The ‘Elephant in the Room’: Physicians Urged to Introduce Hospice and Palliative Care

Physicians pursuing conventional medical evaluation and therapy for patients with lifelimiting illnesses may sometimes need to be reminded to pause, look at the big picture, and give serious reflection to the patient’s entire clinical situation, according to an article published in JAMA Internal Medicine.

“When caring for patients with a terminal illness, physicians are challenged with difficult discussions and decisions, and many times these ignore the ‘elephant in the room’ — the fact that the patient is dying,” write cardiologist Tanya H. Tajouri, MD, and oncologist Timothy J. Moynihan, MD, from the Mayo Clinic College of Medicine, Rochester, MN.

The authors relate the story of a 55-year-old man with multiple symptoms who was referred to their facility for evaluation. He was treated by several different medical specialists, receiving invasive testing and procedures, including the insertion of an implantable cardioverter device following a terminal diagnosis. Not until the 22nd day of hospitalization was the palliative care team consulted. The patient, who was suffering from severe panic and anxiety, shifted his goals of care from curative to palliative, and died peacefully three days later.

“Physicians sometimes focus solely on the disease process and how it can be treated while consciously or unconsciously avoiding the true overall prognosis and outcome, ignoring what is obvious, that the patient is dying,” the authors observe.

The authors note that a recent report from the Dartmouth Atlas Project revealed a trend of increasingly aggressive treatment of patients nearing the end of life. The researchers found that between their previous report on changes in U.S. health care (from 2003 to 2007) and the most recent report (for 2010), the proportion of patients admitted to an intensive care unit during the last month of life increased by almost 22%, from 23.7% to 28.8%. Further, extremely late referrals to hospice rose substantially. The percentage of patients enrolled in hospice within the final three days of life rose by 30.9%, from 8.3% to 10.9%.

Timely introduction of palliative/hospice care is known to:
- Improve quality of life
- Minimize invasive interventions
- Prolong survival, in certain cases
- Diminish caregiver bereavement

In the hospital setting, “effective discussions with patients facing terminal illnesses that address the true underlying prognosis, or the so-called elephant in the room, must be initiated early and should involve members of the palliative care team,” write the authors.

“Earlier involvement of palliative care not only provides patients with better symptomatic relief, but also allows them to make more informed decisions and gives them more time to address end-of-life issues.”

Integrating Geriatrics and Palliative Care

‘The problem is not that we don’t know what to do — the problem is that we don’t do what we know’

The vast amount of current spending on medical care for elderly patients with serious illness not only threatens the American economy, it does not deliver the optimal care for this vulnerable population. A special report published in the Journal of Palliative Medicine found a “disconnect” in the translation of geriatric palliative care models into policy and widespread practice.

“The problem is not that we don’t know what to do — the problem is that we don’t do what we know,” state co-authors Kathleen T. Unroe, MD, MHA, assistant research professor of medicine, Indiana University School of Medicine, Indianapolis, and Diane E. Meier, MD, director of the Center to Advance Palliative Care and professor of geriatrics and palliative medicine, Mount Sinai, New York City.

The authors call for the integration of the principles of geriatrics and palliative care. This will obviously require efforts to expand the number of medical and nursing specialists in these disciplines. But in addition, strategies are needed on how “to best incorporate key geriatric and palliative care principles and practices into the training and competencies of all providers (primary care and specialists such as cardiologists, oncologists, nephrologists, and neurologists) who work with these patients.”

The article presents an outline of recommendations for research priorities that will best promote needed policy development. “It is critical that federal, state, and local regulatory and payment policies evolve to support the delivery of high-quality palliative care to a growing elderly population who often live for many years with the burden of serious, chronic illnesses,” state the authors.

ADVANTAGES OF PALLIATIVE/HOSPICE CARE

Providing coordinated palliative care matched to the changing needs of frail, vulnerable, and seriously ill elderly patients not only improves the quality of care for these patients, it also reduces spending for emergency department visits and hospitalizations.

“Both palliative care and hospice programs improve physical and psychological symptoms... improve caregiver well-being, and increase patient, family, and physician satisfaction.”
— Unroe and Meier, Journal of Palliative Medicine

“The problem is not that we don’t know what to do — the problem is that we don’t do what we know”

“Both palliative care and hospice programs improve physical and psychological symptoms experienced by patients, improve caregiver well-being, and increase patient, family, and physician satisfaction,” the authors write. By addressing patients’ distressing symptoms, palliative/hospice care teams contribute to a reduction in medical complications these patients experience and to resultant hospitalizations.

In addition to expertise in symptom management, “palliative care providers have expertise in the conduct of conversations with patients and families dedicated to assuring understanding of what to expect in the future, including prognosis and the resulting goals of care.” Such care planning discussions have been shown to improve family satisfaction and to reduce health care costs.

HOSPICE BENEFIT REFORM

“Hospice is a rich and complex intervention that has become an integral part of the care of terminally ill patients in the United States, allowing many patients to receive palliative care services in their homes,” write the authors. The Medicare Hospice Benefit, however, is based on the needs and illness trajectory of cancer patients. As increasing numbers of noncancer patients access hospice, the limitations of this structure have become apparent.

“Timing of referral is difficult for patients with unclear prognosis,” observe the authors. Although some patients, such as nursing home residents with advanced dementia, may have longer hospice stays than anticipated, “much larger numbers of patients are referred to hospice too late to benefit from hospice care.”

In 2011, for example, while 11% of Medicare hospice beneficiaries survived longer than the stipulated six months after referral, more than one-third (37%) of dying patients had a hospice stay of one week or less, the authors point out. They recommend that current policy debates on reforming the hospice benefit clearly address the impact of proposed reforms on access to hospice for vulnerable populations.

The report by Unroe and Meier is one of a series of papers from the proceedings of a conference on research priorities in geriatric palliative care. Held in 2013, the conference was co-sponsored by the federal National Institute on Aging. Topics published in the Journal of Palliative Medicine to date include: multimorbidity; informal caregiving; nonpain symptoms; goals, values, and preferences; and policy initiatives.

“Currently and over the next decades, most physicians will be caring for seriously ill elders with multiple comorbidities, lengthy duration of illness, and intermittent acute exacerbations interspersed with periods of relative stability,” wrote senior associate editor R. Sean Morrison, MD, in his introduction to the series. “[T]here is a pressing need to improve the evidence base for palliative care in older adults.”

Unroe KT, Meier DE: Division of Geriatrics, Department of Medicine, Indiana University School of Medicine, Indianapolis, and Center to Advance Palliative Care, Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York City. “Research Priorities in Geriatric Palliative Care: An Introduction to a New Series,” ibid., July 2013; 16(7):726-729. Morrison RS; National Palliative Care Research Center, Hertzberg Palliative Care Institute, Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai.
Many Patients and Surrogates Are Unprepared for Cardiac Device Deactivation

Most deactivations of cardiovascular implantable electronic devices (CIEDs) in terminally ill patients occur within days of death. Further, very few patients have written instructions in their advance directives (ADs) concerning their devices, and more than half of the requests for deactivation are made by their surrogates, according to a study conducted at the Mayo Clinic in Rochester, MN.

“Because hundreds of thousands of people in the U.S. have CIEDs, clinicians inevitably will encounter seriously ill patients with these devices who request device deactivation,” write the authors of a report published in JAMA Internal Medicine. “Although many patients with CIEDs have ADs, these documents rarely address device management.

“Patients with CIEDs should be encouraged to execute ADs with device-specific language to ensure that they receive care consistent with their preferences. This approach may reduce ethical dilemmas and moral distress among surrogates and care providers,” the authors state.

Investigators reviewed the medical records of 150 patients (median age, 79 years; male, 67%) who had their CIEDs deactivated by request at the Mayo Clinic during a 46-month period from 2008 to 2012. All patients but one (99%) had a poor or terminal prognosis. Overall, 79% underwent deactivation of tachycardia therapies only; 21% underwent deactivation of bradycardia therapies with or without tachycardia therapies.

KEY FINDINGS

• More than half (57%) of patients in the study had an AD.
• Only one patient’s AD specifically mentioned the implanted device.
• 51% of deactivation requests were made by surrogates.
• Palliative medicine consultations were provided for 43% of patients; ethics consultations, for 2%.
• Median survival among patients with tachycardia deactivation only was significantly longer than for patients with bradycardia deactivation (3 days vs 0 days). However, a similar proportion of patients in each group died within one month (85% vs 94%).
• Prior research has shown that most clinicians who care for dying patients with CIEDs regard device deactivation as allowing natural death rather than actively hastening death,” the authors note. They also point out that a 2010 consensus statement from the Heart Rhythm Society affirmed that CIED deactivation in seriously ill patients who no longer desire these therapies is both ethically and legally permissible.

“Notably, prior research has also shown that few patients with CIEDs know that device deactivation is an option and that many dying patients with implantable cardioverter-defibrillators experience shocks as they approach death.” The finding that the majority of deactivation requests were for tachycardia therapies alone suggests that patients or their surrogates wanted to avoid shocks during the dying process, they add.

DISCUSSING DEACTIVATION

“[I]nitiating device deactivation discussions and helping patients consider their goals must be the responsibility of all caring clinicians,” state the authors of a commentary accompanying the report. They note that it is unrealistic to expect specialists in palliative medicine to consult on every deactivation case. Such consultations are best reserved for difficult or tertiary cases.

“If a clinician cares enough to learn and perfect the skills needed to implant a CIED, he or she must also care enough to help patients avoid harm and excess burden from the device at end of life.” The commentators offer sample language clinicians can use to inform and support their patients. [See sidebar, above.]

What Clinicians Can Say about Device Deactivation

• At implantation: “While the purpose of this device is to help you live a longer and better life, whether we like it or not, we all eventually die, and there will come a time when this device could be doing more harm than good. I want you to know that this device can be turned off at any time.

“I encourage you to think about this ahead of time. Talk with your family, and write down your wishes in a living will or an advance directive. I’m committed to taking care of you for however long you have this device, and I’m happy to answer any questions you may have.”

• During routine follow-up: “It looks like things are going well for you right now. As we’ve talked about before, there may come a time when this device is no longer helping you, or it might even become burdensome.

“I don’t want to be morbid, but I just want to remind you that you have control here. We can turn the device off at any time. I’m committed to helping you, and I’m happy to answer any questions you may have.”

— Matlock and Mandrola, JAMA Internal Medicine

Source: “Features and Outcomes of Patients Who Underwent Cardiac Device Deactivation," JAMA Internal Medicine; January 1, 2014; 174(1):80-85. Buchhalter LC, Ottenberg AL, Webster TL, Swetz KM, Hayes DL, Mueller PS; Mayo Medical School, Mayo Clinic College of Medicine; Program in Professionalism and Ethics, Mayo Clinic; Division of Cardiovascular Diseases; Mayo Clinic; and Division of General Internal Medicine, Mayo Clinic, all in Rochester, Minnesota. “The Antidote for Unprepared Patients: A Caring Clinician,” ibid., pp. 86-87. Matlock DD, Mandrola JM; Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora; and Louisville Cardiology, Baptist Medical Associates, Louisville, Kentucky.
WHEN TO REFER TO HOSPICE

Call us if your patient exhibits the following indicators:
- Physical / functional decline
- Weight Loss >10% in last 6 months
- Multiple comorbidities

When life expectancy can be measured in weeks or months, hospice is usually the best option. For patients with liver disease, look for the following indicators:
- Endstage cirrhosis, not a candidate for liver transplant
- Serum albumin <2.5g/dl
- Ascites despite maximum diuretics
- Hepatorenal syndrome
- Encephalopathy with asterixis, somnolence, coma

Call us any time, any day.
Geoffrey Coleman, MD
Medical Director
Montgomery Hospice

Some Proxies Misunderstand Do-Not-Hospitalize Orders for Dementia Patients

Health care proxies may be making decisions about do-not-hospitalize (DNH) orders for nursing home patients with advanced dementia without understanding the prognosis associated with advanced dementia, what a DNH order means, or the risks and benefits of hospital transfers near the end of life, according to a report published in the Journal of the American Geriatrics Society.

DNH orders are an important part of advance care planning, point out the authors, particularly among patients with advanced dementia, for whom hospitalization is unlikely to increase survival or improve quality of life. Yet, only 7% of nursing home residents with advanced dementia have DNH orders.

Researchers analyzed the interview responses of 16 health care proxies who were also family members of patients with advanced dementia (median age, 92 years) living in one of two nursing homes in western Massachusetts. Neither nursing home had a special care unit for its residents with dementia, and none of the residents was enrolled in hospice.

**BARRIERS TO DNH ORDER**
- Limited understanding of DNH orders, or fear of limited care
- Lack of awareness of prognosis
- Perceived lack of physician involvement in decision making

“Participants did not necessarily associate the decline they observed in their family member with progression of their dementia,” observe the authors. Some proxies had hopes for their loved one’s improvement, and did not want to restrict hospitalizations until they were certain the end of life was near.

Many proxies felt that the lack of physician presence in the nursing home hindered their ability to understand their family member’s prognosis, and to make appropriate decisions. “End-of-life discussions between physicians and families have been shown to reduce care that does not improve quality of life or outcomes,” point out the authors.

Yet, there has been little impetus to involve physicians in advance care planning in nursing homes, note the authors. “Mandating (and paying for) a yearly discussion between the physician and the health care proxy to address prognosis and goals of care might be one solution.” Or, midlevel providers might be trained to provide DNH counseling, they suggest.