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## Advance Care Planning Discussions 'Buried' in EHRs: Problem Is Pervasive

*Clinicians often 'lost' at time of crisis*

Half of patients with a completed advance care planning legal form had no accompanying explanatory discussion documented in the electronic health record (EHR), found a recent study.<sup>1</sup>

"This is important because contextualization of wishes documented in succinct legal forms is essential to interpreting them appropriately," says **Evan Walker**, MD, the study's lead author.

The 2015 Institute of Medicine report, *Dying in America*, emphasizes the need for standardized and frequent

advance care planning documentation in the EHR.<sup>2</sup> However, how often

discussions are actually documented in the EHR was unknown.

"Better understanding of documentation practices will hopefully lead to quality improvement initiatives to ensure patient safety so that patients' wishes are honored," says Walker, chief resident at the University of California, San Francisco.

Researchers analyzed EHR documentation of 414 patients from the primary care clinics of the San Francisco VA Medical Center, all at

"BETTER UNDERSTANDING OF DOCUMENTATION PRACTICES WILL HOPEFULLY LEAD TO QUALITY IMPROVEMENT INITIATIVES TO ENSURE PATIENT SAFETY SO THAT PATIENTS' WISHES ARE HONORED."

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**AUTHOR:** Stacey Kusterbeck

**EDITOR:** Jill Drachenberg

**EDITOR:** Jesse Saffron

**EDITORIAL GROUP MANAGER:** Terrey L. Hatcher

**SENIOR ACCREDITATIONS OFFICER:** Lee Landenberger

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**EDITORIAL QUESTIONS**

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least 60 years old with multiple medical conditions. About 51% had engaged in some form of advance care planning in the past. Notably, the VA provides dedicated note titles and templates to facilitate standardized recording of patients' wishes. But 55% of discussions were not recorded in this manner, the researchers discovered. "Instead, they were buried as free text in other notes, often years-old, making these documented wishes much more difficult to find when needed at the point of care," says Walker.

Goals of care changed during a subsequent discussion for 18% of participants with completed legal forms. Seventy percent of these changes were not recorded using the dedicated note templates, making them difficult to access in the EHR. This is a patient safety issue, says Walker: "Future providers could mistakenly rely on outdated forms and provide care misaligned with patient wishes."

## Conversations Get Lost

Another group of researchers developed a set of recommendations to improve the state of advance care planning documentation in the EHR.<sup>3</sup>

"There remains a significant deficit when it comes to transmitting this information through the EHR,"

says **Daniela Lamas**, MD, the study's lead author and a pulmonary and critical care physician at Brigham and Women's Hospital in Boston.

Researchers interviewed 18 clinicians, a hospital administrator, a health plan project manager, and a data scientist on the strengths and weaknesses of EHR documentation systems for advance care planning. All of the participants were actively involved in the process of improving advance care planning documentation.

"Conversations get lost. Scanned records never make it into the system. Key patient goals and values are buried at the end of progress notes," says Lamas. All of this means that when it comes to extracting essential information about patient goals and values in the midst of a crisis, "we are often lost," says Lamas.

The researchers wanted to make information about patient goals and values as easily retrievable as a record of allergies. Some key recommendations for clinicians include the following:

- Ensure documentation is complete and available through effective use of advance care planning functionalities.

- Use advance care planning functionalities to clearly record patients' goals and preferences, to record clinical decisions, and to

## EXECUTIVE SUMMARY

Half of patients with a completed advance care planning legal form had no explanatory discussion documented, found a recent study. Other findings include the following:

- About half of patients engaged in some form of advance care planning.
- Discussions were recorded as free text, making them difficult to find.
- Goals of care changes were not recorded using dedicated note templates.

access and continue past discussions, as needed.

- Conduct high-quality advance care planning conversations with appropriate patients.
- Develop clinical action plans to actualize the goals identified by the patients and record these plans in the EHR.

“What was most surprising was how pervasive this problem is,” says Lamas. Advance care planning information is difficult to access across health systems, specialties, and care settings. “From critical care doctors to emergency medicine practitioners to internists working in the outpatient clinics, we struggle with regularly recording and retrieving key information about patient goals and values,” says Lamas.

It is well-established that patients with serious illness should have the

opportunity to discuss their goals and values. “Yet there are few regulations to make sure that this information is easily recorded and retrievable throughout a patient’s course,” says Lamas.

There typically is no system to make sure the record of these essential conversations follows patients across their trajectory of care. This is a concern both in terms of patient safety and ethics, says Lamas: “As we encourage these conversations, we should also build systems to support patients ultimately getting the care that they desire.”

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- **Evan Walker**, MD, University of California, San Francisco. Phone: (415) 221-4810 ext. 2129. Email: [evan.walker@ucsf.edu](mailto:evan.walker@ucsf.edu).
- **Daniela Lamas**, MD, Brigham and Women’s Hospital, Boston. Email: [dlamas@mgh.harvard.edu](mailto:dlamas@mgh.harvard.edu).

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# ‘Tremendous Interest’ in Dementia-specific Advance Directives

Recently developed dementia-specific advance directives spotlight multiple unresolved ethical and legal issues for patients, families, and providers.

“The numbers of people worried about dementia is very high,” says **Barak Gaster**, MD, a professor of medicine at the University of Washington in Seattle.

Many people have very clear wishes about what medical interventions they would want for themselves if they developed advancing dementia. “It is a striking gap that standard advance directive forms are silent on this question,” says Gaster.

With about one-third of people over the age of 85 now living with dementia, it has become the most common reason people lose the

ability to guide their own care. The number of people living with dementia is expected to triple in the coming years.<sup>1</sup>

“There will likely be increasing awareness of the need to provide simple ways for people to communicate their preferences for life-prolonging medical care if they develop advancing dementia,” says Gaster, lead author of a recent paper on this topic.<sup>2</sup>

A new dementia-specific directive allows people to specify the level of care they wish to receive if diagnosed with various stages of dementia. Gaster, one of the tool’s developers, says, “There has been tremendous interest in the tool. This clearly strikes a nerve for many people.” The tool has been

downloaded more than 100,000 times, with downloads continuing at a rate of more than 500 weekly.

*(The free tool can be found at: <https://bit.ly/2pQdt0M>.)*

“As far as its legal standing is concerned, it is best thought of as a standalone document designed as a communication tool to one’s health proxy or as ... an addendum to be attached to someone’s standard state-specific advance directive,” says Gaster.

End Of Life Choices New York’s dementia directive allows people to stipulate in advance that they do not want to be hand-fed if they develop severe dementia. *(For more information, visit: <https://bit.ly/2QJuXHt>.)*

“There is a great deal of interest in this directive, from all types of

audiences,” reports **Judith Schwarz**, RN, PhD, the group’s clinical director. The document offers the option of assisted hand-feeding if a patient allows it during the final stages of the disease or to stop all assisted eating and drinking even if a patient seems willing to accept it. Palliative care is provided once all oral feedings are stopped.

Schwarz expects to see growing public awareness drive change. “My work has arisen directly from patients with early diagnoses of dementia,” she says. “They wanted to know what they can do legally to prevent the worst kinds of insults, the final months and years, this godawful disease imposes.”

Caregivers are understandably concerned about their perceived duty to feed frail, vulnerable elderly patients who appear to want to eat. “Our directive is very specific about stipulating that even if the mouth opens when touched by a spoon, it does not mean the patients want to be fed or that they have changed their mind,” says Schwarz.

One as-yet-unresolved legal question is whether hand-feeding is considered healthcare or ordinary care that is required to be given to all people. Some state regulations stipulate that hand-feeding must be provided. “It’s clearly a work in

progress. This is not settled one way or another,” says Schwarz. “The directive has not yet faced judicial review. But it will for sure in the future.”

Another significant difficulty arises when patients become residents of long-term care facilities. “Long-term care clinicians are unfamiliar with such documents and are, of course, risk-averse,” says Schwarz. One case currently in litigation involves a patient who currently has decision-making capacity, but will inevitably lose cognitive function in the near future. The patient wants to be sure that the long-term care clinicians will honor her choices in the dementia directive.

“We already have a number of lawyers who have offered their services pro bono when such legal challenges are brought,” says Schwarz. Additional court challenges from family members, where long-term care administrators refuse to honor the dementia directives, are likely to crop up.

Recently, Schwarz met with about 50 ethics committee members. “Clinicians are, of course, seeing many patients with advanced dementia whose families are very sure they would not want to be spoon-fed any longer,” says Schwarz. Recent legal cases suggest that absent a

completed directive, judges will not support withholding hand-feedings.<sup>3,4</sup>

“Members of ethics committees can — and should — bring moral clarity to these discussions,” says Schwarz.

Many clinicians express concern about whether the directive would stand up to legal scrutiny. Schwarz notes the evolution of how patients’ autonomy has been treated by the courts over the years: “There was a time when to take someone off a ventilator was considered murder.”

Although the legalities involved are complex, Schwarz asserts that the ethics are not: “At its heart, it’s like any other advance directive. It’s a very simple, autonomous choice that some people would like to make.” ■

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## EXECUTIVE SUMMARY

Court challenges and resistance are expected for recently developed dementia-specific advance directives despite strong demand voiced by patients, family, and providers. Some concerns include the following:

- Clinicians are concerned about whether directives will stand up to legal scrutiny.
- Patients want to be sure that long-term care clinicians adhere to the directives.
- Recent legal cases suggest that absent a completed directive, judges will not support withholding hand-feedings.

# Ethics-Administrator Relations Go From Adversarial to Collegial

*Roles have unexplored common ground*

**G**ood relations between ethics and hospital administration require a solid understanding of their distinct roles, according to **Gavin Enck**, PhD, system director of clinical ethics at Oklahoma City-based Integris Health.

Ethicists address underlying conflicts or uncertainties of patients' or providers' values. In contrast, says Enck, "Hospital administrators focus on the cost and provision of care relating not only to patients and families, but also to providers and the organization."

There is some important, but often disregarded, common ground. Both ethics and administrators want patients to receive high-quality, respectful care. Integris Health's CMO **Tommy Ibrahim**, MD, says, "Understanding these roles as having the same foundational focus reframes the relationship from adversarial to collegial."

At Integris Health, ethicists and administrators have strengthened relationships in these ways:

- **Administrators are encouraged to undergo the mandatory education for participating on an ethics committee.**

- **Clinical ethics invites**

**administrators to shadow clinical ethicists rounding with a healthcare team and, when appropriate, observe an ethics consultation.** This educates administrators on the role, processes, and language of clinical ethics.

"They can see firsthand how ethics connects to clinical practice and patient care," says Ibrahim.

The ethics committee recently reviewed a consultation involving a patient's refusal of care.

"Hospital administrators were able to see how patients, families, and providers are affected by the organization's policy on decision-making capacity and informed consent," says Enck. Ethicists learned how care refusals affect hospital metrics and performance outcomes.

By elucidating the effect that high-level administrative decisions have on individual people, says Ibrahim, "the ethicist helps administrators connect to the importance, and even sanctity, of their work," says Ibrahim.

- **A designated person facilitates communication between ethics and IT.** When Integris created the role of clinical ethics technology liaison earlier this year, **Anne**

**Saunders** initially faced skepticism both from clinicians and IT personnel. IT analysts were not convinced it would be possible to reliably capture hard data on ethics consultations due to the narrative nature of the notes. Clinicians were not sure they were comfortable with a more structured ethics consult note.

"But we have been able to rapidly develop the technological capabilities of clinical ethics while reassuring our clinician partners," says Saunders, software analyst and instructional designer at Integris.

Ethicists did not understand how the process for developing documentation and reporting worked in the EMR. IT learned that the most relevant metrics for ethics are not easily captured.

"Ethicists learned about the capabilities, workflows, and jargon of IT," says Saunders. Software engineers and analysts gained some insight on the technical needs of clinical ethicists in a patient care setting.

"IT became able to take an active role in ethics," says Saunders. Together, clinical ethics and IT implemented an ethics documentation note template. This tracks 50 ethics-specific metrics for consultations on adult, pediatric, and perinatal patients.

"The skepticism around this role is gone," says Saunders.

- **Administrators invite ethicists to work groups and committee meetings.**

"Traditionally, clinical ethics was

## EXECUTIVE SUMMARY

Stronger relationships are mutually beneficial for ethics and administrators.

Ethicists can encourage hospital leaders to:

- undergo required education for participating on an ethics committee;
- shadow clinical ethicists rounding with the healthcare team;
- observe ethics consultations.

only brought in when there was a problem,” says Ibrahim. Hospital leaders have found that ethics can offer a new, unexpected perspective.

“Whether in a family meeting or a board meeting, problem-solving and conflict resolution work equally well,” adds Ibrahim.

## Making a Business Case

Not all ethicists are comfortable making a “business case” to administrators or speaking in terms of cost-effectiveness and resource allocation.

“There are some ethicists who dig in and say, ‘We’re in the business of value. You can’t measure value, so I’m not playing that game,’” says **Steven Squires**, PhD, vice president of mission and ethics at Cincinnati-based Bon Secours Mercy Health.

These ethicists object to correlating the value of ethics with outcomes important to hospital administrators, such as reduced length of stay. “But you need to speak the language of other people,” says Squires.

Quality assurance in ethics is one option. “People can see how we’ve responded and what we need to work on,” says Squires.

The health system began an annual system ethics report in 2016. This includes committee profiles, educational events and initiatives,

and consultation characteristics. “These data are of interest to many, including administrators and board members,” says Squires.

The report compares the hospital’s ethics program to others of similar size and acuity. “Administrators like to know their ethics program isn’t an outlier,” says Squires. “Having an ethics committee three times the size of any other committee should, at minimum, generate questions.”

Data on the type and quantity of ethics consultations could be viewed as the proverbial canary in the coal mine. “Consult patterns can reveal larger problems,” explains Squires.

He recommends that ethics leaders multiply the number of consults in a year by the average time spent per consult, then multiply this by the average hourly wage of volunteer ethics consultants. “The resulting cost may surprise leaders who know that acute care needs a method to resolve ethics disputes,” says Squires.

Strong relationships with hospital or health system leadership are “essential for an ethics consult service to thrive,” says **Margie Atkinson**, DMin, BCC, director of pastoral care, ethics, and palliative care at Morton Plant Mease Hospitals/BayCare Health System in Clearwater, FL. Atkinson suggests these approaches:

- Ensure that an administrator or

other high-level hospital director sits on the ethics committee.

- Develop bylaws that require the ethics committee to report at least annually to the board of directors or quality committees.

- Ensure that ethics bylaws include signatures of hospital administrators. “Administrators, including senior medical officers and chief executives, give power to the program with their ownership,” says Atkinson.

- Do not hesitate to involve administrators when faced with challenging cases that could result in high-profile media coverage. Set up a conference call “sooner rather than later,” suggests Atkinson. “Your administrators will thank you for this.” ■

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- **Steven Squires**, PhD, Vice President of Mission and Ethics, Bon Secours Mercy Health, Cincinnati. Email: ssquires@mercy.com.

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# Nurse-facilitated Discussion Decreases Surrogate Stress

Surrogates reported less stress and greater satisfaction after a nurse-directed discussion on end-of-life preferences, a recent study found.<sup>1</sup>

Researchers looked at 163 patients and their surrogates at two university medical centers. One group had a nurse-directed discussion on end-of-life preferences, and another group discussed nutrition.

“The group that had the end-of-life discussion was more likely to endorse mutual surrogate decision-making — balancing their own wishes with what the surrogate thinks best,” says **Daniel P. Sulmasy**, MD, PhD, MACP, André Hellegers professor of biomedical ethics at Georgetown University’s Edmund D. Pellegrino Center for Clinical Bioethics in Washington, DC.

The study built upon prior research demonstrating that only a small minority of patients actually prefer that their surrogates make decisions based on substituted judgment should they lose decision-making capacity.<sup>2</sup>

Most people prefer a balance between their own preferences and what their surrogates think would

be best. Others would totally defer decisions to their loved ones.

“We thought patients and their loved ones should talk about this — not just what they want done, but how they want decisions to be made,” says Sulmasy.

The researchers saw what they expected to see: Surrogate stress diminished significantly with the nurse-facilitated discussion. However, it was somewhat surprising that their sense of caregiver burden increased. “Perhaps this is because it is more difficult to balance one’s own sense of what would be best for the patient with one’s understanding of the patient’s preferences when making decisions,” says Sulmasy.

Nonetheless, surrogates expressed satisfaction with the intervention. “It may be that they sense that assuming this more complex role is worth the effort,” says Sulmasy.

There are two important messages for hospital ethicists. The first is that evidence now suggests that most patients do not want pure substituted judgments when unable to speak for themselves.

Secondly, says Sulmasy, “This

study demonstrates that getting surrogates to talk to patients about not just what they want, but how they want decisions to be made, is both feasible and effective.” ■

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- **Daniel P. Sulmasy**, MD, PhD, MACP, André Hellegers Professor of Biomedical Ethics, Edmund D. Pellegrino Center for Clinical Bioethics, Georgetown University, Washington, DC. Phone: (202) 687-1122. Email: [sulmasyd@georgetown.edu](mailto:sulmasyd@georgetown.edu).

# Spiritual Self-care Linked to Higher Surrogate Confidence

Spiritual self-care can help prepare people to take on the challenging role of surrogate decision-maker, suggests a recent study.<sup>1</sup>

“Surrogate decision-making can be extraordinarily stressful and potentially traumatic for families,

especially for those who aren’t prepared for the role when the time comes,” says **J. Nicholas Dionne-Odom**, PhD, RN, ACHPN, the study’s lead author.

In palliative care, there is increasing focus on finding ways to help patients and their families

prepare for this role much earlier so that the end of life is not as traumatic for all concerned.

“We wanted to do this study to see if there were characteristics of families that we might be able to intervene on early in the course of illness,” says Dionne-Odom, an

assistant professor at the University of Alabama at Birmingham's School of Nursing.

The researchers sought interventions that would ready people for the possibility of being a surrogate decision-maker in the near future. They found that family members who practiced more day-to-day activities to foster their spiritual self-care felt more confident in taking on this role.

"This may highlight the need for spiritual and faith-based support earlier in the course of cancer," says

Dionne-Odom. Such interventions may facilitate conversations about the patient's future and advance care planning.

"It could be that individuals who are comfortable finding and connecting to meaning in life have better coping skills that endow more confidence in undertaking a future decision-making role," suggests Dionne-Odom. ■

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# Family Important Influencer on Care Preferences

Family has a particularly strong influence on care preferences, found a recent literature review.<sup>1</sup>

"Understanding people's preferences regarding how they wish to be cared for is a core aspect of person-centered care," notes **Simon Noah Etkind**, the study's lead author and a clinical PhD fellow at King's College London's Cicely Saunders Institute.

The researchers wanted to understand more about how care preferences may be influenced. "Knowing this would help health systems to deliver responsive care that is more in line with people's preferences," Etkind explains.

The analysis of 57 articles indicates that care preferences are influenced by a complex interaction of family, individual, and illness factors. "The extent of family as an influence on preferences was surprising, as was the evidence that many people don't have a clear idea of their preferences," Etkind says.

In order to deliver care centered on the individual, there is an ethical duty to take preferences into account. "By synthesizing existing evidence, this research provides

more detailed information to help focus care on what is important to people receiving it," says Etkind.

## Assess as Unit

Ethicists often have less of a direct role in the United Kingdom's healthcare system than they do in the U.S. "Clinicians from across specialties are expected to take on aspects of the ethicist role and consider patient preferences," explains Etkind.

Based on the study's findings, the researchers recommend that a person and the family be considered together as a unit of care. In practice, this means making an effort to ask both the patient and his or her family about preferences.

"The important implication of our research is that you can't fully assess an older person's preferences without also knowing about the views of their family," says Etkind.

It is not always possible for clinicians to discuss preferences together with the patient and family. It is still important to try

and ask the patient about the family's preferences as well as his or her own. In doing so, clinicians can learn whether there are conflicts. "The goal is to explore how family views might affect a person's preferences and whether there is anything that can be done to resolve disagreement," says Etkind.

Preferences sometimes develop during such discussions. "People don't necessarily have fully formed preferences that are ready to go in any situation," Etkind says. "We have found that illness context is an influence on preferences."

It is important for clinicians to discuss preferences in the light of a person's current situation. "If someone has been hospitalized, it might be a trigger for change in preferences," says Etkind. "So this might be a good opportunity to discuss them." ■

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# Study Sheds Light on Why Nurses Want Ethics Consults

A recent analysis of nursing requests for clinical ethics consultations revealed key concerns prompting the requests — and also what nurses felt was most important about the consults.<sup>1</sup>

“This study is part of a larger quality assessment effort. We spent several years gathering feedback from colleagues with whom we, as ethics consultants, interacted,” says **Stuart G. Finder**, PhD, the study’s lead author and director of the Center for Healthcare Ethics at Cedars-Sinai Medical Center in Los Angeles.

The goal was to learn how others viewed the ethics service and whether there were any specific educational or other institutional needs that ethicists needed to address.

“The underlying motivation is to be more fully accountable for the service we provide as ethics consultants,” says Finder. Some findings from the survey include the following:

- **End-of-life issues were not the overwhelming majority of reasons for requesting ethics consultations.** “There is a common perception that clinical ethics and end-of-life issues are closely related,” says Finder. Just 15% of requests were focused on end-of-life issues, while 39% focused on care plan concerns.

“This should not be surprising at all given the role and work nurses do,” says Finder.

Some nurses wanted support in providing what they believed was the best possible care for a patient when life-sustaining treatment was going to be withdrawn. Other nurses felt caught in the middle of poor communication dynamics between

physicians and patients’ families, and wanted help from ethicists.

- **The moral experience of caring for patients and interacting with clinical colleagues was a common factor in requests for consults.**

“Our data helps show that even if not the source of moral distress, moral

“THE UNDERLYING MOTIVATION IS TO BE MORE FULLY ACCOUNTABLE FOR THE SERVICE WE PROVIDE AS ETHICS CONSULTANTS.”

experience is still relevant,” says Finder. Typically, moral experience is seen as relevant only in the context of moral distress.

“This suggests that ethicists should pay greater attention to the scope and breadth of nurses’ moral experience in general — not just in the context of moral distress,” says Finder.

- **Reasons for requesting ethics consultations do not always match up with what, in the end, nurses found most valuable regarding ethics consultation.**

“Here, again, emphasis on moral experience is highlighted,” says Finder. This strongly suggests that ethics consultation is not simply about resolving conflicts. For those performing clinical ethics consultations, the study’s findings are

a reminder to pay careful attention to the specific kinds of moral experiences nurses undergo.

“Do not assume that if a nurse calls due to a question about a patient’s code status, that all that needs to be addressed is code status,” says Finder. “There may well be much more underneath that request.”

When ICU nurses at Northwestern Memorial Hospital in Chicago call an ethics consult, it often is because of a feeling that care is nonbeneficial. “That is the number-one issue that is causing us distress. Sometimes it is not exactly an ethical issue, but sometimes it is,” says **Leah N. Goldschmidt**, MSN, RN, CNL, education coordinator of the medical ICU.

A recent case resulted in significant moral distress for the ICU nurses. The family of an elderly patient insisted he continue to be a full code, despite suffering multiple system organ failure, on a ventilator, and requiring life-saving medications. Since the patient could not speak for himself, the clinical team did not have the opportunity to ask him what he wanted.

“It was hard for us to believe the patient would want to be intubated and attached to IVs, and at the final moments of his life to have CPR performed,” says Goldschmidt.

The entire clinical team, including physicians, were distressed over the case. “But what is different for nursing is that we are the ones who are at the bedside 12 hours a day,” says Goldschmidt. Ethical principles of nonmaleficence and beneficence came into play. “We feel we are causing harm to the patient when we are turning them and cleaning

them and essentially prolonging their death,” says Goldschmidt.

Nurses requested an ethics consult. Still, the family continued to insist they were doing what the patient would have wanted, and CPR was ultimately performed. “From our standpoint, it was not a good outcome,” says Goldschmidt.

A debriefing was held after the case, led by the palliative care team. Ethicists took the opportunity to

encourage nurses to continue to voice their concerns. “I tell my new nurses if they feel something is wrong to speak up — they’re not alone,” says Goldschmidt. ■

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1. Bartlett VL, Finder SG. Lessons learned from nurses’ requests for ethics consultation: Why did they call and what did they value? *Nurs Ethics* 2018; 25(5):601-617.

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- **Stuart G. Finder**, PhD, Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center, Los Angeles. Phone: (310) 423-9636. Email: stuart.finder@cshs.org.
- **Leah N. Goldschmidt**, MSN, RN, CNL, Education Coordinator, Medical Intensive Care Unit, Northwestern Memorial Hospital, Chicago. Phone: (312) 926-0443. Email: lgoldsch@nm.org.

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# Mobile Devices Used by Unregulated Researchers

**H**ealth research is increasingly conducted on mobile devices by unregulated researchers. A new National Institutes of Health-funded project, Mobile ELSI (Ethical, Legal and Social Implications) is developing recommendations for the ethical conduct of this emerging research.

“We are looking at various issues of research ethics raised by this new type of research,” says **Mark A. Rothstein**, JD, principal investigator of Mobile ELSI.

Unregulated researchers — those who are not subject to the Common Rule or FDA regulations — include:

- independent researchers who do not receive federal funding;
- “citizen scientists;”
- patient advocacy organizations, which increasingly sponsor or even perform their own research;
- research use of data collected for another purpose, such as health app data.

“The grant is for three years, and we are approaching the midpoint in our study,” reports Rothstein, founding director of the University of Louisville’s Institute for Bioethics, Health Policy, and Law, and author of a paper on this topic.<sup>1</sup> Ethical issues include:

- lack of external oversight from IRBs;

- online recruitment and inducements to participate;
- informed consent;
- confidentiality and security of sensitive information;
- return of results.

“The next — and most difficult — step will be to analyze numerous potential recommendations and then decide which policies and practices to propose,” says Rothstein.

The overarching goal is to bring this new and largely overlooked form of research to the attention of stakeholders and policymakers. “We believe there is little likelihood that laws will be amended to regulate previously unregulated research,” says Rothstein. Self-regulation is a more realistic outcome.

Anyone can now obtain genomic testing online, laboratory analyses without a physician’s orders, electronic health records with longitudinal data, and connections with a network of similarly affected individuals. “These factors enable research by nontraditional researchers,” says Rothstein. “The theoretical capacity exists for unregulated researchers to attempt biomedical research.”

Citizen science research also is facilitated by commonly available

software that can be used on mobile devices. Notably, nontraditional research participants often include individuals with disorders for which there are no effective standard therapies. “This is a vulnerable population,” says Rothstein. “In some cases, they are willing to trust people without questioning their credentials, experience, or acumen.”

This raises the possibility that individuals will stop taking medications based on dubious medical evidence or will try dangerous, unproven therapies.

“We want to try to figure out how we can protect the welfare of nontraditional research participants without impeding or stifling the creativity of nontraditional researchers,” says Rothstein. ■

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1. Rothstein MA, Wilbanks JT, Brothers KB. Citizen science on your smartphone: An ELSI Research Agenda. *J Law Med Ethics* 2015; 43(4):897-903.

## SOURCE

- **Mark A. Rothstein**, JD, Institute for Bioethics, Health Policy and Law, University of Louisville. Phone: (501) 852-4982. Email: mark.rothstein@louisville.edu.

# Ethics of Patient Access to Experimental Treatments

A new initiative will help more patients gain access to experimental drugs, devices, and biologics. “Typically, these patients are intensely vulnerable and in some cases, frankly, desperate,” says **Andrew G. Shuman**, MD, FACS, co-director of the program in clinical ethics and chair of the adult ethics committee and consultation service at University of Michigan Medical School in Ann Arbor.

The FDA’s expanded access program is designed to provide patients with opportunities to obtain investigational drugs or devices outside of a clinical trial. “The ethical issues involve ensuring that patients and families are adequately informed of the unproven benefits of these interventions and that efforts are made to mitigate unrealistic expectations,” says Shuman.

Partner universities will build a national framework for more efficient, consistent, and widespread use of the program and help more hospitals offer experimental options to their patients. The Michigan Institute for Clinical and Health Research will coordinate the new project, called Transforming Expanded Access to Maximize Support and Study. “Given the vital role of industry in availing access, ethical concerns exist regarding conflicts of interest, cost management, and avoidance of coercion,” notes Shuman.

Collaborating centers will work with companies seeking to make their products available through expanded access. “Ethicists are embedded within these teams to proactively address concerns, both on the part of patients and families, as well as clinicians and the research team,” says Shuman. ■

## SOURCE

- **Andrew G. Shuman**, MD, FACS, Co-Director, Program in Clinical Ethics, Center for Bioethics and Social

Sciences in Medicine, University of Michigan Medical School, Ann Arbor. Phone: (734) 232-0120. Email: [shumana@med.umich.edu](mailto:shumana@med.umich.edu).

## CME/CE QUESTIONS

### 1. Which is true regarding advance care planning in EHRs, according to a recent study?

- Half of patients with a completed advance care planning legal form had no accompanying explanatory discussion documented.
- Discussions were clearly available, but legal forms were not obtainable.
- Use of dedicated templates made documented wishes far more difficult to find.
- Accessibility is no longer problematic in critical care settings but remains a serious concern for the emergency department setting.

### 2. Which did a recent study find regarding patients and surrogates who had nurse-directed discussions on end-of-life preferences?

- Participants were less likely to endorse mutual surrogate decision-making.
- Surrogates reported less stress.
- Surrogates’ sense of caregiver burden decreased significantly.
- Surrogates reported decreased satisfaction.

### 3. Which is true about patients and their surrogates, according to Daniel P. Sulmasy, MD, PhD, MACP?

- Although preferences vary, it is safe to assume all patients want substituted judgments when unable to speak for themselves.
- Most patients prefer a balance between their own preferences and what their surrogates think would be best.
- The majority of patients indicated they wished to defer decisions to their loved ones.
- Surrogates reported less stress if patients asked them to base decisions solely on the principle of substituted judgment.

### 4. Which is true regarding dementia-specific advance directives?

- Stopping hand-feeding is well-established as standard of care for patients with advanced dementia in some states.
- Federal and state regulations require assisted eating and drinking regardless of whether advance directives say otherwise.
- Courts strongly support long-term care facilities in honoring families’ wishes to stop assisted eating and drinking.
- Recent legal cases suggest that absent a completed directive that addresses the issue of hand feeding, judges will not support withholding hand feedings.



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