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Modify hospice eligibility for dementia patients, says Institute for Aging Research study

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The system for hospice admissions for patients with advanced dementia, which is a terminal illness, should be guided by patient and family preference for comfort, not estimated life expectancy, says a new study published in the Nov. 3 *Journal of the American Medical Association* by the Institute for Aging Research at Hebrew SeniorLife, an affiliate of Harvard Medical School.

Currently, patients requesting hospice services must be certified by their physician to have six months or less to live, and must sign a statement choosing comfort care services in lieu of curative treatments.

"Whether a patient with advanced dementia lives one month, six months or longer," says lead author Susan L. Mitchell, M.D., M.P.H., a senior scientist at the Institute for Aging Research, "they should get high-quality palliative [comfort] care if that is their wish. Because we can't predict with a high level of accuracy who will die within six months, hospice eligibility should be guided by a desire for comfort care, not by how long a patient is expected to live."

Hospice has been shown to benefit patients dying with dementia, but hospice has traditionally under-served dementia patients. Only about 10 percent of hospice patients have a diagnosis of dementia and only an estimated one out of 10 people dying with dementia gets hospice care. Hospice professionals cite estimating life expectancy as the main

hindrance to enrolling patients.

Earlier this year, Dr. Mitchell and her colleagues created a new tool to assess mortality risk in advanced dementia patients. The 12-item Advanced Dementia Prognostic Tool (ADEPT) scores such measures as age, shortness of breath, bowel incontinence, and weight loss to estimate a dementia patient's estimated risk of death within six months. The higher the score, the higher the risk of death. The tool was designed using rigorous statistical models and a nationwide database of nursing home residents with advanced dementia.

vThe Institute for Aging Research study then compared the ability of the ADEPT score to current Medicare hospice guidelines to predict six-month survival in a cohort of 606 Greater Boston-area nursing home residents with end-stage dementia.

Medicare hospice eligibility guidelines use two criteria to estimate life expectancy for dementia patients: a score of at least 7c on the Functional Assessment Staging scale (inability to dress, bathe or toilet; bowel incontinence; speech limited to less than 5 words; and non-ambulatory) and the presence of at least one of six serious medical conditions in the past year. How well these criteria actually predict six-month survival had not been previously known.

Dr. Mitchell found that 67 percent of the time the ADEPT score correctly classified residents who died and those who did not die over six months. In comparison, current hospice criteria correctly classified those who died and those who survived only 55 percent of the time, or slightly better than chance.

The findings show that while the ADEPT score was better than the current Medicare criteria at predicting the death of advanced dementia patients within six months, its predictive ability was not perfect. This

underscores the challenge of estimating how long one will live with advanced dementia and suggests, says Dr. Mitchell, that determining eligibility for hospice based on life expectancy for these patients limits their access to hospice services.

"Our study strongly suggests that delivery of palliative care to these patients should be guided by a preference for comfort as the primary goal and not by life-expectancy estimates," says Dr. Mitchell, an associate professor of medicine at Harvard Medical School. "The challenge for health-care professionals is to ensure that high-quality palliative care is accessible to the growing number of individuals dying with dementia in nursing homes, an effort that may necessitate both revisiting the six-month prognosis requirement for hospice and expanding comprehensive palliative care services in the nursing home."

Currently, more than 5 million Americans suffer from dementia, a number that is expected to increase by almost three-fold in the next 40 years. Dementia is a group of symptoms severe enough to interfere with daily functioning, including memory loss, difficulty communicating, personality changes, and an inability to reason. Alzheimer's disease is the most common form of dementia.

A 2009 study by Dr. Mitchell and her colleagues (Oct. 15, 2009 *New England Journal of Medicine*) was the first to rigorously describe the clinical course of dementia and to label the disease a terminal illness similar to other incurable illnesses, such as cancer.

Scientists at the Institute for Aging Research seek to transform the human experience of aging by conducting research that will ensure a life of health, dignity and productivity into advanced age. The Institute carries out rigorous studies that discover the mechanisms of age-related disease and disability; lead to the prevention, treatment and cure of disease; advance the standard of care for older people; and inform public

decision-making.

The Institute has introduced many well regarded assessment tools, including the Minimum Data Set, which helps nursing homes gather information on residents' health, needs and strengths in order to develop the best caregiving plans.

Provided by Hebrew SeniorLife Institute for Aging Research

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