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Clinicians: Patient, family factors obstacles to end-of-life discussions

Important conversations often neglected

Hospital-based clinicians see factors related to patients and family members as more important barriers to end-of-life discussions than clinician and system factors, according to the DECIDE study.¹

“Essentially, these important conversations are often being neglected. There are a number of factors responsible for this,” says study author **James Downar**, MD, CM, MHSc, FRCPC. Downar is an assistant professor in the Divisions of Critical Care and Palliative Care at the University of Toronto in Ontario, Canada.

Researchers asked 1,246 clinicians (512 nurses, 484 residents, and 260 staff physicians) to rate the importance of 21 barriers to goals-of-care discussions with seriously ill hospitalized patients and their families. Clinicians reported that the major patient- and family-related factors that hinder end-of-life discussions are difficulty accepting a poor prognosis; difficulty understanding the limitations and complications of life-sustaining treatment; disagreement among family members about goals of care; and a patient's incapacity to make decisions.

“To say that something is patient- and family-related is not to say that it is their

EXECUTIVE SUMMARY

Hospital-based clinicians see factors related to patients and family members as the most important barriers to end-of-life discussions, according to a recent study. To facilitate these conversations, institutions can:

- Provide communication training.
- Improve patient and family preparedness to participate in these conversations.
- Provide patients and family members with decision aids.

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EDITORIAL QUESTIONS

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fault,” says Downar. The participants’ suggestions for addressing these issues — communication training and decision aids — suggest they were concerned about system factors. “The reason that patients and family members have difficulty accepting a poor prognosis or the limitations of treatment is because the system does not meet their needs,” says Downar. “The findings of the DECIDE study are consistent with previous work in this area.”

The 2014 ACCEPT study looked at patient and family member perceptions of advance care planning discussions.² Researchers asked 233 older adult patients and 205 family members at nine Canadian hospitals about elements of goals-of-care discussions. Both groups identified these elements as being the most important to address: Preferences for care in the event of life-threatening illness, values, prognosis, fears or concerns, and questions about goals of care.

“It showed that physicians, nurses, patients, and family members were all focused on the same issues — goals, values, and prognosis — when talking about advance care planning,” says Downar.

Implications for ethics consults

The 2015 study was primarily focused on typical conversations about goals of care, rather than situations of conflict that require a third party to become involved. “We were partially looking at reasons why communication does not take place, whereas ethicists are typically consulted to help in cases where communication has taken place but has broken down,” Downar explains.

However, the lessons from

this study could be applied to the normal practice of ethicists when the communication breakdown is related to these same factors. “Ethicists will typically probe for differences in understanding between clinicians, patients, and family members,” Downar says. Factual misunderstandings can be easily addressed, whereas disagreements about values and goals may be more challenging to resolve. Downar says the following resources are needed to facilitate goals-of-care discussions:

- **Communication training.**

“This is going to be a vital part of the solution,” says Downar. “The authors are working on training to improve rapport-building, empathic listening, and explanations of prognosis.”

- **Interventions that improve patient and family preparedness to participate in these conversations.**

“The current model of advance care planning focuses on decisional readiness — the clear communication of values in the context of hypothetical, but realistic, situations,” says Downar. The SpeakUp campaign in Canada is an example of such an initiative. (For more information, go to www.advancencareplanning.ca.)

- **Decision aids, such as educational videos or booklets, customized for the particular situation of the patient or family member.**

“These support patients and family members tasked with making difficult decisions at the end of life,” says Downar.

The study shows that healthcare providers feel that the largest barrier to end-of-life conversations has to do with patient and family discomfort around end of life, says **Kate M. Lally, MD**, director of palliative care at the 275-bed, CNE-owned Kent Hospital in Warwick, RI. “Patients

and families often struggle with understanding a poor prognosis or understanding the limits of CPR,” she says.

Communication within a family is often a barrier. “When patients cannot speak for themselves, families are often stressed. Difficult interpersonal dynamics come out,” says Lally. It is important to know who speaks for the patient, and to know that the patient has discussed their end-of-life wishes with that person, she says.

“Families may divide into factions, with differing opinions about what a patient would have wanted,” says Lally. Doctors often try and provide some hope in giving a poor prognosis by admitting they can never be 100% sure of an outcome.

“Patients will sometimes hold on to that sliver of hope, and opt for painful treatments that may not benefit them and may harm them in an attempt to prolong their lives,” says Lally.

Lack of skill is factor

Clinicians perceived their own skills and system factors as less important barriers to end-of-life discussions, according to the study.¹ “While difficulty accepting a poor prognosis and difficulty understanding the limits of life-sustaining treatments are clearly barriers to having these conversations, I also suspect that lack of skill on the providers’ part plays a bigger role than the clinicians acknowledge,” says Lally.

If patients and families were asked to identify barriers to end-of-life conversations, they might respond that providers are the ones uncomfortable with such discussions, and that providers never asked them their preferences, she says.

“Doctors think that patients are

the problem. I suspect if you ask patients, they will think that doctors are the problem,” says Lally. “I think the real problem is a failure of communication between the doctors and patients.”

Often, conflicts over life-sustaining treatments arise because of a breakdown in communication between patients, families, and providers. “The main role of ethicists could be to help rebuild the bridges of communication,” suggests Lally.

Lally attends many family meetings to discuss treatment options about patients with a poor prognosis. “I find that if the meeting starts with the doctor having a prolonged monologue about the patient’s prognosis and treatment options, then the meeting will not go well,” she says.

During a recent meeting about a patient with advanced dementia, the intensive care unit doctor spent about 20 minutes discussing all of the patient’s medical issues. “When the doctor talked about how the patient wasn’t eating, the family asked about a feeding tube. When he told them the kidneys were failing, they asked about dialysis,” says Lally.

After the physician finished talking, Lally asked the family how they felt; they reported feeling overwhelmed by the information, which was difficult to hear. “I then asked how they felt the patient has been doing over the last six months at home,” she says. The family noted significant weight loss, and loss of the ability to speak and walk independently.

“They acknowledged he wasn’t doing well,” says Lally. “We then talked about the dying process with dementia, and how the decline they had been noticing was their father approaching the end of his life.” The discussion then turned to the patient’s kidney failure and inability

to eat. “I helped them to see that these problems were markers of the same disease that had been affecting their father for many years, and that we were now at a point that he was dying,” says Lally. After the family realized this, they were able to shift their focus to comfort, and no longer requested interventions that were very unlikely to help him.

Lally usually starts family meetings by asking the family how they feel the patient is doing and what they understand about what is going on. “By listening to the family and understanding their frustrations, I am often able to better guide the meeting,” she says. “The best thing ethicists can do is to encourage our medical teams to listen more and talk less in family meetings.”

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Caregivers' choices not always aligned with patients' wishes

Caregivers often uncomfortable with patient choices

Caregivers were three times as likely as end-stage cancer patients to pay to extend the patient's life by one year, according to a recent study.¹ The research team, led by members of the Lien Centre for Palliative Care and collaborators from the National Cancer Centre Singapore, surveyed 211 patients and their caregivers. Participants were asked to choose their most-preferred end-of-life scenarios out of a series of options, including years of life remaining, degree of pain experienced, place of death, level of burden on caregivers, quality of healthcare experience, and cost. Based on the results, the authors quantified patients' and caregivers' willingness to pay to improve their end-of-life experience.

The study's findings weren't surprising, says **Charity Scott, JD, MScM**, Catherine C. Henson Professor of Law at Georgia State University College of Law in Atlanta. Prior research demonstrates that there can be significant divergence between a patient's actual treatment preferences and what treatments the

patient's caregivers or providers think the patient would want or should have.^{2,3}

"What is new about this study is assessing the relative value that patients and caregivers place on various end-of-life treatments for stage IV cancer patients by comparing their willingness to pay for them," says Scott.

Caution should be exercised in generalizing from this research, which was undertaken in Singapore, to Western hospital settings due to specific cultural and social factors which pertain to the study population, notes Scott. For example, researchers asked about willingness to pay for certain treatments. In Singapore, approximately three-quarters of health expenditures are paid directly in cash or through patients' or family members' health savings accounts. "With this caveat in mind, there are nonetheless certain common themes and lessons from this study that are relevant to bioethicists, patients, caregivers, and providers in other countries," says Scott. These themes

include the following:

- Where the patient is able to express his or her own preferences about treatment, providers and caregivers should take great care to engage the patient in conversation and to elicit and respect those preferences.
- Supporting patient preferences for good pain management and the opportunity to die at home if desired are consistent with ethical precepts to promote patient autonomy and quality of life.
- It is possible that caregivers' own subconscious biases and emotional responses may be influencing the course of treatment they would choose for the patient. "For example, are their own fears of losing a loved one causing them to deny the gravity of the patient's terminal illness and its effects on the patient's quality of life?" asks Scott.

Clear communication

A patient decides that he or she would not want to be resuscitated and, therefore, wants the defibrillator to be turned off, but his or her spouse feels uncomfortable with this and convinces the patient to leave it on. **Sarah C. Hull, MD, MBE**, clinical faculty in the Section of Cardiovascular Medicine at Yale-New Haven (CT) Medical Center, has seen this scenario unfold several times.

"Many caregivers feel a tremendous amount of guilt when their friend or loved one is dying," says Hull. "Sometimes, in order to

EXECUTIVE SUMMARY

Caregivers were more likely to pay to extend an end-stage cancer patient's life than the patients themselves were, according to a recent study. Suggested approaches to ensure ethical care include the following:

- Offer palliative care in lieu of life-sustaining treatments that are unwanted by the patient.
- Consider that caregivers' biases and emotions may be influencing what they choose for the patient.
- Support patient preferences for good pain management and the opportunity to die at home if desired.

assuage that guilt, they push for everything to be done in order to keep that person alive as long as possible, no matter how aggressive the treatment.”

Hull tries to make it clear to caregivers that they should not feel guilty about “pulling the plug.” She tells them, “Sometimes the most loving and selfless thing you can do is to allow doctors and nurses to focus all our energy on making the person comfortable and allowing him or her to die with peace and dignity.”

“It absolutely paramount that when a patient is critically ill, physicians communicate clearly not only with the family, but also with each other,” adds Hull. She often provides cardiology consultation for patients with multiorgan disease in the intensive care unit (ICU). “I cannot overstate how important it is to have conversations with the ICU team about the patient’s trajectory and get on the same page before I talk with the family,” says Hull.

It can be tempting to sugarcoat a dying patient’s condition and say, “Let’s just see how she does,” when it is clear that the patient has irreversible disease which is reaching its end stages. “Nobody wants to be the bearer of bad news,” says Hull. “As difficult as it is, I try to be clear without being too specific.” Hull may tell a family member, for example, “Your mother is very sick, and while doctors are not very good at making predictions, my best guess is that she has only days to weeks left. I apologize for being so blunt, but I think it would be unfair and disrespectful to you not to tell you the whole truth.”

Not all physicians are comfortable with this kind of communication. “Bioethicists could play a pivotal role in training them if such a formal

service were introduced,” says Hull. “Unfortunately, bioethics education is often limited in medical school and residency.”

Compassion is ethical response

In some cases, it is clear to providers that a caregiver’s choices are not aligned with the patient’s wishes; the provider is ethically obligated to honor a competent patient’s preferences. Respect for

CAREGIVERS MAY OVERESTIMATE THE BENEFITS OF LIFE-SUSTAINING TREATMENTS FOR A TERMINALLY ILL CANCER PATIENT AND UNDERESTIMATE THE BENEFITS OF GOOD PALLIATIVE CARE.

patient autonomy and patients’ rights of self-determination over their healthcare have become hallmarks of Western bioethics, says Scott. “That said, there is much that providers can do to help alleviate caregiver and family distress where the patient chooses less aggressive treatment than they would choose on her behalf,” she says.

This includes providing empathetic counseling and support to the patient’s family and caregivers, with the goal of easing the patient’s concerns over any emotional turmoil caused by conflicts over choices for

care. “Compassion is always a good ethical response for providers, be it for the patient or for her caregivers,” says Scott.

Caregivers may overestimate the benefits of life-sustaining treatments for a terminally ill cancer patient and underestimate the benefits of good palliative care. “By offering palliative care in lieu of life-sustaining treatments that are unwanted by the patient, providers can show caregivers how, together, they all can continue to provide excellent care to the patient at the end of life,” says Scott.

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Burnout common among transplant surgeons

Don't wait for physicians to reach out for help

Forty percent of 218 transplant surgeons surveyed reported high levels of emotional exhaustion, according to a recent study conducted at the Henry Ford Transplant Institute in Detroit.¹ Greater emotional exhaustion was linked to lower decisional authority, higher psychological work demands, and lower coworker support.

No other area of healthcare is as closely scrutinized, monitored, and regulated as transplant surgery, notes **Mary Ellen Olbrisch**, PhD, ABPP, professor of psychiatry and surgery and a clinical psychologist at Virginia Commonwealth University in Richmond. “Statistics for the program must be updated on a timely basis and compared to peers, and inspectors drop in at will,” she adds. “Every team member must prove he or she is up to speed on a regular basis.”

Lead author **Michelle T. Jesse**, PhD, wasn't surprised by the data, except for one finding: Almost half of respondents — all highly-trained individuals who perform life-saving surgical interventions — reported a low sense of personal accomplishment.

“Why they reported this is not entirely clear and requires further

study. But we hypothesized there are a few things at play,” says Jesse, a senior staff psychologist at Henry Ford Health System.

The surgeons did not feel they were having a positive impact or were accomplishing what they intended. Possible reasons for this include the considerable morbidity and mortality of the patient population, and the ever-evolving regulatory oversight of organ transplantation. “Without clear endpoints, it can be difficult to work toward clear goals,” explains Jesse.

Interventions at institutional level

Clinical ethicists could be part of a group that approaches hospital leaders to obtain support for the development of a burnout prevention program if one is not already in place. “Very few institutions have a peer support program. Ethicists are in a position where they could bring these issues to light,” says **Jo Shapiro**, MD, director of the Center for Professionalism and Peer Support at Boston-based Brigham and Women's Hospital.

In Shapiro's experience, most hospital leaders are easily convinced.

This is in part because they are well aware of the hidden costs of burnout, both in terms of financial loss and physician satisfaction. “The amazing thing is that this is such an easy argument to make,” says Shapiro. “But it does require somebody to act as a champion and say, ‘This matters.’”

Jesse says the following practices can help to prevent burnout at the organizational level:

- supportive administrative policies for appropriate work-life balance;
- encouraging providers to take time off when needed or wanted;
- encouraging positive interpersonal interactions;
- providing educational opportunities for identifying and treating burnout.

“Creating institutions where the moral and ethical views of caregivers at all levels are equally valued, and where all can call on the ethics committee or consultants, also contributes to a work atmosphere that is healthy for all,” says Olbrisch.

Burnout sometimes manifests itself as inappropriate behavior. Providers in need of help might be identified as disruptive. “There is far less tolerance for abusive behavior from *prima donna* providers than there used to be, perhaps to the point where there is too little tolerance for appropriate expressions of anger or a little humor,” says Olbrisch.

Ethicists are ideally suited to serve as mediators to keep tense interpersonal situations from escalating. “This may mean that a physician who is experiencing burnout gets appropriate help and support, rather than getting in trouble with the

EXECUTIVE SUMMARY

Forty percent of 218 transplant surgeons surveyed reported high levels of emotional exhaustion, according to a recent study. To prevent burnout, ethicists can do the following:

- Act as mediators to address disruptive behavior.
- Reach out to physicians after unexpected bad outcomes.
- Provide support when clinicians disclose errors.

licensing board or losing a job,” says Olbrisch.

Likewise, ethicists can step in to support individuals who are affected by a colleague’s disruptive behavior. “If there is a pattern of disrespectful behavior, the chance of people in that team experiencing burnout is high,” says Shapiro. Here are two other situations where ethicists can step in to prevent burnout:

• **When unanticipated bad outcomes occur.**

Physicians are often told, “It’s not about you. It’s about the patient and family.” “That’s true. But the well-being of the people providing the care will absolutely influence the care that the patient gets,” says Shapiro.

Physicians are unlikely to ask for support in this scenario; ethicists can approach them instead. “You

can say, ‘That was a tough thing that happened. Let’s make sure you get some peer support,’ instead of waiting for them to reach out,” suggests Shapiro.

• **When a patient is harmed by a medical mistake.**

Physicians are increasingly encouraged to disclose adverse events to patients and family, but often lack guidance in doing so. “Physicians often feel guilty, ashamed, and incompetent, and need to know who is going to say what to the patient,” says Shapiro. “They need support in doing the right thing in being transparent.”

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COPD symptoms untreated prior to palliative medicine referral

Patients, physicians not aware of benefits, study says

Many physical and psychological symptoms were untreated prior to patients with chronic obstructive pulmonary disease (COPD) being seen in the outpatient palliative medicine clinic, according to a recent survey.¹ “One reason that many patients are referred to palliative medicine too late is that many patients and their physicians are not aware of the benefits of palliative medicine,” says **J. Randall Curtis**, MD, MPH, director of University of Washington’s Cambia Palliative Care Center of Excellence and section head of Pulmonary and Critical Care Medicine at Harborview Medical Center, both in Seattle.

In another study, researchers found that 9.1% of 1,455 COPD patients

had palliative care needs. The presence of metastases was the highest risk factor for developing palliative care needs.² The following are some reasons why COPD patients aren’t referred early enough to palliative care:

• **Many patients and physicians incorrectly assume that palliative care is synonymous with hospice or end-of-life care.**

“They don’t realize that palliative care has a lot to offer patients with serious illness, even if they are still interested in pursuing curative or life-prolonging treatment,” says Curtis.

• **Although palliative care availability is increasing, there are still hospitals and areas of the country that do not have good access to palliative medicine**

specialists.

“Most hospitals now have inpatient palliative care consultation teams, but outpatient palliative care programs are just developing now in many parts of the country,” says Curtis.

• **Physicians don’t always recognize the large burden of diverse symptoms that patients with COPD have.**

“Patients experience not just shortness of breath, but also pain, depression, anxiety, and many other symptoms,” says Curtis.

• **It is more difficult to predict prognosis in COPD than in cancer.**

“Therefore, when physicians mistakenly tie their referrals to palliative care to a patient’s prognosis, this can mean that patients with

COPD don't get referred," says Curtis.

• **The evidence of the benefits for palliative care for patients with COPD is more recent than for patients with cancer.**

Thus, some patients and physicians are unaware of these benefits. "We need to increase awareness of the value of palliative care for patients with chronic lung diseases like COPD, as well as pulmonary fibrosis, pulmonary arterial hypertension, cystic fibrosis, and other lung diseases," says Curtis.

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Do physicians assume they know older patients' wishes?

Negative stereotypes may lead to unwanted or inadequate care

Many excellent physicians spend a significant amount of time with their older adult patients, explaining health issues in an understandable and compassionate fashion and answering questions as needed.

"However, just like in our general society, physicians may also hold certain stereotypes about their older patients," says **Susan Peschin**, MHS, president and CEO of the Washington, DC-based Alliance for Aging Research.

Some physicians assume the older adult's goals are just like theirs. "Most physicians are much younger than the older adult patient. There is a culture gap that goes unrecognized," says **Joshua Uy**, MD, clinical assistant professor of medicine in the Division of Geriatric Medicine at Penn Medicine in Philadelphia.

The younger physician might assume that all older patients want to live as long as possible with aggressive treatment, he says. "This is true for some adults. For others, the quality of life is not worth living and all they want is palliative care," says Uy.

Conversely, if physicians assume that the older person's quality of life is not worth living, patients are denied effective, desired care.

A frail 95-year-old man's cardiologist told him that an implantable cardioverter defibrillator would help his heart — without explaining that the device wouldn't slow down the disease process or repair existing damage to the heart. "The patient ended up having this \$35,000 device placed, and came home," says Uy. He explained the device's purpose to the man: To resuscitate him when his heart went into a fatal arrhythmia. "This gentleman was actually OK with passing away. He had a very difficult life," says Uy. "By not discussing the values of the intervention, it didn't let him participate in whether he wanted it."

Physicians are generally focused on whether a patient needs a specific intervention; they fail to ask the question, "To what end?" "The recognition of it as a value-based decision — that there could be more

than one right answer — is not even there," Uy says. "I hate to say it, but physicians are better at treating numbers than they are at listening to patients, probably."

This leads to older patients sent for cancer screenings even though they are dying of heart disease. "It's easier to just order the test and talk about how smoking history is an indication for screening for lung cancer," says Uy. "It's a lot more difficult to say, 'How would it help this specific patient in terms of their values, their goals, and their overall health?'"

On the other end of the spectrum, many physicians stop ordering mammograms, colonoscopies, and Pap smears based solely on guidelines that recommend stopping these screening tests at certain ages. "There is nothing magical that happens at 75. It's an arbitrary cutoff for when things go from being more effective to less effective," says Uy.

Instead of considering the patient's individual situation and having the patient participate in the decision, physicians simply don't order the

screening. “What comes across to the patient is, ‘My doctor doesn’t care if I get cancer anymore,’” Uy says.

Some patients in their 90s ask for mammograms; if so, Uy asks them, “What are you hoping for? What are your fears?” The patient might say, “I’m afraid of getting cancer,” which then opens up the opportunity for a discussion about their goals and values.

“The problem is that physicians need to communicate not in terms of guidelines and physiologic terms, but by putting recommendations in context of the patient’s values and goals,” says Uy. “To me, that is what would make it an ethical decision.”

Some providers automatically switch to “baby talk” when communicating with older adults, says **Jason Karlawish**, MD, professor of medicine, medical ethics, and health policy at the University of Pennsylvania in Philadelphia.

“In taking on the tone of voice one might use with a child, you are essentially conveying a view about the patient’s capacity, and your feeling of pity or even disgust for them,” he says. The provider’s tone of voice gets in the way of effective communication and decision-making, he says.

“It can affect the information and choices you present,” says Karlawish. “Any older adult who is ill in bed will look pretty vulnerable and sick, even those with no cognitive impairment.” He tells residents to imagine Supreme

Court Justice Ruth Bader Ginsburg with pneumonia in the hospital, and tells them, “I certainly hope you wouldn’t be baby-talking Justice Ginsberg.”

The first step is for clinicians to consider how their tone of voice affects the way they think about and make decisions about an older adult. “Taking on a gentle tone of voice might be appropriate. But the default is, you should talk to older adults as you talk to other adults,” he says.

Physicians sometimes make blanket assumptions about what’s typical at certain ages, such as decreased cognitive function or kidney function; this might not reflect the patient before them. “As clinicians, we want to recognize that there is substantial variability between older adults,” says Karlawish. “One must see how well the individual fits within that range of what is expected.” Here are some factors contributing to undertreatment of older patients:

- **Providers may question the point of diagnosing and initiating symptomatic-only treatment, if there is no cure.**

In some cases, says Peschin, “there is a nihilistic attitude regarding identification and intervention for older patients.”

- **Providers may assume that older patients don’t want to know if they have a serious condition such as dementia.**

“Literature on this issue shows that

most older patients and their family caregivers experience a sense of relief in finally knowing, and being able to prepare for what is down the road,” says Peschin.¹

- **Providers may not choose to intervene, even in cases where the intervention has been found to be curative.**

“Older patients sometimes face the ‘We all have to die of something’ perception,” says Peschin. “A good example of this is valve disease, which can lead to loss of independence, disability, and even death.” Older women are often misdiagnosed as having anxiety rather than valve disease, and do not get appropriate treatment.²

“When diagnosed correctly, repair and replacement — the most effective treatments for most valve diseases — have very high success rates, and in most cases improve quality of life and add many more healthy years,” says Peschin.

- **Negative stereotypes about patients can impact access to intervention with atrial fibrillation.**

“While oral anticoagulation is highly effective at reducing stroke risk, elderly patients are often under-anticoagulated,” says Peschin. Healthcare providers tend to prioritize bleeding risk over stroke prophylaxis in older patients. “Providers also harbor misperceptions over falls and bleeding risk — that the older patient will fall and experience a fatal brain bleed — which, in reality, is highly unusual,” says Peschin.

Peschin says bioethicists can play a significant role in debunking common stereotypes that healthcare professionals may have about their older patients. Providing continuing medical education programs is one way of doing this. “These are a good opportunity for bioethicists to capture the attention of physicians,

EXECUTIVE SUMMARY

Clinicians often make inaccurate assumptions about older adults’ goals and cognitive capacity. This can lead to unwanted aggressive care or undertreatment. To ensure ethical care according to experts, providers should:

- Make value-based decisions about interventions.
- Don’t assume older patients are cognitively impaired.
- Order screening tests based on the individual patient’s values, goals, and overall health.

and to test for changes in attitude before and after,” she suggests. Educational programs might cover attitudes about geriatric cardiac patients, the benefits of truth-telling with dementia patients, and positive clinical approaches to older patients. Bioethicists can also publish opinion pieces on these topics. “This can serve to ‘move the needle’ on commonly-held beliefs and practices that need to change,” says Peschin.

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IC requirements may be met, but do subjects comprehend what they sign?

Bioethicists can encourage greater investigator involvement

There is a gap between what is required in the informed consent process for human subjects research, and the reality of how well the information is actually understood by participants. This was the focus of a March 2015 workshop convened by the Institute of Medicine’s Roundtable on Health Literacy. It is possible to make consent documents “massively shorter and easier to understand,” says **Michael Paasche-Orlow**, MD, MA, MPH, a Roundtable participant and associate professor in the Department of Medicine at Boston University School of Medicine. However, that is not enough. “Readability will not be our salvation. In the end, it is a consent process — not a form,” he says.

Leah Eisenberg, JD, assistant professor in the division of medical humanities at the University of Arkansas for Medical Sciences in Little Rock is concerned that too many people sign consent forms without

understanding them. “If we are serious about the importance of informed consent, it is vital that potential research participants are given information about research in a way that is understandable and meaningful to them,” says Eisenberg.

Bioethicists serve a unique role in championing this cause. “Regardless of how we come to read a consent form, it is always our job to bring up ethical concerns,” says Eisenberg. “In addition to addressing such concerns as they arise, we should work to mitigate future problems.” Bioethicists can do this by educating students and researchers, serving on IRBs, and working to develop institutional policies about informed consent.

Bioethicists can encourage investigators to be more involved in the enrollment process. “It’s not that the investigator wants to be an absentee landlord. The investigator is busy,” he says. “But it’s important to show that you care not just about how

many people were enrolled, but also the quality of the process.”

The more that investigators can demonstrate that participants understand the process and are satisfied with it, says Paasche-Orlow, the more solid a footing the whole research enterprise is standing on.

“It is tremendously better protection for you if there does end up being a problem. It gives the institution a much stronger leg to stand on, and the investigators too,” says Paasche-Orlow. “It’s more work up front, but it’s a much stronger position to be in, ethically.”

During the enrollment process, a prospective participant’s comprehension of complex information isn’t typically confirmed. “It should not come as a surprise that some additional work is needed for a potential subject to understand conflicts of interest, risk, randomization and clinical equipoise,” says Paasche-Orlow. “In the end, if

you want to do a good job, it requires evaluation of comprehension.”

Simple yes/no questions won't suffice. Paasche-Orlow promotes a teach-back approach, with the potential subject conveying their current understanding. The research coordinator can say, for instance, “We've been talking about a lot of things. It's my job to communicate properly and make sure you understand this research project. So tell me, please, do you need to be in this study?”

This reveals whether the individual truly understands that his or her participation is voluntary. “If you don't do this, you really don't know if the person understands what they are getting themselves into,” he says. Paasche-Orlow advocates shifting the role of the research coordinator, or whoever is in charge of the enrollment process, from “persuasion to pedagogy.”

“It is a fair assessment to say that what they are doing now is persuasion,” he says. Some researchers worry that confirming subjects' comprehension will slow up the enrollment process. “But if people are enrolling in studies they don't understand, this could lead to lower retention rates or fewer people adhering to the protocols,” he says.

Training of staff involved in the enrollment process is a related consideration. “It's wise to think not only that everyone needs to be certified accordingly, but also about the communication skills that are needed for what is a relatively complicated interaction,” he says.

Paasche-Orlow says that in his own work, he has found that spending significantly more time up front in the consent process improves trust and has no negative effect on enrollment. “We have to go into the process of consent more like an educator and advocate

and supporter of this potential subject, rather than just getting the wheel rolling as quickly as possible,” he says.

Consent forms often contain complex medical language that is not easily understood by research participants. Lack of reading comprehension skills and low health literacy are two contributing factors. “The challenge of simplifying medical language is huge in the world of consent,” says **Kristen Senetar**, MA, a regulatory assistant at Dallas-based UT Southwestern Medical Center's Institutional Review Board (IRB). Bioethicists can do the following, she says:

- Educate medical and research personnel about the importance of using common language that everyone can understand in the consent form;
- conduct site visits where bioethicists sit in on the consent process to help identify areas that might need improvement.
- work with IRBs to create suggested language that can be used in a template consent form.

“By working together, the medical community can create some simpler language for common medical terms that are currently difficult to explain to participants,” says Senetar.

When a participant does not possess information regarding the risks, benefits, and alternatives to a proposed intervention, they are only giving consent, not informed consent, says Eisenberg: “This violates the spirit, if not the letter, of the Common Rule.”

Researchers do not typically

directly withhold information from potential participants; rather, they make it difficult for patients to access by presenting it in complicated, jargon-ridden language. “IRBs are generally predisposed to approve consent forms that follow existing institutional templates, since it is easier to review and regulate such forms,” says Eisenberg.

Many researchers focus on including as much information as possible in the consent form in order to protect themselves from future liability. They may also use a complex consent form if they are part of a multisite study for which a consent was already written.

“In all of these situations, a researcher who takes the time to draft a simple and streamlined consent form will likely run into a slower approval process than one using a more typical consent,” says Eisenberg.

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CME QUESTIONS

1. What do clinicians report regarding end-of-life discussions, according to a recent study?

- A. Factors related to patients and family members are the most important barriers.
- B. Clinician and system factors are the only barriers.
- C. Difficulty accepting a poor prognosis presented no significant barriers.
- D. Discussions were not hindered by disagreements among family members about goals of care.

2. Which is true regarding burnout prevention, according to Jo Shapiro, MD?

- A. Even heavily resourced peer support programs are known to be ineffective.
- B. Hospital leaders do not value peer support programs.
- C. Ethicists are not ideally suited to mediate when disruptive behavior occurs.
- D. Ethicists should approach providers to offer support if a medical error harms a patient.

3. Which is true regarding chronic obstructive pulmonary disease patients, according to recent research?

- A. There is no evidence of unmet palliative care needs.
- B. Many physical and psychological symptoms were untreated prior to palliative care referrals.
- C. Patients are being referred to palliative care too early.
- D. Evidence shows physicians should tie palliative care referrals solely to a patient's prognosis.

4. Which ensures ethical care of older patients, according to Joshua Uy, MD?

- A. Discontinuing cancer screening tests after age 75.
- B. Making value-based decisions about interventions.
- C. Ordering screening tests based solely on age cutoffs in guidelines.
- D. Not ordering oral anticoagulation for patients with atrial fibrillation due to bleeding risk.