan.

Chaplains can help the family shift the way they interpret a miracle as the clinical condition changes. "This may allow for time-limited trials and best- and worst-case scenario examples," Fantus offers.

• **Adaptive.** Families in this category often do not want to speak to a hospital chaplain, and rarely pray or rely on religious texts.

"They utilize religion in order to promote their right to decide on their child's care plan," Fantus explains. Often, the families believe the healthcare team is not listening. "The majority of cases we have been involved with is due to a lack of communication," Fantus notes. Frequent shift changes, with many new providers, make trust difficult. "Establishing a strong working relationship may mean holding more frequent family meetings, consistent informal updates, and check-ins at the bedside," Fantus says. ■

REFERENCE

1. Bibler TM, Stahl D, Fantus S, et al. A process-based approach to responding to parents or guardians who hope for a miracle. *Pediatrics* 2020;145. pii: e20192319. doi: 10.1542/peds.2019-2319.

Chaplains 'Uniquely Positioned' to Help During COVID-19

Chaplains are "uniquely positioned to serve as a critical patient care team member during the COVID-19 pandemic," says **Amy Marcum**, chief mission officer of the Great Lakes Group at Cincinnati-based Bon Secours Mercy Health.

"A chaplain's training has prepared him or her to assist our patients and their loved ones, as well as our care providers and associates, during times of crisis," Marcum says. The following are some examples:

• **Chaplains offer caregivers someone to turn to for words of comfort.** "These are anxious times. Chaplains are providing a calm presence and a quiet strength for the rest of the healthcare team and workers," Marcum observes. Clinicians are working long hours with limited resources and large patient volumes while making difficult decisions. "Being available and helping care providers put situations into a larger context is valuable," Marcum notes.

• **Chaplains are directly involved in ethics consults.** "Their training and skills complement those of the caregivers and ethicists," Marcum says.

Chaplains are trained to deal with emotions and help people come to grips with the reality of a situation. There may be times when the discussion centers on end-of-life care. "Chaplains are trained to adapt their prayers and words of comfort to the person's needs and faith perspective," Marcum adds.

• **Chaplains facilitate phone or FaceTime conversations between the family and clinicians.**

COVID-19 presents the added challenge of strict visitation restrictions. "As a result, loved ones or even clergy are often not able to be present during the final days," Marcum says.

• **Chaplains help family members understand difficult decisions that must be made.** "Chaplains bridge communication gaps," Marcum says.

Sometimes, this means asking clarifying questions on behalf of the patient or family.

For instance, a chaplain can help interpret what a clinician is saying in this manner: "Dr. Smith, since I am not clinical, I want to be sure I understand what you are saying. What I think I hear you saying is that their mom is very sick, the providers have tried several interventions, and at this time her body is not responding to them. You and the other treating physicians recommend discontinuing these aggressive means, and providing her comfort and time for the family to have precious moments with her. Is that correct?"

The ability of a chaplain to de-escalate anger and sadness is essential in any healthcare scenario. "Chaplains engage or ask questions to unlock hidden emotion and feelings," Marcum adds. ■

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CME/CE QUESTIONS

1. **Which is true regarding critical care triage policies?**
   a. Clinicians are ethically obligated to wait until they are certain that triage is necessary before informing families about relevant policies.
   b. Families have the right to information about critical care triage, and hospitals are ethically obligated to be open about it.
   c. Clinicians should assure patients the guidelines offer definitive answers.
   d. Evidence shows obtaining public input results in certain populations receiving preferential treatment.

2. **Which is true regarding moral distress?**
   a. Clinicians who refuse to intubate a patient without personal protective equipment are not meeting ethical obligations.
   b. Physicians are ethically obligated to perform CPR if the family requests it, even if it is clear an actively dying patient cannot recover.
   c. Ethicists should expect clinicians to experience moral distress, due in part to the constraints visitor limitations put on meeting ethical obligations to patients.
   d. It is unethical for clinicians to share frustrations about not being able to provide care as usual, as evidence shows this increases patients' distress.

3. **Which is true regarding families' perception of intensive care unit (ICU) end-of-life care?**
   a. Families identified ICUs as the worst quality place to die.
   b. More ICU time was linked to higher ratings of care.
   c. Staffing ratios were the main reason families rated ICU care poorly.
   d. ICU ratings were higher than nursing homes and hospice units.

4. **Which did the authors of a recent study find about Physician Orders for Life-Sustaining Treatment (POLST) forms?**
   a. No emergency department (ED) patients received orders for full treatment.
   b. ED providers frequently accessed POLST forms.
   c. Patients with treatment limitations on POLST were less likely to be admitted to the ICU.
   d. Presenting with a POLST was strongly linked to shorter hospital stays.