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

FINAL REPORT

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Office of the Assistant Secretary for Planning and Evaluation

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ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ADL	Activity of Daily Living
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BMI	Body Mass Index
CI	Confidence Interval
EOL	End Of Life
HRS	Health and Retirement Study
IADL	Instrumental Activity of Daily Living
LTSS	Long-Term Services and Supports
MedPAC	Medicare Payment Advisory Commission
NDI	National Death Index

1. EXECUTIVE SUMMARY

1.1. Introduction

Dementia, including Alzheimer’s disease and related disorders, is a neurocognitive disease affecting an individual’s cognitive function and behavior. Dementia is a leading cause of death and is particularly prevalent at the end of life (EOL) in older adults. When patients enter the terminal phase of illness, palliative and hospice care services can offer integrated care to relieve symptom burden for patients and their families. However, there is limited knowledge regarding the patterns of decline for adults with dementia, who may also have comorbid terminal conditions. This knowledge gap may prevent providers from offering palliative and hospice services, because they may not be able to identify when a dementia patient has entered the terminal phase of illness. It may also limit patients’ and families’ ability and willingness to access palliative services that can improve and complement EOL care.

This project, funded by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services, aims to understand the functional trajectories of older adults with dementia at the EOL. Specifically, researchers at RTI International sought to answer the following question posed by ASPE: What are the trajectories of functional decline of older adults with dementia near the EOL, and how do these trajectories differ from those of people without dementia? In addition, we examined whether and how these trajectories vary by other patient characteristics such as demographics, comorbidities, and access to caregiving. This project provides new and valuable evidence to: (1) inform clinicians’ understanding of the trajectories of decline near the EOL; and (2) guide future policy regarding the delivery of EOL care for people with dementia.

1.2. Data Sources and Methods

We used a sample of decedents over the age of 65 (and thus eligible for Medicare) from the 2000-2012 Health and Retirement Study (HRS). The HRS is a nationally representative, longitudinal panel study that includes about 20,000 adults who are interviewed every 2 years. Using this sample, we identified decedents and the two HRS surveys that occurred in their last 4 years of life. For each survey, we identified relevant characteristics that might affect the participants’ functional trajectories: demographics, socioeconomic status, residential setting, caregiving utilization, and comorbidities. The primary outcome of functional status, measured by a summed score of activities of daily living¹ (ADLs) in which the respondent reported difficulty (0-6), was also calculated in each survey. A higher score indicates more ADL impairments.

Using these data, we conducted two sets of analyses. The first set (“point-in-time analyses”) were intended to examine the effect of personal characteristics, particularly dementia, that are associated with ADL scores at different time points in the last 4 years of life. To do this, the point-in-time analyses leveraged up to two surveys for each HRS decedent, with each survey

¹ The measured ADLs were bathing, dressing, eating, bed transfer, toileting, and incontinence.

providing a snapshot at a random time relative to death, and treated each survey as an observation. These analyses estimated the effect of dementia and other characteristics on the ADL score in each month in the last 4 years of life. The point-in-time analyses used these estimates to predict ADL scores in each month in the last 4 years of life for patients with and without dementia, controlling for other patient characteristics. The second set of analyses (“longitudinal analyses”) were intended to estimate the effect of personal characteristics, particularly dementia, on individual’s ADL scores over time. To do this, the longitudinal analyses calculated the change in ADL between the two last surveys in a decedent’s life. The longitudinal analyses estimated the effect of dementia and other characteristics on the change in ADL score between the last two surveys of life, controlling for patient characteristics.

1.3. Findings

Overall, the findings from the point-in-time analyses indicated that people with dementia have significantly higher levels of functional impairments than do people without dementia up until the last year of life. The point-in-time estimates are the average predicted ADL score, controlling for other personal characteristics at that time, if all people were to have dementia versus if not. For much of the last year of life, there was no significant difference in ADL scores if people did or did not have dementia.

- In the last 4 years of life, dementia was associated with a higher predicted ADL score from 48 months until 10 months before death. Controlling for other characteristics, the predicted ADL score if people had dementia (compared to if they did not) varied from 10% higher at 1 year before death to 48.5% higher at 4 years before death.
- At 17 months before death people with dementia showed a comparable level of predicted impairment (1.92 ADLs) to people without dementia at 6 months before death.
- Dementia was consistently associated with a significantly higher predicted ADL score from 48 months until 17-10 months before death across the types of long-term services and supports (LTSS) received--including living in a nursing facility or receiving caregiving from one’s spouse or child. The difference in the predicted ADL scores between patients with and without dementia and the timing of when this difference diminished varied by LTSS type.
- Both stroke and obesity were associated with significantly worse (or higher) predicted ADL scores for much of the last 4 years of life compared to not having these conditions, regardless of dementia status. However, if dementia and comorbidities were both present, dementia was associated with a higher predicted ADL score from 48 months before death until 12 months before death if people had a stroke (at 13 months it was 2.49 if decedents had dementia vs. 2.25 if they did not) and until 16 months before death if people were obese (at 17 months before death it was 2.24 if decedents had dementia vs. 1.95 if they did not).

- Cancer and heart disease were not associated with a difference in ADL scores over the last 4 years of life regardless of dementia status.

The findings from the analysis of the effects of dementia and other characteristics on the change in ADL scores suggest that, after starting ADL score and other patient characteristics were controlled for, dementia was not associated with the amount of change in ADL impairments between the last two surveys before death:

- Dementia was not associated with the amount of change in ADL score from the second-to-last survey before death (the “prior” survey) to the last survey before death (the “last” survey).
- When LTSS use at the time of the prior survey and prior ADL score were controlled for, there was no significant difference in the ADL change between people with and without dementia.
- Comorbidities at the time of the prior survey were not associated with subsequent change in ADL score, regardless of dementia status.

1.4. Conclusion

In combination, the findings offer new insight into the role of dementia in functional trajectories at EOL. Analysis of predicted ADL scores in the last 4 years of life suggests that when demographics, comorbidities, and LTSS use are controlled for, people with dementia may experience less decline in functional status in the last 4 years of life than people without dementia. This can be partly explained by the fact that people with dementia have higher levels of functional impairment at 3-4 years before death, and therefore, there is less room for further decline. The functional impairment of people with dementia at 2-4 years before death may look similar to people without dementia in the last 6-12 months before death, after controlling for other characteristics. Indeed, individuals with dementia have the same predicted average ADL score (1.92 impairments) at 17 months before death as individuals without dementia at 6 months before death. This creates challenges for prognostication for dementia patients as they may appear to be at EOL for several years. In the last year of life, patients with and without dementia have similar ADL scores.

The analysis of the longitudinal change score suggests that, when personal characteristics and *particularly* baseline ADL score are controlled for, there may be no independent effect of dementia on ADL decline. People with dementia do not experience more functional decline than those at similar levels of ADL impairment but without dementia. Similarly, after controlling for LTSS use and baseline ADL score at the prior survey, there was not a significant difference in subsequent ADL decline attributable to dementia. However, because of the challenges of repeatedly surveying individuals at the EOL and the high levels of baseline ADL impairments among dementia patients, these results may be applicable only to patients with less severe disease.

The implication of these findings for prognostication for dementia patients is that functional status alone may not be, on average, a clear flag for the terminal phase of dementia; this observation is in contrast to ADL trajectories associated with other terminal illnesses, where change in functional status may be a hallmark of the last months of life. In addition, given their higher levels of functional impairment 2-4 years before death, people with dementia likely have different and greater care needs earlier on compared to people without dementia. As a result, traditional models that offer palliative and supportive care at EOL but focus only on the last few months of life may require modifications to support people with dementia and their families.