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Community-Dwelling Older Patients Have High Symptom Burden in Last Year of Life

Nearly three-quarters of older adults living in the community have two or more comorbid conditions, with symptoms that restrict their activities and reduce their quality of life increasing rapidly during their last months, Yale researchers have found.

“The occurrence of all symptoms increased during the study period, most notably beginning five months before death,” write the authors of a report published in *JAMA Internal Medicine*. “Given the challenges to precise prognostication regarding life expectancy in clinical practice, our results highlight the importance of assessing and managing symptoms in all older patients with comorbid illness, particularly those with multimorbidity, even when they are not clearly at the end of life.”

Investigators analyzed results of interviews conducted among 754 community-dwelling participants aged 70 years or older for the presence of “restricting symptoms,” defined as symptoms leading to restrictions in daily activities in the last year of life. By study’s end, 491 participants had died (mean age at death, 85.8 years). Overall:

- 73.1% of participants had multimorbidity (i.e., two or more comorbid conditions).
- The most common condition leading to death was frailty (28.1%), followed by organ failure (20.8%) and cancer (18.5%).
- The most common symptoms in the last year of life were fatigue, musculoskeletal pain, dizziness, and shortness of breath.

KEY FINDINGS:

- The monthly occurrence of restricting symptoms remained fairly constant (20.4%) until five months before death, when it rose rapidly from 27.4% at five months to 57.2% in the last month of life.
- Factors significantly associated with having restricting symptoms in the last year

of life included multimorbidity (odds ratio [OR], 1.38; 95% confidence interval [CI], 1.09 to 1.75), age younger than 85 years (OR, 1.30; 95% CI, 1.07 to 1.57), and greater proximity to time of death (OR per month, 1.14; 95% CI, 1.11 to 1.16).

- The mean count of restricting symptoms rose during the last year of life from 4.0 to 5.0 in the month prior to death. There were no significant differences in symptom burden by condition leading to death.

Although the study by Chaudhry et al did not examine symptom treatment or hospice enrollment, access to palliative and hospice care for patients with serious illness has been improving in recent years, notes Christine S. Ritchie, MD, MSPH, in a commentary accompanying the report. “Yet, we know that 55.4% of patients still do not receive hospice care at the end of life and that for those who do, referrals to hospice care often occur late in the illness course,” observes Ritchie.

More aggressive efforts are needed to control symptoms among patients nearing the end of life, “regardless of setting or services provided,” states Ritchie. Targets for improvement include increasing access to palliative/hospice care services for seriously ill patients and improving physician training in primary palliative care skills.

Source: “Restricting Symptoms in the Last Year of Life: A Prospective Cohort Study,” JAMA Internal Medicine; Epub ahead of print, July 8, 2013; DOI: 10.1001/jamainternmed.2013.8732. Chaudhry SI, et al; Yale University School of Medicine, New Haven, Connecticut. “Symptom Burden: In Need of More Attention and More Evidence,” ibid.; DOI: 10.1001/jamainternmed.2013.6583. Ritchie CS; University of California, San Francisco.

Professional Medical Organization Offers Recommendations for Decision-Making in Palliative Care

Choosing Wisely, a multi-year initiative of the American Board of Internal Medicine (ABIM) Foundation, has recently released a list of “Five Things Physicians and Patients Should Question” regarding hospice and palliative medicine. The aim of this and other such lists is to encourage physician-patient conversations about utilizing the most appropriate care and avoiding unnecessary tests, procedures, and therapies.

Launched in 2012, the national campaign invited U.S. medical specialty societies to identify five tests or treatments in their field that are commonly ordered, expensive, and have no proven benefit — or have been found to cause harm — among the majority of patients for whom they are ordered. By the spring of 2013, responses from more than 25 specialty societies had been released, including those from American Academy of Hospice and Palliative Medicine (AAHPM) and the American Geriatrics Society (AGS).

The hospice/palliative care list was compiled by a task force of the AAHPM, and the evidence-based recommendations and their supporting rationale have been published in the *Journal of Pain and Symptom Management*. Of note is the fact that both the AAHPM list and the AGS list begin with the identical recommendation regarding the use of feeding tubes.

“These recommendations and their supporting rationale should be considered by physicians, patients, and their caregivers as they collaborate in choosing those treatments that do the most good and avoid the most harm for those living with serious illness,” write the authors.

One of the benefits of the recent growth in hospice and palliative medicine has been its contribution to the national dialogue about end-of-life care, and the growing recognition that palliative/hospice care helps patients to avoid treatment they do not want, while encouraging the receipt of treatment that improves patient and family quality of life, note the authors.

GOALS OF THE PALLIATIVE CARE TREATMENT APPROACH:

- Promote physical and emotional support
- Improve shared decision-making
- Support family members
- Coordinate care across settings

“Numerous studies — including randomized trials — provide evidence that palliative care improves pain and symptom control, improves family satisfaction with care, and reduces costs,” write the authors. “Palliative care does not accelerate death and may prolong life in selected populations.”

The authors caution that the list of recommendations does not comprise a rigid tool; nor does it supersede the independent judgment of a medical professional. Further, no single recommendation should be considered universally applicable. Rather, these recommendations are intended to be “used as a support for

individualized decision making born of conversations between physicians and patients.”

“On a daily basis, hospice professionals are helping individuals and family caregivers coping with serious illness think through what’s best for them and how to share these wishes with their doctors,” says J. Donald Schumacher, PsyD, president and CEO of the National Hospice and Palliative Care Organization, which, along with Consumer Reports, has partnered in the campaign.

A printable copy of each of the specialty societies’ recommendations, including references to the source evidence used, is available on the Choosing Wisely website. Also available are patient-friendly resources on specific tests and procedures, developed by Consumer Reports in collaboration with the pertinent specialty society.

For example, the patient information paper for advanced cancer patients includes the following advice from Consumer Reports: “Talking to hospice does not mean you have to sign up. And, even if you decide to be on hospice care, you can always change your mind.”

For more information, visit www.choosingwisely.org.

Source: “Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine,” Journal of Pain and Symptom Management; March 2013; 45(3):595-605. Fischberg D, Bull J, Casarett D, et al, for the AAHPM Choosing Wisely Task Force; Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawaii, Honolulu; Four Seasons, Flat Rock, North Carolina; University of Pennsylvania Health System, Philadelphia; Division of Geriatric Medicine and University of North Carolina Palliative Care Program, University of North Carolina-Chapel Hill; Hospice and Palliative Care, Visiting Nurse Service of New York, New York; Hosparus, Louisville, Kentucky; Johns Hopkins Medical Institutions and Sidney Kimmel Comprehensive Cancer Center, Baltimore; American Academy of Hospice and Palliative Medicine, Glenview, Illinois; Warren Alpert School of Medicine, Brown University, Providence, Rhode Island; and Division of Geriatrics, University of California-San Francisco, San Francisco.

AAHPM Choosing Wisely Task Force: Recommendations

1. Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.
2. Don't delay palliative care for a patient with serious illness who has physical, psychological, social, or spiritual distress because they are pursuing disease-directed treatment.
3. Don't leave an implantable cardioverter-defibrillator (ICD) activated when it is inconsistent with patient/family goals of care.
4. Don't recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.
5. Don't use topical lorazepam (Ativan), diphenhydramine (Benadryl), haloperidol (Haldol) (ABH) gel for nausea.

— Fischberg et al, *Journal of Pain and Symptom Management*

Hospital Physicians Offered ‘Structured Guidance’ for End-of-Life Care Planning Discussions

With an aging population, people living longer with chronic illness, and “technology-laden” care often offered as a default to hospitalized older patients, it has become increasingly important that physicians know how to help patients and their families make informed decisions about the kind of care they want as the end of life approaches, according to an article published in the *Canadian Medical Association Journal*.

A team from the Canadian Researchers at the End of Life Network (CARENET) has formulated a communication and decision-making framework to guide busy clinicians in conducting effective and compassionate advance care planning discussions with confidence.

“By providing structured guidance, specific advice, and practical tools, our aim is to increase clinicians’ confidence in engaging in meaningful end-of-life communication with patients in hospital and their family members,” write the authors, led by John J. You, MD, MSc, from the Department of Medicine and the Department of Clinical Epidemiology & Biostatistics at McMaster University, Hamilton, Ontario, Canada.

While primary care physicians play a key role in advance care planning, the authors note, hospital-based clinicians share in this responsibility. “In fact, a stay in hospital presents an important opportunity for engaging in discussions about goals of care, because it signals a change in the trajectory of the patient’s illness, giving increased relevance to these conversations, and because potential substitute decision makers (e.g., the most involved family members) are often present,” they write.

To formulate a framework to guide hospital-based physicians in engaging patients in advance care planning conversations, the authors conducted a literature review of relevant evidence on MEDLINE through July 2012.

Their article outlines an approach to conducting a care-planning discussion and includes suggested statements and ques-

tions physicians can use for eliciting goals of care, as well as sources for prognostic tools and other resources for physicians and patients/families.

APPROACH TO ADVANCE CARE PLANNING AND DECISION MAKING

- Identify the patients who are at high risk of dying, for whom end-of-life planning is needed.
- Communicate prognosis clearly.
- Invite and involve substitute decision-makers in the care planning.
- Elicit patient values, especially in light of the risks and expected outcomes of various treatment options (especially of life-sustaining interventions).
- Reach a decision through discussion and deliberation.
- Document the patient’s wishes in the medical record.

USING THE ‘SURPRISE’ QUESTION AS A SCREENING TOOL

The “surprise” question (“Would I be surprised if this patient died in the next year?”) is a quick and suitable screening tool for identifying at-risk patients. The authors suggest supplementing this self-question with objective clinical criteria, which they provide in the article. For example, any community-dwelling patient aged 80 years or older admitted to the hospital for an acute medical or surgical condition should be offered a goals-of-care discussion.

For imparting prognostic information or other “bad news” conversations, the authors recommend the **SPIKES** protocol (Setting up, assessing Perception, obtaining an Invitation, giving Knowledge, addressing Emotion, and Strategy and Summary), which “has been shown to increase clinicians’ confidence in dealing with difficult topics and the emotions they trigger,” they note.

It is important to recognize that an

advance care planning conversation is a process rather than a single event, point out the authors. Some patients may not be ready to engage in such discussions. Sensitivity and compassion can be used to explore a patient’s reluctance.

IN ADDRESSING PATIENT BARRIERS TO DISCUSSION, PHYSICIANS CAN:

- Ask the patient if there are aspects of allowing a loved one to make decisions on his or her behalf that are worrying.
- Ask if there are reasons it is difficult to talk about such things with a loved one or physician.
- Motivate the patient to consider discussing advance care planning by pointing out the benefits, such as reducing the burden of decision making on family and loved ones and maintaining control of future care.

“Clinicians should exercise judgment and flexibility in engaging patients and family members in these discussions, recognizing that determining goals of care is a process,” comment the authors.

For those patients with existing advance directives, this may be a straightforward process. However, “for others who may be less prepared, the discussion may best unfold in a phased approach, with initial introduction and probing of this issue early during the stay in hospital and more detailed follow up later on.”

The authors recommend that hospitals make efforts to establish or improve protocols for quality end-of-life communication and decision making. “Outside of the hospital setting, we suggest that parallel efforts be made to increase public awareness and education about the limitations of life-sustaining technologies and the importance of advance care planning.”

Source: “Just Ask: Discussing Goals of Care with Patients in Hospital with Serious Illness,” Canadian Medical Association Journal; Epub ahead of print, July 15, 2013; DOI: 10.1503/cmaj.121274. You JJ, Fowler RA, Heyland DK; on behalf of the Canadian Researchers at the End of Life Network (CARENET).



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- 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 **pulmonary disease (COPD)**, look for the following indicators:

- Dyspnea at rest
- Poor response to bronchodilators
- Recurrent pulmonary infections
- Right heart failure
- Unintentional weight loss
- Bed to chair existence

Call us any time, any day.

Geoffrey Coleman, MD
Medical Director
Montgomery Hospice



Advanced Lung Cancer Patients Hold Inaccurate Beliefs about Benefits of Radiation Therapy

A national survey of patients with incurable lung cancer has found that although many who are given palliative radiation therapy (RT) are optimistic that it will help improve their quality of life, nearly two-thirds do not understand that the treatment is not at all likely to cure them, according to a report published in the *Journal of Clinical Oncology*.

“Clearly more attention needs to be paid to ensure that clear and accurate information about the goals and limitations of RT is presented and reinforced to patients and their families and that providers are appropriately trained to have these discussions,” write the authors.

Researchers analyzed the survey responses of patients enrolled in the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) who had presented with incurable lung cancer at diagnosis from 2003 to 2005 and were receiving or were scheduled to receive palliative RT (n = 384). Median patient age at diagnosis was 63 years; median survival was 11.5 months.

FINDINGS:

- 78% of patients with incurable lung cancer believed that RT was very likely or somewhat likely to help them live longer.
- 67% felt that RT was likely to help them

with problems related to their lung cancer.

- However, 64% did not accurately understand that palliative RT was “not at all likely” to cure their cancer, with 43% believing RT was very or somewhat likely to cure them.

In an earlier study, the research team had found that patients with metastatic lung and colon cancer frequently held inaccurate beliefs about the chance of a cure from the chemotherapy treatment they were undergoing. Patients in the current study who held inaccurate beliefs about RT were significantly more likely to also have inaccurate beliefs about chemotherapy (P = .002).

“Because RT is frequently used in the palliative care of patients with lung cancer, it is important for the patients to understand both the goals and limitations of RT in order to make the best decisions about the care they elect to receive near the end of life,” comment the authors.

Source: “Expectations about the Effectiveness of Radiation Therapy among Patients with Incurable Lung Cancer,” *Journal of Clinical Oncology*; *Epub ahead of print, June 17, 2013*; DOI: 10.1200/JCO.2012.48.5748. Chen AB, et al; Dana-Farber Cancer Institute and Brigham and Women’s Hospital, Boston; University of Iowa, Iowa City, Iowa; University of California Los Angeles, Los Angeles; and University of Michigan Health System, Ann Arbor, Michigan.