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## Greater palliative care knowledge in nursing homes linked to less aggressive end-of-life care

*Many ethics decisions made in outpatient setting, not hospital*

**T**he more nursing directors knew about palliative care, the less likely their patients experienced feeding tube insertion, injections, restraints, suctioning, and emergency department visits, according to a recent study.<sup>1</sup>

In addition to surveying nursing directors at 1,981 nursing homes, researchers analyzed Medicare data on the 58,876 residents who died during

the study period of July 2009 and June 2010, to ascertain the treatments they experienced when they were dying.

“It’s important for nursing home and hospital administrators to understand that exposure to greater palliative care knowledge is associated with lower rates of costly hospitalizations and less aggressive care,” says **Susan C. Miller**, PhD, the study’s lead author. Miller is a professor of health services, policy

### EXECUTIVE SUMMARY

Greater palliative care knowledge of nursing home directors is linked to less aggressive end-of-life care, but more than 20% had little or no knowledge, according to recent research. Increasingly, ethics decisions are being made in the nursing home setting instead of hospitals.

- Communication between long-term care facilities and hospitals may be incomplete or inaccurate.
- Providers may lack understanding of whether discharged patients will receive hospice care at nursing homes.
- Some bioethicists perform ethics consults at nursing homes or hospital clinics.

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**EDITORIAL QUESTIONS**

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and practice at Brown University's  
Center for Gerontology and Health  
Care Research in Providence, RI.  
"This is especially relevant given  
the trend toward accountable care  
organizations and bundled hospital/  
nursing home payment," adds Miller.  
Other key findings include the  
following:

- More than one in five of the surveyed directors had little or no basic palliative care knowledge.
- Patients in higher-knowledge homes had a higher likelihood of having a documented six-month prognosis. "This suggests that when there is greater palliative care knowledge, facilities are more attuned to the changing needs of residents," says Miller.

## Outside of hospital

Medical education, in general, has  
focused too much on the hospital  
setting, according to **Daniel P.  
Sulmasy, MD, PhD**, Kilbride-  
Clinton professor of medicine and  
ethics at the University of Chicago's  
MacLean Center for Clinical Medical  
Ethics. "And it seems to me that  
bioethics has been in the same rut,"  
he says. "Much of the decision-  
making that is of ethical significance  
now occurs outside the hospital."

Sulmasy sees a significant need  
for involvement of bioethicists at  
long-term care facilities and nursing  
homes, in terms of education and  
training. "We have no presence there,  
but huge ethical decisions are being  
made in those settings," he says. "It's  
sort of the Copernican revolution  
in terms of decision-making — the  
hospital is no longer really at the  
center."

University of Chicago Medical  
Center's geriatric staff also serve as  
medical directors and physicians at

two area nursing homes. "Our ethics  
consults service has begun to do  
consults at the nursing homes," says  
Sulmasy. "This is more difficult to do  
if institutions aren't directly affiliated  
with hospitals."

Sulmasy was recently asked by a  
geriatrics faculty member to conduct  
an ethics consult at a nursing home.  
The patient was often admitted to the  
hospital, but was also cared for by the  
geriatrics staff at the nursing home.  
The case involved decision-making  
capacity and questions about who  
the proper surrogate decision-maker  
might be.

"People in hospitals need to  
realize that there is a need for ethics  
consults in the nursing homes,  
and reach out to these institutions  
educationally," says Sulmasy. Lack  
of reimbursement is one obstacle.  
"Should the volume increase, I would  
hope nursing homes would recognize  
that they can't have people who  
are working in hospitals providing  
this service without some sort of  
remuneration," Sulmasy says.

In some cases, no one in the  
nursing home setting has assessed the  
patient's decision-making capacity;  
the patient is then hospitalized.  
"The patient is making demands  
for treatment, and then comes to  
the hospital where it's clear he or  
she is delusional," says Sulmasy. By  
the time the family is contacted and  
named as appropriate surrogates, the  
patient is already on a ventilator in  
some cases.

Another recent ethics consult  
involved whether a patient being  
considered for hospice referral  
should have a pacemaker implanted.  
Providers had an ethical question as  
to whether the pacemaker, which was  
intended to keep the patient from  
being dizzy until they die, was best  
considered to be palliative or life-  
prolonging, explains Sulmasy.

University of Chicago's ethicists also make an effort to promote ethics consults at hospital clinics. "That's where much of the major decision-making takes place — to treat or not treat, or whether to send patients to hospice without going to the hospital," says Sulmasy.

## Communication often poor

**Blair Henry**, an ethicist at Sunnybrook Health Sciences Centre in Toronto, Ontario, works at a tertiary care hospital that also includes one of the country's largest veterans' long-term care facilities. "Issues pertaining to admissions of seniors from surrounding long-term care facilities is a frequent source of ethics consultations," he notes.

Such consults often reveal missed opportunities to have important goals of care conversations before a resident from a long-term care facility ends up in the emergency department. "Frequently, the prior expressed wishes of elderly patients has been overturned by a distressed family member," Henry says. "This results in care being provided that does not reflect a patient's wishes."

Communication between long-term care facilities and hospitals frequently fails to provide important and time-sensitive information, adds Henry. "This occurs in both directions — admission and discharge," he says. Level of care forms are often misinterpreted as advance directives, for example. Information on the appropriate substitute decision-maker is sometimes incorrect.

Henry often finds that families need education on the limitations and appropriate use of artificial nutrition and hydration, and the

meaning of palliative care.

Bioethicists need to be involved "both upstream and downstream, in terms of education and access for consultations," says Henry. "The time of comfortably working in our respective silos needs to stop."

Ethics consultants often encounter patients who change goals of care in the hospital, notes **James A. Tulsky**, MD, chief of the Division of Palliative Medicine at Brigham and Women's Hospital in Boston. Such patients may end up being discharged to nursing homes, with the understanding that they will likely die there.

"If that is the case, it is essential that the discharging team understands what sort of care will be provided to the nursing home patient," says Tulsky. Whether patients will be able to receive hospice care at the nursing home, and whether nursing home staff are trained in end-of-life care, are two questions to address prior to discharge.

While bioethicists are frequently involved in advance care planning, most are not experts in end-of-life care, says Tulsky, which spans the full range of symptom management and other palliative care competencies.

"Therefore, while they could encourage and even coordinate such education in nursing homes, if the homes were willing to have them, they would need to do this as part of a larger team with all the expertise," says Tulsky.

## Many front-line staff eager

Nursing homes are an increasingly important site for end-of-life care, according to **Kathleen T. Unroe**, MD, assistant professor of medicine

at Indiana University's Center for Aging Research in Indianapolis. Hospice provides formal end-of-life care services for some patients living in nursing homes. "But many people in nursing homes are not on hospice, yet have palliative care needs or goals of care," says Unroe.

Front-line nursing home staff — nurses, nurse aides, and social workers — need to recognize when people have unmet needs, and know how to meet them or refer them to appropriate services, says Unroe.

Unroe led a study to assess the current state of palliative care knowledge and practices in nursing homes. Researchers surveyed a large number of front-line staff in both urban and rural nursing homes in Indiana using a validated survey.<sup>2</sup>

"While the staff scored well in many areas, areas for improvement were certainly identified, particularly around end-of-life care," says Unroe. She was most surprised that 62% of staff indicated they would be interested in being a leader in palliative care for their facility, with the right training and support.

"This represents an exciting opportunity to train champions in nursing homes in this important skill set, who are eager to support their peers in providing this care," says Unroe.

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# Did ethics consults occur too late? Reluctant clinicians are one reason

*Encourage "on the fly" ethics conversations*

**B**y far, the most common situation in which ethicists are asked to provide consultation is when conflict occurs near the end of life, according to **David A. Fleming, MD, MA, MACP**, director of University of Missouri's Center for Health Ethics in Columbia.

Unfortunately, this often occurs when death is inevitable in spite of aggressive treatment. "Both team members and family are distraught, and the patient is no longer capable of engaging," says Fleming. "Disagreements and emotions run high at these times."

Earlier involvement of the ethics team can facilitate discussion at a time when the patient can engage in shared decision-making, along with the family and the team. "Then clear

statements of value, preferences, and beliefs can be expressed, heard and understood by everyone," says Fleming.

## Clinicians lack awareness

In Fleming's experience, there are two major reasons clinicians fail to utilize ethics consult services when needed. "Either they don't recognize that ethical conflict exists, or they find it too cumbersome or uncomfortable to call for a consult," he says. This may be due to time constraints or fear of judgment about the case.

In some cases, physicians and nurses either don't know ethics consult services are available or don't know how to engage them. Here,

clinical ethicists offer the following recommendations to promote utilization of ethics consults:

- **Become a frequent presence in the care arena.** "Being open to questions about cases is a stimulus to begin discussions," says Fleming. By conducting "ethics rounds" on a regular basis, ethicists are in close proximity to care teams in the hospital, making themselves directly available when and where decisions need to be made.

"Case conferences are a good way to bring multiple disciplines together in the discussion," suggests Fleming. For instance, the team may question whether treatment decisions are in the patient's best interest. "This suggests that conflict is either in play now, or soon will be," says Fleming.

Fleming says it can be helpful, upon hearing such concerns, to informally offer suggestions as to ethical responses that might be considered. "But it is also important to offer the opportunity to formally meet with all stakeholders — care teams, consultants, patient, and family — to fully flush out the issues and make decisions in a shared way," he says.

## EXECUTIVE SUMMARY

Ethics consults often are called only after the patient lacks decision-making capacity and death is inevitable despite aggressive treatment. To encourage earlier consults, ethicists can do the following:

- routinely offer brief education to physician and nursing staff,
- participate in various hospital and medical staff committees, and
- encourage questions about cases during ethics rounds.

**Steven S. Ivy**, MDiv, PhD, senior vice president of values, ethics, social responsibility, and pastoral services at Indiana University Health in Indianapolis, says bioethicists should seek opportunities to offer even brief continuing education to physician and nursing staff. “Be available on a regular basis during rounding for ‘on the fly’ conversations,” he advises.

- **Get the word out by offering contact information on websites and other key communication venues.**

University of Missouri’s website lists a phone number and email address for the Center for Health Ethics, where the ethics consult service is coordinated and run, as well as the pager number for the consultant on call.

- **Provide educational sessions and case discussions.** “This fosters awareness, and a willingness to call for assistance when difficult cases arise,” says Fleming. When the consult team gets one ethics consult, several requests often follow from the same service.

“When care teams see how we have facilitated discussion and mediation in often complex cases and helped to

provide resolution to conflict, they see value in our presence,” Fleming says.

- **Do not reinforce perceptions of the “ethics police.”** Sometimes physicians and nurses call ethics seeking to enforce a desired behavior pattern on others. In such cases, advises Ivy, “the ethicist needs to probe enough to hear what ethical challenges may be present, and if they are, transform the conversation to those issues rather than a violation of mores or standards.”

At Indiana University Health, risk management or professional standards would intervene in the case of policy violations; professional standards would intervene in inappropriate behavioral situations. “If clinicians accuse colleagues of violating hospital policy, there are other mechanisms for those issues, when they are actually present,” explains Ivy.

- **Be pragmatic in recommendations.** “While the ethicist must have deep knowledge of theory and history and must use that knowledge effectively, not too often are clinicians attuned to hear such discourse,” says Ivy. Consultations about appropriate courses of action

must be useful in the actual course of patient care.

“Usually the clinician will not find interesting or helpful a discourse on levels of autonomy and capacity to refuse recommended treatments,” Ivy says. In his experience, clinicians appreciate clear statements as to the ethicists’ evaluation of the particular patient’s capacity for accepting and refusing treatments.

- **Participate in various hospital and medical staff committees.**

This “is not often exciting, but can pay great benefits in being known and appreciated,” says Ivy. “Face knowledge is really important.”

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## “Instant access” culture driving trend toward at-home testing

*Experts caution about false or misleading information*

**H**istorically, medical tests have been available only through healthcare providers who communicate results to the patient. This is changing quickly, however.

“At-home self-testing disrupts this provider-centric model by providing access to medical information and test results without necessarily involving a knowledgeable professional in the process,” says **Margaret R. McLean**,

PhD, associate director of the Markkula Center for Applied Ethics at Santa Clara (CA) University.

McLean says desire for knowledge, privacy, and control of information are the main drivers of at-home medical self-testing. “As a former clinical pathologist, I am not wildly enthusiastic about direct-to-consumer medical testing,” adds McLean. “However, it is a logical step in our

do-it-yourself, just-in-time, instant-access culture.”

At-home self-testing can promote autonomy and a proactive role for the patient in healthcare and wellness, McLean acknowledges. Accuracy and test interpretation, however, “are the bedrock of medical testing,” she cautions. Patients need an explanation of their particular findings, such as whether a high glucose level means

they have diabetes.

“There is further concern for patients receiving false or misleading information in a murky regulatory environment,” says McLean. She says the following practices are needed:

- At-home self-testing companies should disclose the risks associated with testing. These include rates of false negatives and false positives, psychological risk, and, in the case of genetic testing in particular, the potential risk to family members of information disclosure.

- Testing laboratories must have a robust procedure for notifying users that a result is abnormal, and encouraging users to see their primary care provider and/or providing a referral and access to needed follow-up services.

“As with other non-emergency medical interventions, at-home self-testing requires informed consent,” says McLean. This means that essential information must be given to the consumer in a way that is clear and understandable. “This mitigates against health decisions being based on incomplete and/or misunderstood test results,” explains McLean.

## More research needed

Healthcare providers have established methods for testing patients and follow recommendations

from organizations such as the Centers for Disease Control and Prevention on how often people should test and what to do if they test positive, notes **Sean Young**, PhD, executive director of the University of California Institute for Prediction Technology and assistant professor of family medicine at University of California, Los Angeles.

“But it’s different with self-testing,” says Young. “It’s new. We don’t have years of experience and research to know how people feel when they test, and what they do after they test.”

It’s unknown how individuals will feel psychologically, whether they will seek help, or whether they will take medication as needed. Still, says Young, “the benefits of self-testing are clear.” He gives the example of people at high risk for HIV who are not testing through traditional methods. For this group, says Young, self-testing kits provide a way to increase identification, potentially decreasing transmission.

Young says more research is needed on the effectiveness of self-testing. “Our research team has shown that groups at high-risk for HIV are willing to use self-tests,” he reports. “But we don’t have enough information on whether these tests prevent new infections.”

A primary ethical concern

with self-testing is that important health decisions will be based on misunderstood data. “I worry that many of those who will engage in at-home self-testing are the ‘worried well’ who will order unnecessary and inappropriate tests, potentially leading to more testing that further burdens the system,” says McLean.

**Kenneth W. Goodman**, PhD, director of the University of Miami Miller School of Medicine’s Institute for Bioethics and Health Policy, says more data is needed on risks of self-testing, especially regarding the consequences of errors and the utility of pre- and post-test counseling. “Such data will help us strike the correct balance between autonomy and paternalism,” he says.

Many home tests are commonly done, such as blood sugar, sexually transmitted infections, and cholesterol, notes Goodman, “and to no ill effect.”

Goodman says that in some ways, self-testing is not unlike representing oneself in court. “If you go into it with eyes wide open, know and freely accept the risks of something going wrong, then you should not be forbidden from doing so. But others will generally do it better,” he says.

Goodman says one often-overlooked ethical issue is the consequences that widespread self-testing could have on public health. Tests in clinics and hospitals are easily analyzed for patterns that reflect the health of communities.

“By taking all these tests offline, we might lose a valuable source of information that has been found to be precious for public health,” says Goodman.

Nonetheless, as technology steadily puts assays in the hands of ordinary people, says Goodman, “we must take a more accommodating stance, albeit with

## EXECUTIVE SUMMARY

Ethical issues involving at-home self-testing include patient autonomy, the fact that knowledgeable providers aren’t interpreting findings, and the possibility of false or misleading results. Ethicists suggest the following:

- At-home self-testing companies should disclose the risks associated with testing.
- Testing laboratories must have a robust procedure for notifying users of abnormal results.
- Patients need an explanation of their particular findings.

adequate regulation.”

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# Many academics on industry boards: Conflicts of interest are ethical concern

*Effects on research, students among chief concerns*

**A**cademics from medical schools and research institutions hold nearly 10% of positions on boards of directors at publicly traded healthcare companies, according to a recent study.<sup>1</sup>

“The numbers aren’t surprising for those of us familiar with academia, although they may be surprising for those outside of it,” says **Jessica Berg**, JD, MPH, professor of law, bioethics, and public health at Case Western Reserve University in Cleveland, OH.

**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, “It is both not surprising and yet deeply disturbing that these sorts of ‘extracurricular’ activities continue to occur at such high rates. This study offers disturbing evidence that there continues to be something rotten in academic medicine.”

Some key findings include the

following:

- Directors were affiliated with 85 geographically diverse nonprofit academic institutions, including 19 of the top 20 National Institutes of Health-funded medical schools.

- Of 442 healthcare companies with publicly accessible disclosures on their boards of directors, 180 had one or more academically affiliated directors.

- The median individual compensation to academically affiliated directors for their services to companies was \$193,000.

“The lines between academic medicine and the medical industry have become more and more blurred over the years,” says Berg. “The potential for conflicts of interest on both sides should be grounds for concern.”

Berg says ethical concerns stem from both the influence of the gift, and whether industry dollars should be spent in this manner. “Is it realistic

to ask academics to remain neutral in these contexts?” she asks. “Should we be concerned about the effect of these agreements on students, and on other research being done at the academic institution?”

## Money is motivator

Rosoff says that the first issue to examine is why companies feel it is in their interest to employ academic medical leaders as members of their boards. “It’s reasonable to presume that their motivation is similar to that of pharmaceutical companies which pay physician ‘thought leaders’ to serve as consultants or spokespeople,” says Rosoff. Companies expect a return on their investment that will provide a direct monetary benefit.

“What’s in it for the academics who serve as directors? The simple answer provided by this study is money — and lots of it,” says Rosoff. He notes that well-known academics are also quite well-compensated by their home institutions.

“Industry has long sought prominent academics to serve on their boards. Academics may view these favorably for a variety of reasons,” says Berg. These include real-world insight, prestige, and financial benefit.

Berg sees high levels of compensation as a central ethical

## EXECUTIVE SUMMARY

Academics from medical schools and research institutions hold nearly 10% of positions on boards of directors at publicly traded healthcare companies, according to a recent study. Ethicists report the following concerns:

- whether industry dollars should be spent in this manner;
- whether it’s realistic to ask academics to remain neutral;
- how students and other research at the academic institutions are affected.

concern. “We used to have direct gifts to physicians, which have fallen out of favor,” she says. “Now these ‘gifts’ often come as consulting agreements and board positions.”

The study authors acknowledge the benefits that have accrued due to collaboration between industry and academia. “However, it is unclear that these kinds of relationships can be plausibly said to make these sorts of positive contributions,” says Rosoff. “These academics work first for their institutions.”

Rosoff argues that it is incumbent upon academics “to engage in outside activities that enhance, rather than detract or conflict with, their primary fiduciary duties.”

## Increased regulation possible

Berg says it’s clear that these arrangements “are not going away.

The question is how they should be regulated.”

A 2008 report issued by the Association of American Medical Colleges and the Association of American Universities called for medical schools and major research universities to develop and implement institutional conflict of interest policies within the next two years, and to refine standards for addressing individual financial conflicts of interest. (*The complete report can be viewed at <http://bit.ly/1HxmlIU>.*)

Most conflict of interest policies are based on traditional disclosure and monitoring and do not set financial limits, notes Berg. “In the absence of additional professional or even industry self-regulation, we might see efforts at external regulation,” she says.

Disclosure won’t alleviate all ethical concerns, however. “We might want to consider restrictions on some of these arrangements, and

also restrictions on the amount of compensation,” Berg says.

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# New guidance on palliative care delivery in oncology practices

*Study authors hope to give clinic personnel greater understanding of palliative care*

**A** new guidance statement to define high-quality primary palliative care delivery in medical oncology has been developed by the American Society of Clinical Oncology (ASCO) and the American Academy of Hospice and Palliative Medicine (AAHPM).<sup>1</sup>

“Our hope is that by reviewing our palliative care service items, oncology clinic personnel will have a greater understanding of what palliative care truly looks like,” says lead author **Kathleen Bickel**, MD, MPhil. Bickel is an assistant professor of medicine at White River Junction Veterans Affairs

Medical Center’s Geisel School of Medicine at Dartmouth in Hanover, NH.

Palliative care “has never quite been broken down or spelled out in such a specific way as we tried to do with our project,” says Bickel. “It will be interesting to see how people respond.”

**Joe Rotella**, MD, MBA, HMDC, FAAHPM, the AAHPM’s chief medical officer, says the following are the primary challenges in delivery of quality palliative care in the oncology practice setting:

- perceived lack of time and

inadequate training to have uncomfortable conversations with patients,

- a culture in our society of fighting cancer at all costs, that inappropriately equates a comfort or quality-of-life focus of care as giving up, and

- underdeveloped access to multidisciplinary teams to address emotional, social, spiritual, and practical aspects of care.

The guidance represents a consensus opinion on which components of palliative care for cancer patients are important,

feasible, and within the scope of care for medical oncology practices to provide without routinely involving a specialized palliative care team, according to Rotella.

“This is an opportunity for every oncology practice to look at how it cares for patients, and to make sure it pays attention to their palliative care needs,” he says.

## Enforcing “moral imperative”

**Salimah H. Meghani**, PhD, MBE, RN, FAAN, an associate professor at University of Pennsylvania’s Department of Biobehavioral Health Sciences in Philadelphia, sees the recommendations as “creating and enforcing a moral imperative to move beyond the cure-oriented mindset in treating patients with advanced life-limiting cancer.” Meghani is also an associate fellow at the University’s Center for Bioethics, and served on the Institute of Medicine committee which developed the 2014 report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*.

Some key recommendations include the following:

- that all symptoms should be

assessed and managed at a basic level, with more comprehensive management for common symptoms such as nausea, vomiting, diarrhea, dyspnea, and pain,

- that oncology practices should be able to describe the difference between palliative care and hospice to patients, and

- that oncology practices should refer patients with an expected survival of less than three months or poor performance status to hospice.

“These are simple recommendations, and do not imply that oncologists do not know how to treat nausea or dyspnea,” says Meghani, adding that the recommendations mirror those of the 2014 IOM report.

“The report called for delivery of palliative care by professionals who are not necessarily palliative care specialists but are in primary or disease-oriented specialties, and frequently work with patients with advanced illnesses,” notes Meghani. Similarly, the ASCO/AAHPM guidance calls for high-quality primary palliative care delivered by medical oncology clinicians.

However, “the physician does not, and probably should not, do all of the primary palliative care delivery,” notes Bickel. “Our hope is to get practices thinking more about true

team-based care.”

Practices associated with large cancer centers typically have a wide range of resources and can likely easily provide most palliative care services. “This might require a bit more creativity for smaller practices with less resources,” says Bickel.

Education of both medical professionals and patients continues to be a major part of improving palliative care delivery, according to Bickel. “We are not talking about hospice here,” she says. “This is just basic, compassionate patient care. It is not very complicated.”

## Not enough specialists

In 2012, the ASCO recommended the integration of palliative care into routine cancer care.<sup>2</sup> “Previously in routine cancer care, palliative care had been sporadically offered at times of great symptom distress or when the patient was close to death,” says **Margaret Quinn Rosenzweig**, PhD, FNP-C, AOCNP, FAAN, associate professor at University of Pittsburgh School of Nursing.

Rosenzweig adds, “Probably the most important issue is that there are not enough specialists in palliative care to meet this recommendation.”

Having advanced practice nurses provide high-quality palliative care is one answer. “Resources can be directed toward nursing to help to ensure that each patient in need of palliative care has access to this specialty,” Rosenzweig suggests.

To ensure that every patient with a life-limiting illness and all patients with metastatic cancer receive palliative care, says Rosenzweig, providers who are not specialists must be able to implement a basic level of palliative care assessment and intervention.

## EXECUTIVE SUMMARY

A new guidance statement from American Society of Clinical Oncology and the American Academy of Hospice and Palliative Medicine defines high-quality primary palliative care delivery in medical oncology. Some recommendations include the following:

- All symptoms should be assessed and managed at a basic level.
- Oncology practices should be able to describe the difference between palliative care and hospice to patients.
- Oncology practices should refer patients with an expected survival of less than three months or poor performance status to hospice.

“This means that physicians, nurse practitioners, physician assistants, and registered nurses must be able to provide at least a basic level of palliative care assessment and intervention,” she says.

## Patients pay heavy price

Meghani suggests that bioethicists use narratives and stories to demonstrate to providers the consequences of decisions such as late referrals to hospice or lack of honest communication about prognosis.

“Often, patients and families pay a hefty price in terms of loss of quality of life, loss of financial assets, and caregiver exhaustion,” she notes. “This creates a burden for patients and families during very vulnerable times in their lives.”

Meghani acknowledges that instruments to accurately assess prognosis and life expectancy are limited, but says prognostic limitations have also been used as “a crutch” by clinicians to avoid engaging in difficult end-of-life discussions.

“Clear clinical guidelines about referral and consistent use of a validated prognostication tool is a step in the right direction,” says Meghani.

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# Families say nursing care is key support for end-of-life care

*Family needs must be addressed, too, study says*

**F**amily members’ needs must be addressed during the dying process — not just during bereavement after the patient passes away, says **Paul Arnstein**, RN, PhD, director of MGH Cares About Pain

Relief at Boston-based Massachusetts General Hospital. Arnstein is also an adjunct associate professor in the nurse practitioner program at the MGH Institute for Health Professionals.

In a recent qualitative study, researchers interviewed seven family members or friends about their needs while a loved one was receiving end-of-life care in the hospital setting.<sup>1</sup>

The motivation for the study came from a staff nurse who worked with cancer patients at the end of life. “She attended to the comfort and emotional needs of family members, and believed this made a big difference for them at a very difficult time,” says Arnstein, one of the study’s authors. Some key findings include the following:

- Vigilance in the provision of nursing care for patients at the end of life provides family with a sense of being cared for, and eases their

## EXECUTIVE SUMMARY

Vigilance in the provision of nursing care, communication of even slight changes in the patient’s condition, and validation of the family’s decision-making increase family members’ comfort during the dying process, a recent qualitative study suggests. Other findings include the following:

- Family members openly discussed concerns.
- Family feared guilt if they were not at the bedside and the patient passed away.
- Family members needed help knowing what resources to ask for.

feelings of uncertainty and anxiety.

“Daily presence of physicians and communication by nurses or physicians of even the slightest changes was essential to a loved one’s comfort and well-being,” says Arnstein.

- Support for family members and validation of difficult decision-making increases family members’ levels of comfort and trust in the healthcare team.

- Family members openly discussed the discomforts, concerns or difficulties they experienced during this difficult time. “It was anticipated there might be a reluctance to talk, which wasn’t encountered,” says Arnstein.

- Family wanted to stay close to their dying loved one because of anticipatory guilt they would feel if they left a patient’s bedside and the patient passed away.

- Family members needed some help knowing what to ask for, or what resources were available to them. “They were so focused on the patient that they needed help in knowing what resources were available to them,” says Arnstein.

## “All about being present”

As comfort measures intensify, so does the need for support to a dying patient’s family, notes **Saurabh Khurana**, MD, a palliative medicine fellow at Cleveland Clinic in Cleveland, OH. “Informing the family of the normal dying process, such as changes in respiratory rate, ability to handle secretions, and changes in level of consciousness, can assist the family in being emotionally prepared to stay with their loved one through the time of death,” says Khurana.

End-of-life care is “all about being present,” says **Craig M. Klugman**, PhD, professor and chair of DePaul University’s Department of Health Sciences in Chicago. “That is, simply being with the person who is dying, and to be a witness to the life that is ending.”

In terms of medicine and clinical ethics, says Klugman, it’s important to explain things “often, simply, and compassionately” to families.

Rather than going through a litany of possible interventions such as ventilators, resuscitation, intubation, antibiotics, and dialysis — Klugman starts off by asking about the patient’s values and goals of care. “Then, offer two or three choices, such as withdrawing care, maintaining current care but not elevating care if new problems arise, or providing aggressive care,” says Klugman.

Families place a high value on open and honest communication during end-of-life care, according to **Jennifer S. Temel**, MD, clinical director of thoracic oncology at Massachusetts General Hospital in Boston. Many want to know what

to expect as the patient’s illness progresses. “It is incredibly helpful to educate families on the physical changes they should anticipate as their loved one dies,” says Temel.

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## CME OBJECTIVES

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

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

## COMING IN FUTURE MONTHS

- Ethics of oncologists soliciting donations from their patients
- New data on palliative care consults in emergency departments
- How Medicare payments will affect advance care planning
- Support clinical team’s choice not to offer life-sustaining interventions

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## CME QUESTIONS

**1. Which is true regarding palliative care knowledge and end-of life care, according to a recent study?**

- A. Greater palliative care knowledge by nursing home directors of nursing is linked to less aggressive end-of-life care.
- B. Nursing home directors of nursing's lack of palliative care knowledge had no effect on patients' end-of-life care.
- C. There was no link between a lower level of palliative care knowledge and more aggressive end-of-life care.
- D. Patients in higher-knowledge nursing homes were much less likely to have a documented six-month prognosis.

**2. Which is true regarding academics holding board of directors positions at publicly traded healthcare companies, according to a recent study?**

- A. Low median individual compensation alleviates concerns about conflicts of interest.
- B. Data suggest academics are able to remain neutral in these contexts.
- C. Such agreements have been shown to positively affect other research at the academic institutions.
- D. Academics from medical schools and research institutions hold nearly 10% of such positions.

**3. Which is recommended by a new guidance statement to define high-quality primary palliative care delivery in medical oncology?**

- A. Oncology practices do not need to provide comprehensive management for common symptoms such as nausea and dyspnea.
- B. Oncology practices should be able to describe the difference between palliative care and hospice to patients.
- C. Providers should not automatically refer patients to hospice based solely on expected survival of less than three months.
- D. Primary palliative care delivery should be provided solely by physicians.

**4. Which is true regarding family's needs during the dying process, according to a recent study?**

- A. Families were very reluctant to discuss their concerns.
- B. Families were fully aware of available resources to help them.
- C. Families appreciated communication by nurses or physicians of even the slightest changes.
- D. Families did not want to be educated on the normal dying process, such as changes in respiratory rate and level of consciousness.



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