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INSIDE

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Study: Biggest Barrier to Advance Care Planning Is Time

It's unclear which physician is responsible

Lack of time was the main barrier to advance care planning discussions cited by physicians, found a recent study.[1]

"Recognizing a gap between what Americans claim they want in terms of advance care planning and the realities, oncologists at NorthShore University HealthSystem initiated a program designed to foster earlier discussions and planning," says **Alan Zunamon**, MD, FACC, FACP, MMI, one of the study's authors. This led to a similar initiative in the cardiology division.

"Unfortunately, we were not as successful, and wondered whether we could understand the barriers better," says Zunamon, a senior attending physician in the health system's division of cardiology.

Researchers surveyed a total of 117 cardiologists, oncologists, primary care physicians, and cardiology and oncology support staff. "The most surprising finding was that there was such variation among the doctors about who was responsible for the advance care directives, depending on the condition," says **Bernard Ewigman**, MD, MSPH, FAAFP, also one of the study's authors. Ewigman is professor and chair in the department of family medicine at the University of Chicago.

> "THE MOST SURPRISING FINDING WAS THAT THERE WAS SUCH VARIATION AMONG THE DOCTORS ABOUT WHO WAS RESPONSIBLE FOR THE ADVANCE CARE DIRECTIVES."

Only 15% of cardiologists felt it was their responsibility to conduct advance care planning discussions

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with their congestive heart failure (CHF) patients. In contrast, 68% of oncologists accepted this discussion as their responsibility in patients with terminal cancer.

While 68% of PCPs felt personally responsible for advance care planning discussions with CHF patients, only 34% felt the same about patients with cancer.

"This may reflect fragmentation of patient care among primary and specialty doctors," says Ewigman. The study's findings suggest that it is not clear which physician is responsible. "As physicians, we have an ethical obligation to know our patients' desires and values regarding end-of-life care," says Ewigman.

There was alignment between primary care and oncology, that, for patients with serious and life-threatening cancers, the oncologist should be the leader in initiating end-of-life discussions.

"On the other hand, even for patients who had congestive heart failure with poor prognoses, primary care physicians and cardiologists seemed to think that the primary care physicians should be the leaders," says Zunamon.

The study's findings underscore just how difficult initiating and implementing advance care planning truly is. "We cannot assume that the specialist, who may understand the prognosis and options better than the primary care physician, is necessarily the most effective individual to initiate and lead such discussions," says Zunamon.

Broken Incentive System

Tim Lahey, MD, MMSc, chair of the clinical ethics committee at Dartmouth-Hitchcock Medical Center in Lebanon, NH, says that clinician failure to engage in advance care planning is "perhaps the most prominent symptom of the disease of misallocation of healthcare resources. Exhorting overextended clinicians to do the right thing misses the point entirely."

Instead, argues Lahey, there is a need to fix a system that incentivizes costly treatments such as chemotherapy or surgery at the expense of conversations with patients.

Medicare now reimburses physicians for advance care planning through a recently established billing code which pays doctors for their time. The code is, unfortunately, rarely used, says **Dana Lustbader**, MD, FAAHPM, chair of the department of palliative medicine at ProHEALTH in Lake Success, NY:

EXECUTIVE SUMMARY

Lack of time and skill are two barriers to advance care planning cited by physicians, according to recent research. There also is a lack of clarity as to who is responsible for these difficult discussions. Some ethical implications include the following:

- Time-pressed providers can offer resources to help patients choose surrogates.
- Most physicians never received training in serious illness communication.
- Poor-quality conversations can result in the provision of unwanted and non-beneficial treatment.

"Perhaps, this is because providers avoid these difficult conversations."

Incentives for advance care planning still are substantially lower than other, more costly therapies. "It should not surprise us, therefore, that millions of patients continue to get care they don't want at the end of life," Lahey says.

Clinicians view the major obstacle to advance care planning to be that they are overbooked. "In a superficial sense, that's true," says Lahey. "But, looking more deeply, the reason clinicians are too overbooked to know what their patients prefer from their care is that clinicians are incentivized to do different kinds of care, and they are busy in doing it."

Lahey says that until healthcare "weans itself off the addiction of fee-for-service care that incentivizes procedures over thinking, and biomedical interventions over listening, we will never fix this problem."

No Training Is Barrier

Most physicians never received training in serious illness communication. "When I was a critical care fellow, we had to perform dozens of procedures, like placing a large intravenous catheter into a large vein in the neck, with supervision and feedback before we were deemed proficient in the task," Lustbader notes.

Having a serious illness conversation with patients and their loved ones also requires training. "Good conversations between provider and patient do not happen by chance," says Lustbader. The provider needs to ask the patient open-ended questions, such as, "What are you worried about most right now?" or "As your disease progresses, what is most important to you?"

Serious illness conversations about treatment preferences need to occur over time as the condition progresses, so the patient and provider can together come up with a treatment plan that aligns with the patient's goals. Most people with serious illness prefer to spend as much time at home as possible with friends and family members, and avoid burdensome ED visits or hospital admissions.

Despite this, half of all patients go to the ED in their final month of life, says Lustbader, mainly because important conversations about end-of-life preferences did not occur.

"Most of the time, physicians have very poor conversations, resulting often in the provision of treatment that patients don't want or value," says Lustbader. "Although these conversations take time, the greatest barrier is skill." ■

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Conversations on Ethics of Difficult Cases Often Help Clinical Team

Something less formal than ethics consults is helpful

Ethicists sometimes provide debriefings after difficult cases, but not much is known about how helpful these sessions are to clinicians.

Healthcare professionals at a publicly funded children's hospital in Sweden participated in ethics case reflection sessions on the care of children with cancer. Clinicians reported that the sessions were valuable, mainly because they permitted the discussion of values.[1]

"The most important finding in this study was that healthcare professionals' main concern is about

striving for common care goals, and creating a shared view of care," says **Cecilia Bartholdson**, PhD, RN, the study's lead author and a pediatric nurse specialist at Karolinska Institutet Childhood Cancer Health Care Research in Stockholm, Sweden.

It would have been understandable if providers saw the sessions mainly as an opportunity to air conflicting views about care. This wasn't the case. "It was not about participants positioning themselves," Bartholdson explains. "It was about clarifying professional perspectives."

The study's findings suggest that when healthcare professionals have the opportunity to reflect on ethical issues involved in the child's care, the group is strengthened.

"The model for ethical analysis used during the sessions is preferably guided by a trained facilitator," Bartholdson notes. An ethicist is an ideal person for this job, she suggests: "The ethicist could guide the sessions when healthcare professionals don't know the right thing to do in ongoing ethical dilemmas."

Clinicians often struggle with whether they did the right thing, particularly in cases where there is a poor prognosis and the patient is suffering. However, not all of these clinicians call an ethics consult.

"Creating a forum where it doesn't have to go to the highest threshold to have a conversation about those cases is really important," says **Timothy E. Quill**, MD, FACP, FAAHPM, Georgia and Thomas Gosnell Distinguished Professor of Palliative Care at the University of Rochester (NY) School of Medicine.

The threshold to call a formal ethical consult varies widely depending on the institution. Some have only a handful of consults a year.

> "CREATING A FORUM WHERE IT DOESN'T HAVE TO GO TO THE HIGHEST THRESHOLD TO HAVE A CONVERSATION ABOUT THOSE CASES IS REALLY IMPORTANT."

If the number of consults is very small, says Quill, "that means the threshold for doing it is really a case where the wheels have fallen off, and there is a horrible outcome." Often, clinicians worry the ethicist will judge them for doing something wrong, or criticize them in some way. They may fear their relationships with others in the clinical team will be damaged.

Given all the tension surrounding calling a formal ethics consult, Quill recommends "bringing it down another notch." This gives clinicians an easier way to talk about ethical issues and concerns.

At the University of Rochester, ethicists hold a monthly case conference on several floors. The sole purpose is to discuss ethical issues or concerns in recent cases. "This allows people to talk about uncertainties in these really difficult cases," says Quill. "It is particularly helpful in places like ICUs that are highly likely to have these kinds of issues."

Ethicists begin by asking, "Did you have any cases with ethical dimensions, or just cases you felt uncomfortable with, for whatever reason?"

"I will tell you that many of the cases we hear about are strikingly complicated," says Quill.

Often, good care was provided with a bad outcome, and clinicians are left wondering if they did the right thing. "There are tons of cases to discuss — there is no shortage," says Quill. "On occasion, you run into a case where there are some real deep ethical issues."

Open Communication

Having regular conferences opened communication between ethicists and clinicians. "It established that the ethicist understands the clinical situations that regularly go on," adds Quill.

Clinicians are then more likely to request a consult in the future, if appropriate. Quill makes a point of letting clinicians know there is a middle ground, too. "Having established trust, the ethicist can

EXECUTIVE SUMMARY

Clinicians found debriefing sessions after difficult cases helpful because they permitted the discussion of values, found a recent study. Informal conversations are effective if clinicians need the following:

- coaching to address a conflict within the team;
- information on the legal implications of administering sedatives to a dying patient;
- help understanding their role in a difficult case.

then explicitly say, 'There are teaching conferences, there are full consults, but there's also the gray ones in the middle — something is wrong here, but it feels scary to get into,'" says Quill. If the clinician is not sure what to do, a conversation with the ethicist can help sort through the options.

A formal ethics consult might still be needed. This is often the case if the problem involves a conflict between caregivers. Quill can still coach clinicians privately about their concerns, and provide strategies to address the issue with their colleagues.

"There may be somebody else on the team that they can go to," says Quill. "Or, it might be trying to approach the problem a different way, or seeing if they can have a direct conversation with somebody."

Discomfort Over Role

Clinicians may be uncomfortable about some aspect of their role in a patient's care, but aren't comfortable saying so. A private conversation with the ethicist can be very helpful. "In talking it through, we can help them understand the ethical principles that underlie the situation," says Quill.

In one case, a clinician gave the last dose of sedative before a patient's death. The clinician stated, "I felt like I killed the patient." The ethicist can begin by informing the clinician that it's normal to feel this way, but that doesn't mean the care provided was unethical.

"Clinicians also worry about getting into trouble legally, and whether they need to keep their role a secret," says Quill. Some worry that by speaking with an ethicist, they'll get their colleagues into legal trouble.

"These are serious things to worry about," says Quill. The ethicist can provide information on both ethics and the law. Some of the cases turn out to be ideal for a teaching conference. If one clinician felt uncomfortable with a case, others may have felt similarly.

"Sometimes, these informal meetings are on the threshold of bigger issues," says Quill.

It may be that a clinician really did give too much medication, for instance. "Then the ethicist has to figure out what kind of advice they could give that's private, or if it goes over a threshold where they need to do something else," says Quill.

CLINICIANS MAY BE UNCOMFORTABLE ABOUT SOME ASPECT OF THEIR ROLE IN A PATIENT'S CARE, BUT AREN'T COMFORTABLE SAYING SO. A PRIVATE CONVERSATION WITH THE ETHICIST CAN BE VERY HELPFUL.

For instance, if a resident in an ICU administers a rapidly accelerating dose of opioids until the patient's death, and is not following the proper procedure, the bedside person delivering the dose might be uncomfortable with his or her role. Not surprisingly, clinicians aren't always comfortable speaking up.

In this situation, a policy is needed, says Quill, "because the current practice is not the right thing to do, and is going to get people in real trouble, both ethically and legally."

A clinician who reports an issue like this can still keep his or her involvement confidential. "There's a lot of people involved in these cases, not just a few. You can do it without naming names," says Quill. The ethicist can explain to the entire department, "It's come to our attention that there is no set way of doing this, and that sometimes people are being really aggressive. We really need to develop a policy. Here's one case we are aware of, and I bet there are other cases like this."

It may be that a policy already exists, and someone is not following it. "Either they don't know about the policy, or they are aware of the policy and they are not adhering to it for some reason," says Quill.

It may be that additional steps need to be taken, beyond the scope of ethics. "But one way or the other, these things need to get surfaced," says Quill. "If they don't, they fester, and lead to bad care happening." ■

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Advance Care Planning for Patients With Hematologic Malignancies

Team must balance goals with limitations

Patients who have hematologic cancers have often had at least one, if not more, stays in the ICU. "This means that they and their family members have a history of experiencing ups and downs and successful treatment so that they can leave the ICU," says **Colleen M. Gallagher**, PhD, FACHE, chief and executive director of the section of integrated ethics in cancer care at The University of Texas MD Anderson Cancer Center in Houston.

Because of this, patients and families often have a hard time understanding that this time is different. "These patients sometimes are experiencing new cancers after the previous ones were successfully treated, giving them years of survival," notes Gallagher.

A recent letter to the editor in the journal *Bone Marrow Transplantation* focused on the unique challenges of end-of-life care in patients with hematologic malignancies.[1] Misconceptions among both patients and clinicians about the role of palliative care and its relationship to "aggressive treatment" contribute to high rates of aggressive interventions at the end of life, and a high proportion of in-hospital deaths, the authors wrote. The following factors hamper prognosis and management, the authors concluded:

- the absence of clear transition points between curative and palliative phases of care;
- the severity of treatment-related complications;
- the potential, in many cases, for significantly life-prolonging transfusion support.

"Advance care planning helps in these situations because the patient, the people who love them, and the healthcare team have a common understanding of the goals and the ways in which these can be balanced with medical possibilities and limitations," says Gallagher.

"An ethicist can assist at various stages in a patient's cancer journey," says Gallagher. "We can assist patients in exploring their own expectations and needs." This is particularly important when the decisions get harder.

When patients are approaching the end of life, the ethicist can help frame questions in ways that may not have been thought about previously.

"Ethicists deal with value-laden decisions," says Gallagher. Often, these go beyond the patient's decisions about medical care. Decision-making also can involve the patient's planning for what happens for those who live on.

"We can assist the patient, and often the family together, to look at legacy and responsibility — both of which are important to patients," says Gallagher. ■

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Study: Trial Results for New Neurological Drugs Often Go Unpublished

Results of clinical trials for "stalled" neurological drugs — those which had at least one completed Phase III trial but failed to receive FDA approval — are heavily underreported, found a new study.[1]

"There are several ethical concerns," says **Jonathan Kimmelman**, PhD, one of the study's authors and an associate professor in the Biomedical Ethics Unit at Montreal-based McGill University.

"Nonpublication fails to redeem the sacrifice that patients make when they enroll in clinical trials to advance medical science," says Kimmelman. The study found that 14,092 and 33,882 volunteers participated

in unpublished trials of licensed and stalled neurological drugs, respectively.

Many patients in neurological trials have advanced disease, and may have diminished mental capacity. "This makes it all the more important to show proper regard for their contributions to science by disseminating the results of such trials," says Kimmelman.

Nonpublication of trials for drugs that never get licensed is "doubly troubling," adds Kimmelman. This is because patients in such trials have been exposed to a drug that is later deemed either unsafe or ineffective.

Nonpublication deprives patients and healthcare systems of safety and efficacy evidence. "It also forgoes an opportunity to update our theories of disease processes, since every time we run a trial we learn indirectly about how those processes work," says Kimmelman.

Results data were not publicly available in any form for 10% (16 of 163) and 46% (94 of 203) of trials of licensed and stalled drugs, respectively.

"All this is especially concerning in neurology for several reasons," says Kimmelman. The failure to report this information slows the process of medical research in neurology — an area characterized by very pressing needs with few effective treatments, notes Kimmelman.

Since the failure rate in neurology drug development is among the highest in any disease area, says Kimmelman, "we ought to be capturing and utilizing every bit of evidence we can."

Some evidence suggests that high failure rates are causing companies to diminish their investments in neurological drug development. "This portends an evidence-spare future for neurological drug development," says Kimmelman. "It further highlights the importance of circulating what evidence we do gather." ■

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'Robust' Error Disclosure Systems Needed for Pediatric Patients

Educate others on need for ethical responses

Ethical obligations to disclose medical errors in the pediatric setting are very similar to those involving competent adults, says **Robert D. Truog**, MD, Frances Glessner Lee professor of medical ethics, anaesthesia, and pediatrics and director of the Center for Bioethics at Harvard Medical School in Boston.

"Close attention should be paid to the unique needs of children at different stages of development," says Truog.

Pediatric settings frequently have access to child life specialists, pediatric social workers, psychologists, and psychiatrists. These experts can provide guidance on how to frame information about a medical error in ways appropriate to the developmental, emotional, cognitive, and spiritual needs of each child.

"I see the role of ethicists as primarily one of making sure that these sources of expertise are explored and utilized," says Truog. "Failure to handle this well could result in lasting harm to the child."

Robust Systems Needed

Philip M. Rosoff, MD, MA, professor of pediatrics and medicine at Duke University's Trent Center for Bioethics, Humanities & History of Medicine in Durham, NC, says ethical obligations are similar for error disclosure in children and adults who have lost decision-making capacity and have surrogate decision-makers.

"The error would then involve another layer of complexity," Rosoff explains. This is because the interventions associated with the error would have necessarily been approved during the informed consent process by the surrogate or parent.

Errors involving people who have capacity primarily affect them and, secondarily, affect their loved ones, notes Rosoff. In contrast, errors with children and adults without capacity "also seem to integrally include the

authorized decision-maker as an 'accessory,' if you will," says Rosoff. "They would be the people legally and morally acting in the patient's stead."

Rosoff says institutions should have robust systems for disclosure, regardless of the age of the patient involved.

"Of course, due to the special cultural sensitivity involved with children — especially if the error produced an injury — institutions should be sensitive to the needs of the pediatric population and their parents," says Rosoff.

Many, but not all, hospitals have error disclosure policies in place. "If some administrators are not already attuned to the modern understanding of what should happen after an error is discovered, there is now a large literature on this issue," says Rosoff. The process includes the following:

- Full disclosure without hiding anything for the fear of legal liability. "It has been demonstrated that honest disclosure lessens liability," says Rosoff.
- An admission of responsibility;
- an apology;
- a promise to try and understand what happened (and why);
- follow-up.

"Ethicists can play a major role if the powers that be need to be educated in both the instrumental and moral benefits of this approach," says Rosoff. ■

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Early Integrated Palliative Care Improved Cancer Patients' Quality of Life

Study suggests that needs vary depending on cancer type

Early integrated palliative care improved quality of life for patients with newly diagnosed incurable cancers, found a recent study.[1]

Researchers randomly assigned patients with newly diagnosed incurable lung or noncolorectal GI cancer to receive either early integrated palliative care and oncology care, or usual care. Patients assigned to the intervention met with a palliative care clinician at least once a month until death; those who received usual care consulted with a palliative care clinician upon request. Some key findings include the following:

- Intervention patients with lung cancer reported improvements in quality of life and depression at 12 and 24 weeks, whereas usual care patients with lung cancer reported deterioration.
- Patients with GI cancers in both study groups reported improvements in quality of life and mood by week 12.
- Intervention patients versus usual care patients were more likely to discuss their wishes with their oncologists if they were dying.

"We were surprised that the effect of the early palliative care was different in patients with lung and GI cancer," says **Jennifer S. Temel**, MD, the study's lead author. Temel is clinical director of thoracic oncology at Massachusetts General Hospital in Boston.

This suggests that patients with different cancers may have different support care needs. For example, patients with GI cancer are more likely to be admitted to the hospital. This group of patients may need more intensive palliative care services during hospitalizations.

"Palliative care is an essential component of cancer care for patients with advanced cancer," says Temel. An important aspect of palliative care is the focus on communicating with patients about their prognoses and end-of-life care preferences.

"In this study, patients who were assigned to early palliative care were twice as likely to report that they discussed their end-of-life care preferences as those receiving oncology care alone," says Temel.

Now Standard of Care

Palliative care is "now standard of care," and the regulatory expectation is that it be available in all healthcare systems, says **David A. Fleming**, MD, MA, MACP, co-director and

scholar at the MU Center for Health Ethics in Columbia, MO.

"Well applied, it does improve quality of life for patients suffering from cancer and other forms of terminal illnesses," says Fleming. Similarly, hospice care has been demonstrated to improve both longevity and quality of life in dying patients.

"This is due to the knowledge and skills of specialists, plus the detailed attention and support both patients and caregivers receive by those trained in end-of-life care," says Fleming.

One barrier to implementing such specialized care early, when it can be most effective, is that patients, families, and even healthcare teams are in denial that treatment may be futile and death imminent. "This is coupled with pernicious hope that cure, or at least delay, of the disease may yet be possible, regardless of clinical facts and prognosis," says Fleming.

Care teams, especially in oncology, may hesitate to offer palliative care, fearing that dampening hope may cause depression in patients and negatively influence response to treatment.

"Unnecessary suffering may ensue because the optimal full complement of care and treatment — including palliative and hospice care — are often withheld from patients who might otherwise gain benefit," says Fleming. ■

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'Predatory' Online Journals Charge Publication Fees — Minus Peer Review

Deceptive practices 'dilute the professional integrity of the field'

Is your email box full of dubious-sounding offers to publish articles with very quick turnaround time — but only for a fee? Increasing numbers of "predatory" online medical journals solicit manuscripts and charge publication fees without providing peer review.

"Predatory journals entice prospective authors by implying their work will be disseminated in a legitimate venue, but fail to provide any peer review or sound editorial oversight," says **James Giordano**, PhD, chief of the neuroethics studies program at Pellegrino Center for Clinical Bioethics at Georgetown University Medical Center in Washington, DC.

A recent paper identified 13 evidence-based characteristics to distinguish predatory journals from legitimate ones.[1] Ninety-three predatory journals, 99 open access, and 100 subscription-based journals were analyzed. Some findings include the following:

- Many more predatory journals' homepages contained spelling errors and distorted or potentially unauthorized images, compared to open access journals and subscription-based journals.
- Thirty-one predatory journals promoted a bogus impact metric (the Index Copernicus Value) compared to three open access journals and no subscription-based journals.
- Nearly three-quarters of predatory journals listed editors or editorial board members whose affiliation with the journal was unverified. This was the case for only two open access journals and one subscription-based journal.

"One of the primary ethical concerns is that such journals essentially engage in a 'pay-to-publish' solicitation scheme," says Giordano.

Many legitimate open access journals incur publication charges in order to defer production costs. However, such journals are well-indexed, and ascribe to the standards and guidelines of the Council on Publication Ethics or other steering bodies. "Such credentialing reflects the extent and quality of the editorial and review process," explains Giordano.

Even if researchers are sufficiently skeptical of predatory journals, readers might be deceived. "Some

believe the editorial and review processes to be on par with the current standards and guidelines for scholarly publication," says Giordano. Many of the journals have names that are almost identical to legitimate, trusted publications. "Predatory journals are essentially being deceptive, and may dilute the professional integrity of the field," says Giordano.

Due Diligence Needed

Eileen F. Baker, MD, FACEP, medical director of the ethics curriculum at University of Toledo College of Medicine and Life Sciences in Ohio, says the "publish or perish" mentality is a contributing factor to the success of predatory online journals.

Thousands of medical journals exist, each competing for the time and attention of clinicians. "The age of electronic journals, electronic publishing, blogging, and 'fake news' now confuse the issue of what constitutes a legitimate journal," says Baker.

Peer review is an important component of legitimacy, says Baker — but even premier medical journals are subject to scrutiny.

"From accepting advertising to publishing manufacturer-sponsored studies, the ethics of what counts as 'predatory' becomes rather murky," says Baker.

Before online journals existed, the dubious practice of "ghost writing" had long been an ethical concern, she says. Physicians are approached by pharmaceutical manufacturers or other companies to attach their names to an already-written article that endorses the company's product.

"The impulse to build one's resumé in this manner should be resisted," says Baker. "Yet, authors still succumb to other temptations." These include data manipulation or outright fraud.

"Solicitations from predatory online medical journals add to the mix of ethical quandaries," says Baker. It may be difficult to ascertain if a journal is a "real," peer-reviewed publication or a sponsored publication.

Giordano suggests searching the journal online, noting whether it is indexed and which indexing sources list the journal. "Engage in some due diligence about the purported editorial board," he says.

Simply Googling "predatory journals" and specifying the discipline can provide listings of those journals that have been identified as predatory, adds Giordano.

The bottom line, says Baker, is that potential authors should be very wary when solicited by an online entity. "Being asked to submit material to a journal of which you have never heard, especially in a field in which you do not specialize, is cause for pause," she says. ■

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1. Shamseer L, Moher D, Maduekwe O, et al. Potential predatory and legitimate biomedical journals: can you tell the difference? A cross-sectional comparison. *BMC Medicine* 2017; 15(28): DOI: 10.1186/s12916-017-0785-9.

SOURCES

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Does Cancer Patient Want Fertility Preserved? Ethical Issues Arise

Oncofertility, a fairly new but growing field, addresses the special reproductive needs of cancer patients — but guidelines for how to deal with ethical dilemmas have not yet been established.

"Clinicians are left to deal with these issues without much guidance," says **Ann Partridge**, MD, MPH, professor of medicine and founder and director of the Program for Young Women with Breast Cancer at Harvard Medical School in Boston.

Partridge and colleagues authored a recent paper presenting the following three cases in which the patient wished to pursue reproductive assistance, but her decision was met with hesitance by her care team:[1]

• a patient who desired fertility treatments despite the danger in the context of her medical state;

• a patient who wished to have a child as a means of coping with her

illness despite the risk to her and the fetus;

• a patient who had to weigh her cancer risk and treatments against the possibility of delivering a baby.

"Ideally, decisions are discussed as a multidisciplinary care team with the patient at the center," says Partridge. "More tools for teams to rely on will help all parties approach the decisions with more knowledge and support."

A central ethical challenge is how to recognize the personal significance of childbearing and patient autonomy, while still protecting and addressing the safety of the patient. "Clinicians have a duty to do no harm, which sometimes may be in conflict with patient wishes," says Partridge.

There are many ethical considerations involved with preserving cancer patients' fertility, says **Lisa Campo-Engelstein**, PhD, associate professor at the Alden March Bioethics Institute and Department of OB/GYN at Albany (NY) Medical College. The following are some scenarios that may require ethical deliberation:

• Patients may be unable to afford the cost of fertility preservation.

While cancer treatment is routinely covered by insurance companies, fertility preservation for cancer patients frequently is not included.

"Patients and their doctors are sometimes able to work together to ensure insurance coverage for fertility preservation, as otherwise this would be an expensive out-of-pocket cost for patients," notes Campo-Engelstein.

• The fertility preservation treatment being offered may be established or experimental.

"There may be certain circumstances, such as age or lack of time, that exclude the possibility of pursuing established fertility preservation treatments," says Campo-Engelstein.

If patients' only options are experimental methods, they need to be made aware of this fact, as well as all the potential risks and benefits associated with experimental treatments, she explains. This ensures proper informed consent.

• The patient may be a minor.

"As with all procedures involving minors, various ethical issues arise, such as whether the patient is able to provide consent or assent," says Campo-Engelstein.

Established fertility preservation treatments aren't always possible, depending on the patient's physical maturity. "Instead, they may have to rely upon experimental fertility preservation treatments," says Campo-Engelstein.

• Healthcare professionals aren't always comfortable offering the patient fertility preservation, based on the patient's diagnosis and prognosis.

A patient may have an extremely poor prognosis, or fertility preservation may be contraindicated given the type of cancer she has.

Despite this, fertility preservation may be very important to the patient, says Campo-Engelstein: "She may want to pursue it despite her prognosis and the risk it may pose to herself." ■

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1. Walsh SK, Ginsburg ES, Lehmann LS, et al. Oncofertility: Fertile ground for conflict between patient autonomy and medical values. *Oncologist* 2017 Apr 13. pii: theoncologist.2016-0373. doi: 10.1634/theoncologist.2016-0373. [Epub ahead of print]

SOURCES

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CME/CE 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.

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CME/CE QUESTIONS

1. **Which is the main barrier to advance care planning discussions cited by physicians, according to a recent study?**

   a. Patients' resistance
   b. Lack of time
   c. Lack of training
   d. Lack of adequate reimbursement

2. **Which did a recent study find regarding who was responsible for advance care planning discussions?**

   a. Physicians agreed it was the specialists' responsibility.
   b. Most oncologists accepted it was their responsibility in patients with terminal cancer.
   c. Primary care physicians believed they should be the leader in initiating discussions for patients with any terminal illness.
   d. Most physicians agreed this role should fall on oncology support staff due to time constraints of oncologists.

3. **Which is recommended to promote ethical discussions, according to Timothy E. Quill, MD, FACP, FAAHPM?**

   a. Teaching conferences can replace formal ethics consults at institutions where resources are scarce.
   b. Ethicists should not agree to discuss complex cases outside of a formal ethics consult because of privacy concerns.
   c. Teaching conferences and informal face-to-face conversations both are good approaches to air ethical issues.
   d. Formal ethics consults are necessary whenever a clinician reports moral distress over sedation, due to legal implications.

4. **Which is true regarding preserving a cancer patient's fertility, according to Lisa Campo-Engelstein, PhD?**

   a. Financial costs pose no little barrier, except for uninsured patients, because health insurers are required to cover these treatments.
   b. It is unethical to deny patients fertility preservation treatments regardless of the patient's prognosis.
   c. The use of experimental treatments is unethical in minors.
   d. Providers should realize this may still be important to patients despite an unpromising prognosis.