

HOSPICE MATTERS for physicians

End-of-life care news & clinical findings for physicians

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Contents

Determining Prognosis in Dementia
Patients Remains Elusive.....**Page 1**

Step-Wise Approach to Surrogate
Decision Making Honors Patients'
Unique Values and Surrogates' Needs
.....**Page 2**

American Society of Clinical Oncology
Issues Statement Urging Physicians
to Integrate Early Palliative and End-
of-Life Care Discussions into Cancer
Care.....**Page 3**

Hospice Rotation Broadens Medical
Students' Perspective on Healing.....
.....**Page 4**

Determining Prognosis in Dementia Patients Remains Elusive

Researchers urge care guided by goals, not life expectancy

Prospective validation of a recently developed tool for predicting six-month survival in patients with advanced dementia yielded “modest” results, although the prognostic tool was found to be slightly better than the current Medicare hospice criteria, an investigation funded by the federal National Institutes of Health has found.

“These findings underscore the challenge of prognostication in advanced dementia, and suggest that determining access to hospice based on life expectancy for patients with dementia limits access to the supportive care hospice offers,” write the authors of a report published in the *Journal of the American Medical Association*.

The team conducted a prospective cohort study of 606 residents with advanced dementia in 21 Massachusetts nursing homes from November 2007 to July 2009. Performance of the 12-item Advanced Dementia Prognostic Tool (ADEPT) was assessed and compared with the performance of the full Medicare hospice eligibility guidelines.

“Hospice eligibility guidelines for dementia are widely used, but have never been validated in a large, prospective fashion,” the authors note. “In corroboration with prior retrospective studies, we found the discrimination of hospice guidelines to predict six-month mortality was poor.”

In predicting six-month survival, the ADEPT risk score was found to have high interrater reliability, good calibration, and only modest discrimination, whether used as a continuous measure or as a dichotomous measure with a single cutoff.

One potential advantage of ADEPT is that when used as a continuous measure, it can offer physicians the flexibility to select cutoffs with different operating characteristics, the authors point

out. However, since most hospice referrals occur when care preferences shift following a clinical setback, the practical usefulness of this tool may be limited.

“Our study strongly suggests that delivery of palliative care to these residents should be guided by a preference for comfort as the primary goal of care and not by prognostic estimates,” state the authors.

They suggest that the challenge for health care professionals and policy makers is to “ensure that high-quality palliative care is accessible to the growing number of individuals dying with dementia in nursing homes,” adding that the effort “may necessitate both revisiting the six-month prognosis requirement for hospice, as well as expanding comprehensive palliative care services in the nursing home.”

Source: “Prediction of Six-Month Survival of Nursing Home Residents with Advanced Dementia Using ADEPT vs Hospice Eligibility Guidelines,” Journal of the American Medical Association; November 3, 2010; 304(17):1929-1935. Mitchell SL, Miller SC, et al; Hebrew SeniorLife, Institute for Aging Research, Boston; Department of Medicine, Beth Israel Deaconess Medical Center, Boston; and Department of Community Health, Brown University Medical School, Providence, Rhode Island. “Treatment of Alzheimer Disease and Prognosis of Dementia: Time to Translate Research to Results,” ibid, pp. 1952-1953. Yaffe K; Departments of Psychiatry, Neurology, Epidemiology, and Biostatistics, University of California, San Francisco.

Step-Wise Approach to Surrogate Decision Making Honors Patients' Unique Values and Surrogates' Needs

Understanding the values and interests of the patient as a person, rather than attempting to interpret the patient's specific stated or assumed preferences for care at the end of life, is the focus of a model for surrogate decision making introduced in a commentary published in the *Journal of the American Medical Association*.

A reframing of the current model for making decisions on behalf of patients who have lost their decision-making capacity, the "substituted interests" model concentrates on the role of the surrogate as expert in knowing the patient, and as a person in his or her own right. It also encourages a recommendation for care on the part of the physician.

"Under the substituted interests model, the clinician and the surrogate jointly judge what advances the individualized good of the patient in particular clinical circumstances, based on the patient's values," write lead author Daniel P. Sulmasy, MD, PhD, professor of medicine and ethics at the University of Chicago, and colleague.

OBJECTIONS TO THE CURRENT MODEL OF SURROGATE DECISION MAKING

The current "hierarchical" model relies on separate standards, which often do not reflect either clinical reality or the interests of patients and families, notes Sulmasy. These standards are typically valued in the following order:

1. **Formal written or oral directives**: The emphasis is on information, the intellectual process of decision making, and the interpretation of specific patient preferences, if declared. Yet few patients can anticipate all possible future scenarios, and their preferences are likely to change as their illness progresses.

2. **Substituted judgment**: Surrogates are expected to correctly predict patient wishes, typically being asked something like, "*What would your mother choose, if she could tell us?*" Research has found that surrogate decisions are accurate only

two-thirds of the time, and can be insensitive to family and cultural values. Further, most patients do not want strictly substituted judgments.

3. **Decisions in the patient's best interests**: The decision making is delegated to the surrogate, who is asked, "*What do you think is best for your mother?*" Surrogates experience enormous stress in these circumstances, and families are less satisfied and more stressed when decisions are delegated strictly to surrogates, rather than being shared with a clinician who then makes a clinical recommendation.

THE SUBSTITUTED INTERESTS MODEL

Sulmasy's model of surrogate decision making integrates the above separate standards into a contextualized rather than an intellectual process, emphasizing "authenticity" (a decision true to who the person really is) and asking surrogates to provide "substituted interests" (knowledge of pa-

tients' values and real interests) rather than substituted judgments (guessing what the patient would have decided).

"Surrogates, ideally formally designated, know the patient as a person, even if they do not know his or her precise wishes," notes Sulmasy. Thus, the clinician in the substituted interests model would begin by saying to the surrogate, "*Tell us about your mother.*"

"This teachable model truly respects patients as persons," write the authors. "The open-ended questions may appear time consuming, but failing to attend to the needs of surrogates and the underlying values of the patient may lead to greater conflict later."

Source: "Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making," Journal of the American Medical Association; November 3, 2010; 304(17):1946-1947. Sulmasy DP, Snyder L; Department of Medicine and Divinity School, University of Chicago, Chicago; Center for Ethics and Professionalism, American College of Physicians, Philadelphia.

An Integrated Approach to Shared Surrogate Decision Making

1. **Address surrogate needs and acknowledge the difficulty of the role.** "*It must be very difficult to see your loved one so sick.*"
2. **Elicit and understand the values of the patient as a person and the patient's beliefs about how decisions should be made.** "*Tell us about your loved one.*" "*Has anyone else in the family experienced a situation like this?*"
3. **Describe the patient's clinical situation and prognosis.** "*All of that is important for us to know, as we face the current situation. Here is what is wrong... " "Here is what is likely to happen... "*"
4. **Determine what the patient's real interests are, in light of the patient's values and clinical circumstances.** "*Knowing your loved one, what do you think would be the most important for him/her right now? Avoiding pain? Having family members here?*"
5. **Share options and recommend a course of action, based on clinical experience and an understanding of the patient's real interests.** "*Here's what could be done." "This is what we would recommend, based on what we know and what you've told us about your loved one.*"
6. **Make a best judgment based on the individual interests of the patient.** "*Knowing your loved one, does our recommendation seem right for him/her? Do you think another plan would be better, given his/her values, preferences, relationships?*"

—Adapted from Sulmasy and Snyder,
Journal of the American Medical Association

American Society of Clinical Oncology Issues Statement Urging Physicians to Integrate Early Palliative and End-of-Life Care Discussions into Cancer Care

The American Society of Clinical Oncology (ASCO) has issued a new policy statement strongly recommending that physicians initiate discussions about palliative care and the full range of treatment options available to patients just diagnosed with advanced cancer, then individualize care to enhance patients' quality of life.

"There is a need to change the paradigm for advanced cancer care to include an earlier and more thorough assessment of patients' options, goals, and preferences, and to tailor the care that we deliver to these individual needs throughout the continuum of care," write Jeffrey M. Peppercorn, MD, MPH, of Duke University Medical Center, Durham, NC, and colleagues, authors of the statement, which was published in the *Journal of Clinical Oncology*.

The statement updates prior ASCO statements on end-of-life care (1998) and palliative care (2009), in light of results from the society's Quality Oncology Practice Initiative (QOPI) analysis, which found that despite the wide availability of palliative care and hospice services, patients "are often referred to hospice care in the last days of life as a means of managing death, rather than as a tool for palliation of symptoms in the later months of advanced disease."

Other findings from the analysis include:

- Less than half of cancer patients (45%) are enrolled in hospice before death.
- Of these, one-third are enrolled in the last week of life.
- In their final two medical visits, two-thirds of patients do not receive adequate symptom management for dyspnea, and one-fifth do not receive appropriate treatment for pain.

"While improving survival is the oncologist's primary goal, helping individuals live their final days in comfort and dignity is one of the most important responsibilities of our profession," comments George W. Sledge, Jr, MD, Presi-

dent of ASCO. "Patients have a right to make informed choices about their care. Oncologists must lead the way in discussing the full range of curative and palliative therapies to ensure that patients' choices are honored."

KEY ELEMENTS OF INDIVIDUALIZED CARE

According to the statement, physicians must address several core issues in discussions with all advanced cancer patients, if the goals for individualized care are to be achieved.

Core elements of patient care include:

- Patients should be well informed about their prognosis and treatment options soon after an advanced cancer diagnosis, and given the opportunity to make their preferences and concerns known.
- Conversations about anticancer treatment should include information on the likelihood and nature of response, and the adverse effects and risks of each therapy.
- Quality of life should be an explicit priority throughout the course of advanced cancer care. In cases where active treatment is unlikely to extend survival, palliative care should be discussed as a concurrent or alternate therapy.
- Opportunities for patients to participate in clinical trials should be increased.
- When disease-directed options have been exhausted, patients should be encouraged to transition to symptom-directed palliative care alone, with the goal of minimizing suffering and ensuring "that patients with advanced cancer are given the opportunity to die with dignity and peace of mind."

ADDRESSING BARRIERS TO PROVIDING INDIVIDUALIZED CARE

The statement recommends some of the following steps that individuals and organizations can take to remove current barri-

ers to optimal advanced cancer care:

- Emphasize individualized care in physician education, training, and quality improvement programs.
- Support provision of direct reimbursement for advanced cancer care planning from private and public insurers.
- Increase the opportunities for advanced cancer patients to participate in clinical research, particularly regarding quality of life.
- Empower patients to initiate realistic discussions by increasing their educational resources.

"Oncologists recognize the importance of palliative therapy and other quality-of-life measures in advanced cancer, but physician education and training programs historically have provided little guidance in this area," notes ASCO CEO Allen S. Lichter, MD. "Although patients are entitled to make informed choices about their palliative care and treatment options, our nation's health care system currently places no value on conversations that can guide these decisions."

To help oncologists initiate these discussions and to better integrate palliative therapy into their practice, ASCO plans to issue its first clinical guidance on the topic later this year. A free educational booklet for patients, entitled, "Advanced Cancer Care Planning: What Patients and Families Need to Know About Their Choices When Facing Serious Illness," is available at: www.cancer.net/patient/Coping/Advanced+Cancer+Care+Planning.

Source: "American Society of Clinical Oncology Statement: Toward Individualized Care for Patients with Advanced Cancer," Journal of Clinical Oncology; published online ahead of print, January 24, 2011; DOI: 10.1200/JCO.2010.33.1744. Peppercorn JM, Smith TJ, Heft PR, DeBono DJ, et al; Duke University Medical Center, Durham, North Carolina; Massey Cancer Center of Virginia Commonwealth University, Richmond; Indiana University School of Medicine, Indianapolis; Henry Ford Hospital, Detroit; Sunnybrook Odette Cancer Center, Toronto; American Society of Clinical Oncology, Alexandria, Virginia.

MONTGOMERY HOSPICE CORE VALUES:

- **UNCONDITIONAL COMPASSION:** Compassionate care, partnered with professional excellence, is the heart of our service.
- **DIGNITY OF THE DYING:** We affirm the right of our patients to be treated with respect, and to be honored as unique individuals.
- **DEDICATION:** We are committed and privileged to ease the burdens and challenges that our patients and families face.
- **COLLABORATION:** Mutual respect, empathy and trust unite us in providing care.



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Hospice Rotation Broadens Med Students' Perspective on Healing

Participation in a one-week hospice rotation, followed by a written account of the care concepts learned from this new field of medicine, can effectively expand medical students' knowledge, skills, and beliefs, according to a report in the *Journal of Palliative Medicine*.

"[D]espite the growth of the field of palliative medicine in the U.S., few academic institutions offer their trainees bedside educational programs in palliative care," note the authors. They report that providing medical students with the opportunity to interact with dying patients and their families, and with the multidisciplinary team, "challenged and expanded students' prior notions and assumptions about the goals of medicine, illness and suffering, and the role of health care professionals."

Researchers analyzed the essay responses of 104 third-year medical students who had participated in a required one-week rotation in hospice during the 2006-2007 academic year at one medical college. Students were asked to reflect upon and report the three most important lessons they had learned during their rotation.

APPRECIATION OF HOSPICE

More than 91 percent of students wrote

that they valued learning about the philosophy and benefits of hospice, and expressed appreciation for key elements of hospice care, such as:

- Treating the patient rather than treating the disease
- Preserving patient dignity
- Honoring patient autonomy
- Viewing death as a natural part of life
- Supporting the patient/family unit

"The health care community has long viewed death as a failure," wrote one participant in the study. "When physicians delay a patient's referral to hospice because of their fear of failure...we do a great disservice to the patient and their family."

"Students' learning experiences in end-of-life care are needed to strengthen the ethos for such training in medical education," the authors conclude. "The results of our study strongly support the proposition that 'not educating the next generation of physicians in palliative care is not an option.'"

Source: "The Impact of a Clinical Rotation in Hospice: Medical Students' Perspectives," Journal of Palliative Medicine; January 2011; 14(1):59-64. Jacoby LH, Beehler CJ, Balint JA; Alden March Bioethics Institute, Albany Medical College, Albany, New York; and Saint Elizabeth Regional Medical Center, Lincoln, Nebraska.