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Patients with Hematologic Malignancies Enter Hospice 'Late or Never,' Study Finds

In what they note as “some of the first modern data about hospice use in hematologic malignancy (HM) patients,” a team of Johns Hopkins researchers has found that only one-quarter of patients who died of HM were enrolled in hospice, according to their report published in the *Journal of Palliative Medicine*.

“This is better than the national rate of 2% for HM decedents, but means that 75% of patients never experienced the benefits of hospice, including good symptom management, bereavement programs, less cost, and even slightly lower mortality of the surviving spouse,” observe the authors.

Investigators analyzed data on the use of hospice and length of stay among 209 adult patients with HM (refractory leukemia, refractory lymphoma, myelodysplastic syndrome, and refractory myeloma) treated at Johns Hopkins Sidney Kimmel Comprehensive Cancer Center in Baltimore who died between 2010 and 2012. A few of those referred to hospice had “expanded access”; i.e., hospice care that allows patients to receive some standard medical treatments while concurrently enrolled in hospice.

KEY FINDINGS:

- Among the 209 decedents with HM, 53 (25%) used hospice services.
- Median length of stay for patients who received home hospice was 9 days (range, 1 to 50 days).
- Median length of stay for hospice inpatients was 6 days (range, 3 to 51 days).

“The median hospice length of stay for U.S. all-diagnosis patients is 19.1 days, double that observed here,” the authors point out. “In addition to no referral, ‘late’ referral to hospice means that patients may have less chance of having their end-of-life wishes known and

honored, with more chance of dying with aggressive care or in the hospital rather than at home.”

The integration of palliative care into standard oncology care and the transition to hospice when appropriate was recommended by the American Society of Clinical Oncology in 2012. “Both hospice and palliative care discern choices near the end of life, allow more home care and death at the preferred place, and reduce readmissions,” point out the authors.

Because the course for most patients with refractory HM is predictable once cure is no longer possible, and the survival rate is similar to that of patients with solid tumors who have a prognosis of six months or less, more HM patients should be accessing hospice, the authors note.

Since HM patients are currently “referred late or never for hospice services,” the authors recommend further research to define the role of palliative care in this population. This effort will help to determine optimal timing, duration, and type of hospice services, including expanded access that will best meet the needs of these patients.

“Patterns of Hospice Use in Patients Dying from Hematologic Malignancies,” Journal of Palliative Medicine; February 2014; 17(2):195-199. Sexauer A, Cheng JM, Knight L, Riley AW, King L, Smith TJ; Oncology Department, Palliative Medicine Department, Johns Hopkins School of Medicine, Baltimore, Maryland; Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Medical Institutions, Baltimore; and Gilchrist Hospice, Towson, Maryland.

Stroke Patients: First Guidelines Issued for Palliative and End-of-Life Care

Care should be customized for patients and families, statement says

The first scientific statement in the U.S. to outline fundamental palliative care for patients with serious or life-threatening stroke has been issued by the American Heart Association (AHA) and the American Stroke Association. It calls for well-coordinated medical teams to personalize care, optimize quality of life, and minimize suffering in this population.

“Any patient with a stroke that adversely affects daily functioning or will predictably reduce life expectancy or quality of life should have access to primary palliative care,” write the authors of the statement, which was published in *Stroke*, a journal of the AHA.

The needs of patients who have suffered a serious stroke are “enormous,” state the authors, and are related to symptom control, complex decision making, and aligning treatments with goals. “Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of illness,” and should begin immediately following the diagnosis.

PRIMARY PALLIATIVE CARE

Primary palliative care for patients with stroke and their families includes:

- Providing care that is centered on patient and family
- Effectively estimating prognosis
- Assessing and managing the patient’s emerging symptoms
- Developing appropriate goals of care
- Having familiarity with the evidence for stroke decisions that have end-of-life implications
- Being experienced with end-of-life care
- Ensuring care coordination, including referral to a palliative care specialist or hospice

The core elements of primary palliative care should be routinely integrated by any practitioner caring for patients and families with stroke, according to the statement. Optimally, palliative care is a collaboration between patients and their families, a

Practical End-of-Life Communication Approaches

- **Pace information and “check in” regularly.** “Are we on track? What haven’t we touched upon that is important to you?”
- **Use the word “dying” effectively.** “Based on what is happening to you and how sick you have become, I believe you are (your loved one is) dying.”
- **Use silence effectively.** After delivering bad news, resist the urge to fill silence with more medical facts.
- **Use “I wish” statements.** Try to express empathy yet communicate limits of treatment. “I wish we had better treatments for your condition.”
- **Respond to emotions by using the NURSE mnemonic:** Name the emotion being expressed — “You seem overwhelmed by this news.” Understand and empathize, if you genuinely feel it — “I would probably feel the same way.” Respect the family’s behavior — “Anyone in your shoes would be upset.” Support the family by expressing a willingness to help — “We will work through this together. Is there anyone you would like me to call?” Explore what is underneath the emotion — “Tell me what is most upsetting to you.”
- **Help with coping strategies.** “Where do you find your strength or support? In past circumstances, what has helped?”
- **Reframe hope.** Use lighthearted humor, life review, or a focus on meaningful activities.
- **Address conflict.** Techniques include active listening, explaining your view, reframing, and brainstorming.
- **Summarize and restate your understanding.** “Let me make sure I understand you correctly.”

— Adapted from Holloway et al, *Stroke*

stroke team, and various providers, including neurologists, neurosurgeons, primary care providers, geriatricians, nurses, and therapists.

Recommendations for the detection and management of troubling symptoms that are common among stroke patients are discussed in the paper, along with approaches to overcoming challenges with “preference-sensitive” decisions. For the management of more complex problems, the statement includes a list of situations in which a formal palliative care consultation is recommended.

HOSPICE CARE

“For patients approaching the end of life, hospice may be a viable option to provide symptom care and supportive services for patients and their families while promoting

patients’ ability to die in their preferred environment,” write the authors. There were nearly 130,000 stroke-related deaths in the U.S. in 2010, accounting for more than 5% of all deaths. In 2009, 6% of hospice patients had an admitting diagnosis of stroke.

Criteria for terminal stages of stroke and coma “have not been updated or validated in contemporary health care settings,” the authors warn. Nevertheless, “patients... with a stroke that adversely affects daily functioning or will predictably reduce life expectancy or quality of life should...be provided with palliative care services appropriate to their needs.” The authors urge clinicians to develop and communicate an individualized prognostic estimate for each patient when setting a treatment plan.

Because some patients and families may

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More Older Americans Complete Advance Directives, Yet Hospitalization Rates Continue to Rise

During the past decade, the percentage of elderly people in the U.S. who completed an advance directive (AD) nearly doubled, suggesting an increased comfort level in discussing end-of-life preferences, say researchers. Yet the rates of hospitalization in the last two years of life also rose, according to a report published in the *Journal of the American Geriatrics Society*.

“People seem more comfortable having ‘the talk’ about those dire ‘what-if’ scenarios and death in general,” says lead author and palliative medicine specialist Maria Silveira, MD, MA, MPH, of the VA Ann Arbor Healthcare System and the Department of Internal Medicine, University of Michigan, also in Ann Arbor.

“As a physician, when you help a patient prepare for the end of life, it depends on the patient’s age, their medical conditions, and their lifestyle,” says Silveira. “As a family, it can never be too early to talk about these issues.”

However, the authors consider it unlikely that an AD document alone — which summarizes treatments or care desired in the last days of life — would have any great effect

on the likelihood of being hospitalized close to death or of dying in the hospital. They suggest encouraging clinicians and patients to participate more fully in advance care planning (ACP), which has a broader scope.

“To stem hospitalization rates, the decisions to hospitalize, die in hospice, or die in the hospital must be addressed more directly,” the authors write. “It may be that ACP conversations in which individuals are given the choice not to be hospitalized and provided with the appropriate support to safely and comfortably stay home (e.g., with hospice) are much more likely to affect hospitalization rates than ADs are.”

Investigators analyzed data on 6122 adults aged 60 years and older (mean age at death, 81 years; range, 60 to 111 years) who died between 2000 and 2010. Subjects were participants in the Health and Retirement Study, a biennial survey of a nationally representative sample of older Americans and their proxies, conducted by the University of Michigan Institute for Social Research for the federal National Institute on Aging.

Overall, there was a 25% increase in

the rates of AD completion over the last decade, with the increasing use of durable power of attorney for health care (DPAHC) designations appearing to be “the primary driver of the increase in rates,” the authors note. People were also completing their AD plans by as many as three months earlier in 2010 than in 2000.

KEY FINDINGS

- The percentage of decedents with an AD increased from 47% in 2000 to 72% in 2010.
- The proportion of older Americans with at least one hospitalization in the last two years of life rose from 52% to 71%.
- More decedents died in hospitals (38%) than at home (27%) or in a nursing home (23%).
- The number of hospitalizations per decedent during the two years before death increased from a mean of 2.6 in 2000 to 3.4 in 2010.
- Subjects with ADs had higher adjusted odds of hospitalization (adjusted odds ratio [AOR], 1.45; 95% CI, 1.29 to 1.62) but lower adjusted odds of hospital death (AOR, 0.80; 95% CI, 0.72 to 0.89).

“[T]hese findings suggest that ADs are increasingly popular but alone are insufficient to stem increasing rates of hospitalization or account for increasing rates of hospital death,” write the authors. “Although it is important to continue to encourage ADs (to protect autonomy), those looking to reshape end-of-life care should create systems that promote advance care planning.”

“The results of the current study should serve as a warning to those who hope that ADs may, in and of themselves, reduce rising rates of hospitalization and expenditures at the end of life.”

Source: “Advance Directive Completion by Elderly Americans: A Decade of Change,” *Journal of the American Geriatrics Society*; Epub ahead of print, April 2, 2014; DOI: 10.1111/jgs.12736. Silveira MJ, et al; Center for Clinical Management Research, Ann Arbor Veterans Affairs Medical Center, Ann Arbor, Michigan.

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view the introduction of hospice into a care planning discussion as “bad news,” the authors recommend that clinicians use a structured strategy based on techniques of effective communication and goal setting. They urge clinicians to “frame the discussions around the benefits and burdens of hospice in achieving the patient’s and family’s overall goals of care.”

The knowledge and use of effective communication techniques are critical for establishing the goals of care in stroke, note the authors. They include a list of communication techniques helpful in sharing essential information with terminally ill stroke patients and their families. [See sidebar, page 2.]

The scientific statement has been endorsed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, American Academy of Hospice and Palliative Medicine, American Geriatrics Society, Neurocritical Care Society, American Academy of Physical Medicine and Rehabilitation, and American Association of Neuroscience Nurses.

Source: “Palliative and End-of-Life Care in Stroke: A Statement for Healthcare Professionals from the American Heart Association/American Stroke Association,” *Stroke*; Epub ahead of print, March 27, 2014; DOI: 10.1161/STR.000000000000015. Holloway RG, et al; on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology.



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



Addressing Timely Hospice Entry for 'Unbefriended' Patients

Patients who lack surrogates and decision-making capacity, and who have a terminal illness and are not candidates for disease-modifying treatments, are known as "unbefriended" patients. According to a report published in the *Journal of Pain and Symptom Management*, unbefriended patients are at risk for both undertreatment of symptoms and overly aggressive care at the end of life.

Few U.S. jurisdictions have policies regarding decision making for unbefriended patients, note the authors, and those that do fail to address the time-sensitive nature of opting for enrollment in hospice. "For some of these patients, hospice care may be their best option in terms of reducing suffering," write the authors. Yet unbefriended patients approaching death are often at risk for being enrolled in hospice too late, or not at all.

Investigators performed a literature search for topics on end-of-life surrogate decision making for those who lack both capacity and known family or friends to act as surrogates. They found that unbefriended patients are most likely to be in hospitals and nursing homes. An estimated 3% to 4% of the nursing home population is unbefriended. These patients are often elderly, homeless, mentally disabled, in same-sex relationships, or irrevocably estranged from their families.

The authors recommend that health care

facilities establish an ethical decision-making framework, one grounded on principles of patient autonomy, beneficence, nonmaleficence, and justice.

While prognostic uncertainty may make some clinicians hesitant to refer these patients, "there are no penalties for inaccurate hospice referrals made in good faith," observe the authors. The Medicare benefit requires a reasonable probability, not absolute certainty, that a patient will die within six months. A patient who survives longer can be recertified for another six-month period.

HOW PHYSICIANS CAN HELP UNBEFRIENDED PATIENTS

- Encourage patients who still have decision-making capacity to engage in advance care planning.
- Talk with local hospices about enrollment policies on a case-by-case basis.
- Help promote better care coordination between care facilities.

Source: "Patients Who Lack Capacity and Lack Surrogates: Can They Enroll in Hospice?" *Journal of Pain and Symptom Management*; Epub ahead of print, April 4, 2014; DOI: 10.1016/j.jpainsymman.2013.12.244. Effiong A and Harman S; Union Graduate College-Icahn School of Medicine at Mount Sinai, Schenectady, New York, and Georgetown University, Washington, DC; Division of General Medical Disciplines, Stanford University School of Medicine, Stanford, California.