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### Authors

Jenkins, Derek  
Stickel, Ariana  
González, Hector M  
[et al.](#)

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# Out-of-Pocket Health Expenditures and Health Care Services Use Among Older Americans With Cognitive Impairment: Results From the 2008–2016 Health and Retirement Study

Derek Jenkins, PhD,<sup>1</sup> Ariana Stickel, PhD,<sup>2</sup> Hector M. González, PhD,<sup>2</sup> and Wassim Tarraf, PhD<sup>1,3,\*</sup>

<sup>1</sup>Institute of Gerontology, Wayne State University, Detroit, Michigan, USA. <sup>2</sup>Department of Neurosciences and Shiley-Marcos Alzheimer's Disease Research Center, University of California San Diego School of Medicine, San Diego, California, USA. <sup>3</sup>Department of Healthcare Sciences, Wayne State University, Detroit, Michigan, USA.

\*Address correspondence to: Wassim Tarraf, MBA, PhD, Department of Healthcare Sciences and Institute of Gerontology, Wayne State University, 87 East Ferry Street, Knapp Bldg, Room 240, Detroit, MI 48202, USA. E-mail: [wassim.tarraf@wayne.edu](mailto:wassim.tarraf@wayne.edu)

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## Abstract

**Background and Objectives:** The evidence base on health services use and cost burdens associated with transition to severe cognitive impairment (SCI) and dementia is underdeveloped. We examine how the change in cognitive impairment status influences nursing home use, hospitalizations, and out-of-pocket (OOP) expenditures.

**Research Design and Methods:** We use prospective data from the Health and Retirement Study (2007/2008–2015/2016) on adults 70 years and older meeting research criteria for cognitive impairment not dementia (CIND) at baseline (unweighted  $n = 1,692$ ) to fit 2-part models testing how reversion to normal cognition, stability (CIND maintenance), and transition into SCI/dementia influence change in yearly nursing home use, hospitalizations, and OOP expenditures.

**Results:** Over 8 years, 5.9% reverted, 15.9% remained CIND, 14.9% transitioned to SCI/dementia, and 63.3% died. We observed substantial increases in the propensity of any nursing home use which were particularly pronounced among those who transitioned or died during follow-up and similar but less pronounced differences in patterns of inpatient hospitalizations. Average baseline OOP spending was similar among reverters (\$1156 [95% confidence interval = 832–1,479]), maintainers (\$1,145 [993–1,296]), and transitioners (\$1,385 [1,041–1,730]). Individuals who died during follow-up spent \$2,529 (2,101–2,957). By the eighth year of follow-up, spending among reverters increased to \$1,402 (869–1,934) and \$2,188 (1,402–2,974) and \$8,988 (5,820–12,157) for maintainers and transitioners, respectively. Average spending at the wave preceding death was \$7,719 (4,345–11,094). Estimates were only partly attenuated through adjustment to covariables.

**Discussion and Implications:** A better understanding of variations in health services use and cost burdens among individuals with mild cognitive impairment can help guide targeted care and financial planning.

**Keywords:** Cognitive aging, Dementia, Health services use, Out-of-pocket spending

The increased longevity and aging of the U.S. population present important public health and health care challenges. By 2060, close to a quarter of Americans are expected to be older than the age of 65, and the population aged 85 and older will grow threefold (Ortman & Velkoff, 2014; U.S. Census Bureau, 2012). With these aging trends, the total number of people with dementia will reach close to 14 million by 2050, although an appropriate focus on known modifiable life-course risk factors (e.g., cardiovascular risk) can alter these estimates (Livingston et al., 2020). More than 300 billion dollars were spent on dementia care in 2020, half of which was covered by Medicare, a public health insurance program for individuals 65 years and older, younger individuals who qualify due to disability, and those with end-stage renal disease. Medicare part A provides coverage for inpatient hospitalizations (IHs), hospice and home health, and skilled nursing facilities for rehabilitative care up to 100 days without a premium (<https://acl.gov/ltc/costs-and-who-pays/who-pays-long-term-care>). Around 50 billion dollars were spent by Medicaid (Alzheimer's Association, 2016); a shared federal and state safety net insurer for individuals with limited income and assets. Estimates suggest that close to one in two residents of nursing home facilities with Medicaid coverage are admitted as private payors and switch to such coverage after depleting their financial resources (Branch et al., 2020). The costs of care for dementia are expected to pass a trillion dollars by midcentury (Alzheimer's Association, 2018) coinciding with the growth in absolute numbers of patients and changes in treatment modalities and care expectations and requirements. Understanding the economic and social consequences of severe cognitive impairment (SCI) and dementia is critical for structuring resources and creating an optimal health care and public health infrastructure. In this work, we use longitudinal data from the Health and Retirement Study (HRS) to examine how changes in cognitive disease severity influence cost burdens and use of health care resources.

As the prevalence of dementia grows and the U.S. population ages and diversifies, focusing on the early stages of cognitive impairment and understanding the implications of heterogeneities in impairment progression to health care spending and health services use, using nationally representative data, become increasingly critical. Such knowledge can inform effective policy construction and help guide more targeted health care services and clinical interventions. A 2013 Alzheimer's workgroup review of evidence regarding early detection of cognitive impairments outlines how such diagnosis and a better understanding of the early stages of impairment and its progression can realign health care use and spending by (a) better informing patients and their families about expectations and (b) potentially guiding the development of patient-centered standards for formal and informal care that better reflect the available resources, values, and priorities of patients and their families (Borson et al., 2013).

Research studies examining links between cognitive status and health services use have (a) relied on community-based cohorts without controlling for baseline cognitive health (St-Hilaire et al., 2017), (b) ignored or had limited capabilities to examine transitions from preclinical to higher severity stages (Cai et al., 2009; Hurd et al., 2013), or (c) used well characterized but much more restricted clinical samples (Stephens et al., 2012). No study, to the best of our knowledge, has shown how these utilization and costs patterns, particularly patient cost burdens, change over time and as the severity of disease worsens. A key contribution of this article is the focus on individuals satisfying criteria for mild symptoms of cognitive impairment (i.e., potentially in the early stages) at the study baseline. This work adds to the literature on SCI and dementia burdens in two ways. First, we aimed to better characterize how changes in cognitive function over time contribute to overall out-of-pocket (OOP) health care expenditures, expenses that are paid privately by the individual or their family to cover health services (e.g., nursing home care), and the use of high-cost/high-burden health services such as IHs and nursing home use (NHU) among those with baseline cognitive impairment but not dementia (CIND). Second, borrowing from Andersen's Behavioral Model of health services use (Andersen, 1995), our analytic framework controlled for relevant individual predisposing, enabling, and health need factors that have the potential to influence access to and consumption of health services and resources among the cognitively impaired as they transition into more severe levels of cognitive impairment and dementia (SCI/dementia) or die. In particular, our analytic framework and the use of longitudinal data allowed us to test whether and to what extent change in health needs, controlling for predisposing and enabling factors, influence the use of health care resources and OOP spending over the transition period. We hypothesized that (a) the temporal trajectories of spending and health services use among individuals with baseline evidence of impairment will be more pronounced among those transitioning to more severe cases of impairment and those who die, after adjusting for differences in predisposing (age, sex, race/ethnicity, and education) and enabling (insurance status/payor) factors; (b) the patterns of change over time will differ based on the specific type of service considered; and (c) time-varying health needs, reflecting the change in health acuity, will attenuate differences in health services and OOP spending between the considered transition groups.

## Method

### Data

We use longitudinal data covering 2007/2008–2015/2016 from the HRS. The HRS is a biennial survey that has been ongoing since 1992 with sample replenishments occurring every 6 years to account for participant attrition, population aging, and cohort representation. As of 1998, each

wave of the HRS is weighted to allow representation and inferential generalization to the U.S. population 50 years and older. Around 10% of HRS interviews are conducted via a proxy if respondents are not present or unable to participate (Weir et al., 2011). The HRS is conducted by the University of Michigan and is supported by the National Institute on Aging and the Social Security Administration.

The HRS includes a set of core modules that are repeated biennially and includes detailed questionnaires that probe participants socioeconomic background, health status and conditions, disability, experiences of daily living, access to insurance and use of major health services, and a detailed set of questions to assess psychosocial measures and constructs. HRS data are de-identified and publicly available from the HRS site (<https://hrs.isr.umich.edu/data-products>). As such, the work qualifies for Institutional Review Board “Exemption” according to the Department of Health and Human Services Code of Federal Regulations.

### Analytic Subpopulation

This study focuses on participants who satisfy criteria as cognitively impaired not dementia, using the Langa–Weir (LW) classification scheme, at the 2007/2008 baseline wave. The baseline unweighted sample includes  $n = 17,217$ . We exclude participants younger than 70 years ( $n = 8,990$ ) and those who are classified as cognitively normal ( $n = 5,332$ ) or who met research criteria for SCI/dementia ( $n = 1,051$ ). We also exclude participants with undetermined cognitive or death status at the 2015/2016 wave ( $n = 152$ ) for an unweighted analytic sample at baseline  $n = 1,692$ . Additionally, in regression models, we exclude participants with missing data on the baseline covariates ( $n = 14$ ). We focus on participants 70 years and older to increase the sensitivity of classification for detecting “true” cognitive impairment. The LW algorithm and its established thresholds were constructed and extrapolated to HRS based on a subset of individuals 70 years and older participating in the Aging, Demographics, and Memory Study (ADAMS; Langa et al., 2005). We exclude individuals who were cognitively normal at baseline for two reasons: (a) because the rates of conversion from normal to SCI/dementia are much lower in this group and (b) to maintain focus on a more clinically, policy, and research interesting group of higher-risk individuals with mild symptoms of cognitive impairment.

### Outcomes

Our outcomes consist of two measures of health care utilization (IHs and nursing home care) and one measure of OOP (privately paid by the patient or their family) health expenditures. For the utilization measures, the HRS probes participant biennial usage of several health care services (e.g., nursing home care) over the past 2 years. In this study, we focus on two measures of use that are highly pertinent to dementia patients and that have strong policy

implications: high cost and lower quality of care. These two measures include (a) the count of nursing home visits and (b) the number of IHs.

The HRS also measures biennial OOP health care expenditures. These expenditures include self-reported privately (i.e., by patient/family) paid expenses for costs not covered by Medicare, Medicaid, or other public or private health insurance. These expenditures include costs associated with inpatient hospital stays, nursing home stays, physician visits, home health care, and prescription drugs. HRS OOP measures have high validity and have been used extensively in the literature (Delavande et al., 2013; Goldman et al., 2011; Goldman & Zissimopoulos, 2003; Hurd et al., 2017; Kelley et al., 2013; Fahle et al., 2016). Detailed discussions of their construction methods, validity, and quality are published elsewhere (Delavande et al., 2013; Goldman et al., 2011; Goldman & Zissimopoulos, 2003; Hurd et al., 2017; Kelley et al., 2013; Fahle et al., 2016). OOP expenditures have important implications for the older populations, overall, given that the majority of older adults in the United States have limited assets and are on a fixed income (Norris, 2018). OOP expenditures, which would include spending down toward Medicaid coverage, can have particularly adverse financial and social effects on higher-risk populations and their families including socioeconomically disadvantaged and minority populations. Our models cover four waves of these outcomes: 2007/2008 through 2015/2016. Yearly estimates are obtained by dividing the reported level of use or expenditures by two. OOP expenditures reported were adjusted for inflation using 2016 dollars.

### Primary Exposure

The HRS collects data on cognitive function from respondents able to complete an interview using a modified version of the Telephone Interview for Cognitive Status (TICS-M; Fisher et al., 2017; Langa et al., 2017; Ofstedal, 2005). The 27-point TICS-M scale includes the (a) 10-word immediate and (b) 10-word delayed word recall, (c) serial-7s subtraction, and (d) backward counting, as measured at each biennial wave to examine trajectories of cognitive change. These four items assess episodic and working memory and are sensitive to age-related cognitive decline (Fisher et al., 2017). For respondents who were unable to complete the interview, the HRS collects data from proxy respondents. Proxy questions probe (a) reports on participant memory (0 = excellent; 4 = poor); (b) number of limitations in five instrumental activities of daily living (IADLs; managing money, taking medication, preparing meals, use a telephone, and grocery shopping; range = 0–5); and (c) interviewer assessment of respondent’s challenge in completing the interview due to cognitive limitation (score 0–2).

We use the LW algorithm to classify cognitive impairment status according to established thresholds for normal cognition, CIND, and SCI/dementia (Langa et al., 2008,

2017; Plassman et al., 2007). The thresholds for the LW classification are based on extrapolations from data from the ADAMS (a subsample of the HRS). The ADAMS followed a comprehensive adjudication process to establish research criteria for clinical classification. TICS and proxy responses thresholds were subsequently calibrated in ADAMS to determine appropriate thresholds for prevalent CIND and SCI/dementia that would be applied to HRS (Plassman et al., 2007). The rationale for the underlying algorithm and the details for adjudication and validation are published elsewhere; LW classifications have been used extensively in the literature (Crimmins et al., 2011; Diaz-Venegas et al., 2016; Langa et al., 2008, 2017; Plassman et al., 2007; Rocca et al., 2011). In line with the LW algorithm, we grouped respondents scoring 12 or greater on TICS as having normal cognition, 7–11 as CIND, and  $\leq 6$  as SCI/dementia (Crimmins et al., 2011; Langa et al., 2008). For proxied respondents, in line with published work, we classified respondents scoring  $\leq 2$  as normal cognition, 3–5 as CIND, and 6 or higher as SCI/dementia (Plassman et al., 2008).

We generate a four-category indicator to group individuals according to their cognitive status classification at the end of the observation period (2015/2016 wave) and whether they died between baseline and 2015/2016. “Reverters” are individuals who switch from CIND at the baseline wave to normal cognitive status in 2015/2016. “Maintainers” represent individuals who maintain CIND status by 2015/2016. “Transitioners” are individuals who satisfy the criteria for SCI/dementia in the 2015/2016 wave. The majority of attrition within the HRS is due to respondents’ deaths that we model explicitly as an outcome category. To determine deaths, we use data from the HRS tracker that includes wave-specific records of whether a respondent is (a) alive and responding, (b) attrited from the sample as a result of death, and (c) was lost to follow-up but not due to death (Banks et al., 2011; Weir, 2016).

## Covariates

We account for a series of time-invariant and time-varying covariables. Our time-invariant measures include age measured continuously in years, sex, race/ethnicity (non-Latino Whites, non-Latino Blacks, Latinos, and other), and educational attainment (less than high school [HS], general educational diploma, HS, some college, and college or more). Additionally, we control for wave-specific time-varying measures of insurance status (measured using a binary indicator for government-provided only, and other), disability, physical dysfunction, and major chronic diseases. Disability is assessed using a binary indicator distinguishing between participants reporting any difficulties on 10 measures combining activities of daily living (ADLs) and IADLs (Fonda, 2004). Physical function is measured using a count of affirmative responses regarding respondents’ ability to perform 10 physical challenges (Fonda, 2004). Finally, a major

disease is based on a count of the number of eight chronic conditions with high social and economic costs and associated with high mortality (Fisher, 2005). These measures were operationalized concordant with previously published work using HRS data (Delavande et al., 2013; Hurd et al., 2013; Langa et al., 2017; Rocca et al., 2011).

## Analyses

We followed a three-step process in analyzing our data. First, we generated descriptive analysis to characterize our sample on the covariates of interest by cognitive group classification (Table 1). We used survey-adjusted chi-squared tests to test for significant differences in categorical measures (e.g., race/ethnicity) and survey-adjusted *t*-tests to test group differences in continuous measures. Second, we characterized the crude OOP spending and health services use of the cognitive groups of interest. To do so, we estimated both the probability of incurring any OOP spending and of having a nursing home admission and inpatient hospital visit within each cognitive group. Additionally, we estimated the average OOP spending and number of nursing home admissions and IHS among those who reported OOP spending and health services use. Third, we fit a series of two-part models (TPMs) to test the association between our primary exposure (cognitive classification by 2015/2016) and each of the spending and health services outcomes of interest. TPMs are used for modeling outcomes with a known extensive left skew in their distribution such as population-based health spending and services use outcomes (Deb & Norton, 2018). Detailed theoretical and applied treatments of TPMs are published elsewhere (Farewell et al., 2017). Relying on ordinary least squares models for this estimation could lead to biased estimates (Deb & Norton, 2018). As such, we follow recommendations by Deb and Norton (2018) that suggest using a logistic regression for the first part and a generalized linear model (GLM) with a gamma distribution to estimate positive expenditures/use. For each outcome at each wave, we sequentially fit two models. The first adjusts for nonvarying covariates including baseline age, sex, race/ethnicity, and wave-specific insurance status. The second additionally adjusts for ADL/IADLs, a count indicator for chronic conditions, and a count of measures of physical dysfunctions.

## Sensitivity Analyses

In sensitivity models, we used negative binomial regression models to refit all the models detailed above to assess the robustness of our estimates and reported findings under competing distributional assumptions for the outcomes of interest (Supplementary Table 5). All analyses were done using survey regression techniques with the Stata-16 software to ensure appropriately weighted estimates (to the baseline target population) and correct standard errors for appropriate target population inferences (Holt et al., 1980).



**Table 1.** Baseline Target Population Characteristics by Cognitive/Death Status in 2015/2016

Characteristics	Status in 2016				Total	<i>p</i>
	Normal	CIND	SCI/Dementia	Deceased		
Baseline (2008) age, years: Mean (SD)	74.64 (4.39)	76.40 (5.45)	79.32 (6.52)	82.38 (7.58)	80.36 (7.64)	<.001
Sex: % (SE)						
Male	42.58 (5.75)	43.21 (3.20)	32.46(3.56)	45.68 (2.25)	43.14 (1.58)	.027
Female	57.42 (5.75)	56.79 (3.20)	67.54 (3.56)	54.32 (2.25)	56.86 (1.58)	
Race/ethnicity: % (SE)						
Non-Hispanic White	74.42 (4.74)	63.52 (3.68)	63.53 (3.91)	79.16 (1.87)	74.07 (2.05)	<.001
Non-Hispanic Black	15.56 (3.56)	17.28 (2.26)	16.40 (2.18)	11.48 (0.99)	13.37 (0.84)	
Hispanic	9.11 (3.00)	15.05 (2.99)	17.23 (3.99)	8.04 (1.41)	10.59 (1.89)	
Other	0.92 (0.93)	4.15 (1.62)	2.84 (1.22)	1.32 (0.41)	1.97 (0.58)	
Education: % (SE)						
Less than HS	25.67(4.71)	47.75 (3.14)	46.26 (3.09)	38.62 (1.87)	40.44 (1.62)	.002
GED	5.94 (2.59)	3.95 (1.25)	7.51 (1.78)	3.29 (0.65)	4.18 (0.60)	
HS	36.28 (5.80)	27.45 (2.70)	28.55 (3.04)	32.62 (1.88)	31.41 (1.57)	
Some college	21.63 (4.72)	14.73 (2.61)	7.99 (2.02)	14.39 (0.99)	13.92 (0.87)	
College or more	10.48 (3.14)	6.13 (1.49)	9.69 (2.37)	11.09 (1.26)	10.05 (1.05)	
Baseline (2008) Insurance status: % (SE)						
Other insurance	42.89 (6.34)	41.84 (3.11)	36.66 (3.30)	43.84 (2.45)	42.40 (1.96)	.342
Public insurance only	57.11 (6.34)	58.16 (3.11)	63.34 (3.30)	56.16 (2.45)	57.60 (1.96)	
ADL/IADL count: Mean (SD)	0.24 (0.92)	0.47 (1.38)	0.94 (1.86)	1.59 (2.61)	1.20 (2.31)	<.001
Physical function: Mean (SD)	2.49 (1.55)	2.41 (1.82)	2.69 (1.89)	3.06(1.82)	2.85 (1.84)	<.001
Chronic conditions count: Mean (SD)	1.94 (2.43)	2.06 (2.41)	2.73 (2.86)	3.33 (2.79)	2.93 (2.79)	<.001

Notes: CIND = cognitive impairment not dementia; SCI = severe cognitive impairment; public insurance only = Medicare or Medicaid and no other source of insurance reported; ADL/IADL = activities of daily living/instrumental activities of daily living; HS = high school. All estimates are weighted to generalize to the target population of individuals 70 years and older meeting Langa–Weir criteria for cognitive impairment no dementia at the baseline wave (2007/2008). *p* Values for continuous measures are based on survey-adjusted *t*-tests. *p* Values for categorical measures are based on survey-adjusted chi-squared tests.

## Results

### Descriptive Statistics

Among individuals meeting criteria for CIND at study baseline (2007/2008), 5.9% reverted back to normal (“reverters”) by 2015/2016, 15.9% remained CIND (“maintainers”), 14.9% transitioned to SCI/dementia (“transitioners”); 44% of which [i.e., 6.5% overall] based on proxy reports), and 63.3% died. The transition matrix for cognitive status over the four considered waves is provided in [Supplementary Table 1](#).

Characteristics of respondents by cognitive status and death classifications are presented in [Table 1](#) (also [Supplementary Table 2](#) for time varying covariables). The mean baseline age was 80.4 ± 7.6 years, 57% were females, and two in five (40.5%) had less than a HS education. Compared to those who maintained CIND status, individuals transitioning to SCI/dementia and those who died during the observation period had significantly (statistically) different profiles. Individuals transitioning to SCI/dementia were more likely to be females, were older at baseline, had higher average ADL/IADL counts, higher average physical dysfunction score, and higher count of chronic conditions. The discrepancy in health profiles between those maintaining CIND status and those transitioning to SCI/dementia widened consistently over time. Individuals

who died during the observation period were older at baseline (82.4 ± 7.6 years), more likely to be non-Latino White, and had consistently worse disability and health profiles over all five considered waves.

### Annual NHU

Individuals who died by 2015/2016 had 8.1% (95% confidence interval [CI] 3.99–12.18), 7.5% (4.71–10.27), and 7.4% (4.29–10.45) higher absolute prevalence of NHU at baseline ([Table 2](#), Panel A includes the estimated crude proportions and [Supplementary Table 3](#) includes the analysis of variance [ANOVA] contrasts), relative to reverters, maintainers, and transitioners, respectively, and those differences increased to 37.1% (29.75–44.54), 32.0% (23.91–40.03), and 13.1% (2.7–23.5) by 2013/2014 (wave preceding death). We found no differences in the propensity of NHU at baseline between the three cognitive groups. By 2011/2012, clear evidence of pattern separations emerged between the cognitive groups such that worse cognitive outcomes were associated with a significantly higher propensity of NHU. By 2015/2016, individuals who transitioned to SCI/dementia had 33.0% (25.94–40.03) and 24.4% (16.96–31.9) higher prevalence of NHU compared to

**Table 2.** Unadjusted Estimates for Proportion With Yearly Use/Expenditures (Panel A; 0 = No, 1 = Yes) and Mean Level of Yearly Use/Expenditures (Panel B)

Comparisons	2007–2008	2009–2010	2011–2012	2013–2014	2015–2016
<b>Panel A (Prop or mean [95% CI])</b>					
<i>Nursing home</i>					
Normal: Reverter	0.04 [–0.00, 0.07]	0.02 [–0.00, 0.05]	0.04 [–0.01, 0.08]	0.02 [–0.00, 0.03]	0.02 [–0.00, 0.04]
CIND: Maintainer	0.04 [0.02, 0.07]	0.06 [0.02, 0.09]	0.06 [0.02, 0.10]	0.07 [0.04, 0.10] <sup>a</sup>	0.10 [0.06, 0.15] <sup>a</sup>
SCI/dementia: Transitioner	0.04 [0.02, 0.07]	0.10 [0.05, 0.14] <sup>a</sup>	0.15 [0.08, 0.21] <sup>a,b</sup>	0.26 [0.19, 0.32] <sup>a,b</sup>	0.35 [0.28, 0.42] <sup>a,b</sup>
Deceased	0.12 [0.10, 0.14] <sup>a,b,c</sup>	0.26 [0.22, 0.30] <sup>a,b,c</sup>	0.28 [0.23, 0.33] <sup>a,b,c</sup>	0.39 [0.32, 0.46] <sup>a,b,c</sup>	n/a
<i>Inpatient hospitalization</i>					
Normal: Reverter	0.27 [0.20, 0.35]	0.28 [0.19, 0.38]	0.34 [0.21, 0.46]	0.27 [0.20, 0.35]	0.29 [0.20, 0.38]
CIND: Maintainer	0.27 [0.21, 0.34]	0.33 [0.28, 0.39]	0.32 [0.26, 0.38]	0.36 [0.29, 0.43] <sup>a</sup>	0.35 [0.28, 0.42] <sup>a</sup>
SCI/dementia: Transitioner	0.38 [0.31, 0.45]	0.37 [0.32, 0.43] <sup>a</sup>	0.35 [0.29, 0.41] <sup>a,b</sup>	0.35 [0.28, 0.42] <sup>a,b</sup>	0.50 [0.41, 0.58] <sup>a,b</sup>
Deceased	0.47 [0.44, 0.50] <sup>a,b,c</sup>	0.52 [0.49, 0.56] <sup>a,b,c</sup>	0.49 [0.43, 0.55] <sup>a,b,c</sup>	0.54 [0.48, 0.61] <sup>a,b,c</sup>	n/a
<i>OOP expenditures (\$)</i>					
Normal: Reverter	0.90 [0.83, 0.96]	0.90 [0.84, 0.96]	0.92 [0.87, 0.98]	0.85 [0.79, 0.91]	0.86 [0.79, 0.93]
CIND: Maintainer	0.85 [0.81, 0.90]	0.90 [0.86, 0.94]	0.86 [0.82, 0.91]	0.85 [0.80, 0.89] <sup>a</sup>	0.81 [0.76, 0.87] <sup>a</sup>
SCI/dementia: Transitioner	0.81 [0.75, 0.88]	0.86 [0.81, 0.90] <sup>a</sup>	0.81 [0.76, 0.87] <sup>a,b</sup>	0.75 [0.68, 0.81] <sup>a,b</sup>	0.77 [0.70, 0.83] <sup>a,b</sup>
Deceased	0.86 [0.83, 0.89] <sup>a,b,c</sup>	0.88 [0.85, 0.90] <sup>a,b,c</sup>	0.84 [0.80, 0.87] <sup>a,b,c</sup>	0.82 [0.76, 0.88] <sup>a,b,c</sup>	n/a
<b>Panel B (Mean [95% CI])</b>					
<i>Nursing home</i>					
Normal: Reverter	0.02 [–0.00, 0.04]	0.01 [–0.00, 0.02]	0.03 [–0.01, 0.06]	0.01 [–0.00, 0.02]	0.01 [–0.00, 0.02]
CIND: Maintainer	0.02 [0.01, 0.04]	0.04 [0.01, 0.06] <sup>a</sup>	0.04 [0.01, 0.06]	0.04 [0.02, 0.06] <sup>a</sup>	0.07 [0.03, 0.12] <sup>a</sup>
SCI/dementia: Transitioner	0.03 [0.01, 0.06]	0.06 [0.03, 0.09] <sup>a</sup>	0.08 [0.04, 0.13] <sup>a,b</sup>	0.15 [0.11, 0.19] <sup>a,b</sup>	0.23 [0.18, 0.29] <sup>a,b</sup>
Deceased	0.08 [0.06, 0.10] <sup>a,b,c</sup>	0.18 [0.14, 0.22] <sup>a,b,c</sup>	0.18 [0.14, 0.22] <sup>a,b,c</sup>	0.25 [0.20, 0.30] <sup>a,b,c</sup>	n/a
<i>Inpatient hospitalization</i>					
Normal: Reverter	0.24 [0.14, 0.34]	0.17 [0.11, 0.23]	0.26 [0.16, 0.35]	0.23 [0.14, 0.32]	0.27 [0.16, 0.38]
CIND: Maintainer	0.22 [0.15, 0.29] <sup>a</sup>	0.32 [0.25, 0.39]	0.30 [0.21, 0.39]	0.29 [0.23, 0.35]	0.38 [0.28, 0.47]
SCI/dementia: Transitioner	0.31 [0.23, 0.39] <sup>b</sup>	0.37 [0.31, 0.43] <sup>a</sup>	0.41 [0.31, 0.50] <sup>a,b</sup>	0.35 [0.25, 0.44] <sup>a</sup>	0.64 [0.44, 0.84] <sup>a,b</sup>
Deceased	0.45 [0.40, 0.50] <sup>a,b,c</sup>	0.67 [0.56, 0.78] <sup>a,b,c</sup>	0.56 [0.45, 0.67] <sup>a,b,c</sup>	0.64 [0.46, 0.82] <sup>a,b,c</sup>	n/a
<i>OOP expenditures (\$)</i>					
Normal: Reverter	1,156 [832, 1,479]	1,593 [1,098, 2,087]	1,541 [960, 2,123]	1,327 [960, 1,694]	1,402 [869, 1,934]
CIND: Maintainer	1,145 [993, 1,296]	1,992 [1,415, 2,569]	1,829 [1,224, 2,433]	1,597 [1,328, 1,865]	2,188 [1,402, 2,974]
SCI/dementia: Transitioner	1,385 [1,041, 1,730]	2,876 [1,334, 4,417]	2,825 [1,832, 3,819] <sup>a,b</sup>	4,342 [2,642, 6,041] <sup>a,b</sup>	8,988 [5,820, 12,157] <sup>a,b</sup>
Deceased	2,529 [2,101, 2,957] <sup>a,b,c</sup>	3,683 [2,989, 4,376] <sup>a,b</sup>	4,810 [3,821, 5,798] <sup>a,b,c</sup>	7,719 [4,345, 11,094] <sup>a,b</sup>	n/a

Notes: CI = confidence interval; CIND = cognitive impairment not dementia; SCI = severe cognitive impairment; OOP = out of pocket. Results reflect the target population of individuals 70 years and older meeting Langa–Weir criteria for cognitive impairment no dementia at the baseline wave (2007/2008).

<sup>a</sup>Significantly different than reverters.

<sup>b</sup>Significantly different than maintainers.

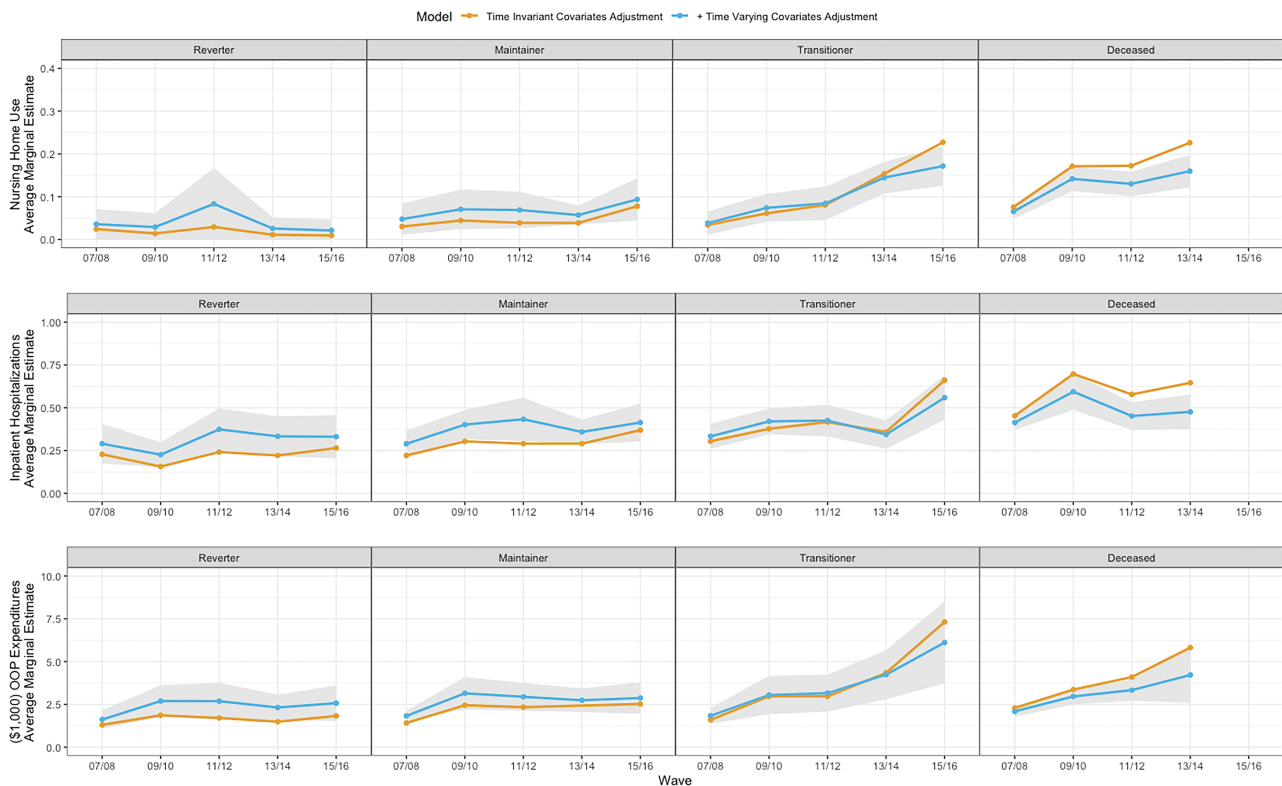
<sup>c</sup>Significantly different than transitioners. Significant is  $p < .05$ .

reverters and maintainers, respectively (Supplementary Table 3). Results remained consistent after adjusting for sociodemographic factors and insurance, but differences were driven primarily by the propensity for use (Supplementary Table 4, Logit) rather than the number of reuse (multiple admissions) among users (Supplementary Table 4, GLM). Individuals who died over the observation period had consistently higher average NHU at each wave (Figure 1; Supplementary Table 6). Differences were evident in both higher odds ratios for propensity of NHU (Supplementary Table 4, Logit) as well higher use levels among users (Supplementary Table 4, GLM). Differences in average NHU became more pronounced over time specifically when compared to maintainers and reverters (Figure 2; details of contrasts tests are included

in Supplementary Table 7). The differences between transitioners and maintainers and reverters increased to 0.15 ( $SE = 0.03$ ;  $p < .0001$ ) and 0.22 ( $SE = 0.03$ ;  $p < .0001$ ), respectively, by 2015/2016 (Supplementary Table 7, Model 1). Close to half of the estimated differences in levels of NHU between transitioners relative to reverters and maintainers in 2015/2016 were explained by adjustments to the time-varying health covariables (Figure 2; Supplementary Table 7, Model 2).

### Annual IH

CIND status maintenance was associated with a higher propensity of hospitalization relative to reversion. By 2015/2016, individuals transitioning to SCI/dementia



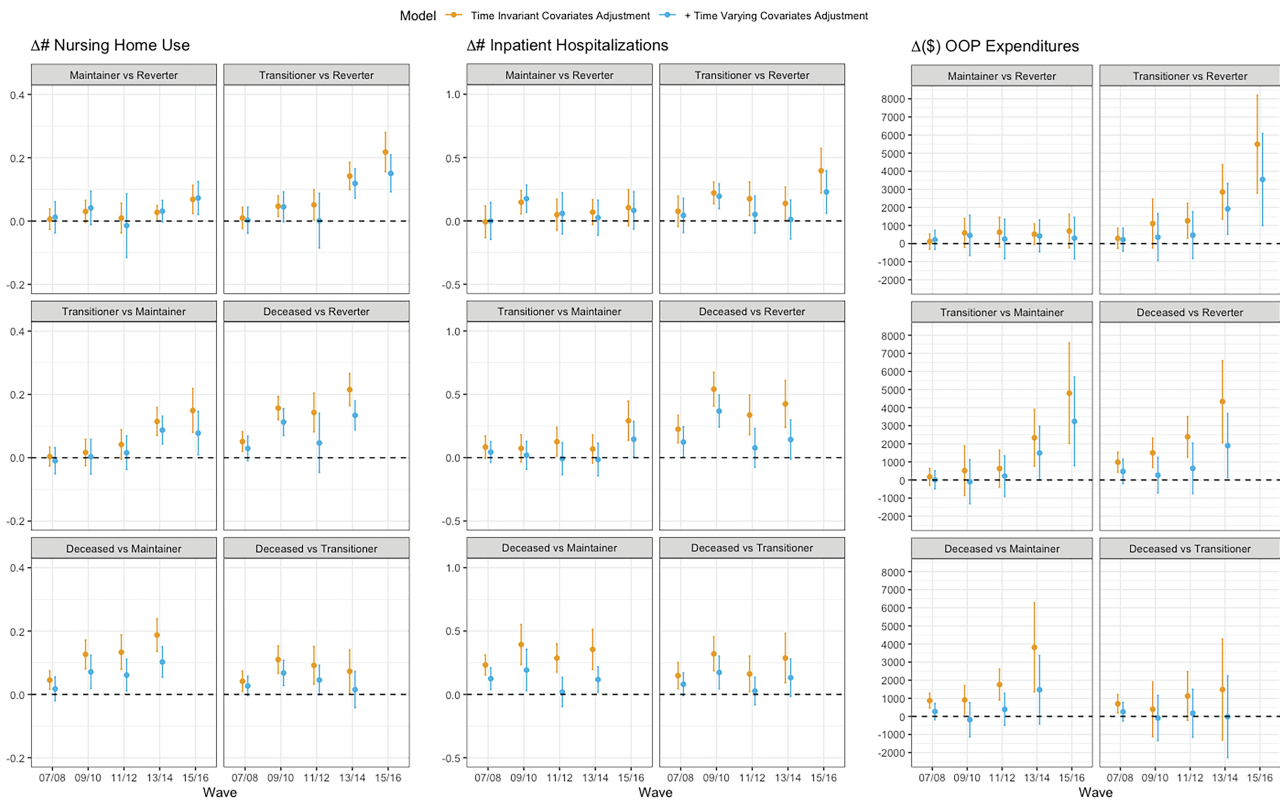
**Figure 1.** Average marginal estimates of yearly health services use and out-of-pocket spending among individuals 70 years and older meeting Langa–Weir criteria for cognitive impairment no dementia at the baseline wave (2007/2008). *Notes:* Estimates are derived post hoc based on two-part models. Two-part models include a logistic regression to model propensity of use, and generalized linear models with gamma distribution to model level of use among users. The marginal estimates are based on the combined product of propensity and level of use. Model 1: adjusts for age, sex, education, and wave-specific insurance status; Model 2: Model 1 covariates and additional adjustment for time-varying ADLs/IADLs, count of physical limitations, and comorbid chronic conditions. ADL/IADL = activities of daily living/instrumental activities of daily living; OOP = out of pocket.

had 20.7% (8.04–33.42) and 14.9% (3.35–26.43) higher absolute prevalence of IH compared to reverters and maintainers, respectively (Table 2, Panel A includes the estimated crude proportions and Supplementary Table 3 includes the ANOVA contrasts). Results remained consistent after adjusting for sociodemographic factors and insurance. Individuals who died over the observation period had consistently higher average IH at each wave (Figure 1; Supplementary Table 6). Differences were evident in both higher odds ratios for propensity for IH (Supplementary Table 4, Logit) as well higher use levels of IH among the hospitalized (Supplementary Table 4, GLM). Differences in average IH became more pronounced over time specifically when compared to those who maintained CIND status or reverted back to normal (Figure 2). Controlling for time-invariant covariates, differences in average annual IH between transitioners and maintainers and reverters increased to 0.40 ( $SE = 0.09$ ;  $p < .001$ ) and 0.29 ( $SE = 0.08$ ;  $p < .001$ ), respectively, by 2015/2016. Differences in levels of annual IH between transitioners and reverters and transitioners and maintainers were reduced to 0.23 ( $SE = 0.08$ ;  $p = .009$ ) and 0.15 ( $SE = 0.07$ ;  $p = .043$ ) after adjustment to the time-varying health covariables (Figure 2; Supplementary Table 7, Model 2).

### Annual OOP Spending

Individuals transitioning to SCI/dementia had statistically equivalent OOP spending levels at baseline compared to those who maintained status or transitioned to normal cognition (Table 2, Panel B includes the estimated crude means and Supplementary Table 3 includes the ANOVA contrasts); however, the average differences widened consistently over time to reach  $\Delta = \$7,587$  (4,412–10,762) and  $\Delta = \$6,800$  (3,625–9,976) by 2015/2016, compared to those reverting to normal cognition or maintaining CIND status, respectively. Results remained consistent after adjusting for sociodemographic factors and insurance. Individuals who died over the observation period had consistently higher average OOP spending at each wave (Figure 1; Supplementary Table 6). Increased OOP expenditures were the result of higher relative spending (Supplementary Table 4, GLM) rather than to group differences in the propensity to incur costs. Differences in OOP spending became more pronounced over time specifically when compared to those who maintained CIND status or reverted back to normal (Figure 2; Supplementary Table 7). Adjusting for these covariates, transitioners, maintainers, and reverters had similar OOP spending over the first three waves (2007/2008–2011/2012). Differences





**Figure 2.** ANOVA-based contrasts in average marginal estimates, and their 95% confidence intervals, for yearly health services use and out-of-pocket spending among individuals 70 years and older meeting Langa–Weir criteria for cognitive impairment no dementia at the baseline wave (2007/2008). *Notes:* Estimates are derived post hoc based on two-part models. Two-part models include a logistic regression to model propensity of use, and generalized linear models with gamma distribution to model level of use among users. The marginal estimates are based on the combined product of propensity and level of use. Model 1: adjusts for age, sex, education, and wave-specific insurance status; Model 2: Model 1 covariates and additional adjustment for time-varying ADLs/IADLs, count of physical limitations, and comorbid chronic conditions. ADL/IADL = activities of daily living/instrumental activities of daily living; ANOVA = analysis of variance; OOP = out of pocket.

between transitioners and maintainers and reverters increased to \$2,335 ( $SE = 784$ ;  $p = .0044$ ) and \$2,854 ( $SE = 750$ ;  $p < .001$ ), respectively, in 2013/2014 and to \$4,797 ( $SE = 1,384$ ;  $p = .0011$ ) and \$5,494 ( $SE = 1,347$ ;  $p < .001$ ) in 2015/2016 (Supplementary Table 7, Model 1). The 2015/2016 differences were further reduced by 32.5% ( $\Delta = \$3,241$  [ $SE = 1,224$ ;  $p = .011$ ]) and 35.5% ( $\Delta = \$3,544$  [ $SE = 1,270$ ;  $p = .007$ ]) through adjustments for the time-varying covariates.

## Discussion

For people who were CIND, transition to SCI/dementia or death during the observation period was associated with considerable overtime changes in admission to nursing homes and, to a lesser extent, IHs, as well as OOP health spending. Among transitioners, in the last 4 years of observation, when changes are particularly notable, the propensity for inpatient NHU was only partially explained by adjusting for health acuity and need measures including ADLs/IADLs, physical function, and counts of comorbid conditions. People who maintained, or improved, in terms of cognitive status had relatively stable use rates and OOP

spending. Overall, these findings provide support for our first and second hypotheses and only partial support for our third hypothesis. Recent estimates indicate that within a decade, 54% of older adults will not be able to afford the care needed as they transition out of the home (Pearson et al., 2019). This situation will be particularly pronounced for those with dementia. While low-income older adults may be able to maintain low OOP expenditures through public assistance, many middle-income older adults in the United States who do not qualify will be particularly vulnerable and could be left unable to afford proper care (Pearson et al., 2019). A large part of OOP health expenditures for U.S. older adults is on nursing home care, especially later in life. An estimated 55% of spending on nursing home care, and 49% of hospital care is spent in the time preceding the last year of life (Fahle et al., 2016). In line with this evidence, we found that individuals who transitioned to SCI/dementia or died by the final wave considered in this study had sizeable OOP health care spending and were much more likely to use nursing homes than those who maintained status.

Our results are consistent with previous literature on the health services correlates of cognitive decline. Unlike

previous work (Delavande et al., 2013; Hurd et al., 2013, 2017), however, we used longitudinal cognitive data to distinguish between regressive, stable, and progressive cognitive dysfunction and linked these varying forms to household financial expenditures and systemically costly health services utilization. Within 8 years, 15% of individuals with baseline CIND were alive and transitioned to SCI/dementia and 63.3% died. Individuals in these two groups had distinct patterns of NHU, IHs, and OOP health expenditures. Transition to SCI/dementia was associated with a higher probability of institutionalization but not with repeat nursing home entries, whereas individuals who died during the observation period had a higher likelihood for both being admitted at least once to a nursing home as well as for being readmitted, particularly so during the last year's observation. For IHs, individuals who transitioned to SCI/dementia as well as those who died during the observation period were both more likely to be hospitalized as well as to be readmitted to the hospital. Finally, transitioners and those who died were equally or less likely to have any OOP health care costs; however, spending levels were increased among those who needed to spend OOP. These variabilities suggest that appropriately addressing the needs of these differing patient constituencies and their families and potentially changing the trajectories of these considered outcomes require specifically targeted programs and interventions. While our data show evidence for a simultaneous and pronounced increase in spending and use during the latter years of the observation period, our findings do not allow us to explicitly propose specific policies for how to change this course. However, existing research shows potential (but also challenges; Bardo et al., 2014; Freeman et al., 2017) for nursing home diversion and back to community discharge programs for reducing care costs (Irvin et al., 2017) and improving quality of life for patients and their caregivers (Robison et al., 2015) and offer positive evidence that we can extrapolate from.

Our results indicate that adjustment for health acuity and health needs had a limited attenuating impact on the uncovered patterns of increase in NHU and IHs among those who transition to SCI/dementia. This suggests that these factors are only partially driving decisions related to health services use and thus provide targets for interventions. Among individuals with cognitive impairment and dementia, hospital admissions, and particularly readmissions, are highly preventable, especially in low health risk groups (Ma et al., 2019). Patient health complexities and severity of need are also critical factors for institutionalization and for reduced success of back to community diversion and transition programs (Gassoumis et al., 2013). Patient-centered care plans have potential for altering the trajectories of costly and, arguably, lower-quality care (e.g., nursing home placement and hospital admissions) among individuals with low health needs. While we cannot provide specific policy prescriptions, our results suggest that

providers and policymakers should continue to focus their efforts on programs designed to boost ambulatory care for higher-risk individuals. Doing so has the potential to reduce costly hospitalizations and hospital readmissions as well as nursing home placements.

OOP health expenditures grew at a much faster rate among those transitioning to SCI/dementia relative to those with stable CIND. Previous studies have reported differences in OOP spending among patients with dementia relative to other groups (Delavande et al., 2013). Our results add to this literature by documenting evidence of differential patterns of OOP health expenditures and use over time among individuals with baseline evidence of impairment. Our findings also highlight that differences in OOP spending are mainly driven by the amount spent by those who needed to spend OOP. Individuals with progressively worsening cognitive impairment have a non-linear increase in spending over time that reflects higher demands for care, especially institutional care. The severity of disease and morbidity progression ultimately leading to death during the observation period are related to spending patterns that are slightly more pronounced but on par with those who transition to SCI/dementia. Individuals with CIND who converted to SCI/dementia will face critical financial burdens. However, the increase in OOP spending over time does not translate to a steep increase in IHs and NHU until later years. The extra spending in early years likely reflects premiums, deductibles, and other costs associated with increased requirements for specialists, outpatient, and personalized care. Disability and decrements in ability to self-manage in the presence of cognitive decline increase the risk for falls, accidents, and injuries (Allali et al., 2017; Chen et al., 2018; Muir et al., 2012). In later years, as NHU increases, OOP expenditures do so as well. Medicare covers short-term stays in skilled nursing facilities but not custodial nursing care, and while individuals meeting income and assets criteria can be eligible for Medicaid coverage up to one in two individuals in nursing homes enter as private payors and deplete their resources before attaining such coverage (Branch et al., 2020). In the absence of interventions, our findings suggest that for ineligible individuals, the financial burdens of skilled and custodial nursing home care can exact acute financial costs on the oldest and the sickest (Johnson & Wang, 2019) and can potentially force many into accelerated assets liquidation. If the cognitively impaired and their families continue to seek nursing home stays more often, Medicaid expenditures will also increase substantially. Medicaid paid an estimated 50 billion dollars on dementia care in 2015 (Alzheimer's Association, 2016), and with nursing home stays increasing, this number will continue to rise.

This study has several strengths. First, our study design and population focus are responsive to the recommendations provided by the Alzheimer's Foundation of America and Alzheimer's Drug Discovery Foundation workgroup calling for better charting and

clearer understanding of the implications of early cognitive disease recognition to health care and care redesign (Borson et al., 2013). We also focused on high burden measures reflecting health spending and health care services utilization. A better understanding of associations between cognitive impairment and these indicators is critical for improving care and maintaining health in the face of cognitive disease progression. As such, our findings can inform multiple stakeholders about the consequences of heterogeneities in disease progression to policy critical health care measures. We make use of the most recent nationally representative data on cognitive impairment and health services outcomes available to date. Additionally, the use of longitudinal data enhances the robustness of the directionality of the reported increases and thus our confidence in our attributions.

### Limitations

This work has several limitations that should be considered when interpreting our findings. First, while HRS used adjudicated classification from the ADAMS to extrapolate the thresholds for cognitive impairment, threshold-based classifications can have low specificity for capturing preclinical stages of the disease. Designations of CIND and SCI/dementia in our study are therefore research specific and not diagnostic. Future work should confirm our findings using clinical and claims-based data. Published work has also shown that specificity of MCI, the preclinical equivalent of CIND, is also low with close to a third of clinically diagnosed individuals reverting back to normal cognitive function (Wood, 2016). Our study's longitudinal design explicitly accounts for these reversions by using multiple assessments over time. Additionally, threshold-based classifications, particularly in the context of the HRS, have been shown to be biased for lower educated and minority populations. As important, our design and measures do not allow us to assess or control for specific causes or subtypes of cognitive disabilities including delirium. The uncertainty in defining subtypes of cognitive impairment has critical implications for cost attributions and for guiding recommendations for potential interventions. Finally, the outcomes of interest, including the OOP spending measures, are self-reported and biennially. Future work using administratively linked data can enhance the precision of the reported estimates. Future work should also examine other critical measures including lost wages to informal caregiving, adult day programs use, and their associations with health care costs as well as improvements in mortality outcomes. Our findings also point to research opportunities to examine differences in the considered outcomes based on types of primary care received (e.g., geriatrics vs. family medicine). These outcomes were out of scope given the current design but can better inform policy and decision making in anticipation of the forecasted aging and cognitive disease prevalence growth in the United States and worldwide.

### Conclusions

Findings from this study suggest that OOP spending on health care grows substantially as cognitive impairment worsens over time. Growth in OOP precedes the period where the probability of institutional care requirements pick-up and accelerates as demand for such care becomes necessary. Nearly one in four Americans will be 65 years or older by 2050 (Ortman & Velkoff, 2014; U.S. Census Bureau, 2012). Within this context, our findings should raise serious concerns for health policy stakeholders about the implications of these health services use patterns and expenditures to dementia patients and their families.

### Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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### Conflict of Interest

None declared.

### References

- Allali, G., Launay, C. P., Blumen, H. M., Callisaya, M. L., De Cock, A. M., Kressig, R. W., Srikanth, V., Steinmetz, J. P., Verghese, J., & Beauchet, O.; Biomathics Consortium. (2017). Falls, cognitive impairment, and gait performance: Results from the good initiative. *Journal of the American Medical Directors Association*, 18(4), 335–340. doi:10.1016/j.jamda.2016.10.008
- Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 12(4), 459–509. doi:10.1016/j.jalz.2016.03.001
- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 14(3), 367–429. doi:10.1016/j.jalz.2018.02.001
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10. doi:10.2307/2137284
- Banks, J., Muriel, A., & Smith, J. P. (2011). Attrition and health in ageing studies: Evidence from ELSA and HRS. *Longitudinal and Life Course Studies*, 2(2), 101–126. doi:10.14301/ljcs.v2i2.115
- Bardo, A. R., Applebaum, R. A., Kunkel, S. R., & Carpio, E. A. (2014). Everyone's talking about it, but does it work? Nursing home diversion and transition. *Journal of Applied Gerontology*, 33(2), 207–226. doi:10.1177/0733464813505702
- Borson, S., Frank, L., Bayley, P. J., Boustani, M., Dean, M., Lin, P. J., McCarten, J. R., Morris, J. C., Salmon, D. P., Schmitt, F. A., Stefanacci, R. G., Mendiondo, M. S., Peschin, S., Hall, E. J.,

- Fillit, H., & Ashford, J. W. (2013). Improving dementia care: The role of screening and detection of cognitive impairment. *Alzheimer's & Dementia*, 9(2), 151–159. doi:10.1016/j.jalz.2012.08.008
- Branch, L. G., Friedman, D. J., Cohen, M. A., Smith, N., & Socholitzky, E. (2020). Impoverishing the elderly: A case study of the financial risk of spend-down among Massachusetts elderly people. In B. B. Hess & E. W. Markson (Eds.), *Growing old in America* (pp. 241–252). Routledge.
- Cai, Q., Salmon, J. W., & Rodgers, M. E. (2009). Factors associated with long-stay nursing home admissions among the U.S. elderly population: Comparison of logistic regression and the Cox proportional hazards model with policy implications for social work. *Social Work in Health Care*, 48(2), 154–168. doi:10.1080/00981380802580588
- Chen, R., Chien, W. C., Kao, C. C., Chung, C. H., Liu, D., Chiu, H. L., & Chou, K. R. (2018). Analysis of the risk and risk factors for injury in people with and without dementia: A 14-year, retrospective, matched cohort study. *Alzheimer's Research & Therapy*, 10(1), 111. doi:10.1186/s13195-018-0437-0
- Crimmins, E. M., Kim, J. K., Langa, K. M., & Weir, D. R. (2011). Assessment of cognition using surveys and neuropsychological assessment: The Health and Retirement Study and the Aging, Demographics, and Memory Study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(Suppl. 1), 162–171. doi:10.1093/geronb/gbr048
- Deb, P., & Norton, E. C. (2018). Modeling health care expenditures and use. *Annual Review of Public Health*, 39, 489–505. doi:10.1146/annurev-publhealth-040617-013517
- Delavande, A., Hurd, M. D., Martorell, P., & Langa, K. M. (2013). Dementia and out-of-pocket spending on health care services. *Alzheimer's & Dementia*, 9(1), 19–29. doi:10.1016/j.jalz.2011.11.003
- Díaz-Venegas, C., Downer, B., Langa, K. M., & Wong, R. (2016). Racial and ethnic differences in cognitive function among older adults in the USA. *International Journal of Geriatric Psychiatry*, 31(9), 1004–1012. doi:10.1002/gps.4410
- Fahle, S., McGarry, K., & Skinner, J. (2016). Out-of-pocket medical expenditures in the united states: Evidence from the Health and Retirement Study. *Fiscal Studies*, 37(3–4), 785–819. doi:10.1111/fj.1475-5890.2016.12126
- Farewell, V. T., Long, D. L., Tom, B. D. M., Yiu, S., & Su, L. (2017). Two-part and related regression models for longitudinal data. *Annual Review of Statistics and its Application*, 4, 283–315. doi:10.1146/annurev-statistics-060116-054131
- Fisher, G., Faul, J.D., Weir, D.R., & Wallace, R.B. (2005). *Documentation of chronic disease measures in the Health and Retirement Study*. Institute for Social Research, University of Michigan. <https://hrs.isr.umich.edu/sites/default/files/biblio/dr-009.pdf>
- Fisher, G., Halimah, H., Faul, J., Rogers, W., & Weir, D. (2017). *Health and Retirement Study imputation of cognitive functioning measures: 1992–2014*. Institute for Social Research, University of Michigan. <http://hrsonline.isr.umich.edu/modules/meta/year/cogimp/desc/COGIMPdd.pdf>
- Fonda, S., Herzog, A. R. (2004). *Documentation of physical functioning measures in the Health and Retirement Study and the Asset and Health Dynamics Among the Oldest Old Study*. Institute for Social Research, University of Michigan. <https://hrs.isr.umich.edu/sites/default/files/biblio/dr-008.pdf>
- Freeman, S., Bishop, K., Spirgiene, L., Koopmans, E., Botelho, F. C., Fyfe, T., Xiong, B., Patchett, S., & MacLeod, M. (2017). Correction to: Factors affecting residents transition from long term care facilities to the community: A scoping review. *BMC Health Services Research*, 17(1), 694. doi:10.1186/s12913-017-2636-y
- Gassoumis, Z. D., Fike, K. T., Rahman, A. N., Enguidanos, S. M., & Wilber, K. H. (2013). Who transitions to the community from nursing homes? Comparing patterns and predictors for short-stay and long-stay residents. *Home Health Care Services Quarterly*, 32(2), 75–91. doi:10.1080/01621424.2013.779353
- Goldman, D. P., & Zissimopoulos, J. M. (2003). High out-of-pocket health care spending by the elderly. *Health Affairs (Project Hope)*, 22(3), 194–202. doi:10.1377/hlthaff.22.3.194
- Goldman, D. P., Zissimopoulos, J., & Lu, Y. (2011). Medical expenditure measures in the Health and Retirement Study. *Forum for Health Economics & Policy*, 14(3), 4. doi:10.2202/1558-9544.1267
- Holt, D., Smith, T.M.F., & Winter, P. D. (1980). Regression analysis of data from complex surveys. *Journal of the Royal Statistical Society. Series A*, 143(4), 474–487. doi:10.2307/2982065
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *The New England Journal of Medicine*, 368(14), 1326–1334. doi:10.1056/NEJMsa1204629
- Hurd, M. D., Michaud, P. C., & Rohwedder, S. (2017). Distribution of lifetime nursing home use and of out-of-pocket spending. *Proceedings of the National Academy of Sciences*, 114(37), 9838–9842. doi:10.1073/pnas.1700618114
- Irvin, C. V., Bohl, A., Stewart, K., Williams, S. R., Steiner, A., Denny-Brown, N., Wysocki, A., Coughlin, R., Smoot, J., & Peebles, V. (2017). *Money follows the person 2015 annual evaluation report*. Mathematica Policy Research. <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101741203-pdf>
- Johnson, R. W., & Wang, C. X. (2019). The financial burden of paid home care on older adults: Oldest and sickest are least likely to have enough income. *Health Affairs (Project Hope)*, 38(6), 994–1002. doi:10.1377/hlthaff.2019.00025
- Kelley, A. S., McGarry, K., Fahle, S., Marshall, S. M., Du, Q., & Skinner, J. S. (2013). Out-of-pocket spending in the last five years of life. *Journal of General Internal Medicine*, 28(2), 304–309. doi:10.1007/s11606-012-2199-x
- Langa, K. M., Larson, E. B., Karlawish, J. H., Cutler, D. M., Kabeto, M. U., Kim, S. Y., & Rosen, A. B. (2008). Trends in the prevalence and mortality of cognitive impairment in the United States: Is there evidence of a compression of cognitive morbidity? *Alzheimer's & Dementia*, 4(2), 134–144. doi:10.1016/j.jalz.2008.01.001
- Langa, K. M., Larson, E. B., & Weir, D. R. (2017). Could the adoption of unleaded gasoline in the 1970s play a role in the precipitous decline in dementia prevalence? Reply. *JAMA Internal Medicine*, 177(6), 893. doi:10.1001/jamainternmed.2017.1083
- Langa, K. M., Plassman, B. L., Wallace, R. B., Herzog, A. R., Heeringa, S. G., Ofstedal, M. B., Burke, J. R., Fisher, G. G., Fultz, N. H., Hurd, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., Weir, D. R., & Willis, R. J. (2005). The Aging,



- Demographics, and Memory Study: Study design and methods. *Neuroepidemiology*, 25(4), 181–191. doi:10.1159/000087448
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., ... Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet (London, England)*, 396(10248), 413–446. doi:10.1016/S0140-6736(20)30367-6
- Ma, C., Bao, S., Dull, P., Wu, B., & Yu, F. (2019). Hospital readmission in persons with dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 34(8), 1170–1184. doi:10.1002/gps.5140
- Muir, S. W., Gopaul, K., & Montero Odasso, M. M. (2012). The role of cognitive impairment in fall risk among older adults: A systematic review and meta-analysis. *Age and Ageing*, 41(3), 299–308. doi:10.1093/ageing/afs012
- Norris, M. (2018). Approaches to easing the affordable housing and health care challenges. *Journal of Affordable Housing & Community Development Law*, 27(2), 319–328. [https://www.americanbar.org/content/dam/aba/publications/journal\\_of\\_affordable\\_housing/volume\\_27\\_number\\_2/ah\\_27-2\\_06norris.pdf](https://www.americanbar.org/content/dam/aba/publications/journal_of_affordable_housing/volume_27_number_2/ah_27-2_06norris.pdf)
- Ofstedal, M., Fisher, G. G., Herzog, R. A. (2005). *Documentation of cognitive functioning measures in the Health and Retirement Study*. Institute for Social Research, University of Michigan. <https://hrs.isr.umich.edu/sites/default/files/biblio/dr-006.pdf>
- Ortman, J. M., & Velkoff, V. A. (2014). *An aging nation: The older population in the United States, current population reports*, P25-1140. U.S. Census Bureau. <https://www.census.gov/prod/2014pubs/p25-1140.pdf>
- Pearson, C. F., Quinn, C. C., Loganathan, S., Datta, A. R., Mace, B. B., & Grabowski, D. C. (2019). The forgotten middle: Many middle-income seniors will have insufficient resources for housing and health care. *Health Affairs (Project Hope)*, 38(5), 851–859. doi:10.1377/hlthaff.2018.05233
- Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., Burke, J. R., Hurd, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., McArdle, J. J., Willis, R. J., & Wallace, R. B. (2008). Prevalence of cognitive impairment without dementia in the United States. *Annals of Internal Medicine*, 148(6), 427–434. doi:10.7326/0003-4819-148-6-200803180-00005
- Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., Burke, J. R., Hurd, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., Willis, R. J., & Wallace, R. B. (2007). Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology*, 29(1–2), 125–132. doi:10.1159/000109998
- Robison, J., Porter, M., Shugrue, N., Kleppinger, A., & Lambert, D. (2015). Connecticut's 'money follows the person' yields positive results for transitioning people out of institutions. *Health Affairs*, 34(10), 1628–1636. doi:10.1377/hlthaff.2015.0244
- Rocca, W. A., Petersen, R. C., Knopman, D. S., Hebert, L. E., Evans, D. A., Hall, K. S., Gao, S., Unverzagt, F. W., Langa, K. M., Larson, E. B., & White, L. R. (2011). Trends in the incidence and prevalence of Alzheimer's disease, dementia, and cognitive impairment in the United States. *Alzheimer's & Dementia*, 7(1), 80–93. doi:10.1016/j.jalz.2010.11.002
- Stephens, C. E., Newcomer, R., Blegen, M., Miller, B., & Harrington, C. (2012). Emergency department use by nursing home residents: Effect of severity of cognitive impairment. *The Gerontologist*, 52(3), 383–393. doi:10.1093/geront/gnr109
- St-Hilaire, A., Hudon, C., Prévaille, M., & Potvin, O. (2017). Utilization of healthcare services among elderly with cognitive impairment no dementia and influence of depression and anxiety: A longitudinal study. *Aging & Mental Health*, 21(8), 810–822. doi:10.1080/13607863.2016.1161006
- Weir, D. R. (2016). *Validating mortality ascertainment in the Health and Retirement Study*. Survey Research Center, Institute for Social Research, University of Michigan. <https://hrs.isr.umich.edu/publications/biblio/9022>
- Weir, D., Faul, J., & Langa, K. (2011). Proxy interviews and bias in the distribution of cognitive abilities due to non-response in longitudinal studies: A comparison of HRS and ELSA. *Longitudinal and Life Course Studies*, 2(2), 170–184. doi:10.14301/lcs.v2i2.116
- Wood, H. (2016). Alzheimer disease: Meta-analysis finds high reversion rate from MCI to normal cognition. *Nature Reviews Neurology*, 12(4), 189. doi:10.1038/nrneurol.2016.29