



# ASPE ISSUE BRIEF

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION  
OFFICE OF DISABILITY, AGING AND LONG-TERM CARE POLICY

## FUNCTIONAL TRAJECTORIES AT THE END OF LIFE FOR INDIVIDUALS WITH DEMENTIA

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### BACKGROUND

Dementia, a terminal condition marked by cognitive impairment, affects at least 5.5 million Americans. Palliative care offers integrated care for patients with terminal illnesses including dementia, with a focus on improving quality of life through symptom management. One way Medicare beneficiaries can access palliative care is through the hospice benefit, which provides a comprehensive and holistic approach to treatment for patients who are terminally ill with a life expectancy of 6 months or less. Despite the potential benefits, health providers may be slow to offer the hospice benefit, and patients may be slow to opt for it until they are too near the end of life (EOL) to take full advantage of this type of care. For dementia patients, uncertainty around how long they may survive with their disease further complicates the difficult decision regarding when to focus on symptom relief rather than treatment.

One marker of approaching the EOL is a person's functional decline, as measured by a person's difficulty with the actions involved in daily self-care and mobility activities (also known as activities of daily living, or ADLs). There is growing evidence that functional decline near the EOL may differ depending on diagnosis and comorbidities. A better understanding of how functional decline may be different for people with dementia could help providers and policymakers assess whether existing models of care meet the needs of terminally ill people with dementia. We sought to understand whether the trajectories of functional status are different for older adults with and without dementia near the EOL and whether these trajectories vary by other patient characteristics like their comorbidities.

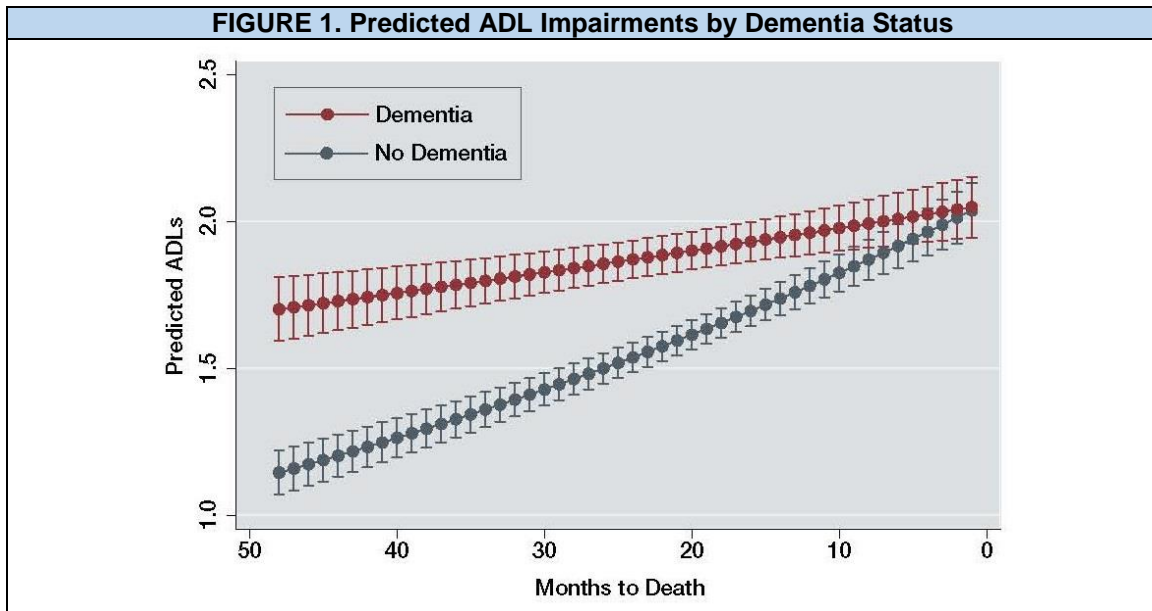
### STUDY METHODS

We used data from the 2000-2012 Health and Retirement Study (HRS), a nationally representative, longitudinal panel study that interviews participants or their proxy every 2 years. Our sample included 5,853 people over the age of 65 who died ("decedents") during this time. We used the last two HRS surveys in decedents' lives to estimate the effect of dementia on functional status in each month in the last 4 years of life.

We measured a person's level of functional impairment by adding together the number of ADLs that the participant reported were difficult to perform (ranging from 0-6). ADLs included bathing, dressing, eating, bed transfer, toileting, and continence. An increasing number of ADL impairments from one time to the next indicates a person is experiencing a decline in his or her functional status. Using survey data, each decedents' number of ADL impairments was

calculated in each of the last two surveys before death. We then constructed models to predict ADL impairments in each month in the last 4 years of life if patients did or did not have dementia, controlling for other patient characteristics such as demographics, socioeconomic status, residential setting, caregiving use, and comorbidities.

## FINDINGS



- People with dementia had **notably higher and sustained levels of predicted ADL impairment for longer periods of time before death** compared to people without dementia. The predicted levels of ADLs for people with dementia 1-4 years before death were as high as predicted levels of ADLs for people without dementia only 6 months before death. In other words, people with dementia experience higher levels of difficulty with ADLs sooner and for more years in their EOL trajectory than people without dementia.
- Dementia was associated with a **slower and more gradual increase in ADL impairments** in the last 4 years of life, after adjusting for demographic characteristics, comorbidities, and use of long-term services and supports.
- After controlling for comorbidities (including cancer, stroke, obesity, etc.) and other characteristics, the adjusted **functional status in the last 6 months of life was not significantly different** between those with or without dementia.
- Using this model, we found similar predicted ADL impairment (1.9 impairments) at 17 months before death for those with dementia, and 6 months before death for those with no dementia.

## IMPLICATIONS

People with dementia have high and sustained levels of functional impairment several years before the end of their life, whereas people without dementia have comparably high functional impairment only at the very end of their life (last 6 months). In addition, people with dementia do not show a sharp functional decline in the last year of life as observed in patients without dementia. Without a clear functional change in the last year of life, accurately forecasting the remaining survival time for people with dementia may be challenging for providers, family members, and caregivers. Mischaracterizing the EOL timing of patients with dementia based on their functional decline alone may fail to recognize the specific care needs and treatments for this population in their last years of life. This might include adult day care, home care, and other services that people with dementia and their families could benefit from using.

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Misinterpreting functional decline in patients with dementia may also affect how providers treat patients who have additional comorbidities. Because functional decline in the last months of life may be more marked for other terminal conditions, clinicians treating patients with a mix of diagnoses, like both cancer and dementia, may be tempted to look at functional status as a marker for the last months of life across clinical groups. These findings suggest that functional status change alone may not be a good indicator for determining the final phase of illness for people with dementia and comorbid conditions.

People with dementia may need a longer period of sustained caregiving and more tailored care for their specific needs.

Given these findings, existing models of EOL care may be insufficient and inappropriate to serve the longer period of decline typically observed in people with dementia. Multi-year periods of functional impairment in patients with dementia look similar to the last months of life for many other disease cohorts, highlighting that people with dementia may need a longer period of sustained caregiving and more tailored care for their specific needs. Models that offer palliative and supportive care at EOL but focus only on the last few months of life may be more effective with modifications to support people with dementia and their families.

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## Reports Available

### **Functional Trajectories at the End of Life for Individuals with Dementia: Issue Brief**

HTML <https://aspe.hhs.gov/basic-report/functional-trajectories-end-life-individuals-dementia-issue-brief>

PDF <https://aspe.hhs.gov/pdf-report/functional-trajectories-end-life-individuals-dementia-issue-brief>

### **Functional Trajectories at the End of Life for Individuals with Dementia: Final Report**

HTML <https://aspe.hhs.gov/basic-report/functional-trajectories-end-life-individuals-dementia-final-report>

PDF <https://aspe.hhs.gov/pdf-report/functional-trajectories-end-life-individuals-dementia-final-report>