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INSIDE

Physicians provide high-intensity end-of-life care for patients, but "no code" for themselves

System biased toward overtreatment, say researchers

Physicians often provide high-intensity care for patients at the end of life, even when the physicians would not choose this for themselves, according to a 2014 study.[1]

Mark Pfeifer, MD, senior vice president and chief medical officer at University of Louisville (KY) Hospital, doesn't find this too surprising. "Physicians understand they are both the gateway to modern, life-saving technology, and a beacon of hope for seriously ill patients," he says. "In those roles, I find they do feel obligated to encourage more care than they might choose for themselves."

The majority of 1081 physicians at two academic centers surveyed chose "no code" for themselves, indicating that they would refuse cardiopulmonary

EXECUTIVE SUMMARY

Physicians often provide high-intensity care for patients at the end of life, even when the physicians would not choose this for themselves, according to a 2014 study. Researchers argue that the current health care system is biased toward overtreatment. To address this, bioethicists can:

- Fully inform involved parties of risks, benefits, and limitations of near-futile treatments.
- Educate providers on legal protections involving medical decisions.
- Ensure everyone involved understands the prognosis with both continued and discontinued treatment.

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resuscitation. "Physicians are seen by the public as being insiders on the real value of aggressive care in the face of incurable serious illness," notes Pfeifer.

If physicians choose less intense care in certain situations, this raises the question as to whether others should do so as well. "Experts' decisions impact the rest of us," says Pfeifer.

Determine "tipping point"

The study raises questions about why doctors continue to provide high-intensity care for terminally ill patients but personally forego such care for themselves at the end of life, according to the researchers.

"The current health care system is very much biased toward overtreatment. There is a 'tipping point' in every disease trajectory, whether it is cancer, heart failure, or dementia," says **V.J. Periyakoil**, MD, the study's lead author. Periyakoil is director of Palliative Care Education & Training at Stanford (CA) University School of Medicine.

Beyond this "tipping point," she says, high-intensity treatment becomes more of a burden than the disease itself. Talking to patients and families to understand what matters to them is the best way for providers to find out what that "tipping point" is, says Periyakoil. "Any doctor who cares for seriously ill patients has an obligation to do this, and to help the patient with advance care planning," she adds.

Near-futile treatments common

Ethics consults are often called because family members request more chemotherapy or surgery when these treatments are clearly futile. "But there are a whole range of near-futile treatments," says **Timothy E. Quill**, MD, professor of medicine, psychiatry, and medical humanities in the Palliative Care Division at University of Rochester (NY).

When treatments might possibly help a little, and they have some very small potential utility, patients can typically get access to these, says Quill, "at least in the way our health care system is currently constructed."

This may change down the road, says Quill, "but we aren't even close to being there as a profession, or as a society. In the U.S., for better or worse, cost consideration is not really supposed to be part of the conversation for the individual patient."

Bioethicists can fully inform the involved parties of the risks, benefits, and limitations of a near-futile treatment. "But if the patient or family really wants a treatment and there is some utility, ultimately they are going to get it," says Quill.

On the other hand, a patient may indicate he or she doesn't want treatment, but providers think there is some utility to the treatment.

"From a legal point of view, this issue is settled. But to some doctors, withholding possibly effective treatment may seem like a violation of medical ethics or seem like the wrong thing to do," says Quill. "Having a bioethicist come in can be very helpful."

In one such case, a patient asked to stop post-surgical treatments due to a difficult recovery with complications. "After a week, potential recovery was way tougher than he had imagined," says Quill. "The surgeon told the patient, 'We just did the surgery. You may well recover.' But the patient was very clear that he wanted to stop."

An ethics consult was called to ensure everyone understood the

prognosis with continuing treatment, and the prognosis with stopping treatment. The patient chose to stop the treatments. "Ultimately, this man had capacity to make the decision, and it was a reasonable decision to make," says Quill.

Interventions demanded by family

Stuart G. Finder, PhD, director of the Center for Healthcare Ethics at Cedars-Sinai Medical Center in Los Angeles, CA, says that decades ago, when patients indicated they didn't want treatments, it was not uncommon for providers to disregard these wishes.

"Especially problematic was when those interventions would not change the ultimate outcome," says Finder — for instance, for a patient nearing the end of life in which, at best, intervention would prolong the dying process, and might actually increase the patient's suffering.

"This was, in fact, the impetus for the development of the concept of an advance directive by Luis Kutner in the late 1960s," says Finder.[2] "Forty-five years later, however, matters are, more often than not, reversed."

Finder says it's now far more common for patients or families to request and even demand medical interventions that physicians, nurses, and other health care providers do not believe to be medically appropriate, especially in large tertiary or quaternary care institutions.

"It is physicians wanting to withhold interventions, as opposed to wanting to provide interventions, that now often serves as the more common scenario in which the threat of patients' wishes not being honored by providers arises," says Finder.

Patient autonomy over-emphasized

Many health care providers fear being sued for failure to provide treatments at the end of life. "Part of that fear is based in lack of understanding of what actually is contained in various health care-related laws, and what kinds of medical decisions are, and are not, protected under those laws," says Finder.

Misunderstanding of the notion of respect for patient autonomy that has emerged in recent years carries even greater significance, according to Finder. "Unfortunately, in the effort to promote the crucial role patients' goals, values, and preferences should play in medical decision-making, we have over-emphasized the importance of autonomy," he says. "We have made it the primary ethical consideration for medical decision-making."

As a result, says Finder, the equally important issue of the scope of responsibility of physicians, nurses, and other health care providers has been under-emphasized. "Many within the health care professions no longer recognize the breadth of input necessary for making good clinical judgments, and hence, the professional cum moral dimensions of their obligations," he adds.

What began in the 1960s as a movement to empower patients by recognizing their rights to refuse unwanted medical care has transformed into a common belief that patients can both refuse and demand medical intervention, says Finder, and that providers are obligated to respond accordingly.

"Inherent commitments associated with being a professional care provider are undercut," he adds. According to the 2014 study, physicians:

- do not feel that widespread acceptance of advance directives would result in less aggressive treatment even of patients who do not have an advance directive;
- have greater confidence in their treatment decisions if guided by an advance directive;
- are less worried about legal consequences of limiting treatment when following an advance directive.

The study's findings show that providers know both the value and the limitations of advance directives, says Pfeifer, "and can be used to educate, inform, and counsel individuals, groups, and the broader public." ■

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Advance directives covering dementia care: Patient preferences can change over time

Ethical challenge to comply with patients prior — or current — wishes

Advance directives covering dementia care are complex, according to **Rebecca Dresser**, JD, Daniel Noyes Kirby Professor of Law and Professor of Ethics in Medicine at Washington University in St. Louis, MO.

Although the mental capacities of individuals with a dementia diagnosis diminish over time, she notes, they remain able to experience benefits and harms and maintain relationships and enjoy activities for much of that time. "These considerations can make it difficult for competent persons to anticipate the treatment decisions that would be best for them in the future," says Dresser.

At the bedside, clinicians, designated proxy decision-makers, and informal surrogates may face conflicts between what the patient once requested in a directive and what seems best for the patient in his or her current situation.

"Many of the things that are important to them as competent persons might not matter to them as dementia patients," Dresser says.

Bioethicists can help clinicians and families make treatment decisions that respect a patient's previous competent wishes, says Dresser, while giving adequate protection to the vulnerable and dependent dementia patients before them.

Individuals making advance directives don't always take into consideration that their preferences can change over time.

"Bioethicists can raise these issues with people making advance directives, and give them a realistic sense of the control that directives offer over future care," says Dresser.

Few hospices have VSED policies

The use of advance directives to indicate what a patient wants at a later point in time, when he or she no longer has decision-making capacity, is "problematic" when it comes to voluntarily stopping eating and drinking (VSED), argues **Timothy Kirk**, PhD, assistant professor of philosophy at the City University of New York-York College.

"On the one hand, it seems to fit in with how we use advance directives already," he says. Many patients indicate in an advance directive that they don't wish to be put on a ventilator, for instance. Patients may believe they should be able to do the same thing with VSED.

Patients hastening death by VSED is not a new issue, notes Kirk. "This is one of the oldest ways people have used to die more quickly. Given that, it's surprising that there isn't more public discussion about it," he says.

Kirk is chair of the National Hospice and Palliative Care Organization's Ethics Advisory Council and chair of the American Society for Bioethics and Humanities' Hospice and Palliative Care Affinity Group. "In states where aid in dying is not legal, VSED has become one of the primary ways that advocacy groups counsel folks to die because it's not illegal," he says. "I suspect the practice is a lot more common than we realize."

Kirk says VSED differs from declining more complex treatments because very few dementia patients do not have the capacity to decide whether they want to eat or drink. "Decision-making capacity is always evaluated relative to specific decisions that need to be made," he explains.

Patients with dementia may not have the capacity to understand the risks and benefits of a complicated surgical procedure. But even people with moderately advanced dementia understand whether they are hungry or not, says Kirk, and can make those decisions even if they've lost the

EXECUTIVE SUMMARY

Advance directives covering dementia care pose unique ethical considerations for clinicians due to conflicts between what the patient once requested in a directive and what seems best for the patient in his or her current situation.

- Bioethicists can raise the issue that preferences may change over time with individuals making advance directives.
- Medicare quality indicators which assess a patient's weight loss exclude patients who are losing weight because they decline a feeding tube.
- Providers often mistakenly believe they are at risk if they don't do everything they can for a patient, including inserting feeding tubes.

capacity to make more complicated decisions.

"It's usually only in the most advanced stages of dementia that people can lose the capacity to know whether or not they want to eat or drink," says Kirk. "If the patient has the capacity to make a decision now about eating or drinking, that should override any prior wishes."

There is also a significant question regarding the extent to which using advance directives to begin VSED in dementia patients is voluntary. "By definition, VSED is a voluntary course of action," says Kirk. "If a patient is sufficiently incapacitated such that his advance directive comes into effect regarding eating and drinking, it is not clear to me how withholding food and drink from him — even if this was a prior expressed wish — is voluntary."

Kirk estimates that only a handful of hospices have policies on VSED, and is unaware of any existing case law on this issue.

"There is very little guidance in the law and the literature on this," he says. "We also don't know how many people are putting clauses like this in their advance directives. In 10 years, we may see a wave of these clauses."

Disincentives to respecting patients' wishes

Kirk hears of several cases a year of patients whose advance directives indicated they would not want a feeding tube inserted, and nursing homes insert them anyway. "There are individual clinicians who don't respect patients' wishes involving medical procedures that are much higher risk than VSED," says Kirk. "So it's not hard for me to imagine that a facility would not honor that piece of their advance directive."

A patient's right to refuse a medical procedure is uncontested in terms of the law, and is a well-established right, but feeding tubes are nonetheless occasionally inserted against a patient's will. "It still happens for any number of reasons — because a family member insists, or maybe the nursing home is owned by a religiously affiliated organization," says Kirk.

Honoring patients' stated wishes is a "settled question" in the world of health care ethics, says Kirk. This isn't necessarily the case elsewhere.

"Outside that world, for many people who run hospitals and nursing homes, providers sometimes feel comfortable evaluating whether patient preferences should be followed," he says. Providers want to do the right thing, but they are managing competing pressures. "There are some disincentives out there to listening to patients' wishes," says Kirk.

Nursing home providers may be concerned that their quality indicators will be negatively impacted if they don't insert a feeding tube and the patient loses weight. This comes from a misunderstanding about Medicare quality indicators which assess a patient's weight loss to ensure that patients are getting appropriate care, says Kirk. The measures exclude patients who are losing weight because they decline a feeding tube.

"Unlike some regulatory bodies, Medicare is concerned about patients' rights," he says. "But nursing home managers may not know that there is that exception in there."

Providers often believe they are at risk if they don't do everything they can for a patient, including inserting feeding tubes. "I spend a lot of time as an ethics consultant correcting that misconception," Kirk says. "Providers' perception of risk is often skewed. What puts your organization at risk is treating people without their consent." ■

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Preclinical detection of Alzheimer's disease poses some unique ethical concerns

Predictive testing raises "very hot ethical and social issues"

Preclinical diagnosis of Alzheimer's disease shares some of the same controversies surrounding preclinical states of other diseases such as cardiovascular disease, osteoporosis, and diabetes, says **Jason Karlawish**, MD, professor of medicine, medical ethics, and health policy at University of Pennsylvania's Perelman School

of Medicine. However, there are also some unique ethical considerations.

"We operationalize our ethic of autonomy through our brain," he explains. "So as we talk about labeling people's brain at risk of decline before they are ill, we are playing with very hot ethical and social issues."

From a clinical point of view, the primary ethical consideration is whether diagnosing preclinical disease will make patients better or worse off, says **Kenneth Covinsky**, MD, MPH, professor at the School of Medicine at University of California, San Francisco. He says in most cases, imaging modalities cause more harm than benefit.

There is currently no treatment for individuals at higher risk for Alzheimer's disease. "So it is not clear how the early identification of those at risk will lead to benefit," says Covinsky. "But the more important reason is that the tests are of limited accuracy."

The tests identify amyloid in the brain, which is thought to be part of the pathology that leads to Alzheimer's, but many persons who have positive tests will never develop the condition. Labeling persons as having preclinical Alzheimer's disease who have a good chance of never developing the condition in their lifetimes is more likely to cause harm than benefit, argues Covinsky.

"We know that many persons who die of other causes have amyloid in their brains, and some who develop dementia do not have amyloid," says Covinsky. "At this point, brain amyloid may be a risk factor, but not destiny."

Should results be disclosed?

Karlawish says that with longitudinal studies, which measure various biological and clinical features of individuals and follow them over time to look for change, the primary concern is preserving the validity of the study, while at the same time protecting subjects from the harms of the study.

"There is a strong argument that you don't want subjects to learn preclinical biomarker results, for two reasons," says Karlawish. First, the study's validity could be harmed. Once participants learn their result, it could affect how they view their cognition and how they perform on a test. It could also affect how the clinical researchers assessing them view their performance.

"So if biomarker information is given out to individuals who are cognitively normal on cohort studies, you run the risk that you are going to corrupt the validity of the study, which is ethically inappropriate," says Karlawish.

Another reason not to reveal the results is that the information could result in stigma or discrimination. Karlawish is co-author of a 2014 paper outlining the current lack of preparedness to address the health care policy and legal implications of preclinical detection of Alzheimer's disease.[1] "The general ethic to govern cohort studies is a policy that data are gathered, but not returned to individuals," says Karlawish.

Karlawish says that researchers would want to disclose results to participants in clinical trials looking at whether an intervention affects individuals with one or more features that might be diagnostic for a preclinical stage of the disease. "There is a good case to be made that a valid study requires this," he says.

In clinical practice, individuals would learn their results, and based on these results, would get the intervention. "So you'd want your study to test that paradigm — I tell you the result and based on the result, I give you a drug. Knowing the result and getting the drug, how do you do?" says Karlawish.

Researchers have to address the possibility of stigma and discrimination, he adds, by setting up steps in the enrollment and screening processes to identify individuals who understand the limits of the information, and are psychologically prepared to receive it.

This results in "a very informed consent-heavy process, to make sure people fully understand what they're getting involved in," says Karlawish. "Researchers can draw analogies to the world of genetic testing for some

EXECUTIVE SUMMARY

Preclinical diagnosis of Alzheimer's disease presents significant ethical concerns, such as the tests' limited accuracy and lack of effective treatment for individuals identified at higher risk.

- Labeling persons as having preclinical Alzheimer's disease who have a good chance of never developing the condition in their lifetimes is potentially harmful.
- Informed consent processes need to address the possibility of stigma and discrimination.
- It is difficult to establish the value of predictive testing in the absence of effective therapies.

guidance on how they ought to do that."

Two possible futures

Karlawish says there are two possible futures involving preclinical diagnosis of Alzheimer's disease. One is that there will be rapid progress in personalized medicine for the brain, driven by therapeutics that successfully treat people.

In that scenario, says Karlawish, "the tight link between the therapeutic and the biomarker will rapidly carve out a space for patients to be diagnosed, labeled, and treated."

Ethical questions would include whether fringe or borderline conditions should be treated, and the cost and duration of therapy. "But it's generally a positive future, because it would show that at least some proportion of the population is benefiting from early intervention," says Karlawish.

The second possibility is that over time, longitudinal data accumulate in the absence of any effective therapies. "People will make the case that we should be using the data to diagnose people just because they want to know the information," says Karlawish. "But that will be a very difficult, steep, rocky road for us to climb, as a society and as a profession."

Risk prediction models are only so certain, he explains, and it is very difficult to translate those into clinical practice. "Large issues loom about what the value of the diagnostic is in the absence of a biologically validated therapy," says Karlawish. "That scenario is a clinical and policymaking nightmare."

One reason is the difficulty of validating a preclinical marker without a therapeutic. "The therapeutic is not just to help people — it's also valuable to validate the construct of preclinical disease," he says. "I think a lot of people don't recognize that second aspect of the role of therapeutics."

For this reason, Karlawish is generally pessimistic about a future of predictive testing that is driven simply by individuals' desire to know the information.

"It strikes me as very difficult to establish value in that setting," he says. "With competing resources for health care, I don't see how you can make the argument that that is a high priority." ■

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Providers don't always meet ethical obligations for patients with limited English proficiency

Problem is ongoing but "has gotten harder"

Approximately 62 million Americans speak a language other than English at home, and 25 million have limited English proficiency (LEP), notes **Glenn Flores**, MD, FAAP, director of the Division of General Pediatrics at University of Texas (UT) Southwestern and Children's Medical Center Dallas (TX). Flores is director of the American Pediatric Association's Research in Academic Pediatrics Initiative on Diversity.

"A substantial body of literature, from decades of research, documents the often profound adverse impact of language barriers on health and health care," says Flores. These include access to care, health status, use of health services, quality of care, patient-physician communication, satisfaction with care, and patient safety.[1,2]

"Language barriers are associated with significantly higher odds of prolonged lengths of stay for hospitalizations, and serious medical events during hospitalizations," notes Flores.

Many studies, however, link the use of trained professional interpreters and bilingual clinicians with optimal communication, patient satisfaction, and quality of care for LEP patients and their families.[3]

"Therefore, one of the most important ethical obligations is to ensure that every LEP patient is provided with a trained professional

medical interpreter or bilingual clinician," underscores Flores.

Many providers are still unclear that the onus of providing effective care across a language barrier is on them, says **Alicia Fernandez**, MD, a professor of clinical medicine at University of California, San Francisco.

"We need to ensure we use professional interpreters, and that we do not cut corners in care because of the hassle factor involved in obtaining and working with interpreters," she emphasizes.

"Huge ethical challenges"

Providers not meeting their ethical obligations to communicate with LEP patients is "not a new problem," says **Elizabeth Heitman**, PhD, a faculty member of Vanderbilt University Medical Center's Center for Biomedical Ethics and Society in Nashville, TN, noting that her 1988 dissertation addressed this topic.[4]

"It is an old problem that still poses huge ethical challenges, and it has gotten harder," she says. This is not just due to increased numbers of immigrants, but also because of the increased diversity of languages used by immigrant and refugee populations.

"There are probably lots of unrecognized ethical problems in the care of patients who don't speak English," says Heitman. All the same ethical challenges that exist for English-speaking patients are there for LEP patients, she says, but are further complicated by miscommunications and cultural barriers, particularly with end-of-life care.

Here are some potential obstacles in providers' meeting their ethical obligations to LEP patients:

• It is difficult for providers to communicate at the same level with an LEP patient as they would with an English-speaking patient.

"This is horrifically hard to do in a lot of contexts," says Heitman. "Even the best communication through an interpreter takes longer and may be less complete." There is no getting around the fact that having patients participate in discussions about their care is logistically much harder when they don't speak the same language as the provider, she adds.

Providers often view access to qualified interpreters solely as a patient's right, adds Heitman, but "providers themselves have an ethical and legal responsibility to make sure that they understand their patients fully."

• Hospitals struggle with financing of interpreter services.

Skilled interpreting can be expensive, and is rarely covered by insurance. Hospitals that can't afford to have in-house interpreters typically contract with off-site telephone interpreting services, says Heitman. Another option is for hospitals to certify bilingual staff to serve as medical interpreters, but staff may be reluctant to do so if their additional work is not recognized and if no additional compensation is offered.

"A lot of hospitals don't recognize that the ability to communicate professionally in another language is a skill," says Heitman. If a hospital relies on bilingual staff to work with LEP patients, the institution should certify that the staff member can actually work at a professional level in that additional language, and pay them for that skill, she advises.

• Some facilities use "ad hoc" interpreters to provide language assistance, including children, family members, friends, or untrained medical staff.

"Despite the number of LEP Americans and federal policy requiring providing adequate language assistance to LEP patients, many LEP patients do not receive professional medical interpretation," says Flores.

Although family members and friends may know the patient well, they are put in an "awkward and unfair" position when pressed into service as interpreters, says **Margaret R. McLean**, PhD, director of bioethics at Markkula Center for Applied Ethics at Santa Clara (CA) University.

Family members usually lack an understanding of the language of medicine, she explains, and often have a large emotional stake in the situation.

"There are a lot of problems with using uncertified translators,"

EXECUTIVE SUMMARY

Providers have ethical and legal obligations to communicate fully with patients with limited English proficiency, but there are many potential obstacles in doing so. To ensure ethical care, organizations can:

- Avoid using "ad hoc" interpreters such as family members instead of trained medical interpreters or bilingual clinicians.
- Offer additional compensation to bilingual staff who are certified as medical interpreters.
- Have a member of the facility's interpretive services staff sit on the ethics committee.

says Heitman. There is no way for providers to determine how well the family member speaks the patient's language, or if he or she understands the medical information or is translating it accurately.

Some institutions have patients sign a waiver if they request that a family member translate for them instead of an interpreter. "Waivers don't eliminate the providers' responsibility to gather and convey accurate health information," says Heitman.

If the patient wants to rely on a family member to translate, says Heitman, the caregiver should still have a qualified interpreter present to ensure that the appropriate information is being communicated.

• Language barriers can cause confusion during ethics consults.

Ethics consultants are typically not accustomed to working with interpreters, but need to learn how to do so, advises Heitman. A member of Vanderbilt's interpreter services staff sits on the hospital's ethics committee.

"We have had several consults where we had to bring in an interpreter," says Heitman. Under medical interpreters' own ethical standards, she notes, interpreters should convey the words being spoken, rather than using their own words to explain the concepts being discussed.

Adding explanatory or editorial comments can be perceived as interfering. "An interpreter can say, 'Stop, I need an explanation of this concept,' to be sure that they understand what the clinician means." Likewise, the ethicist needs to recognize where there may be a cultural issue that needs to be spelled out for the patient or provider.

• Some clinicians believe their ethical duty to provide adequate language services to LEP patients and their families ends after the office visit, hospital encounter, or procedure is completed.

"A key ethical consideration is that LEP patients and their families have comprehensive, 'door-to-door' language access," underscores Flores. He recommends these practices to ensure ethical care:

• Facilities should have multilingual operators and phone trees for making appointments; and provide multilingual signage, consent forms, and patient information materials.

• Clinicians should have interpreters write discharge instructions for patients and their family in their primary language.

• Pharmacists should print prescription instructions in the patient/family's primary language.

• Interpreters should accompany the patient to procedures, imaging, lab procedures, and to schedule follow-up appointments and referrals.

"A professional medical interpreter also should always be present for discussions regarding end-of-life care, advance directives, palliative care, and life-support decisions," says Flores.

Providers need to ensure that other areas of the health system also provide language access services so that LEP patients can, for example, make an urgent care appointment or obtain interpretation of a complex radiology procedure.

"Our ethical obligation to provide language access services transcends our encounter with the patient, and encompasses other essential health services," says Fernandez. ■

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Almost all oncology nurses report barriers to ethical end-of-life care

Nurses "working in the dark" on prognosis

Almost all (96%) of 173 oncology nurses surveyed reported concerns about system barriers in their efforts to help patients prepare for the end of life, according to a 2014 study.[1]

"A surprisingly large number of nurses reported experiencing ethical dilemmas regarding prognosis-related communication with advanced cancer patients," says **Susan McLennon**, PhD, ANP-BC, the study's lead author. McLennon is associate professor and assistant chair in the Department of Science of Nursing Care at Indiana University in Indianapolis.

"That 60% of the nurses reported concerns about truth-telling was particularly surprising," says McLennon. Nurses perceived physicians as:

- avoiding difficult conversations about a dire prognosis;
- failing to ascertain end-of-life wishes with their patients;
- using vague or medically obscure language.

Improvements in communication among the health care team about prognosis that identify patient goals of care, particularly in terminal conditions such as advanced cancers, are critically needed, urges McLennon.

"All parties did not have a clear understanding of treatment plans and goals of care," she says. One nurse stated, "We are working in the dark regarding patient prognosis."

Nurses are accountable both legally and ethically for their own nursing practice, emphasizes McLennon. The American Nurses Association's 2001 Code of Ethics directs nurses to meet the comprehensive needs of patients, particularly at the end of life.

"In the heirarchy of our health care system, physicians generally lead and direct patient care," says McLennon. "However, nursing care extends beyond simply following physicians' orders."

Lack of communication

Ruth Ludwick, PhD, RN-BC, CNS, a nurse researcher and gerontological nurse educator, recently sat in on an ethics committee on the topic of advance care planning. Ludwick is professor emeritus at Kent (OH) State University and a research consultant at several hospitals.

"I heard a lot of people expressing isolation. The physicians, nurses, and respiratory therapists all feel alone in dealing with this issue," she says. Poor communication among the team members can lead to problematic end-of-life care.

"You've got different people on different shifts, and different physicians coming in with different viewpoints about how to handle it," says Ludwick. The patient may have an oncologist, but is now being treated by a cardiologist, for instance, and the nurse doesn't know which physician to talk to.

"If you have a primary care physician who doesn't want to talk about it, and you don't have a family member producing a document, then you start to see the issue of 'Who do I go to next?' coming up," says Ludwick.

To address obstacles faced by nurses in providing ethical end-of-life care, Ludwick offers these practices:

• Organizations need clear policies on the pathway to follow.

"You don't want policies that are too prescriptive. There are always going to be situations that aren't covered," says Ludwick.

Often, policies are unclear on the point at which to call in a bioethicist. As a result, says Ludwick, "sometimes that bioethicist gets called in awfully late in the game. Another thing that providers often don't realize is that it doesn't have to be a bioethicist."

Clinicians shouldn't hesitate to call in a physician, nurse, or social worker with experience and education

EXECUTIVE SUMMARY

Almost all oncology nurses surveyed reported concerns involving barriers to ethical end-of-life care, according to a recent study. Some key findings:

- Nurses perceived physicians as avoiding difficult conversations about a dire prognosis.
- Involved parties may lack a clear understanding of the goals of care.
- Physicians may fail to ascertain patients' end-of-life wishes.

in end-of-life care, she advises. "A clinical nurse specialist might have expertise in oncology and palliative care, and also have expertise in advance care planning," says Ludwick.

If this individual isn't directly involved in the case, he or she may be the first "go-to person" for a discussion. "A policy on how to pull together a diverse group, consisting of a bioethicist and several practitioners experienced with end-of-life care, may be necessary in complex cases where discussions may already have started to deteriorate," says Ludwick.

• Professionals may need to be re-educated on the ethics of advance care planning.

Providers' own comfort level with the topic of advance care planning is sometimes an obstacle to ethical end-of-life care. "There are a surprising number of providers that haven't had a lot of education about advance care planning," says Ludwick. "Frequently, a 'tick box' approach is used — that is, 'Does the patient have an advance directive or not?'"

Advance care planning is an ongoing process, says Ludwick — starting with the diagnosis of a life-limiting, often chronic disease, and continuing through the end of life. This involves ongoing discussions among health care providers, patients, and families about values, preferences, trajectories of disease, and decisions that may be needed as diseases progress.

The question "Is there an advance care directive in place?" is typically asked and answered, Ludwick says, but "nobody asks to see it, and nobody asks whether it needs to be reconsidered."

She recommends using interprofessional simulation to address common end-of-life scenarios. "A nurse may walk in and sees the patient is not doing well, and knows the diagnosis. The question becomes, 'What are we going to do?'" says Ludwick.

A family member may arrive and demand interventions that conflict with the patient's known wishes, while the physician says it's not their concern, and the respiratory therapist is about to start the patient on a continuous positive airway pressure machine.

By simulating challenging real-life situations such as this, says Ludwick, "instead of following a didactic, static approach, that's where you get at the best teaching related to ethics — and probably the best improvement beyond just straight knowledge." ■

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CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

1. Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems;
2. Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings;
3. Discuss the effect of bioethics on patients, their families, physicians, and society.

COMING IN FUTURE MONTHS

- Identify unethical practices in care of undocumented patients
- Improve ethics consults with best practices from conflict resolution field
- How to incorporate ethics in all stages of neuroscience research
- Why nurses often aren't included in end-of-life care discussions

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CME INSTRUCTIONS

To earn credit for this activity, please follow these instructions:

1. Read and study the activity, using the provided references for further research.

2. Scan the QR code to the right, or log on to www.cmecity.com to take a post-test; tests are taken after each issue. First-time users will have to register on the site using the 8-digit subscriber number printed on their mailing label, invoice, or renewal notice.

3. Pass the online tests with a score of 100%; you will be allowed to answer the questions as many times as needed to achieve a score of 100%.

4. After successfully completing the test, your browser will be automatically directed to the activity evaluation form, which you will submit online.

5. Once the completed evaluation is received, a credit letter will be e-mailed to you instantly.

CME QUESTIONS

1. **Which is true regarding physicians' attitudes toward advance directives, according to a 2014 *PLOS ONE* study?**

   A. The majority of physicians indicated "no code" for themselves.

   B. Physicians always chose more intense care for themselves than they would for their patients.

   C. Virtually all physicians felt that widespread acceptance of advance directives would result in less aggressive treatment even of patients without an advance directive.

   D. Physicians were more worried about legal consequences of limiting treatment when following an advance directive.

2. **Which is true regarding preclinical diagnosis of Alzheimer's disease, according to Jason Karlawish, MD?**

   A. There is no potential harm in labeling persons as having preclinical Alzheimer's disease who have a good chance of never developing the condition in their lifetimes.

   B. Informed consent processes cannot be used to address the possibility of stigma and discrimination.

   C. There is demonstrably clear value of predictive testing, even in the absence of effective therapies.

   D. It is difficult to establish the value of preclinical diagnostic testing in the absence of a biologically validated therapy.

3. **Which is true regarding providers' ethical obligation when caring for patients with limited English proficiency, according to Glenn Flores, MD, FAAP?**

   A. "Ad hoc" interpreters such as family members can be used effectively.

   B. Facilities should use only trained professional medical interpreters or bilingual clinicians.

   C. No additional compensation should be offered to bilingual staff who are certified as medical interpreters.

   D. It is acceptable to have patients sign a waiver if they request that a family member translate for them instead of an interpreter.

4. **Which is true regarding advance directives covering dementia care, according to Timothy Kirk, PhD?**

   A. All hospices have policies covering voluntarily stopping eating and drinking in patients' advance directives.

   B. Medicare quality indicators which assess a patient's weight loss include patients who are losing weight because they decline a feeding tube.

   C. A patient's right to refuse a medical procedure is well-established, but feeding tubes are nonetheless occasionally inserted against a patient's will.

   D. Providers face significant legal risks if they don't do everything they can for a patient, including inserting feeding tubes wthout consent.