

Association of Dementia Severity at Diagnosis With Health Care Utilization and Costs Around the Time of Incident Diagnosis

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Abstract

Background and Objectives: This study provides the first analysis of heterogeneity in health care use and costs by level of dementia symptom severity around the time of incident dementia diagnosis for a population-representative sample of older Americans.

Research Design and Methods: We used the Aging, Demographics, and Memory Study (ADAMS), the Health Retirement Study (HRS), and traditional Medicare (TM) claims. We modeled dementia severity measured by the Clinical Dementia Rating scale for ADAMS respondents and applied parameter estimates to HRS respondents older than 70 years who had a claims-based incident dementia diagnosis in 2000–2016. We used claims-based measures of health care costs and use and quantified levels in the quarters before, at, and after a dementia diagnosis. We reported separate results for groups of persons diagnosed at mild, moderate, and severe stages of dementia.

Results: Health care use and costs increased a quarter before dementia diagnosis and increased most significantly in the quarter of diagnosis. Both use and costs declined thereafter but remained elevated relative to prediagnosis. This general pattern was consistent for persons diagnosed at different stages of dementia. Acute care costs were similar across dementia severity categories throughout the period, whereas outpatient use and costs were consistently higher among persons diagnosed at mild stage disease.

Discussion and Implications: Findings from this study provide new insights on how heterogeneity of dementia severity at diagnosis is associated with health care use and costs. Under the current system of care in TM, early dementia diagnosis may not substantially reduce health care use and spending around the time of dementia diagnosis.

Keywords: Cognitive impairment, Dementia severity, Health care costs, Health care use, Timely dementia diagnosis

Translational Significance: This study analyzes how heterogeneity of dementia severity at diagnosis is associated with health care use and costs for a population-representative sample of older Americans. Regardless of dementia severity at diagnosis, health care use and costs increased a quarter before dementia diagnosis and increased most significantly in the quarter of diagnosis and declined thereafter. Acute care costs were similar across dementia severity categories, whereas outpatient use and costs were consistently higher among persons diagnosed at mild stage disease. Under the current system of care in traditional Medicare, early dementia diagnosis may not substantially reduce health care use and spending.

Background and Objectives

Dementia affects 7.6 million older U.S. adults (Alzheimer's Association, 2023) and extracts a heavy financial toll on persons living with dementia, their families, and society. The average annual medical care costs for persons living with dementia are about three times higher than for similar persons without dementia (Zissimopoulos et al., 2014). Studies have reported substantial increases in medical care costs around the time of dementia diagnosis (Lin et al., 2016; White et al., 2019; Zhu et al., 2015) associated with intensive use of hospitalizations,

emergency room (ER) visits, and postacute rehabilitative services (Bynum et al., 2004; Coe et al., 2023; Daras et al., 2017; Desai et al., 2019; Hoffman et al., 2022; Zhu et al., 2015). Dementia diagnoses are often made in later-stage disease, particularly among non-White populations (Amjad et al., 2018; Chen et al., 2019; Lin et al., 2021), or determined at the time of a hospitalization for a health event (Barnett et al., 2014; Knox et al., 2020; LaMantia, Lane, et al., 2016; LaMantia, Stump, et al., 2016; Wolf et al., 2019).

The symptomatology of dementia at the time of diagnosis and its relationship with medical care costs is largely unknown.

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Symptoms of dementia may include cognitive and functional limitations as well as behavioral symptoms, such as depression and anxiety. There is significant heterogeneity in symptoms across persons and in progression of symptoms that may affect the use of care and the costs of care leading up to and at the time of diagnosis. Prior estimates of costs around time of diagnosis reflect averages of persons at various stages of disease and across ranges of symptoms primarily due to the lack of longitudinal data that includes timing of a dementia diagnosis and characteristics of dementia symptoms.

In this study, we combine cognitive, functional, and behavioral data from the Health and Retirement Study (HRS) and data on Clinical Dementia Rating scale from the Aging, Demographic, and Memory Study (ADAMS) for a measure of dementia symptom severity. We link these data to respondents' Medicare claims data in order to describe the relationship between medical care costs before, at, and after a dementia diagnosis for persons with varying levels of dementia symptom severity at the time of diagnosis. We build on prior work documenting changes in health care use and spending around the time of diagnosis while adding heterogeneity in use and spending for persons diagnosed at different dementia symptom severity for insight into the variation in health care use and costs for a representative sample of older U.S. adults.

Research Design and Methods

Data and Study Population

This study used data from the 2000–2016 waves of the HRS with data linkage to Medicare claims for respondents enrolled in traditional Medicare (TM). The HRS is a nationally representative longitudinal study that has surveyed U.S. adults older than 50 years and their spouses biennially since 1992. The HRS collects information on sociodemographic characteristics, health, health care utilization, employment, and financial resources of respondents and their spouses (Juster & Suzman, 1995). Eighty-eight percent of HRS respondents agreed to have their survey data linked to their Medicare claims (St Clair et al., 2017). Medicare claims data are important data source for studying dementia diagnosis and health care utilization and spending in the older U.S. population as it includes information on all diagnoses, health care use and their costs for 97% adults older than 65 in the United States. and is not subject to recall bias of survey reports.

This study also used the ADAMS, a nationally representative study of dementia with a subsample of HRS respondents aged 70 years and older (Langa et al., 2005). Because the ADAMS features detailed in-person clinical assessment of dementia, including a clinician-rated measure of dementia severity, we used data from the ADAMS to model dementia severity and apply model parameters to the longitudinal HRS.

We identified a retrospective cohort of older adults with incident dementia from HRS respondents with linked TM claims in the years 2000–2016. Incident dementia was identified in TM claims using ICD-9 and ICD-10 codes listed in [Supplementary Table 1](#) and a rigorous algorithm for measuring diagnosed dementia in claims that is described in detail in a prior publication and publicly available (Thunell et al., 2019). Briefly, dementia cases were ascertained using a combination of established dementia diagnosis codes and dementia symptom codes. To ensure that we capture incident dementia, we required a 2-year “wash-out” period with no dementia diagnosis prior to the year of incident

dementia diagnosis. To exclude potential rule-out diagnosis, we required a dementia diagnosis to be followed by a second diagnosis or symptom code within 2 years or death within 1 year. Dementia diagnosis and symptom codes are identified in the inpatient, outpatient, skilled nursing facility, home health care, and carrier settings. Dementia symptom codes are used only in combination with dementia diagnosis codes and at a different time point for verification. Date of incident dementia was based on the first claim with the documented diagnosis. This algorithm was found to improve identification of diagnosed dementia among minority populations in claims data (Thunell et al., 2019). We restricted the sample to individuals aged 70 years or older at incident dementia to match the ADAMS sample. To reduce measurement error of dementia severity at time of diagnosis, we imposed an asymmetrical time window restriction that required the matched HRS interview to be up to 12 months before or up to 6 months after incident dementia that occurred no earlier than 2000 (Chen et al., 2019). The sample selection criteria are detailed in [Table 1](#). The final study sample of 2,015 older adults with incident dementia consisted of 1,577 non-Hispanic White older adults (78.3%), 285 non-Hispanic Black older adults (14.1%), 119 Hispanic older adults (5.9%), and 34 older adults of other races (1.7%).

Dementia Severity at Diagnosis

We modeled dementia severity using the validated Clinical Dementia Rating scale (CDR). The CDR is a clinician-rated 5-point dementia staging instrument designed to clinically quantify dementia severity based on the participant's performance in six areas: memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care (Langa et al., 2005). In the ADAMS, the CDR score is determined by a trained clinical professional during a structured interview with both participants and informants (Morris, 1993). We used Poisson regressions to model the CDR score based on data from 852 ADAMS respondents using variables also available to all HRS respondents, including age, sex, race, education level, cognitive function, activities of daily living (ADLs), instrumental activities of daily living (IADLs), depression status, and whether a proxy responded for the participant. [Supplementary Table 2](#) provides estimates from the Poisson regression. We assessed model fit in multiple ways. [Supplementary Figure 1](#) shows the density curve of predicted CDR scores as compared to the observed CDR

Table 1. Sample Selection Criteria for the Study Population

Selection criterion	N
HRS respondents with linked traditional Medicare (TM) claims data in 2000–2016	23,856
Three-year continuous TM enrollment and incident dementia	4,435
Aged 70 years and older	4,074
HRS interview up to 12 months before or up to 6 months after incident dementia	2,281
HRS interview was no earlier than 2000	2,021
Complete information on cognitive or functional limitations	2,015

Notes: HRS = Health and Retirement Study; TM = traditional Medicare.

scores in the ADAMS. In [Supplementary Table 3](#), we show the pseudo *R*-squared test statistics for models that include only cognitive status and compared them to our model with additional covariates that are associated with severity of dementia. Additional Technical Documentation ([Xu et al., 2024](#)) provides details of our dementia severity measure, including how the variables were operationalized and recorded, how missing observations were handled and results from sensitivity tests of the model. In [Supplementary Material](#), we also provide link to code for replication of the dementia severity measure for the use of the research community.

We applied the model parameters from Poisson regressions estimated in ADAMS to all HRS respondents older than 70 years with incident dementia in TM claims. We predicted CDR at diagnosis using data from the closest HRS interview to the time of incident diagnosis for each HRS respondent diagnosed with dementia. To reduce measurement error of dementia severity at the time of diagnosis, we required the closest HRS interview to be up to 12 months before or up to 6 months after incident diagnosis. Based on the predicted CDR score at diagnosis, we classified individuals into three categories of dementia severity at diagnosis: mild cognitive impairment ($CDR < 0.5$) hereinafter “mild”; mild-to-moderate dementia ($0.5 \leq CDR < 2.5$) hereinafter “moderate”; and severe dementia ($CDR \geq 2.5$) hereinafter “severe.”

Health Care Utilization and Spending

The outcome variables are measured using TM claims data. These data contain information about service use and payments rendered by Medicare, beneficiary, and other payers. We measured quarterly health care utilization and spending in different health care settings: inpatient, ER, and outpatient. We used inpatient claim files to identify inpatient stays, length of stay, and expenditures. ER visits were identified in inpatient and hospital outpatient claims files based on established revenue center codes (0450-0459, 0981). Hospital outpatient and carrier (physician) files were used to obtain outpatient visits and expenditures. We calculated quarterly health care utilization and expenditures in the four quarters before, the quarter of, and the four quarters after the date of incident dementia diagnosis. For health care spending, we summed up payments made by Medicare, beneficiary, and other primary payers to get total expenditures. Expenditures were inflation-adjusted to 2016 dollars using the Personal Consumption Expenditure Price Index for health care.

Statistical Analysis

We report descriptive statistics of the study population for each of the three categories of dementia severity at diagnosis and overall. Next we used an event study framework to model health care use and costs adjusted for observable differences that may affect use and spending for persons independent of dementia severity. To compare health care utilization and spending across severity groups over time, we predicted health care use and spending outcomes at each time point with other covariates set at overall sample means and report model predictions of health care use and costs for each category of dementia severity at diagnosis.

The models include interactions between dementia severity at diagnosis (mild, moderate, and severe) and quarters relative to the date of incident diagnosis ($-4, -3, -2, \dots, +2, +3, +4$, with quarter 0 indicating the quarter of incident dementia diagnosis) to study the association of dementia severity at

diagnosis on health care utilization and spending before, at and after the diagnosis. The interaction term between quarter -4 and mild severity was excluded such that the other indicators captured changes relative to this initial quarter for individuals diagnosed at mild stage of dementia. Individuals deceased after dementia diagnosis were dropped from subsequent quarters after the quarter of death in the analysis. We estimated ordinary least squares (OLS) regressions of any hospitalizations and any ER visits, and separately, the average number of outpatient visits by dementia severity at diagnosis and quarter relative to diagnosis. Inpatient length of stays and expenditures were estimated using two-part models to address the presence of a substantial proportion of zeros in the data. The first part estimated the probability of having any length of inpatient stay or expenditures during each quarter using a probit model, and the second part estimated the magnitude of length of stay or expenditures conditional on having non-zero length of stay or costs using a generalized linear model with gamma family link. Outpatient expenditures were estimated using OLS regressions. The models adjusted for age, age squared, sex, race/ethnicity (non-Hispanic white, non-Hispanic Black, Hispanic, and non-Hispanic other), education level (<12 years, $12-15$ years, and ≥ 16 years), total wealth quartiles (relative to the position in this sample), and diagnosis with the following comorbid conditions: diabetes, hypertension, hyperlipidemia, stroke, acute myocardial infarction (AMI), and atrial fibrillation (ATF). Comorbid conditions were identified in TM claims using diagnosis codes and the Chronic Conditions Data Warehouse algorithms in each year. Standard errors were clustered at the individual level to account for within-person correlation.

Unadjusted quarterly health care utilization and costs by dementia severity at diagnosis are provided in [Supplementary Figure 2](#). Model estimates of any hospitalizations, any ER visits, number of outpatient visits and outpatient spending based on OLS models are reported in [Supplementary Table 4](#). Model estimates of inpatient length of stay and inpatient spending based on two-part models are reported in [Supplementary Table 5](#). All analyses were conducted in STATA 15 (StataCorp LP, College Station, TX, USA).

Sensitivity Analysis

Several sensitivity analyses were conducted to evaluate the robustness of results. First, we estimated health care utilization and spending adjusting additionally for calendar year of diagnosis and whether the HRS interview was before diagnosis in the models. Second, we excluded individuals living in nursing homes from the analytical sample (based on self-report in the closest HRS interview from the dementia diagnosis). Third, we tested the sensitivity of results using an alternative time window that required the closest HRS interview to be up to 12 months before or after the dementia diagnosis. Finally, we tested the sensitivity of results using alternative regression models. For dichotomous outcomes of any hospitalizations and any ER visits, we tested whether predictions from probit regression models confirm the OLS predictions of the share of individuals who were hospitalized or had an ER visit in each quarter. In addition, to account for the fact that health care spending is often skewed and may drive results, we tested the sensitivity of inpatient and outpatient spending results using alternative two-part models: the first part still involves a probit regression of any spending and the second part, instead of using linear regression, involves logarithm spending to

estimate the magnitude of expenditures conditional on having positive expenditures. We then tested the differences in logarithm spending in each quarter across different levels of dementia symptom severity at diagnosis.

Results

Characteristics of Study Population by Dementia Severity at Diagnosis

Table 2 presents the characteristics of the sample by dementia severity at first diagnosis. Among the 2,015 respondents aged 70 and older with an incident dementia diagnosis, 376 (18.7%) were diagnosed at mild stage, 1,338 (66.4%) at moderate stage, and 301 (14.9%) at severe stage of the disease. The mean (*SD*) age at diagnosis was 80.2 (5.9) years among persons diagnosed at mild, 83.9 (6.9) at moderate, and 86.1 (6.9) at severe stage. Females were 57.7%, 64.1%, and 68.8% of individuals diagnosed at mild, moderate, and severe stages of disease, respectively. About 89% of persons diagnosed at mild stage are non-Hispanic White persons with 10% non-Hispanic Black or Hispanic persons. In contrast, about 21% and 26% of persons diagnosed at moderate or severe stage, respectively, were non-Hispanic Black or Hispanic persons.

Individuals diagnosed at mild stage were the most educated, with 28.7% of them having a bachelor's degree or higher. Only 12.5% and 9.6% of those diagnosed at moderate and severe stages of disease completed college. Median wealth (2016 dollars) was \$288,731 among persons with mild disease at diagnosis. This compares to \$114,410 and \$56,852 among those with moderate and severe disease at diagnosis, respectively. Persons diagnosed at moderate and severe stages of disease were more likely to be without a spouse or partner (59.8% and 73.1%) than persons diagnosed at mild stage disease (46.5%). About 43.5% of individuals diagnosed at severe stage dementia were living in nursing homes. Respondents diagnosed at severe stage had the highest rates of AMI (12.3%) and stroke (37.5%) but lower rates of diabetes (35.9%), hypertension (86.4%), and hyperlipidemia (56.5%) compared to persons diagnosed at mild and moderate stages of disease. The majority of persons diagnosed at mild stage disease reported no difficulty with ADLs or IADLs (83.0% and 93.1%), whereas 58.5% and 93.0% of persons diagnosed at severe stage reported at least three ADL and IADL difficulties. Among persons diagnosed at mild stage of dementia, 13.6% were diagnosed in inpatient settings and 82.2% in outpatient settings. In contrast, more persons were diagnosed in inpatient settings among those diagnosed at moderate and severe stages of disease (15.7% and 21.6%). Fewer, about 78.3% and 71.8% of persons diagnosed at moderate and severe dementia, respectively, received the incident diagnosis in outpatient settings. About 35.6% of persons diagnosed at severe stage died within four quarters following the dementia diagnosis, compared to 24.2% and 27.4% among persons diagnosed at mild and moderate stage disease, respectively.

Regression Models of Health Care Utilization and Costs

Outpatient use and spending

Figure 1 shows regression-adjusted model predictions for the average number of outpatient visits and outpatient spending

for each category of dementia severity at diagnosis with other covariates set at overall sample means. There were increases in outpatient visit counts and spending in the quarter preceding diagnosis and in the quarter of diagnosis. Outpatient visit counts and spending declined in the quarters after diagnosis but remained elevated relative to before diagnosis.

Outpatient visits

Persons diagnosed at mild stage had higher levels of outpatient visits relative to those diagnosed at moderate or severe stage disease (Figure 1A). Four quarters prior to diagnosis, persons diagnosed at mild stage had 6.3 visits. This level was fairly steady until the quarter prior to diagnosis where number of visits was 8.1, a 29% increase. In the quarter of diagnosis, persons diagnosed at mild stage had 13.1 visits, a further 62% increase from the quarter before. Outpatient visits reduced to 8.6 the quarter after diagnosis, declined further but remained above prediagnosis levels four quarters after diagnosis (7.1 visits). Among persons diagnosed at moderate stage, outpatient visits increased from 6.8 to 12.2 visits (81% increase) in the quarter of diagnosis and from 6.2 to 11.2 visits (81%) among persons diagnosed at severe stage disease.

In the four quarters prior to diagnosis, persons diagnosed at moderate stage dementia had 0.7_{Q-4} ($p < .1$), 0.9_{Q-3} ($p < .05$), 0.8_{Q-2} ($p < .05$), and 1.3_{Q-1} ($p < .01$) fewer outpatient visits relative to persons diagnosed at mild stage. Persons diagnosed at severe stage dementia had 1.2_{Q-4} ($p < .01$), 1.1_{Q-3} ($p < .05$), 1.3_{Q-2} ($p < .01$), and 1.9_{Q-1} ($p < .001$) fewer visits. In the quarter of diagnosis, persons diagnosed at moderate and severe stage had 0.9 ($p < .1$) and 1.9 ($p < .01$) fewer visits relative to mild stage. In the four quarters following diagnosis, while counts of outpatient visits remained lower among persons diagnosed at later stages compared to mild stage, the differences across categories of dementia severity narrowed over time and were no longer statistically significant thereafter.

Outpatient spending

Four quarters prior to diagnosis, persons diagnosed at mild stage dementia had \$1,739 of costs associated with outpatient care, which were relatively stable until the quarter before diagnosis (\$2,660). In the quarter of diagnosis, outpatient costs increased further to \$4,498 among persons diagnosed at mild stage, a 69% increase from the quarter before (Figure 1B). In the four quarters prior to diagnosis, outpatient spending was \$183_{Q-4} ($p = .34$), \$421_{Q-3} ($p < .1$), \$258_{Q-2} ($p = .21$), and \$632_{Q-1} ($p < .05$) lower among persons diagnosed at moderate stage disease relative to mild stage. Outpatient spending was \$500_{Q-4} ($p < .05$), \$578_{Q-3} ($p < .05$), \$419_{Q-2} ($p < .1$), and \$923_{Q-1} ($p < .01$) lower among persons diagnosed at severe stage disease relative to mild stage.

During the quarter of diagnosis, outpatient spending almost doubled from the quarter before among persons diagnosed at later stages of the disease. Spending increased from \$2,028 to \$3,979 (96% increase) among persons diagnosed at moderate stage and from \$1,737 to \$3,454 (99% increase) among those diagnosed at severe stage disease. In the quarter of diagnosis, outpatient spending was \$518 ($p < .1$) and \$1,044 ($p < .01$) lower among persons diagnosed at moderate and severe stages relative to mild stage. Outpatient spending declined sharply after diagnosis for all persons but remained lower for persons diagnosed at later stages of disease several quarters after diagnosis. In the quarter immediately following

Table 2. Characteristics of Study Population by Dementia Severity at Diagnosis

Variable	Total sample	Mild cognitive impairment (CDR < 0.5)	Mild to moderate dementia (0.5 ≤ CDR < 2.5)	Severe dementia (CDR ≥ 2.5)
Sample, no.	2,015	376	1,338	301
Mean age in years at diagnosis (<i>SD</i>)	83.54 (6.94)	80.24 (5.93)	83.89 (6.89)	86.08 (6.86)
Female, %	63.57	57.71	64.05	68.77
Race/ethnicity, %				
Non-Hispanic White	78.26	88.56	76.98	71.10
Non-Hispanic Black	14.14	6.91	15.32	17.94
Hispanic	5.91	*	6.05	8.64
Education, %				
Less than high school	34.14	13.30	36.47	49.83
High School/some college	50.77	57.98	51.05	40.53
College and above	15.09	28.72	12.48	9.63
Median total wealth (2016\$)	129,769	288,731	114,410	56,852
Single, %	59.31	46.54	59.79	73.09
Live in nursing home, %	13.35	*	9.72	43.52
Comorbid conditions, %				
Acute myocardial infarction	10.57	9.57	10.46	12.29
Atrial fibrillation	26.55	23.67	27.80	24.58
Stroke	32.80	26.33	33.56	37.54
Diabetes	39.06	37.23	40.28	35.88
Hypertension	89.63	87.50	90.96	86.38
Hyperlipidemia	70.97	78.72	72.05	56.48
ADL, %				
No difficulty	52.16	82.98	52.84	10.63
1–2 difficulties	26.15	13.83	28.55	30.90
3–5 difficulties	21.69	*	18.61	58.47
IADL, %				
No difficulty	48.14	93.09	46.34	*
1–2 difficulties	26.55	6.91	36.47	*
3–5 difficulties	25.31	*	17.19	93.02
Location of incident diagnosis, %				
Inpatient	16.18	13.56	15.70	21.59
Outpatient	78.01	82.18	78.25	71.76
Other locations	5.81	*	6.05	*
Died in 4 quarters after diagnosis, %	28.04	24.20	27.43	35.55
Survey before diagnosis, %	70.17	78.99	71.45	53.49

Notes: ADL = activities of daily living; CDR = Clinical Dementia Rating scale; IADL = instrumental activities of daily living; *SD* = standard deviation. Sample is HRS respondents with linked traditional Medicare claims data in 2000–2016 who had an incident dementia diagnosis in claims data that was verified over time by second claim, aged 70 years and older, and had an HRS interview up to 12 months before or up to 6 months after incident dementia. Dementia diagnosis identified in skilled nursing facility and home health care are combined into “Other Locations.” Values with * are censored ($n < 25$).

the diagnosis, outpatient spending was \$442 ($p < .1$) and \$578 ($p < .05$) lower among persons diagnosed at moderate and severe stages relative to mild stage. Among the most severe group, outpatient spending remained \$502_{Q-2} ($p < .05$), \$210_{Q-3} ($p = .44$), and \$405_{Q-4} ($p < .1$) lower compared to the mild group two to four quarters after diagnosis.

In [Supplementary Table 6](#), we tested differences in outpatient spending before, at, and after incident diagnosis across different levels of dementia severity at diagnosis based on results from two-part models with the second part being log function of outpatient spending. The results confirmed our main findings in [Figure 1B](#): outpatient spending was consistently lower among persons diagnosed at moderate and severe stages of disease relative to mild stage in the four

quarters prior to diagnosis as well as in the quarter of diagnosis. Moreover, outpatient spending remained significantly lower among the most severe group compared to the mild group several quarters after diagnosis.

Inpatient use and spending

[Figure 2](#) shows regression-adjusted model predictions for hospitalization rates, length of inpatient stay, and inpatient spending for persons diagnosed at each category of dementia severity with other covariates set at overall sample means. Across all levels of dementia severity at diagnosis, hospitalization rates, inpatient length of stay, and inpatient spending increased in the quarter preceding the incident dementia diagnosis and peaked in the quarter of diagnosis. Inpatient care

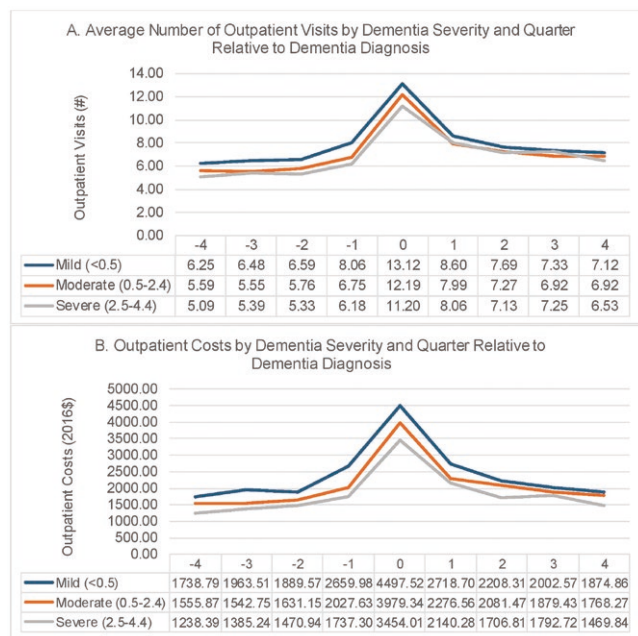


Figure 1. Predicted outpatient visits and costs before and after dementia diagnosis by dementia severity at diagnosis. Predicted number of outpatient visits (A) and outpatient spending (B) by dementia severity at diagnosis and quarter relative to the date of incident dementia diagnosis, with other covariates at overall sample means. OLS models were estimated, adjusting for age, age squared, sex, race, education, total wealth quartiles, and comorbid conditions. Outpatient spending is converted to 2016 dollars. Based on traditional Medicare claims and HRS data. HRS = Health and Retirement Study; OLS = ordinary least squares.

utilization and expenditures declined sharply after diagnosis but remained elevated for several quarters compared to pre-diagnosis period.

Hospitalization rates

Among persons diagnosed at mild stage disease, hospitalization rates increased from 18.4% in the quarter prior to diagnosis to 47.3% in the quarter of diagnosis. Hospitalization rates increased from 15.9% to 50.7% among persons diagnosed at moderate stage and from 16.4% to 54.0% among persons diagnosed at severe stage (Figure 2A). Hospitalization rates were statistically indistinguishable across dementia stages in the quarters before diagnosis (with exception of Q-3 between mild and severe stages). During the quarter of diagnosis, hospitalization rates were 3.4 ($p = .23$) and 6.7 ($p < .1$) percentage points higher among persons diagnosed at moderate and severe stage disease relative to mild stage. Hospitalization rates were not statistically different across categories of dementia severity in the quarters following diagnosis. In Supplementary Figure 3, we report regression-adjusted model predictions for hospitalization rates based on sensitivity checks using probit models. In general, results from the probit models confirmed what we found using OLS models: hospitalization rates were not statistically different across different levels of dementia severity at diagnosis before and after diagnosis. The rates were higher (but by a lesser degree compared to OLS) and were not statistically different among the more severe groups in the quarter of diagnosis.

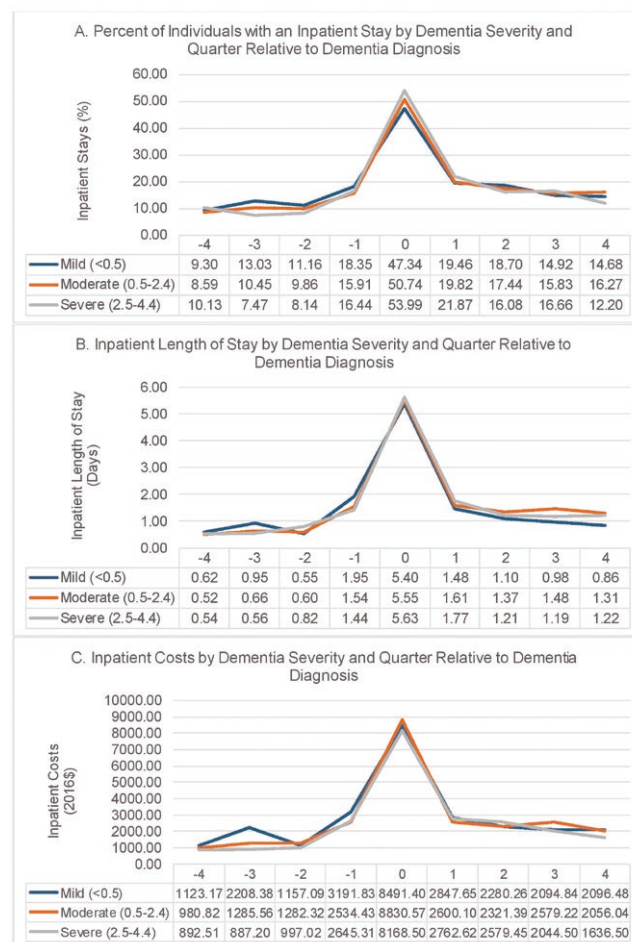


Figure 2. Predicted inpatient care utilization and costs before and after dementia diagnosis by dementia severity at diagnosis. Predicted hospitalization rates (A), inpatient length of stay (B), and inpatient spending (C) by dementia severity at diagnosis and quarter relative to the date of incident dementia diagnosis, with other covariates at overall sample means. OLS model was estimated for hospitalization rates and two-part models for inpatient length of stay and spending, adjusting for age, age squared, sex, race, education, total wealth quartiles, and comorbid conditions. Inpatient spending is converted to 2016 dollars. Based on traditional Medicare claims and HRS data. HRS = Health and Retirement Study; OLS = ordinary least squares.

Inpatient length of stay

Among persons diagnosed at mild stage disease, inpatient length of stay increased from 2.0 days in the quarter prior to 5.4 days (177% increase) in the quarter of diagnosis. This compares to an increase from 1.5 to 5.6 days (260%) among persons diagnosed at moderate stage and from 1.4 to 5.6 days (291%) among persons diagnosed at severe stage (Figure 2B). In the four quarters before, the quarter of, and four quarters after diagnosis, differences in average inpatient length of stay across dementia stages were not statistically significant.

Inpatient spending

From the quarter before to quarter of diagnosis, inpatient spending rose from \$3,192 to \$8,491 (166% increase) among persons diagnosed at mild stage disease. Inpatient spending increased from \$2,534 to \$8,831 (248%) and from \$2,645 to \$8,169 (209%) among persons diagnosed at moderate

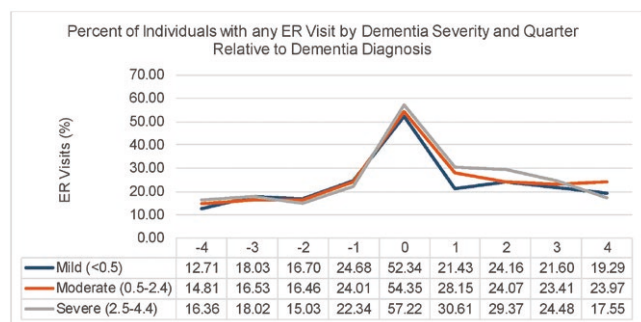


Figure 3. Predicted emergency room utilization before and after dementia diagnosis by dementia severity at diagnosis. Predicted ER rates by dementia severity at diagnosis and quarter relative to the date of incident dementia diagnosis, with other covariates at overall sample means. OLS model was estimated, adjusting for age, age squared, sex, race, education, total wealth quartiles, and comorbid conditions. Based on traditional Medicare claims and HRS data. ER = emergency room; HRS = Health and Retirement Study; OLS = ordinary least squares.

and severe stage disease, respectively (Figure 2C). Average inpatient spending was statistically indistinguishable across categories of dementia severity in the four quarters before (with exception of Q-3 between mild and severe stage), the quarter of, and four quarters after diagnosis. Results from sensitivity checks using two-part models with the second part being log function of inpatient spending support our main findings in Figure 2C that there were no statistically significant differences in inpatient spending across different levels of dementia severity at diagnosis throughout the entire 2-year period (Supplementary Table 7).

Emergency room use

Regression-adjusted model predictions for ER rates were reported in Figure 3. Regardless of dementia severity at diagnosis, quarterly ER rates were relatively stable four to two quarters preceding the dementia diagnosis, ranging from 13% to 18%, and increased to between 22% and 25% in the quarter prior to diagnosis. ER rates were statistically indistinguishable among persons diagnosed at different stages of dementia in the four quarters prior to diagnosis. During the quarter of diagnosis, ER rates increased from 24.7% to 52.3% among persons diagnosed at mild stage dementia. This compares to an increase from 24.0% to 54.4% among persons diagnosed at moderate stage and from 22.3% to 57.2% among persons diagnosed at severe stage disease. The differences across dementia stages in the quarter of diagnosis were not statistically different. In the quarter immediately following diagnosis, ER rates declined to almost prediagnosis levels (21.4%) among persons diagnosed at mild stage disease. ER rates, however, remained elevated among those diagnosed at moderate and severe stages (28.2% and 30.6%). In particular, compared to persons diagnosed at mild stage, ER rates were 6.7 ($p < .01$) and 9.2 ($p < .01$) percentage points higher among persons diagnosed at moderate and severe stage in the quarter following diagnosis. ER rates remained 5.2 and 2.9 percentage points higher for the most severe group relative to the mild group two to three quarters after diagnosis but the differences were no longer statistically significant. In Supplementary Figure 4, we report predictions of ER rates from sensitivity checks using alternative probit models. The predictions closely mirror the OLS ones and the same pattern

is observed in terms of differences in ER rates across dementia stages at diagnosis.

Discussion and Implications

This study used HRS data linked with administrative TM claims data to quantify how heterogeneity in dementia severity at the time of diagnosis is related to levels and trends in health care utilization and costs over 2 years beginning with the year before a dementia diagnosis to the year after a dementia diagnosis. Adjustments for race/ethnicity, education, and wealth using HRS data and comorbid conditions using TM claims-based diagnoses allowed for quantifying the relationship between severity of disease at diagnosis and health care use and costs independent of potentially correlated demographic and socioeconomic factors and comorbid conditions.

We found use of health care services and spending increased a quarter before the dementia diagnosis and increased most significantly in the quarter of diagnosis. Both health care use and spending declined in the quarter after diagnosis but remained elevated relative to the second and earlier quarters before diagnosis. The large increases in use of health care services and spending around the time of diagnosis we reported are consistent with findings from prior studies (Coe et al., 2023; Hoffman et al., 2022; Jacobson et al., 2023; Lin et al., 2016; White et al., 2019; Zhu et al., 2015). This general pattern was consistent for persons diagnosed at mild, moderate, and severe stages of dementia. The consistencies and differences in the levels and changes in health care use and costs for persons diagnosed at different levels of dementia severity uncover new information about what does and does not drive high medical care spending around the time of diagnosis. The consistency of spending across dementia stages at diagnosis for hospitalizations suggests that inpatient spending spikes associated with a dementia diagnosis may not be driven primarily by severity of cognitive, functional, or behavioral dementia symptoms. This is consistent but distinct from what is found in prior research that increased spending around the time of dementia diagnosis may be driven by costs associated with a health event during which dementia is recognized (Hoffman et al., 2022). The consistently higher outpatient spending among persons diagnosed at mild stage dementia suggests that routine access to and interaction with the health care system in ambulatory settings may lead to more opportunities for early detection and diagnosis of dementia.

In this study of older TM beneficiaries diagnosed with dementia, acute care (i.e., inpatient and ER) use and costs as well as physician/outpatient use and costs four quarters before a diagnosis, and most evident the quarter before diagnosis, is higher for persons diagnosed at mild stage compared to persons diagnosed at moderate or severe stage disease. Although the higher level of health care use and costs associated with mild impairment relative to moderate or severe holds for the quarter of diagnosis for physician/outpatient care, it reverses for acute care; persons with severe and moderate dementia at diagnosis have higher use of acute care compared to persons diagnosed with mild dementia during the quarter of diagnosis. The likelihood of being hospitalized in the quarter of diagnosis is 3 and 7 percentage points higher among persons diagnosed at moderate and severe stage disease compared to mild stage. Persons diagnosed at moderate and severe stages also had higher ER rates relative to mild dementia—about 2 and 5 percentage points higher in the quarter of diagnosis

and 7 and 9 percentage points higher in the quarter following a dementia diagnosis. Inpatient spending, however, is similar for persons diagnosed at different stages of dementia in the quarter of diagnosis and thereafter.

To the extent that some acute care services after a dementia diagnosis are considered low value and potentially preventable (Bynum et al., 2004; Phelan et al., 2012), prior study has pointed to the potential for reducing dementia attributable acute care utilization via early detection and diagnosis of the disease. The health care use and costs patterns of this study suggest some but limited opportunity for reducing acute care services use of persons with moderate or severe dementia around the time of diagnosis with little to no impact on health care spending. Inpatient spending profiles may be similar across dementia stages at diagnosis due to other unobserved factors correlated with differences across dementia stages. By way of example, persons diagnosed at more advanced stages of dementia may receive fewer procedures during hospitalizations compared to persons diagnosed at mild stage disease. Hospitalizations may be prompted by conditions other than dementia and at the time of hospitalization, dementia was detected. In [Supplementary Table 8](#), we compare procedures received during hospitalizations for congestive heart failure, one of the most common reasons of hospitalizations among persons living with dementia (Phelan et al., 2012), among persons diagnosed at different stages of disease. We find that persons diagnosed at the most advanced stage of dementia received both fewer number and less invasive procedures during their hospitalizations compared to those diagnosed at earlier stages of disease. The small sample size of persons diagnosed at severe stage precludes other promising avenues for insight into these factors. Future work will benefit from larger sample sizes as data linkages continue to expand.

Prior studies examined the relationship between dementia severity and health care costs although not severity at diagnosis. A few studies reported that health care costs increase as the disease progresses (Leicht et al., 2011; Mauskopf et al., 2010; Zhu et al., 2008), whereas other studies reported contradictory results (Ku et al., 2016; Michalowsky et al., 2018; Schwarzkopf et al., 2011). For example, one study of persons in Taiwan reported that persons with mild dementia had higher medical costs, including drug expenditures and inpatient costs, compared to persons with more severe dementia (Ku et al., 2016). Another study based on a community sample reported slightly higher inpatient, outpatient, and rehabilitative costs for patients with mild stage dementia compared to later stages (Schwarzkopf et al., 2011). However, there is a lack of generalizability of prior studies to older U.S. adults due to nonrepresentative or non-U.S. based samples, data limitations including small sample sizes, cross-sectional data, and lack of comprehensive measures to capture all dimensions of dementia symptom severity (cognitive, functional, and behavioral; Mauskopf et al., 2010; Rapp et al., 2012). Moreover, the extant literature has focused exclusively on estimating medical costs based on contemporary disease severity among prevalent dementia cases. These estimates are useful for assessing use of health care resources over the course of the disease but have limited use for quantifying the impact of timely dementia diagnosis. By considering dementia symptom severity at diagnosis, our findings enhance understanding of health care use and costs associated with the timing of diagnosis. A possible explanation of why medical costs do not vary substantially across dementia stages is related to the nature of dementia

which, unlike many other chronic conditions, relies more on support in daily living through long-term care and informal care as the disease progresses (Ku et al., 2016; Schwarzkopf et al., 2011). We do not measure spending on pharmaceutical treatments as disease-modifying medicine has only recently been approved in the United States. As discussed earlier, there may be a different set of co-occurring conditions and types of medical care received and thus costs depending on dementia stage leaving spending levels similar on average.

This study has limitations. First, there may be misclassification in diagnoses of dementia. However, misclassification is reduced by use of a validated algorithm that includes two claims of dementia diagnosis and dementia symptoms over time to account for rule-out diagnoses. Second, the dementia severity measure used in this study is a prediction based on cognitive and functional limitations, depression score and other observable factors. We tested multiple models and assessed overall explanatory power and selected Poisson models based on overall prediction accuracy. The pseudo *R*-squared doubles when covariates other than cognition are included in the model ([Supplementary Table 3](#)). Additional Technical Documentation (Xu et al., 2024) provides more details on model validation. Third, and as discussed above, while we adjusted for potentially correlated socioeconomic factors and comorbid conditions in all of our models, there may be unobserved differences associated with dementia severity at diagnosis and health care use and costs, which may lead to overestimates for persons diagnosed with mild dementia and underestimates of persons with severe. Fourth, our sample was drawn from beneficiaries enrolled in traditional Medicare. The different benefit design, care organization, and financial incentives to diagnose health conditions in Medicare Advantage (MA) may elicit different patterns of dementia diagnosis and health care utilization and costs (Haye et al., 2023; Jacobson et al., 2023). During the study period, MA enrollment was low but growing and by 2016, about one-third of Medicare beneficiaries were enrolled in an MA plan. Today about 50% of all beneficiaries are enrolled in an MA plan thus it is increasingly important to examine dementia diagnosis and patterns of health care use and costs for beneficiaries in TM and MA. Fifth, our measure of dementia severity at diagnosis is based on the closest HRS interview to diagnosis date and may be a noisy measure of severity at diagnosis. We reduce measurement error by adopting a time window which requires the closest HRS interview to be up to 12 months before or up to 6 months after the date of incident dementia diagnosis. Furthermore, to assess robustness of results, we adjusted the model for calendar year and indicator for timing of severity measure before or after diagnosis and the results were robust ([Supplementary Figure 5](#)). We also tested robustness of results by excluding individuals living in nursing homes ([Supplementary Figure 6](#)) and using an alternative time window requirement ([Supplementary Figure 7](#)) and found consistent results. The results for dichotomous outcomes were robust to the use of probit models and two-part regression model results were robust to use of the log function for spending ([Supplementary Figures 3 and 4](#); [Supplementary Tables 6 and 7](#)). Finally, we only examined use and costs of inpatient, ER, and outpatient care. Other components of medical care and informal care were not examined in the current study nor was spending on pharmaceutical treatments. The first disease-modifying Alzheimer's drugs have recently been approved for persons with early stage disease and at a high

cost. There is also a robust pipeline of dementia treatments in clinical trials potentially targeting different disease stages.

Despite the limitations, the study provides new findings of how the heterogeneity of dementia symptom severity at the time of diagnosis for the older adult population is associated with health care use and costs. Under the current system of care for persons in TM, the findings suggest that early detection of dementia will not substantially reduce health care use and spending around the time of dementia diagnosis. However, new models of care coordination, such as the Guiding an Improved Dementia Experience (GUIDE) model, may have implications for health care use and costs. Projected savings however, is expected through delaying nursing home care and there is uncertainty of what the impacts of the care model will be on outpatient and inpatient spending. Improving detection for early diagnosis will likely still have significant value to persons living with dementia and their families by providing opportunities for planning for and sustaining a better quality of life.

Supplementary Material

Supplementary data are available at *Innovation in Aging* online.

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Conflict of Interest

None.

Data Availability

The Aging, Demographics, and Memory Study (ADAMS) data are available from the Health and Retirement Study (HRS) after submitting the Sensitive Health Data Order Form to request access at <https://hrsdata.isr.umich.edu/data-products/aging-demographics-and-memory-study-adams-wave>. The HRS-Medicare linked data are available from the Centers for Medicare & Medicaid Services after obtaining data use agreements. This study was not preregistered with an analysis plan in an independent, institutional registry.

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