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INSIDE

RELIAS
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Ethics of Unilateral DNR Orders: Physicians Are Evenly Divided

Ethical debate 'remains unsettled'

Physicians are evenly divided as to whether unilateral do not resuscitate (DNR) orders — decisions about resuscitation made by doctors without patient or surrogate consent — are appropriate, found a recent study.[1]

"The debate over this topic in the ethical literature remains unsettled," says lead author **Michael S. Putman**, MD, a fellow in the department of medicine at Northwestern University in Chicago.

Some physicians argue that resuscitation efforts can, and should, be withheld if a reasonable chance of benefit does not exist. Others argue that unilateral DNR orders violate patient autonomy and lack objective criteria.

Putnam was surprised at how evenly physicians were divided on the issue, with roughly half in favor and half opposed. "It's interesting to see such equipoise over something that many find so contentious," he says. Some key findings of the research, which surveyed 1,156 physicians, include the following:

- physicians who endorsed unilateral orders were more likely to be in pulmonary or critical care medicine, and less likely to be religious;
- 6% of all physicians, and 20% of pulmonary critical care physicians, reported

> "UNILATERAL DNR ORDERS REPRESENT ONE END OF THE SPECTRUM OF AUTONOMY AND PATERNALISM. THEIR IMPLEMENTATION SHOULD BE UNDERTAKEN WITH CARE."

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AUTHOR: Stacey Kusterbeck
EDITOR: Jill Drachenberg
EDITOR: Jesse Saffron
EDITORIAL GROUP MANAGER: Terrey L. Hatcher
SENIOR ACCREDITATIONS OFFICER: Lee Landenberger

EDITORIAL QUESTIONS
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(404) 262-5508

performing a unilateral DNR in the previous year.

Putman says greater attention should be paid to this topic: "Unilateral DNR orders represent one end of the spectrum of autonomy and paternalism. Their implementation should be undertaken with care."

Unilateral DNR orders often are considered when the patient or surrogate wishes to continue treatment, but the medical team believes this would be nonbeneficial or even harmful.

"Sometimes physicians feel so compelled to act according to the principles of nonmaleficence and beneficence that they want to write a DNR order over the objection of the patient or surrogate," says **Monica Gerrek**, PhD, assistant professor in the department of bioethics at Case Western Reserve University and co-director of MetroHealth System's Center for Biomedical Ethics, both in Cleveland.

Unilateral DNRs should be implemented as a last step, after all other options have been exhausted, says **Cheyn Onarecker,** MD, MA, chair of the healthcare ethics council at Trinity International University's Center for Bioethics & Human Dignity in Deerfield, IL.

"In the not-too-distant past, families were concerned that physicians were keeping their loved ones on life support too long," says Onarecker. The opposite scenario is more common now, with families worried that the medical team is withdrawing life support too soon.

"Physicians can become frustrated trying to help a family come to a reasonable decision," says Onarecker. "They might enter a DNR order to shut down a very challenging dispute."

Physicians are usually reluctant to order unilateral DNRs. This is due to potential legal consequences and perceived ethical obligations to honor surrogate preferences regarding resuscitation in all circumstances. "The current model of decision-making for DNRs gives significant ethical weight to the patient's autonomy," says **Adam Pena**, MA, an instructor at Baylor College of Medicine's Center for Medical Ethics and Health Policy and a clinical ethicist at Texas Medical Center, both in Houston.

On the other hand, an obligation to attempt resuscitation in the absence of clinical indications for CPR may compromise the clinician's professional integrity. If the patient is imminently dying, says Pena, "the provider's medical judgment about whether or not there are medical indications for CPR is a major ethical consideration."

Conflict over unilateral DNRs often arises within a larger context, says Pena. There often is conflict between the reality of the prognosis and what the surrogate understands the situation to be. A poorly informed surrogate might have no idea why the unilateral DNR is being requested. "If a conflict arises in real time, ethicists could help clarify the reasoning behind the request for a unilateral DNR, and help the team and family achieve consensus," suggests Pena.

Typically, the family, or a single family member, wants maximum treatment to continue, and the medical team is asking to limit or withdraw maximum treatment. "These situations usually bring up the concept of futility, a word that sometimes muddies the water because it has been used in many ways," says Onarecker.

Providers may use "futility" to refer to treatments that simply will not work — for instance, administering penicillin to a person dying from an infection that is

resistant to penicillin. "No physician is required to offer this sort of futile treatment," says Onarecker. "But futility is also used to describe treatments that have only a small chance of success, maybe 1 in 100. The surgeon might think of such a treatment as futile, but the family might think that 1 in 100 is better than no chance at all."

Other times, "futility" is used to describe a situation where the patient's ultimate quality of life will be poor even if the best possible outcome occurs from an intervention. "You might hear a comment like, 'That's not how I would want to live.' But that is a value judgment and not really a medical decision," says Onarecker. Quality of life decisions must be made in light of what the patient, not the clinician, would find acceptable.

Families sometimes worry that a DNR order means their loved one won't continue to receive excellent care. Once a decision has been made to limit treatment, the patient might be moved out of the ICU to a floor with less monitoring and fewer nurse visits. "To the family, it could look like the patient is being abandoned," says Onarecker. "It is important to remember that DNR means that the patient will not receive CPR, but other treatments could still be continued."

The medical team must reassure the family that certain treatments will be stopped, but compassionate care always will be given. "Ethicists can facilitate open discussion, ensure that that everyone's voice is heard, and help all parties come to a reasonable solution," says Onarecker.

An institutional policy can encourage consistent decision-making by outlining criteria for when a unilateral DNR order may be appropriate. "The champion for this policy will need to establish institutional and administrative buy-in," says Pena.

It seems that physicians often feel that, without a DNR order, they are obligated to provide medical treatments or CPR — even if they believe it will do more harm than good.

"A good unilateral DNR policy can assist in these situations," says Gerrek.

She says that the policy should ensure that all possible avenues for conflict resolution — ethics, palliative care, chaplaincy, social work, and psychology — have been exhausted, and outline a process for resolution if a medical team member is strongly opposed to the unilateral DNR order, as follows:

1. Ensure the surrogate/family fully understand the nature of the patient's medical situation.
2. Try to determine what might be influencing the surrogate/family's position.
3. Offer a second opinion.
4. Request a palliative care consult.
5. Request a chaplaincy consult. "Chaplains are very good at assisting with psychosocial or spiritual issues that may be influencing the surrogate/family," says Gerrek.
6. Request an ethics consult:

• offer for the team to assist in facilitating a transfer to another institution;

• include options for the patient or surrogate to pursue if they disagree with the order.

For example, a policy should allow time for patients or surrogates to find institutions willing to provide treatment or seek legal recourse. "While good policies are important and necessary, good conversations in advance of a crisis are even more important," says Gerrek.

This means in-depth discussions between patients, surrogates, and physicians about treatment options and goals of care.

"Furthermore, there needs to be a culture change in the way Americans think about treatment at the end of life," says Gerrek. Studies show that people often want to die at home, yet most die in a medical institution. Studies also show that surrogates often lack good understanding of patient wishes.[2,3]

"It stands to reason that if patient wishes were better known by the physician and surrogate, the need for unilateral DNR orders would decrease — as would conflicts between the surrogate and team," says Gerrek.

In many states, there is no law supporting unilateral DNR orders. "In fact, in some states, the patient or surrogate has the right to revoke a DNR order," says Gerrek. This means that physicians are faced not only with overriding the wishes of the patient or surrogate, but also with whether to act in a way that could lead to legal conflict.

"Yet, without the option of a unilateral DNR order, physicians often do not have a way of communicating to other team members that they do not believe CPR or other life-sustaining interventions are appropriate," says Gerrek.

Physicians' litigation fears sometimes are groundless. This is why it's important to understand relevant state laws. "There is a variance in the legal landscape regarding unilateral DNRs," notes Pena.

States that do offer guidance allow unilateral DNRs in limited circumstances.[4] Texas's 1999 Advance Directives Act allows physicians to withdraw life-sustaining treatment unilaterally, but only after an extensive process is followed. A Texas physician may write a unilateral DNR only in circumstances where 1) the physician has certified in writing that the patient has a terminal and/

or irreversible condition; 2) when, after diligent inquiry, a surrogate has not been identified; and 3) when a second physician not directly involved in the patient's treatment concurs with the attending physician's medical judgment.[5]

"In my experience, physicians may be hesitant to write the DNR order because it is unclear what constitutes a 'diligent inquiry,'" says Pena. Physicians are unclear on what exact measures are required to try to identify an appropriate surrogate.

In Vermont, assuming a surrogate is not available to make medical decisions, two clinicians must determine that resuscitation "would not prevent the imminent death of the patient."[6] "Here, is it unclear what the law means by 'imminent death,'" says Pena. Further complicating matters, studies have demonstrated that physician prognostication of a patient's imminent death often is inaccurate.[7]

While some states require multiple-step processes — second opinions, legal input, and extensive participation by the ethics committee — others offer no legal guidance at all. "Therefore, hospital policy may be the appropriate mechanism to govern these unilateral DNR decisions," says Pena. ■

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- **Monica Gerrek**, PhD, Co-Director, Center for Biomedical Ethics, MetroHealth System, Cleveland. Phone: (216) 778-7290. Email: mlg86@case.edu.
- **Cheyn Onarecker**, MD, MA, Chair, Healthcare Ethics Council, The Center for Bioethics & Human Dignity, Trinity International University, Deerfield, IL. Phone: (405) 272-7494. Email: cheyn.onarecker@ssmhealth.com.
- **Adam Pena**, MA, Instructor, Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston. Phone: (713) 441-4925. Email: adam.pena@bcm.edu.
- **Michael S. Putman**, MD, Department of Medicine, Northwestern University, Chicago. Phone: (312) 695-1510. Email: msputman@gmail.com.

'Ethical Obligation to Go Further' if Patients Are Nonadherent for Financial Reasons

A provider prescribes a promising new medication and the patient is in complete agreement with the treatment plan. Weeks later during a follow-up appointment, the patient admits she never filled the prescription — and what she doesn't say is that this decision was made at the drugstore counter, after learning the cost.

"Patients might have financial difficulties that they are embarrassed to share, or do not feel the healthcare provider would be open to listening to," says **Craig M. Klugman**, PhD, a professor in the department of health sciences at DePaul University in Chicago.

Patients may find that the prescribed medication costs hundreds of dollars a month even with insurance coverage — or that they have to pay the cost in full because of an unmet deductible.

"It is not unusual for patients to have to decide between paying utility bills or rent, or buying their medications," says Klugman.

Patients who don't follow the provider's recommended treatment plan often are labeled "nonadherent" in the chart — when in reality, they can't afford the care. Stigmatizing patients as "noncompliant" is an outdated notion, says Klugman: "The concept comes out of the

nursing literature, which defined 'noncompliance' as a deliberate spurning by the patient of a healthcare provider's orders."

The clear implication is that patients are choosing to oppose healthcare providers' efforts. "Today, we use the term 'nonadherence' to show that this notion of deliberate defiance is not at the core of the modern concept," says Klugman. However, even the term "nonadherent" carries a suggestion that patients are acting against the healthcare provider. "This is inherently paternalistic and judgmental," says Klugman.

Healthcare providers have no legal obligation to ensure that patients receive and take their medications. "However, if the patient-provider relationship is one based on trust and compassion with a shared goal of helping the patient, then there may be an ethical obligation to go further," says Klugman.

First, providers should not assume the patient is being deliberately belligerent. "Most likely, the noncompliance has nothing to do with the healthcare provider," says Klugman.

After explaining the importance of the recommended treatment, the next step is to ask why the patient hasn't followed the plan. If the answer is that the medication is unaffordable, a generic or cheaper drug can be offered instead. "Misunderstandings labeled as noncompliance are often a lack of communication," says Klugman.

Even if a patient can't afford the recommended treatment plan, some providers take offense. "If you simply do not connect with the patient in a way that you can unpack why he or she is not taking the drug, it might be better to consider transferring the patient's care to another physician," says Klugman.

High-deductible health insurance plans are increasingly common, especially among low-income Americans. Nearly 40% of U.S. adults had a high-deductible health plan in 2016, according to a report from the CDC's National Center on Health Statistics.[1] Privately insured adults with employment-based high-deductible plans were more likely than adults enrolled in traditional plans to forgo or delay medical care.

"Reasonable patients with plans like these may make informed and calculated decisions to forgo more efficacious but costly treatments in favor of less efficacious but less costly treatments," says **Benjamin Stoff**, MD, MAB, a senior faculty fellow at the Emory Center for Ethics in Atlanta. Stoff also is an assistant professor of dermatology at Emory University School of Medicine.

In his own practice, Stoff sees some patients with severe psoriasis choose not to fill a prescription for a biologic, which is generally the most effective treatment, but by far the most costly. Instead, patients opt for a less-effective, cheaper drug. That is the patient's prerogative, says Stoff: "In scenarios like this, lack of adherence to therapy on the part of the patient really represents an expression of that patient's autonomy."

Patients are making a reasonable value judgment that for them, the potential benefit of a medical intervention is not worth the financial cost.

"This judgment is similar to others made by patients," says Stoff. For instance, it's not uncommon for patients to decide that the side effects are not worth the possible benefit of a given medication.

"Healthcare providers need not insist that patients choose the most medically efficacious therapy in all circumstances," adds Stoff. The informed consent process requires that providers elicit patient values relevant to medical decisions. Together, patient and provider come to a joint decision about what therapy best aligns with those values, has a reasonable likelihood of benefiting the patient, and limits harm.

"In order to mitigate the potential harm from high costs, physicians may have an obligation to work with their patients to find a medically effective and financially viable treatment," says Klugman.

Newer drugs with sky-high price tags are unaffordable for many patients, insured or not. "The U.N. Declaration of Human Rights says that medical care is a human right. The high cost of these drugs in the U.S. may hinder practicing this right," notes Klugman.

Comparing drug costs can be next to impossible for providers, because so many factors affect what the patient will pay. These include the size of the pharmacy (larger pharmacies often negotiate bulk discounts from suppliers), whether the patient has drug insurance coverage, whether a generic is available, how long the drug has been on the market, and even whether the manufacturer has recently been acquired by another company.

"Many drug companies have a retail price that may be higher than what most people pay, but offers an idea of what the drug costs compared to other drugs on the market," says Klugman.

In any case, Stoff says a general discussion of cost is crucial to medical decision-making and informed consent for some people: "For those patients, healthcare providers should offer a range of reasonable treatment options at different cost points." ■

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- **Craig M. Klugman**, PhD, Professor, Department of Health Sciences, DePaul University, Chicago. Phone: (773) 325-4876. Email: cklugman@depaul.edu.
- **Benjamin K. Stoff**, MD, MAB, Emory University Center for Ethics, Atlanta. Phone: (404) 712-8307. Email: bstoff@emory.edu.

Unique Informed Consent Challenges if Research Participant Is Incarcerated

It is well-established that incarcerated people suffer disproportionately from low literacy and health-related conditions that can affect cognition. Despite this, modified informed consent processes are not required by federal guidelines.

"The prison system in America is deeply, profoundly, unfixably unethical. How you do ethical research in such a system is always a quandary," says **Nancy Neveloff Dubler**, senior associate at the Montefiore-Einstein Center for Bioethics and professor emerita of bioethics at the Albert Einstein College of Medicine, both in Bronx, NY. Dubler co-authored *The Ethics and Regulation of Research with Human Subjects*.

Prisoners can arguably provide consent to research in the same way they provide consent or refusal of medical care. "On the other hand, if the inducements are very great, it's an unfair position to put the inmate in," says Dubler, noting the long history of unethical research practices involving incarcerated subjects. "Prisoners were used to test and develop random things, and would be promised a better place to live or better food," says Dubler.

The Federal Policy for the Protection of Human Subjects, or Common Rule, was designed to prevent such research.

The regulations permit only certain types of research on prisoners, including:

- research that is solely the study of the possible causes of incarceration and of criminal behavior, provided that the study presents no more than minimal risks and no more than inconvenience to the subjects;
- research on prisons as institutional structures;
- research on conditions particularly affecting prisoners as a class, such as drug addiction or vaccine trials for hepatitis;
- research on practices of innovative or accepted interventions that have the intent or probability of improving the health of the subject.

"This means that you can't use prisoners to test new drugs simply because they are useful, you know where they are, you can come back to them, and they're convenient," says Dubler.

Drugs being tested have to, in some way, relate to the population that is being studied. For example, anonymous surveys of one detoxification unit revealed that over half of inmates were HIV-positive, says Dubler: "Clearly this was an issue that you could study in the prison population, with proper safeguards."

In a prison setting, however, it's not possible to distinguish between refusal of care and denial of care, says Dubler: "It's a very complicated setting in which to provide care, which makes it a super complicated setting in which to do medical research. The other problem is that prisons are basically untrustworthy settings."

When someone does not show up for an appointment, researchers have no way of knowing if it's because that person chose not to come, or whether a guard prevented him or her from coming. "Prisons are not places of transparency, and they're settings in which prisoners are used often to their own detriment, but sometimes for their benefit," says Dubler. "This makes it a quite complicated area."

Mitigating potential conflicts of interest is a thorny ethical challenge if research participants are incarcerated.

"It's possible that the researcher, the researcher's university, and the correction facility are all funded by a single source," says **Alina Bennett**, MPH, PhD, a postdoctoral fellow at McGovern Center for Humanities & Ethics at University of Texas Health Science Center at Houston.

Bennett offers a hypothetical to illustrate the complexity of conflicts of interest. A highly infectious agent, "Hepatitis Z," is quickly spreading among certain prison populations who share a behavioral exposure. If left untreated, it can cause liver failure or hepatocellular carcinoma. A significant

percentage of inmates are infected, despite the fact that the virus is almost nonexistent in the general population. While the standard of care is a liver transplant, this is not financially feasible in the prison setting.

In this scenario, a researcher at a state-sponsored university working on a potentially curative therapy approaches the institutional review board seeking approval for a prisoner-only study. This researcher believes that prisoners are suffering from this virus's complications at much higher rates than others and thus, the study ought to prioritize therapy for inmates over therapy for nonincarcerated people.

"On the face of it, this situation might not ring any alarm bells," says Bennett. "However, an inherent conflict of interest exists concerning what is responsible for the problem and what is responsible for the solution."

One issue is that the state bears responsibility for prisoners being exposed to the virus in the first place. The state also benefits from access to a relatively static pool of human subjects who are newly diagnosed, yet are denied the standard of care by the state. Lastly, the state stands to benefit from the development of a drug should the trial be successful.

"Because the state will benefit both during the study and potentially after its completion, the ethical justifiability of this work hinges on the successful efforts of the correctional facilities to stop the creation of newly eligible human subjects for this state-run trial," says Bennett.

Simple disclosure is not sufficient. In this scenario, securing a person's informed consent requires a two-step process.

"The first step is that the study team must recruit decision scientists," says Bennett. Decision science is a growing field that focuses on supporting patients facing complex decisions. The consent process must inform patients about not only the study, but also the relationships between the state, the researcher, the institution, and the correctional facility.

"Participants must understand that an entity might benefit from a successful discovery — which was made possible because the entity did not honor their obligation to protect prisoners from infectious diseases," says Bennett.

The second step is to design a decision aid. The decision scientists will assess the decision that is facing potential study participants, and will create an evidence-based decision aid that meets — and far surpasses — all federal guidelines concerning consent. "These aids can take a variety of forms, such as an iPad application, a webpage, or a document," says Bennett.

Lastly, knowledge checks are performed during the use of the aid, and afterward.

"These conversations take a neutral, nondirective tone, so that the patient will remain free of influence as they make an informed decision," says Bennett. ■

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Initiative's Goal: To Honor Seriously Ill Patients' Wishes

There is widespread recognition of the need to have proactive goals of care conversations with patients diagnosed with serious, life-limiting illnesses such as congestive heart failure, end-stage renal disease, and terminal cancer.

"A number of organizations are working on getting this right," says **Jill S. Lowery**, PsyD, ethics policy consultant at the Veterans Health Administration (VHA)'s National Center for Ethics in Health Care (NCEHC). These include the National Academy of Medicine, the National Quality Forum, Ariadne Labs, the American College of Physicians, and the Hastings Center.

"At VHA, we are rolling out the Life-Sustaining Treatment Decisions Initiative. This is a comprehensive, national quality improvement project led by NCEHC," says Lowery. The initiative's aims are threefold:

1. to ensure that before a healthcare crisis threatens the patient's ability to make decisions, the patient is given the opportunity to have a conversation about his or her goals, values, and preferences related to life-sustaining treatments;

2. to clearly document the conversation and life-sustaining treatment decisions so the information is accessible to everyone on the patient's treatment team;

3. to honor those decisions.

"One of the things that makes this initiative unique is that it doesn't target just one or two quality gaps," says Lowery. "It really tries to address multiple barriers to best practice, simultaneously and at a system level."

From its inception, the initiative was "informed and inspired by" healthcare ethics, says **Mary Beth Foglia**, RN, PhD, a healthcare ethicist at NCEHC. "But rather than simply addressing issues downstream in individual ethics consultations, we waded upstream to find and address the barriers to genuine patient-centered care planning," she explains.

Some patients have living wills that include information about preferences, but these are not actionable. Such documents can be difficult to interpret, and aren't translated into medical orders that guide care. "What we've done is to make it possible for patients' goals, values, and preferences to be translated into a care plan with actionable medical orders," says **Virginia Ashby Sharpe**, PhD, NCEHC's chief of ethics policy.

In addition, notes Lowery, "a lot of things need to happen to ensure goal-concordant care for seriously ill patients." This includes:

- strong care teams that identify patients appropriate for a goals-of-care conversation, and help prepare patients and families for that conversation;
- clinicians who are skilled in initiating and conducting goals-of-care conversations;
- a standardized, visible, and accessible place to document the patient's goals and preferences;
- translation of the patient's goals and preferences into durable medical orders, available across care settings, to help ensure that the patient's wishes are carried out;
- the ability for people to easily retrieve the information during a health crisis.

"We know that if you do four of these things well, but the fifth thing isn't there, you're less likely to be successful," says Lowery.

The VHA's national policy was issued in January 2017, and the new practice standards are being implemented over an 18-month period. Facilities are expected to have fully adopted the initiative's new standards and processes by July 2018.

"To get there, we're providing robust support," says Sharpe. This means regular implementation support calls, a detailed step-by-step implementation guide, technical support, policy interpretation, and an intranet site loaded with practical resources.

Before the national roll-out, the group worked with clinicians and healthcare administrators in a four-site demonstration project. Every aspect of the initiative, including the policy, was tested and improved.

"All of those subject matter experts were called on to help us think about how we would establish standards that were clinically and ethically appropriate — and also to do so in a way that was sensitive to clinical workflow," says Foglia.

A particularly important insight: the role that multidisciplinary team members play in setting the stage for high-quality goals of care conversations with the patient. Nurses, social workers, psychologists, or chaplains can help people to anticipate issues related to life-sustaining treatments. When the patient actually meets with a practitioner licensed to write life-sustaining treatment orders, these issues have already been discussed.

The progress note template and order set were developed with input from clinicians in the field, through rigorous human factors assessment. "It was designed with sensitivity to the time that the clinicians had," says Lowery.

It is not an easy process to make changes to the EHR in a way that works for people providing many different levels of care in various regions. The end result is that patients' wishes are available anywhere within the VHA system. "The fact that these orders are durable and portable within VA is really distinct," says Lowery. "That really hasn't been available, until now."

This means that patients won't be asked the same questions about goals of care and treatment preferences repeatedly in different care settings. It lessens the burden on patients and clinicians, and also reduces the chance of handoff errors if patients change locations of care. "Those conversations can be revisited when it's either clinically appropriate, or when the patient would like a change," says Lowery.

The education was designed so that clinicians can take one module at a time and complete the training over a period of weeks, instead of completing all the modules at once. Providers are given skills training in how to initiate the conversations. "Over 80% of our facilities across the country now have trainers in place," says Lowery.

Many ethics consultations revolve around communication, conflict, or uncertainty about values related to end-of-life treatment planning. By proactively engaging patients in a conversation about their goals and preferences as a basis for care plans involving life-sustaining treatments, then translating these preferences

into portable VA orders, some ethics consults are avoided.

"The kinds of issues that the initiative addresses are actually recurrent throughout all healthcare systems when caring for patients with serious, life-limiting illnesses," notes Foglia. Over time, many recurring issues will be addressed in a systematic way.

Ethicists can't make these practice and culture changes alone, cautions Sharpe: "An enterprise-wide approach, including leadership support and involvement of key stakeholders from throughout the organization, is crucial."

Other organizations can use or adapt the tools to improve the way patients' wishes are elicited, documented, and ultimately honored. "Our hope is that the resources that we have developed will also be useful to people outside the VA who want to take very practical steps to touch on widely acknowledged quality gaps in the care of seriously ill patients," says Lowery.

Resources on the VHA's Life-Sustaining Treatment Decisions Initiative, including the national policy, implementation guide, and monitoring tool, are available at: http://bit.ly/2mguGy4. ■

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- **Jill S. Lowery**, PsyD, Ethics Policy Consultant, National Center for Ethics in Health Care, Veterans Health Administration, Durham, NC. Email: jill.lowery@va.gov.
- **Virginia Ashby Sharpe**, PhD, Chief of Ethics Policy, National Center for Ethics in Health Care, Veterans Health Administration, Washington, DC. Email: Virginia.Sharpe@va.gov.
- **Mary Beth Foglia**, RN, PhD, Health Care Ethics Consultant, National Center for Ethics in Health Care, Veterans Health Administration, Seattle. Email: marybeth.foglia@va.gov.

Emotional Support for Surrogates Linked to Better Decisions

Emotional support is important, and not only for surrogates' psychological well-being: It's also linked to the quality of their decision-making, found a recent study.[1]

As the population ages, a growing number of people will find themselves faced with making decisions for a family member. "We wanted to know if there are things we can do as healthcare providers to relieve their stress," says **Alexia Torke**, MD, MS, who led the study. Torke is associate director of Indiana University's Center for Aging Research and a research scientist at Regenstrief Institute, both in Indianapolis.

The researchers surveyed 364 surrogate decision-makers using a newly developed Family Inpatient Communication Survey. This measured two aspects of communication: information and emotional support during the patient's hospitalization or shortly afterward.[2]

"We wanted to see if quality of communication is associated with the stress they feel. If it is, that might be a point where we can intervene," says Torke.

The researchers expected these individuals to have high levels of anxiety and depression. "Other studies have shown that decision-making is stressful — not only in the ICU, but in the hospital setting," notes Torke.

A more striking finding was just how important emotional support is — not only for the surrogate, but also the patient. Participants who agreed that "hospital staff really listened to me when we talked" tended to make higher-quality decisions. Provision of information, with participants agreeing that they received as much detail about their loved one's care as they needed, was less important in terms of quality decision-making.

Researchers also assessed surrogates' anxiety, depression, and post-traumatic stress disorder (PTSD), both during the hospital stay and six to eight weeks later. "Information and emotional support affected outcomes differently," says Torke.

Emotional support was associated with less anxiety, depression, and PTSD. Receiving high-quality information was linked to higher overall satisfaction during the hospital stay, but was not associated with less anxiety, depression, and PTSD.

Notably, while some of the surrogate distress experienced during the acute illness resolved, it remained high for more than 10% of surrogates. Interestingly, researchers found that receiving more information without emotional support was associated with higher levels of PTSD. "It is an intriguing finding that needs more exploration," says Torke. "But it does suggest that providing just information without emotional support might be stressful."

The study's findings suggest that improved emotional support could lead to better decisions for

the patient, and better psychological outcomes for the surrogate. This underscores the ethical obligation of the healthcare team to consider surrogates' psychological well-being, says Torke.

"We do have an obligation to family members as well as to our patients, to support them during these difficult times," says Torke. Support does not need to come from the physicians, or even the clinical team. It can come from chaplains, social workers, or ethicists, or a healthcare team member who already is involved in the patient's care, even indirectly.

"Yes, hospitals are busy places, but families appreciate support from any member of the interdisciplinary team," says Torke. "It should be everyone's responsibility."

No matter how much advance care planning is done, surrogates still need support when actual decisions must be made. "We need to recognize the impact that making decisions has on people," says Torke. "No matter what happens with the patient, the family survives with the memory of what happened in the hospital." ■

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2. Torke AM, Monahan P, Callahan CM, et al. Validation of the family inpatient communication survey. *J Pain Symptom Manage* 2017; 53(1):96-108.

SOURCE

- **Alexia Torke**, MD, MS, Associate Director, Indiana University Center for Aging Research, Indianapolis. Phone: (317) 503-8084. Email: atorke@iupui.edu.

'Mere Presence' of Ethicist Can Encourage Nursing Participation

At some hospitals, ethics consultations are viewed as clinical orders and can only be requested by physicians. "This limits a nurse, or any other member of the healthcare team, including the patient, from exercising the right to pursue an ethics consultation," says **Liz Stokes**, JD, MA, RN, director of the American Nurses Association's Center for Ethics and Human Rights in Silver Spring, MD.

Many nurses are eager for ethics advice, but they're not always comfortable raising a concern on their own, says Stokes. Some lack awareness that a particular issue is ethical in nature. Others don't see the value of ethics involvement in a case, or simply don't know how to request a consult.

"Given that some nurses are unable to recognize an ethical dilemma or may not know how to make an ethics consultation, education and awareness are essential in encouraging nurses to do so," says Stokes. The following are some approaches:

• Perform ethics consultation rounds, including nursing.

Nurses will see the ethics consultant on the unit on a regular basis. "The mere presence alone can spark conversation and raise awareness of the value of the ethicist," says Stokes.

• Ethicists can make it known they're open to providing consultations to healthcare providers anonymously.

"Although this does not necessarily speak to a culture of safety and transparency, it can be used as a mechanism for a nurse's voice to be heard without the fear of risk of reprisal," says Stokes.

• Reward nurses who do seek ethics consultations.

"Some hospitals have 'moral courage' awards or awards that recognize a nurse's advocacy efforts, especially in difficult situations or ethical dilemmas," says Stokes.

Nurses from the ethics committee and the ethics service at Houston-based MD Anderson Cancer Center instituted a Nursing Ethics Patient-Aligned Care Team. The group performs nursing ethics rounds in both inpatient settings and outpatient clinics. Nurses are able to discuss an ethical issue generally or related to a particular patient.

"We also have an ethicist attend the nursing and interdisciplinary meetings about patients so that recommendations can be given," says **Colleen M. Gallagher**, PhD, LSW, FACHE, chief and executive director of MD Anderson's Section of Integrated Ethics in Cancer Care. This approach hasn't increased the number of requested consults. "It does however, give nurses an opportunity to raise their concerns and have them addressed," says Gallagher.

Some nurses need help with bringing their concerns to physicians or other clinicians on the healthcare team. "It is about coaching for good communication, as much as it is about finding the right thing to do for each patient," says Gallagher.

Physicians sometimes become upset because they feel their judgment is being questioned by nurses. "We also hear stories of how nurses are hard on each other and do not want to be seen as 'rocking the boat,'" says Gallagher.

Often, the way in which the concern is raised is the reason for less-than-professional responses. Phrases such as "We have a problem" can take a negative turn. Gallagher suggests that nurses instead say, "Doctor, it seems that (patient name) is having a hard time with…. How can nurses help?"

The following steps are taken once a nurse raises an ethical concern:

- the ethicist contacts the physician and lets him or her know that a concern exists;
- the ethicist helps with the communication among the team members, or with decision makers.

"We include nurses and physicians together as presenters when conducting ethics education of difficult cases," adds Gallagher. "This highlights the interdisciplinary team approach."

If nurses report a conflict within the clinical team, ethicists can help by swiftly providing a trusting environment for deliberation.

"As part of the ethicist's assessment, it is important to recognize that some ethical issues are unique to nurses," says Stokes. While physicians often make the treatment decisions, nurses are responsible for actually performing the tasks involved. Nurses may be asked to continue life-sustaining treatment where it is deemed to be of no clinical benefit. "This can be contrary to a nurse's moral belief or integrity, especially if that treatment is causing harm or suffering to the patient," says Stokes.

Ethicists at Dartmouth-Hitchcock Medical Center in Lebanon, NH, use these approaches to encourage nursing involvement with ethics:

- they explicitly invite nurses to request consults;
- nursing leadership is included on the clinical ethics committee;
- representatives of the clinical ethics committee attend nursing meetings;
- clinical ethicists provide regular educational conferences to nursing staff;
- nurses are included in ethical discussions during consultations.

"The availability of the service in general, and to nurses in particular, is clear," says **Tim Lahey**, MD, MMSc, chair of the Dartmouth-Hitchcock clinical ethics committee.

Coaching on communication strategies by phone, and talking through the ethical issues in a particular case, is sometimes enough. "We simply help them identify effective communication behaviors that allow them to raise a concern in a team conversation," says Lahey.

In these cases, ethicists don't need to be directly involved. "Ideally, such interactions would occur in a healthy organizational context, in which nurses occupy high positions of leadership at many points in the organization — so that historical disrespect of the contributions of nurses is fully and publicly absent," notes Lahey.

A nurse recently called ethicists because she felt the treatment plan was more aggressive than a delirious patient had said she wanted while in a clearer state of mind. The nurse acknowledged that she hadn't brought it up with the patient's physician. Instead of calling a formal consult, the ethicist and nurse brainstormed about effective ways to raise the issue. Perhaps she could ask clarifying questions on rounds, or ask other nurses if they had the same concerns.

"I assured the nurse that I could back her up if that didn't go well," says Lahey. "A good conversation ensued, and concerns about ethical problems evaporated."

It turned out the physician had spoken with both the patient and a loved one about their preferences, but hadn't kept the nurse in the loop. "The episode was a good example to both of them to stay in close collaboration," says Lahey. ■

SOURCES

- **Colleen M. Gallagher**, PhD, LSW, FACHE, Chief and Executive Director, Section of Integrated Ethics in Cancer Care, MD Anderson Cancer Center, Houston. Email: CMGallagher@mdanderson.org.
- **Tim Lahey**, MD, MMSc, Chair, Clinical Ethics Committee, Dartmouth-Hitchcock Medical Center, Lebanon, NH. Phone: (603) 650-6060. Email: Timothy.Lahey@Dartmouth.edu.
- **Liz Stokes**, JD, MA, RN, Director, Center for Ethics and Human Rights, American Nurses Association, Silver Spring, MD. Phone: (301) 628-5394. Email: liz.stokes@ana.org.

COMING IN FUTURE MONTHS

- Early DNR orders having unintended effect on quality metrics
- Continuation of nonessential medications in dying patients
- Ethical concerns for caregivers of patients with left ventricular assist devices
- Ethicists share real-life solutions for physicians' disruptive behavior

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CME QUESTIONS

1. **Which is true regarding unilateral DNR orders, according to a recent study?**

   a. Half of physicians endorsed unilateral DNR orders, while the other half said the practice is inappropriate.
   b. Physicians are legally and ethically obligated to honor patients' preferences regarding resuscitation in all circumstances.
   c. The practice is far more common than expected, with the majority of physicians reported performing a unilateral DNR in the previous year.
   d. Patients or surrogates now have the right to revoke a DNR order in all 50 states.

2. **Which is true regarding informed consent for research involving incarcerated people?**

   a. Modified informed consent processes are required by federal guidelines.
   b. Prisoners cannot provide informed consent to research due to their incarcerated status.
   c. Drugs being tested must, in some way, relate to the population that is being studied.
   d. Only research that has the intent of improving the health of the subject is permitted.

3. **Which is true, according to Benjamin Stoff, MD, MAB?**

   a. Providers should document patients who fail to follow recommended treatment plan as "noncompliant," indicating that the patient has made a decision to oppose the healthcare provider's efforts.
   b. Patients may make a reasonable decision in favor of cheaper but less effective treatments.
   c. Lack of adherence to recommended therapy should lead to termination of the provider/patient relationship.
   d. Cost should not be part of informed consent discussions.

4. **Which did a recent study find regarding surrogate decision-makers?**

   a. Emotional support is linked to better decisions and lower anxiety.
   b. Information was the most important factor in high-quality decision-making.
   c. Families expected emotional support to come from the physician.
   d. Anxiety resolved for all the surrogates surveyed after the acute illness resolved.