

# New study says dementia is a terminal illness

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The clinical course of advanced dementia, including uncomfortable symptoms such as pain and high mortality, is similar to that experienced by patients of other terminal conditions, according to scientists at the Institute for Aging Research of Hebrew SeniorLife, an affiliate of Harvard Medical School.

The study, published in the Oct. 15 issue of the [New England Journal of Medicine](#), is the first to rigorously describe the clinical course of advanced dementia, a leading cause of death in the United States. Previous studies suggest that patients with advanced dementia are under-recognized as being at high risk of death and receive suboptimal palliative care, which aims to improve the comfort of terminally ill patients.

"Dementia is a terminal illness," says lead author Susan L. Mitchell, M.D., M.P.H., a senior scientist at the Institute for Aging Research. "As the end of life approaches, the pattern in which patients with advanced dementia experience distressing symptoms is similar to patients dying of more commonly recognized terminal conditions, such as cancer."

The study underscores the need to improve the quality of palliative care in nursing homes to reduce the physical suffering of patients with advanced dementia, and to improve communication with their family members. "This will help to ensure that patients and families understand what to expect in advanced dementia, so that appropriate advance care plans can be made," says Dr. Mitchell.

In an accompanying editorial in the *New England Journal of Medicine*, Greg A. Sachs, M.D., of the Indiana University Center for Aging Research, says Dr. Mitchell's paper "moves the field forward in major ways with regard to both prognosis and the terminal nature of advanced dementia" and should be used to inform public policy about palliative care for patients with the disease.

The "Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life," or CASCADE, study prospectively followed the clinical course of 323 nursing home residents with advanced dementia living in 22 Boston-area nursing homes for up to 18 months. At the final stage of the disease, patients had profound memory deficits such that they could not recognize close family members, spoke fewer than six words, and were non-ambulatory and incontinent.

Over the course of the study, 177 patients died. The researchers found that the most common complications were pneumonia, fevers and eating problems, and that these complications were associated with high six-month mortality rates. Uncomfortable symptoms, including pain, pressure ulcers, shortness of breath, and aspiration, were also common and increased as the end of life approached.

Dr. Mitchell, an Associate Professor of Medicine at Harvard Medical School, said that she and her team found that while 96 percent of the patients' health-care proxies believed that comfort care was the primary goal of care for their loved one, nearly 41 percent of patients who died during the study underwent at least one intervention, including hospitalization, an emergency room visit, intravenous therapy, or tube feeding, in the last three months of life. However, patients whose health-care proxies understood the clinical course of the disease were less likely to receive aggressive treatment near the end of life.

"Many of the patients in our study underwent interventions of

questionable benefit in the last three months of life," says Dr. Mitchell. "However, when their health-care proxies were aware of the poor prognosis and expected clinical complications in advanced dementia, patients were less likely to undergo these interventions and more likely to receive palliative care in their final days of life."

At the beginning of the study, 81 percent of the proxies felt they understood which clinical complications to expect in advanced dementia, yet only one third said that a physician had counseled them about these complications.

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. A recent study by Alzheimer's Disease International estimates that the number of people with dementia worldwide will exceed 35 million by 2050. Dementia is a group of symptoms severe enough to interfere with daily functioning, including memory loss, difficulty communicating, personality change, and an inability to reason. Alzheimer's disease is the most common form of dementia.

"A better understanding of the clinical trajectory of end-stage [dementia](#) is a critical step toward improving the care of patients with this condition," says Dr. Mitchell. "This knowledge will help to give health-care providers, patients and families more realistic expectations about what they will confront as the disease progresses and the end of life approaches."

Source: Hebrew SeniorLife Institute for Aging Research

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