Dementia Severity and its Consequences for Care Arrangements, Health, and Wealth

Péter Hudomiet,* Jodi Liu,* Susann Rohwedder,* Michael D. Hurd*
***RAND**
February 27, 2026

Abstract

Background

Dementia progression entails cognitive and functional decline as well as behavioral challenges, making care increasingly complex. Despite declines in prevalence, dementia remains among the costliest medical conditions, driven by medical and long-term care needs that strain families and public programs. Yet a reliable population-level measure of dementia severity has been lacking, limiting analysis of how disease progression relates to care, health, and financial outcomes. This study develops and validates a novel severity measure in a nationally representative U.S. sample and examines its associations with care arrangements, health status, out-of-pocket medical expenditures, and household wealth.

Methods

We classify Health and Retirement Study (HRS) participants aged 65 and older (2000-2018) into normal cognition, mild cognitive impairment, and mild, moderate, and severe dementia using cognitive test results and self-assessed cognitive function. The measure is validated against the Clinical Dementia Rating scale using data from the Aging, Demographics, and Memory Study, an HRS substudy with clinical dementia diagnoses. We use that measure to estimate cross-sectional and longitudinal fixed-effects regression models of the associations between dementia severity and the outcomes.

Results

Between 2000 and 2018, age-adjusted rates of mild, moderate, and severe dementia declined by 1.6, 1.0, and 1.7 percentage points, while mild cognitive impairment and normal cognition increased by 1.6 and 2.7 points. Persistent racial and ethnic differences exist across severity levels, though gaps narrowed over time. Dementia severity markedly increases nursing-home residence, paid and unpaid in-home care, out-of-pocket medical spending, and functional and health problems. Two-year mortality rates are 22, 36, and 55 percentage points higher for mild, moderate, and severe dementia, respectively, compared with normal cognition. As individuals

progress to more severe stages, both housing and non-housing household wealth decline substantially. These relationships are stable across model specifications and control sets.

Conclusions

Dementia severity is strongly associated with care use, health outcomes, costs, household wealth, and mortality. Understanding these relationships is critical for patients, families, practitioners, and policymakers. Our validated severity measure enables population-level research on dementia progression, care needs, and economic burden, providing vital evidence for improved care and resource planning.

Acknowledgements

Research support from the National Institute on Aging under grants R01AG088896 (PI: Hudomiet) and R01AG079230 (PI: Hurd) is gratefully acknowledged. This content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health's National Institute on Aging. The authors report no conflict of interest.

Table 1. Trends in age-adjusted cognitive status in the HRS, 2000-2018, weighted

	Normal cognition	Cognitive impairment	Mild dementia	Moderate dementia	Severe dementia	Any dementia
2000	69.3%	18.6%	7.1%	2.0%	3.2%	12.2%
2002	70.9%	17.9%	6.6%	1.7%	2.9%	11.2%
2004	70.5%	19.2%	5.8%	1.8%	2.6%	10.2%
2006	71.4%	19.2%	5.8%	1.4%	2.2%	9.4%
2008	71.1%	19.3%	6.4%	1.4%	1.8%	9.6%
2010	69.9%	20.3%	6.3%	1.6%	1.9%	9.8%
2012	69.1%	21.0%	5.9%	1.8%	2.2%	9.9%
2014	69.4%	20.7%	6.1%	1.6%	2.2%	9.9%
2016	70.3%	20.6%	5.9%	1.3%	1.9%	9.1%
2018	71.9%	20.2%	5.5%	1.0%	1.5%	7.9%

Table 2. Changes in cognitive status by race/ethnicity in the HRS, 2000-2018, weighted

		Normal cognition	Cognitive impairment	Mild dementia	Moderate dementia	Severe dementia	Any dementia
All	2000	69.3%	18.6%	7.1%	2.0%	3.2%	12.2%
	2018	71.9%	20.2%	5.5%	1.0%	1.5%	7.9%
	Difference	2.7%	1.6%	-1.6%	-1.0%	-1.7%	-4.3%
White	2000	73.7%	16.0%	5.9%	1.7%	2.7%	10.3%
	2018	75.0%	18.0%	5.0%	0.8%	1.3%	7.0%
	Difference	1.3%	2.0%	-0.9%	-1.0%	-1.4%	-3.3%
Black	2000	49.5%	29.4%	12.3%	3.0%	5.8%	21.1%
	2018	63.4%	25.5%	7.2%	1.4%	2.5%	11.2%
	Difference	13.9%	-3.9%	-5.1%	-1.6%	-3.2%	-9.9%
Hispanic	2000	55.3%	26.9%	10.6%	3.2%	4.0%	17.8%
	2018	66.3%	23.8%	6.3%	1.5%	2.0%	9.9%
	Difference	11.1%	-3.1%	-4.3%	-1.7%	-2.0%	-7.9%

Figure 1. Percentage living in a nursing home by cognitive status in the HRS, 2000-2018, weighted

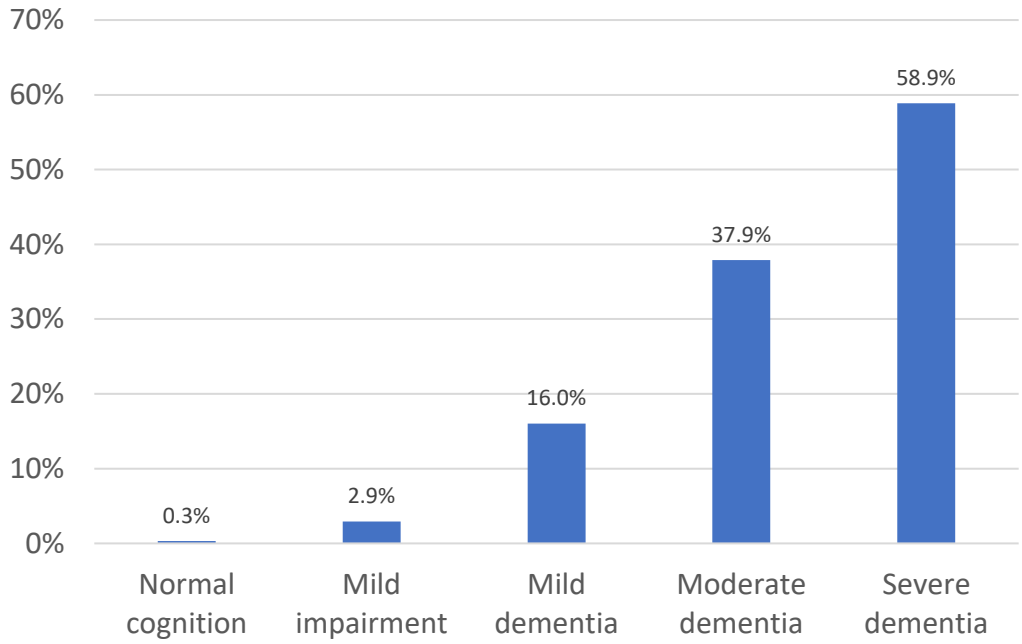


Table 3. OLS and FE regression models of living in a nursing home on cognitive status, HRS 2000-2018, unweighted.

	[1]	[2]	[3]	[4]	[6]
	OLS				FE
	Base	+ Wave	+ Demog	+ Health	~[4]
Normal cognition	ref.	ref.	ref.	ref.	ref.
Mild impairment	0.027	0.027	0.018	0.010	0.017
	0.001***	0.001***	0.001***	0.001***	0.002***
Mild dementia	0.156	0.156	0.136	0.117	0.139
	0.005***	0.005***	0.005***	0.005***	0.003***
Moderate dementia	0.381	0.381	0.353	0.325	0.340
	0.013***	0.013***	0.013***	0.013***	0.005***
Severe dementia	0.589	0.589	0.547	0.509	0.493
	0.014***	0.014***	0.014***	0.014***	0.005***
Wave dummies	-	Y	Y	Y	Y
Demographics	-	-	Y	Y	Y
Health	-	-	-	Y	Y
Constant	0.003	-0.001	0.022	0.026	0.205
	0.000***	0.001	0.005***	0.006***	0.082**
R-squared	0.296	0.296	0.315	0.327	0.237

* The mean of the outcome variable is 3.7%. The regressions are based on 106,632 person-year observations from 22,506 individuals.

Table 4. FE regression models of care arrangements on cognitive status among people living in the community, HRS 2000-2018, unweighted.

	[1]	[2]	[3]	[4]	[5]
	Home care	Any paid help	Unpaid help	Paid hours	Unpaid hours
Normal cognition	ref.	ref.	ref.	ref.	ref.
Mild impairment	0.036	0.033	0.107	4.528	14.878
	0.004***	0.002***	0.004***	0.590***	1.150***
Mild dementia	0.150	0.136	0.361	28.351	81.292
	0.007***	0.004***	0.006***	1.027***	2.003***
Moderate dementia	0.267	0.321	0.554	75.850	177.308
	0.012***	0.007***	0.012***	1.874***	3.655***
Severe dementia	0.348	0.436	0.577	126.063	236.484
	0.015***	0.008***	0.014***	2.223***	4.336***
Constant	-0.332	0.177	0.223	-48.918	-111.498
	0.173*	0.097*	0.165	26.155*	51.004**
Mean outcome	0.110	0.0396	0.157	5.479	21.47
R-squared	0.079	0.114	0.176	0.079	0.108

* All regression models include detailed wave, demographic, and health controls. The regressions are based on 102, 676 person-year observations from 22,022 individuals. Paid and unpaid hours are reported monthly.

Table 5. FE regression models of health status on cognitive status, HRS 2000-2018, unweighted.

	[1]	[2]	[3]	[4]	[5]
	Fair/poor health	Dementia diagnosis	# ADLs	# IADLs	Dies in 2 yrs
Normal cognition	ref.	ref.	ref.	ref.	ref.
Mild impairment	0.078	0.046	0.214	0.322	0.075
	0.005***	0.002***	0.011***	0.009***	0.003***
Mild dementia	0.130	0.281	1.038	1.598	0.222
	0.008***	0.004***	0.019***	0.015***	0.006***
Moderate dementia	0.209	0.624	2.272	3.187	0.361
	0.012***	0.006***	0.030***	0.024***	0.009***
Severe dementia	0.269	0.815	3.440	3.766	0.554
	0.013***	0.006***	0.033***	0.027***	0.010***
Constant	0.077	0.199	-1.369	0.227	0.065
	0.205	0.097**	0.503***	0.413	0.157
Mean outcome	0.322	0.0639	0.592	0.500	0.100
R-squared	0.091	0.313	0.340	0.445	0.236

* All regression models include detailed wave, demographic, and health controls. The regressions are based on 106, 632 person-year observations from 22,506 individuals. “Dementia diagnosis” is survey participants’ report of prior doctor diagnoses of Alzheimer’s disease or other dementias.

Table 6. FE regression models of medical spending on cognitive status, HRS 2000-2018, unweighted.

	[1]	[2]	[3]	[4]	[5]	[6]
	Total OOP	Nursing home	Home health	Special facility	Drugs	Dental
Normal cognition	ref.	ref.	ref.	ref.	ref.	ref.
Mild impairment	0.568	0.391	0.060	0.026	0.069	-0.028
	0.095***	0.067***	0.013***	0.008***	0.060	0.012**
Mild dementia	2.457	2.053	0.177	0.094	-0.015	-0.059
	0.158***	0.113***	0.022***	0.014***	0.100	0.020***
Moderate dementia	5.892	5.575	0.238	0.176	0.113	-0.087
	0.253***	0.181***	0.035***	0.022***	0.159	0.033***
Severe dementia	9.606	9.190	0.273	0.254	-0.124	-0.132
	0.281***	0.202***	0.039***	0.025***	0.177	0.037***
Constant	4.360	-0.397	0.112	0.056	0.310	0.139
	4.282	0.883	0.171	0.107	2.697	0.161
Mean outcome	2.366	0.494	0.0408	0.0253	1.034	0.337
R-squared	0.039	0.061	0.006	0.005	0.008	0.003
Person-wave observations	106,632	95,894	95,894	95,894	106,632	95,894
Number of persons	22,506	21,067	21,067	21,067	22,506	21,067

* All regression models include detailed wave, demographic, and health controls. Spending is expressed in thousands of 2018 dollars.

Table 7. FE regression models of household wealth on cognitive status, HRS 2000-2018, unweighted.

	[1]	[2]	[3]	[4]	[5]	[6]
	Primary residence		Non-housing total		Total	
	w>0	ln(w)	w>0	ln(w)	w>0	ln(w)
Normal cognition	ref.	ref.	ref.	ref.	ref.	ref.
CIND	-0.038	-0.018	-0.013	-0.073	-0.011	-0.082
	0.003***	0.008**	0.003***	0.016***	0.003***	0.012***
Mild dementia	-0.110	-0.050	-0.037	-0.132	-0.037	-0.256
	0.005***	0.015***	0.006***	0.027***	0.005***	0.021***
Moderate dementia	-0.185	-0.007	-0.068	-0.218	-0.084	-0.444
	0.009***	0.027	0.009***	0.044***	0.007***	0.035***
Severe dementia	-0.245	-0.046	-0.074	-0.412	-0.107	-0.810
	0.010***	0.031	0.010***	0.049***	0.008***	0.039***
Constant	1.010	12.030	0.625	11.013	1.074	13.478
	0.148***	0.357***	0.154***	0.220***	0.122***	0.553***
Mean outcome	0.754	11.82	0.873	11.22	0.921	12.11
R-squared	0.088	0.043	0.020	0.083	0.019	0.091
Person-wave observations	106,632	80,398	106,632	93,090	106,632	98,230
Number of persons	22,506	18,244	22,506	21,073	22,506	21,547

* All regression models include detailed wave, demographic, and health controls.