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INSIDE

Aggressive end-of-life care persists in cancer patients

Almost 40% of patients didn't discuss preferences

Despite a 40% increase in the number of patients with cancer who designated a durable power of attorney, there was no decrease in the rates of aggressive medical care received in the last weeks of life, according to a recent study.[1]

"The study findings were very surprising to us," says **Amol Narang**, MD, the study's lead author and a radiation oncologist at Johns Hopkins School of Medicine in Baltimore.

Researchers used survey data from the University of Michigan's Health and Retirement Study, which surveys a representative sample of approximately 20,000 Americans over the age of 50 every two years. The researchers analyzed responses from the next of kin of 1,985 participants with cancer who died between 2000 and 2012, about whether patients had signed durable power of attorney documents or living wills or participated in conversations

EXECUTIVE SUMMARY

There was a 40% increase in the number of cancer patients designating a durable power of attorney over a 12-year period, but this didn't impact the rates of aggressive medical care received in the last weeks of life, according to a recent study.

- Nearly 40% of family members said that patients did not discuss end-of-life preferences with them.
- Granting power of attorney decreased the odds of terminally ill patients dying in the hospital as opposed to hospice or their home.
- There was no increase in patients who created a living will or communicated end-of-life care preferences.

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MANAGING EDITOR: Jill Drachenberg (jill.drachenberg@ahcmedia.com)
ASSOCIATE MANAGING EDITOR: Dana Spector
DIRECTOR OF CONTINUING EDUCATION AND EDITORIAL: Lee Landenberger.

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about their end-of life-preferences. The researchers then examined the association between these advance care planning activities and the medical care the cancer patients received at the end of life.

"The oncology community has long recognized that the type of care that cancer patients receive before dying is often overly aggressive and inconsistent with patients' preferences," explains Narang.

Advance directives have been endorsed as an important part of care by all major cancer-related professional societies. "As such, we figured that the prevalence of advance directives amongst patients dying of cancer would have increased over the study period," says Narang. Instead, the researchers found that important forms of advance care planning, such as creating a living will or communicating one's preferences for end-of-life care to loved ones, had not increased. Other key findings include the following:

• Nearly 40% of family members said patients did not discuss end-of-life preferences with them.

"Most of these patients likely recognized that they had a terminal condition much before death, and so 40% is too high," says Narang.

• Granting power of attorney decreased the odds of terminally ill patients dying in the hospital as opposed to hospice or their home, but was not associated with treatment limitations.

This suggests that assigning a durable power of attorney is likely not an effective form of advance care planning, if patients haven't communicated their preferences for end-of-life care to that individual.

"While this can be a difficult conversation, it is one that has to happen," says Narang. "It's much better for this conversation to take place in a controlled environment than in an urgent, hospital-based setting."

• There was no difference in use of aggressive end-of-life care for cancer patients who did not have a durable power of attorney, and those whose durable power of attorney lacked written or oral information about their loved one's preferences.

This finding highlights the importance of engaging patients and their families in advance care planning in ways that are more substantive than merely appointing a durable power of attorney, says **Lauren Hersch Nicholas**, PhD, one of the study's authors and assistant professor of health policy and management at Johns Hopkins Bloomberg School of Public Health.

"Hospital bioethicists can play an important role in catalyzing meetings with patients and their families early in the treatment process, so that family members are prepared when treatment decisions need to be made," says Nicholas.

Clear recommendations needed

One often-overlooked factor is the reluctance of providers to make clear recommendations about what types of treatments are reasonable and appropriate under the circumstances, according to **Robert D. Truog**, MD, Frances Glessner Lee professor of medical ethics, anaesthesiology, and pediatrics and director of the Center for Bioethics at Harvard Medical School in Boston.

"Too often, clinicians assume that, if the patient does not have an advance directive, they are obligated to pursue life-sustaining treatments at all cost," says Truog. "This is not true."

Rather, he says, in the absence of a clear directive from the patient, clinicians and the family should work together to decide what is best for the patient. "Caregivers have an ethical obligation to tell the family what they think would be most reasonable and appropriate given the patient's condition and prognosis, as well as known values and preferences," adds Truog.

One reason why patients receive curative treatments in the final stages of illness is that both physicians and patients avoid discussions about palliative care options. "It feels contrary to treatment plans," explains **John Carney**, MEd, president and CEO of the Center for Practical Bioethics in Kansas City, MO. "No one has told the patient that the curative treatment efforts have failed them, rather than the patient 'failing' the treatment."

Patients will likely take into account disease burden, other life-limiting conditions and illnesses, and the perceived effectiveness of past and current treatment. "Patients want their providers asking about their well-being, not just physical health status," says Carney. "The more reluctant physicians are in addressing the non-physical aspects of care, the more complicated the dance steps become."

Carney says bioethicists and palliative care professionals need to impress upon patients, families, caregivers, and providers the importance of goals of care discussions. Such discussions "can be great tools for exploring the impact of current treatment regimens on day-to-day quality of life, independence, and functional status," he explains.

Carney recommends providers explore areas of life that are most meaningful to patients, instead of focusing solely on the patient's physical experience of the illness. "This can go a long way in reframing goals of care," he says.

Encouraging patients to explore all options is part of the provider's commitment to promote autonomy and ensure informed consent, says Carney. "Battlefield metaphors fail miserably when our only frame of reference in altering the treatment plan is viewed as 'surrender' and 'defeat,'" he says. He suggests providers instead use terms such as "next phase of the journey."

"This allows the patient to devote energy on 'life-completion' tasks facilitated by palliative care, rather than solely on the work of recovery burdened by unwanted or ineffective treatment," says Carney.

Each patient, spiritually and culturally, will have a different approach to end-of-life decision-making, says **Robert Wergin**, MD, president of the Leawood, KS-based American Academy of Family Physicians. "Our job as physicians, particularly family physicians, is to keep patients as functional as possible and minimize symptoms as much as possible," he says. Part of the physician's role, as early as possible in the stage of illness, is to ask patients what they want to do if they reach a point where they can't make decisions regarding their care. "Sometimes the advance planning process falls on me," Wergin says.

Wergin often sees advance planning documents that are not specific enough in terms of what providers need to do clinically as disease progresses, however. "It may say 'no heroic life-sustaining treatments,' but what does that mean? Does the patient want not to be put on a ventilator, no feeding tubes, no IV, no antibiotics?" he asks. Wergin recommends that his patients living with advanced illness complete Physician Orders for Life-Sustaining Treatment (POLST) forms, relying on the strong bonds he's established as a family physician in rural Nebraska. "Having a continuous relationship with the patient, and often their family members, gives us an 'in' to begin these discussions," he says.

REFERENCE

1. Narang AK, Wright AA, Nicholas LH. Trends in advance care planning in patients with cancer: Results from a national longitudinal survey. *JAMA Oncol* 2015; 1(5):601-608.

SOURCES

- John Carney, President/CEO, Center for Practical Bioethics, Kansas City, MO. Phone: (816) 221-1100. Fax: (816) 221-2002. Email: JCarney@practicalbioethics.org.
- Amol Narang, MD, Fellow, Radiation Oncology and Molecular Radiation Sciences, School of Medicine, Johns Hopkins University, Baltimore. Phone: (410) 955-7390. Email: anarang2@jhmi.edu.
- Lauren Hersch Nicholas, PhD, Assistant Professor, Health Policy & Management, Johns Hopkins School of Public Health, Baltimore. Phone: (443) 287-5680. Email: lauren.nicholas@jhu.edu.
- Robert D. Truog, MD, Professor of Medical Ethics, Anaesthesiology & Pediatrics, Harvard Medical School, Boston, MA. Email: Robert_Truog@hms.harvard.edu. ■

Placebo effect eases pain — even if participants are aware

Effects are "independent of reported expectations for pain relief"

In some cases, the placebo effect still works even if research participants know the treatment they are receiving to ease pain has no medical value whatsoever, according to a recent study.[1]

Researchers applied a heating element to research subjects' forearms to induce pain sensations, though not enough to burn the skin. They then applied what the subject thought was an analgesic gel and turned down the temperature.

The participants were divided into two groups — those who received four "conditioning" sessions or only one session. After the researchers revealed the treatment was fake, only the group who received four sessions continued to get pain relief from the placebo.

"These findings suggest that reinforcing treatment cues with positive outcomes can create placebo effects that are independent of reported expectations for pain relief," says the study's lead author, University of Colorado Boulder graduate student **Scott Schafer**.

The effectiveness of a placebo in providing pain relief is often related to a subject's expectations for pain relief. "While conditioning procedures that pair a placebo with pain relief enhance the subsequent placebo response, they also strengthen expectations for pain relief," notes Schafer.

Conditioning effects on pain are largely thought to be linked to changes in expectations. "By that theory, removing expectations should have eliminated the placebo response," says Schafer. "So, in that sense, these results were quite surprising."

Ben A. Rich, JD, PhD, emeritus professor of medicine (Bioethics) at University of California, Davis School of Medicine, participated in the development of ethical guidelines addressing the use of placebos in pain medicine.

The deceptive use of placebos and the misinterpretation of the placebo response to discredit the patient's pain report are unethical and should be avoided, according to the American Pain Society's 2005 position statement.[2] In its 2007 Ethics Charter, the American Academy of Pain Medicine states that placebo use for the treatment of pain in other than research settings is usually considered unjustifiable, both for ethical and clinical reasons.[3]

In light of these two guidelines, says Rich, "the burden of persuasion that the benefits of the deceptive use of placebos outweigh the risks falls on those who would keep patients or research subjects uninformed — either for their own good, or in the cause of the advancement of medical science."

Rich notes that in the 2015 study, the placebo effect could not be achieved without the initial conditioning effect. This required nondisclosure of placebo use. "There is a potential adverse effect on the trust relationship between clinician and patient or clinical investigator and research subject," says Rich.

The research subjects were surprised with the knowledge that their previous treatments were a placebo. "A fully ethical implementation of the same procedure in clinical practice, such as pain management post-surgery, would necessitate a disclosure of future placebo administration," says Schafer.

However, says Schafer, the exact timing of the shift from a verum drug treatment to a placebo could be hidden in order to preserve the conditioning effect. "This could replicate our effect and maintain the effectiveness of a placebo, even after subjects are sure that the treatment has shifted to a placebo," he says.

Use of placebos in human subjects research is generally ethically acceptable when subjects are informed in advance that they may receive a

EXECUTIVE SUMMARY

The placebo effect eases pain even if research participants know the treatment they are receiving has no medical value whatsoever, according to a recent study. Some ethical considerations of treatment include the following:

- Reinforcing treatment cues with positive outcomes can create placebo effects that are independent of reported expectations for pain relief.
- The placebo effect could not be achieved without the initial conditioning effect, which required nondisclosure of placebo use.
- The use of deception or non-disclosure may be necessary in clinical trials.

placebo and they nevertheless consent to participate, says Rich. "The deception or deliberate nondisclosure of otherwise pertinent information, whether or not it involves the use of placebos, is likely to undermine trust in either the patient care or clinical research enterprise," he says.

Studying the placebo effect is an important part of medical science, and involves many complex, ambiguous factors, says **Joyce Plaza**, MS, MBe, manager of New York City-based Columbia University's IRB. "The use of deception or non-disclosure may be necessary," she adds. Plaza says the use of placebos in research is ethical if one of the following two conditions exists:

- For studies involving minimal risk, the use of deception is permissible if the study could not be otherwise conducted, the study presents minimal risk, the rights and welfare of the subjects are not adversely affected, and subjects are fully debriefed after their participation, or at the conclusion of the study, if appropriate.
- Placebos may be used in double-blinded clinical studies in which subjects are informed that they may receive the placebo instead of the experimental active treatment, but subjects are also provided standard care in addition to the placebo or active treatment. "The review of the studies by the institutional review board would determine that the ethical responsibilities of the research were met," says Plaza.

In an earlier study, openly administered placebos were found to be as effective as lidocaine at treating pain from irritable bowel syndrome.[4] "Critically, in this case subjects were informed about the effectiveness of placebos in treating pain, and were implicitly encouraged to expect the placebos to work," notes Schafer.

In the 2015 study, participants were permitted to stop their participation if they experienced discomfort from the heat, and gave informed consent to participate in a study of treatment effects on pain relief. "All participants were fully debriefed at the conclusion of the study," notes Plaza.

REFERENCES

1. Schafer SM Colloca L, Wager TD. Conditioned placebo analgesia persists when subjects know they are receiving a placebo. *J Pain* 2015; 16(5):412-420.
2. AAPM Council on Ethics. Ethics charter from American Academy of Pain Medicine. *Pain Med* 2005; 6(3):203-212.
3. American Pain Society Ethics Committee. APS position statement on the use of placebos in pain management. *J Pain* 2005; 6(4):215-217.
4. Kaptchuk TJ, Friedlander E, Kelley JM, et al. Placebos without deception: A randomized controlled trial in irritable bowel syndrome. *PloS One* 2010; 5(12):e15591.

SOURCES

- Joyce Plaza, MS, MBe, Institutional Review Board, Columbia University, New York City. Phone: (212) 851-7041. Email: jp2199@columbia.edu.
- Ben A. Rich, JD, PhD, Emeritus Professor of Medicine (Bioethics), UC Davis School of Medicine. Phone: (916) 734-6010. Fax: (916) 734-1531. Email: barich@ucdavis.edu.
- Scott Schafer, University of Colorado Boulder. Email: scott.schafer@colorado.edu. ■

Is patient's POLST form inaccessible to provider?

ePOLST gives immediate access

Even if patients' end-of-life wishes are meticulously documented using a Physician Orders for Life-Sustaining Treatment (POLST) form, they sometimes are ignored simply because a provider can't locate the form.

"Patients and family expect that if they have completed POLST forms with their clinician, whether in a nursing home, clinic, or home hospice setting, that their wishes will be honored," says **Susan W. Tolle**, MD, director of the Oregon Health & Science University (OHSU)'s Center for Ethics in Health Care in Portland. Tolle is chair of the Oregon POLST Task Force and a leader behind the original development of the POLST program.

In reality, says Tolle, "there are problems with electronic systems that are not integrated across different systems of care." Using the newly launched ePOLST, a fully integrated electronic version of the POLST form, OHSU clinicians can immediately view the patient's POLST form. "This is a next step in assuring the treatment preferences of those with advanced illness are elicited, recorded, and honored," says Tolle.

The current statewide error rate for paper POLST forms submitted to the Oregon POLST registry is 18%. POLST forms are sometimes undated, or the patient or provider's name is illegible. "ePOLST has

taken us to a new place of reducing technical completion errors to zero," reports Tolle. *(To view OHSU's POLST: Doing it Better" instructional video, visit http://bit.ly/1Lmyz7W.)*

Just one click needed

The national POLST Paradigm Task Force recommends that a patient's POLST form be available within one click in the electronic medical record. "This means that those caring for a patient in a crisis can see that a patient has a POLST form, with a 'yes/no' tab on the patient header," says Tolle. Providers can click just once on "yes" without having to search anywhere else in the record, and view a scanned copy of the patient's most recent POLST form.

"Even without the added benefits of the ePOLST system, ethics leaders should encourage their health system to develop electronic record systems, to be able to find POLST forms in a single click," says Tolle.

Creating an ePOLST system is a significant IT investment, however. Alternatively, hospitals can create their own integrated systems that link all POLST forms completed in their inpatient and outpatient settings.

"This is the low-budget option that everyone can do," says Tolle. "This is not hard to fix, and all ethics leaders should be pushing for this."

Two tabs are created on the patient header that link to a "yes/no" indicator. "It is very important to keep POLST orders in a separate tab from advance directive forms," notes Tolle. "Medical orders need to be found in seconds."

More than 5,000 healthcare professionals have called the Oregon POLST registry seeking POLST forms urgently; 2,000 of those patients had POLST forms. "While providers can contact the POLST registry to get the information, the new ePOLST system is faster," says Tolle.

Currently, 18 states have endorsed POLST programs, with many more in development. "Most states are moving toward a POLST paradigm because of its effectiveness," says Tolle. Of 58,000 records of natural deaths in Oregon in 2010 and 2011 examined by researchers, nearly 18,000 had a POLST form in the Oregon registry. Only 6.4% of patients with "comfort measures only" orders on their POLST died in a hospital.[1]

"Knowing the POLST scope of treatment orders are strongly associated with the care patients ultimately receive increases our ethical obligation to be able to locate POLST forms within our health systems," says Tolle.

Currently, OHSU clinicians are pilot-testing the ability to electronically search the Oregon POLST registry through ePOLST. This will make it easier to find POLST forms from other healthcare systems.

When OHSU converted to ePOLST in April 2015, 10,000 POLST forms were loaded into the system. "Ever since we went live with this, we stopped automatically intubating patients whose POLST form said 'comfort measures only,'" says Tolle.

In the initial 3-month period of implementation at OHSU, the ePOLST button was clicked more than 6,000 times. "Because they can find it so easily, the internist, the attending, the ED nurse are all checking it," says Tolle.

This means that providers aren't starting from scratch with code discussions; instead, they can begin by stating something like, "I see that two weeks ago you completed a POLST form with your primary care physician. Would you like us to honor the wishes you've recorded on that form?"

"This is very different from saying, 'If your heart stops, do you want us to start it?' as if no conversation had ever happened before," says Tolle. "It lifts a burden from families by not having to start again from the beginning."

A month before ePOLST was implemented, a patient with advanced heart and lung disease was brought to OHSU in pulmonary edema, unable to speak for herself. She was being cared for at home and had completed a POLST form signed by her primary care physician, stating "comfort measures only."

"Only the hired caregiver was with her, and she didn't know if the patient had a POLST form,"

EXECUTIVE SUMMARY

Clinicians at Oregon Health & Science University can immediately access patients' Physician Orders for Life-Sustaining Treatment (POLST) forms with the newly launched ePOLST, a fully integrated electronic version of the POLST form.

- Patient wishes are sometimes ignored because providers can't access POLST forms.
- Creating an ePOLST system is a significant IT investment.
- Health systems can create integrated EMR systems internally to link to POLST forms.

says Tolle. The hospital's EMR didn't have the form because it was completed by a physician at a different health system. "She ended up being intubated in our ICU, with family saying, 'What on earth are you doing?'" recalls Tolle. "Palliative care was consulted; later that day, she was extubated and died peacefully that night." The family insisted that clinicians should have been able to find the POLST form, and that their loved one should not have been intubated.

Tolle recommends that bioethicists learn the details of similar cases occurring at their institutions. "Ask the ICU team when they have looked into the eyes of a family member who said, 'Why did you do this? She never wanted this. Here's the documentation and why couldn't you find it?'" she says.

Each time this has happened in recent years, OHSU has made the case the focus of a morbidity and mortality conference. "Whenever one happens, do it again. Just keep having these conferences for your egregious cases," says Tolle.

Tolle raised the issue repeatedly with OHSU's IT department, president, and medical director before leaders agreed to launch ePOLST. "Don't take 'no' or 'later' for an answer," she says. "We have an ethical obligation to consistently find POLST orders."

REFERENCE

1. Fromme EK, Zive D, Schmidt TA, et al. Association between physician orders for life-sustaining treatment for scope of treatment and in-hospital death in Oregon. *J Am Geriatr Soc* 2014; 62(7):1246-1251.

SOURCES

• Susan W. Tolle, MD, FACP, Director, Center for Ethics in Health Care, Oregon Health & Sciences University, Portland. Phone: (503) 494-4466. Fax: (503) 494-1260. Email: tolles@ohsu.edu. ■

Is it ethical to practice invasive procedures on the newly dead?

Living patients harmed when used for physician instruction

Is it ethical to use the bodies of newly dead patients to practice invasive procedures such as thoracotomies, cricothyrotomies, lateral canthotomies, or venous cutdowns?

"Ethical tension stems from the potentially competing imperatives: To respect the body of the deceased and the family's interests in and obligations to the decedent, and societal interests," says **Jeffrey T. Berger**, MD, FACP, professor of medicine at Stony Brook (NY) University School of Medicine. Berger is also chief of the Division of Palliative Medicine and Bioethics at Winthrop-University Hospital in Mineola, NY.

Clearly, there is a need for technically competent physicians who can provide invasive medical interventions with relatively low risk to patients. If newly dead patients are to be used for learning, however, a degree of transparency about the activity is needed, says Berger. "The profession must maintain public trust," he says. "This could be undermined if word leaked out that physicians were using dead patients without the family's knowledge."

Providers shouldn't underestimate the downside risk of undermining public trust, says Berger. "If the profession were to advocate for routinely using newly dead patients, a mechanism that would allow patients to opt in or opt out could be considered, although either would be somewhat cumbersome," he suggests.

Without transparency, there is a risk that the bodies of patients from socioeconomically disadvantaged populations could be used more often than others, says Berger. "This mirrors the historical phenomenon of these patient populations bearing a disproportionate share of medical care rendered by resident physicians," he adds.

Patients believe consent is necessary

At one time, practicing on the newly dead was very commonly done, says **Barry Brenner**, MD, PhD, program director of the emergency medicine residency program at University Hospitals Case Medical Center in Cleveland. "People then started questioning whether this was reasonable, and the ethics of this," he says.

Years ago at an international conference, Brenner was surprised when some attendees suggested simply asking for consent to practice on the newly dead. "I said that saying, 'Your family member is

unfortunately expired, but we have medical students here who need to practice intubation' would infuriate people," says Brenner. A Norwegian researcher responded that in his country, most people would readily agree to this practice.

"Things that were considered absolutely fine in Norway, and I suspect throughout Europe, were considered abhorrent here in the U.S.," says Brenner. The two physicians set out to study the matter by administering identical surveys to adult emergency department patients and family members in Brooklyn and Oslo, to determine their willingness to consent for teaching of specific invasive techniques in the event of their own death or that of a family member. "What we found was an enormous cultural divide," says Brenner.

Respondents in Brooklyn were much less willing to grant permission than Norwegians: 48.5% indicated they'd be angry if approached for permission, compared with only 8.4% in Oslo.[1]

Other research suggests that patients and families will often grant permission for such training.[2,3,4] In a 2014 study, 150 patients were asked whether they would give consent to have endotracheal intubation training on their own bodies after death; more than half (55%) agreed.[4]

Obtaining consent entails more than just signing a form, however, says Berger. The informed consent process must include an opportunity for clarifications, questions, and exploration of potential harms, likely benefits, and alternatives.

"THE BOTTOM LINE IS THAT WHEN FACED WITH A MORAL DILEMMA, THE WORST POSSIBLE ACTION IS CONFUSED INACTION."

"Often, there is an over-emphasis on the instrumental component of consent — 'getting the form signed' — and under-emphasis on the content and process leading to an informed decision," says Berger.

Simulation doesn't accurately mimic doing procedures on real people, according to **Kenneth V. Iserson**, MD, MBA, FACEP, FAAEM, FIFEM, professor emeritus in the Department of Emergency Medicine at The University of Arizona in Phoenix.

"Even unembalmed cadavers that have been refrigerated and donated for medical purposes often lack the veracity of a live patient or newly deceased corpse," he says.

Iserson expects that in the future, virtual reality simulators will accurately mimic the human body's feel and response to procedures. "At that point, no one will permit trainees to do any procedure on live patients without first demonstrating their expertise on these simulators," he says.

Until that day comes, however, Iserson says there is an ethical imperative to have practitioners learn and be proficient in life-saving procedures. This is especially true of those who will need to act in emergencies.

"Ethics is always a balance between better and worse options," says Iserson. He says providers should ask themselves this question: Would you rather practice and teach emergency procedures on the newly dead, or tell a grieving family that you didn't know how to do what may have been a lifesaving procedure?

"The bottom line is that when faced with a moral dilemma, the worst possible action is confused inaction," says Iserson. Providers have an important choice to make, he says: To train medical personnel using practices that can actually hurt living ill and injured people, or to permit an admittedly distasteful, yet physically harmless, method of teaching to continue on the newly dead.

"We dare not make the mistake, in medicine or in bioethics, of

EXECUTIVE SUMMARY

Using the newly dead to practice invasive medical procedures results in ethical tension between the provider's obligations to the decedent and family and societal interests. Living patients undergoing resuscitation or surgery are at risk for harm if used for physician instruction. Some ethical concerns include the following:

- Public trust can be undermined if the practice occurs without the family's knowledge.
- There is an ethical imperative to ensure practitioners' proficiency in life-saving procedures.
- Without transparency, the bodies of patients from socioeconomically disadvantaged populations might be used more often than others.

confusing a good public image with real and practical benefits for all of society," says Iserson.

Live patients are harmed

Iserson routinely asks trainees: "Who does practicing and teaching procedures on harm? Is it the now-deceased patient on whom you or your senior residents and attending physicians used the skills they learned on other patients? Or the live patient, with a chance to live, on whom you will learn or practice an invasive procedure?"

"Much less thought or concern seems to go into preparation for novice practitioners' learning or practice on living patients," says Iserson. He says that two groups of living patients are most harmed if they are used for physician instruction: Patients undergoing surgery using general anesthesia, and patients being resuscitated.[5]

"Surgical training commonly occurs in the operating room, and aside from some very basic anatomical instruction, is not amenable to substitution with corpses," says Iserson.

Resuscitations are often prolonged until everyone who needs to learn or practice has had a chance to perform a critical procedure. "This process takes place after the team has determined that the person cannot be resuscitated, but before death is pronounced," says Iserson. "Unfortunately, there can be adverse outcomes to practicing on these still-living patients."

The patient's family or third-party payer must pay for any equipment used, and possibly even the unnecessary procedures. "Worse, by this time the patient has invariably suffered severe brain, heart, and other devastating systemic damage," says Iserson. When continued cardiopulmonary resuscitation during these practice sessions occasionally restarts the patient's heart or restores the blood pressure to a measurable level, the dying process is prolonged for hours or days.

"THIS COMMON SCENARIO CAN ONLY BE CONSIDERED ABHORRENT, GIVEN THE AVAILABILITY OF NEWLY DEAD BODIES THAT CAN NO LONGER BE HARMED AND THAT OFFER THE SAME PRACTICAL OPPORTUNITIES."

This comes at an enormous expense, says Iserson — both in terms of money and emotional turmoil for the patient's survivors.

"This common scenario can only be considered abhorrent, given the availability of newly dead bodies that can no longer be harmed and that offer the same practical opportunities," he says.[6]

REFERENCES

1. Morag RM, DeSouza S, Steen PA, et al. Performing procedures on the newly deceased for teaching purposes: what if we were to ask? *Arch Intern Med* 2005; 165(1):92-96.
2. Hergenroeder GW, Prator BC, Chow AF, et al. Postmortem intubation training: patient and family opinion. *Med Educ* 2007; 41:1210–1216.
3. Oman KS, Armstrong JD, Stoner M. Perspectives on practicing procedures on the newly dead. *Acad Emerg Med* 2002; 9:786–790.
4. Mirzazadeh A, Ostradrahimi N, Ghalandarpoorattar SM, et al. Teaching endotracheal intubation on the recently deceased: opinion of patients and families. *J Med Ethics Hist Med* 2014; 7: 5.
5. Iserson KV. Law versus life: the ethical imperative to practice and teach using the newly dead emergency department patient. *Ann Emerg Med* 1995; 25:1:91-94.
6. Iserson KV. Teaching without harming the living: performing minimally invasive procedures on the newly dead. *Journal of Health Care Law & Policy* 2005; 8(2):216-231.

SOURCES

• Jeffrey T. Berger, MD, FACP, Professor of Medicine, Stony Brook University School of Medicine, Chief, Division of Palliative Medicine and Bioethics, Winthrop-University Hospital, Mineola, NY. Phone: (516) 663-4640. Fax: (516) 663.4644. Email: JBerger@Winthrop.org.
• Barry Brenner, MD, PhD, Program Director, Emergency Medicine Residency Program, University Hospitals Case Medical Center, Cleveland, OH. Phone: (216) 844-3610. Fax: (216) 844-7783. Email: barry.brenner@uhhospitals.org.
• Kenneth V. Iserson, MD, MBA, FACEP, FAAEM, Professor Emeritus, The University of Arizona, Tucson. Phone: (520) 241-7744. Email: kvi@email.arizona.edu. ■

Did the provider "Google" a patient?

Some searches ethically justified

Of 530 medical students, residents and physicians, 64 used Google to research a patient, and 10 had searched for patients on Facebook, according to a recent survey.[1] A quarter of physicians surveyed considered using Facebook to learn about a patient to be "very unethical." Patient confidentiality, dignity and consent were the most frequent ethical concerns reported.

The study's lead author, **Maxim Ben-Yakov**, MDCM, FRCPC, a resident physician in the Department of Emergency Medicine at University of Toronto, Ontario, was surprised that a fairly large number of both trainees and faculty had looked up patients. The study also revealed that the practice was prevalent among all levels of emergency practitioners.

"If information is sought after for voyeuristic reasons, it cannot be ethically or clinically justified," says Ben-Yakov. "But in an emergency situation, the only avenue to obtain pertinent patient information may be to search their public profile on a social media site." In this case, a Google search may be ethically justifiable, he concludes.

The researchers suggest that providers use offline interactions as guiding principles for whether online searches on patients are ethical. "One would not go sifting through a patient's wallet or look for his or her social or demographic information without a clinical indication," says Ben-Yakov. "The same could be applied to engaging in online searching for patient's information."

> "IF INFORMATION IS SOUGHT AFTER FOR VOYEURISTIC REASONS, IT CANNOT BE ETHICALLY OR CLINICALLY JUSTIFIED."

Only 14% of providers who did online searches disclosed this to patients, while 83% disclosed it to senior colleagues.

"If the provider performed a search without first obtaining consent, then an ethical dilemma about disclosure exists," says **Claire Zilber**, MD, chair of the Denver-based Colorado Psychiatric Society's Ethics Committee and clinical assistant professor of psychiatry at University of Colorado Denver. It is preferable to ask the patient's permission before performing a search, she adds. This is consistent with the practice of obtaining informed consent before doing an intervention that may have consequences for a patient.

In an emergency situation, however, information obtained by an online search could provide clues to the patient's underlying medical conditions, substance use, history of violence, or other relevant data. "In an emergency room or an acute hospitalization where the patient is unable to provide information, and there are no identified third-party sources of information, an online search may be appropriate," says Zilber.

Trust is central concern

The main concern with online searching of patient information is that it could negatively affect the provider-patient relationship, which is founded on trust, says **Maria J. Baker**, PhD, FACMG, associate professor of medicine at Penn State College of Medicine in Hershey.

"If information is learned outside the traditional office setting, the provider must then decide whether to introduce this newfound information at the next appointment," says Baker. This risks jeopardizing the professional relationship established with the

EXECUTIVE SUMMARY

Ethical concerns involving providers performing online searchers on patients include patient confidentiality, dignity, and consent. Some ethical considerations include the following:

- Online searching could negatively affect the provider-patient relationship.
- Providers don't always disclose the online search to the patient.
- Providers must decide whether to document the information in the patient's medical record.

patient.

"Regardless of whether or not the provider confronts the patient, they must also decide whether or not to document the information in the patient's chart/medical record at the risk of being discovered by the patient," says Baker. In a recent paper, Baker and colleagues outlined a number of potential situations that might justify patient-targeted Googling:[2]

- Duty to re-contact/warn patient of possible harm,
- evidence of doctor shopping,
- evasive responses to logical clinical questions,
- claims in a patient's personal or family history that seem improbable,
- discrepancies between a patient's verbal history and clinical documentation,
- levels of urgency/aggressiveness incommensurate with clinical assessment,
- receipt of discrediting information from other reliable health professionals that calls a patient's story into question, and
- dissonant or incongruent statements by the patient, or between a patient and their family members.

"It is clearly unethical to Google a new patient, simply out of curiosity, to learn where she lives or socializes with friends or whether she currently is in a relationship," says Baker. Information gained from this type of search has no relevance to the provider-patient relationship or the provider's ability to address the patient's medical issues.

"In contrast, if a new patient invites you to read her blog to better understand how her disease impacts her life on a daily basis, the information gained can enhance the provider's understanding of the patient's situation," says Baker. This can help solidify a working relationship toward a common goal.

"If, however, after reading the blog, the provider looks at other information or pictures that are freely available, the provider may have lost sight of the original intent of the search," says Baker.

Is the search being done specifically to retrieve information that may be used in the treatment of the patient? If not, it should be carefully reconsidered, says Zilber.

"It is unethical to search a patient merely to satisfy our own curiosity," she says. "Be mindful that our relationship with a patient always hinges on the premise that we are placing their needs above ours."

REFERENCES

1. Ben-Yakov M, Kayssi A, Bernardo JD, et al. Do emergency physicians and medical students find it unethical to 'look up' their patients on Facebook or Google? *West J Emerg Med* 2015; 16(2):234-239.
2. Baker MJ, George DR, Kauffman GL Jr. Navigating the Google blind spot: An emerging need for professional guidelines to address patient-targeted Googling. *J Gen Intern Med* 2015; 30(1):6-7. doi: 10.1007/s11606-014-3030-7.

SOURCES

- Maria J. Baker, PhD, FACMG, Associate Professor of Medicine, Division of Hematology/Oncology, Penn State Hershey (PA) Medical Center. Phone: (717) 531-3849. Fax: (717) 531-0822. Email: mbaker@hmc.psu.edu.
- Maxim Ben-Yakov, MDCM, FRCPC, Department of Emergency Medicine, University of Toronto, Ontario. Email: maximby@gmail.com.
- Claire Zilber, MD, Clinical Assistant Professor of Psychiatry, University of Colorado Denver. Email: clairezilber@gmail.com. Web: www.clairezilbermd.com. ■

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

- Ethics of proposed federal requirements for human subjects research
- Nursing home staff knowledge of palliative care can affect patients
- Update on reimbursement for advance care planning discussions
- Why opioid abuse is harming patient/physician relationships

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CME INSTRUCTIONS

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

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2. Scan the QR code at right or log onto AHCMedia.com and click on My Account. First-time users must register on the site. Tests are taken after each issue.

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CME QUESTIONS

1. Which is true regarding end-of-life care of cancer patients, according to a recent study?

A. Very few patients designate a durable power of attorney
B. Designating a durable power of attorney correlated strongly with less aggressive medical care
C. Virtually all family members reported discussing end-of-life preferences with patients
D. Granting power of attorney decreased the odds of terminally ill patients dying in the hospital as opposed to hospice or home

2. Which is true regarding the use of the newly dead for training, according to Kenneth V. Iserson, MD?

A. Asking the decedent's family for consent is clearly unethical due to a high likelihood of emotional distress.
B. It is ethical for physicians to practice on the newly dead without the family's knowledge because transparency about this practice would undermine public trust.
C. When obtaining the family's consent, a simple signature suffices because there are no harms, benefits, or alternatives in such cases.
D. There is an ethical imperative to have practitioners learn and be proficient in life-saving procedures.

3. Which is true regarding the placebo effect, according to a recent study?

A. The placebo effect eased pain even if individuals knew it had no medical value
B. The placebo is dependent upon reported expectations of pain relief
C. The placebo effect was achieved even without the initial conditioning effect
D. The use of deception or non-disclosure is unethical under any circumstances

4. Which is recommended regarding POLST forms, according to Susan W. Tolle, MD?

A. Forms should be submitted on paper, because patient wishes are more likely to be honored than if archived electronically
B. A patient's POLST form should be available within one click in the electronic medical record
C. If institutions choose not participate in the ePOLST system, they don't need to create their own integrated systems to access completed POLST forms
D. Systems should use a single tab for both POLST forms and advance directives to speed providers' access