Public Spending on Acute and Long-Term Care for Alzheimer’s and Related Dementias

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**Background**

Current estimates of the cost of Alzheimer’s disease and related dementias (ADRD) to the United States government are incomplete, largely ignoring Part D and Medicaid, and static, overlooking variation in costs over the course of the disease.

**Methods**

We estimate the longitudinal spending attributable to ADRD using data from the Health and Retirement Study matched to Medicare and Medicaid claims. Using a retrospective cohort of older adults with a claims-based ADRD diagnosis along with matched controls, we examine Medicare and Medicaid expenditures for up to 60 months following a diagnosis of ADRD.

**Results**

For a cohort aged 65 years and older, the costs attributable to ADRD are $15,632 [95% CI: $12,780; $18,588] to traditional Medicare and $8,833 [95% CI: $7,267; $10,509] to Medicaid per dementia case over the first five years after diagnosis. Seventy percent of Medicare costs occur in the first two years after diagnosis, and are driven by inpatient use (hospitals and skilled nursing facilities). Medicaid costs are driven by long-term care (home health and nursing homes), and concentrated among the longer-lived beneficiaries who are more likely to need long-term care and become Medicaid-eligible.

**Conclusions**

On average, ADRD costs the government $24,465 per case for the first 5 years after diagnosis, with a 64-36 split between the Medicare and Medicaid programs. However, the distribution of these costs varies; Medicare expenditures are front-loaded while Medicaid expenditures are back-loaded. Delaying onset will have a larger financial impact on Medicare; delaying disease progression will have a larger impact on Medicaid spending.

**Introduction**

Over 5.7 million adults are currently living with Alzheimer’s disease and related dementias (ADRD) in the United States (US) today1-3. Current estimates suggest that ADRD is costing Medicare (Parts A and B) between $3,019 and $10,598 per person per year, in 2017 dollars4-7. However, these cost estimates are incomplete. In order to prepare for the future, policy makers need to be armed with reliable estimates of the incremental costs of ADRD to both public health insurance programs, Medicare and Medicaid.

Medicaid is the primary payer for long-term care in the U.S.8 Since ADRD is characterized by cognitive impairment leading to difficulties with daily activities9, long-term care expenditures are likely considerable. The literature estimating the impact of ADRD on Medicaid is sparse due to data limitations6. Four papers estimate the costs to Medicaid nationally, relying on self-reported utilization and imputed Medicaid expenditures6,10-12. Two papers use Medicaid claims, but only for one state13 or one urban area14.

The prescription drug program within Medicare, Part D, was enacted in 2006 and thus these expenditures are missing from the older literature.

In addition to the incompleteness of the costs estimated, the literature has predominantly focused on estimating costs based on prevalent cases. Prevalent cost estimates are useful for knowing current spending but have limited use for predicting future costs if the case mix is changing or if the costs of the disease vary over the course of the disease. Recent work suggests both are happening. The incidence rate of ADRD is declining in high-income countries2,15, leading to a changing case mix, and evidence suggests that costs associated with dementia vary greatly based on time since diagnosis or time prior to death12,16-18.

This paper builds on work by White et al.18 to estimate the incremental costs of ADRD to the public purse via the Medicare (Parts A, B, and D) and Medicaid programs for the first five years after diagnosis. We examine total spending and spending by cost component (inpatient, prescription drugs, nursing homes and home health care, and other spending) to understand what utilization is driving costs. These elements are crucial to understanding the current and future cost burden of ADRD.

**Methods**

*Data*

We use data from the *Health and Retirement Study (HRS)* 1992-2015, a publicly available, nationally representative bi-annual survey that gathers information on the health, health services utilization, and financial resources of older Americans (age 50+). We use the subset of survey respondents who consented to link survey responses to Medicare Parts A (inpatient), B (outpatient), and D (prescription drug) claims from 1992-2015 (over 80% of Medicare-eligible participants). Minimal bias is introduced by this sample restriction19,20. In addition, we use Medicaid claims from 1999-2012 for those who were enrolled in Medicaid at any point during the study period.

*Sample*

We defined the dementia cohort using ICD-9-CM diagnostic codes from Medicare claims. To qualify as a dementia case, individuals were required to be enrolled in Medicare Parts A and B coverage for at least 12 months before and one month after receipt of one of the following diagnosis codes in an inpatient, skilled nursing facility (SNF), home health, hospital outpatient or carrier claim: 331.x, 290.x, 294.x, or 797.16,21 (Specific codes provided in Appendix Table A1.) We defined the diagnosis date for dementia cases as the date of the first qualifying diagnosis code, which is likely after the true onset date. We eliminate individuals in Medicare Advantage plans around the time of diagnosis due to incomplete utilization information.

To isolate the incremental costs due to ADRD, we selected a comparison group of HRS participants matching on sex, race/ethnicity, birth year, HRS-survey entry year, and state of residence. After matching the dementia cases, up to five controls were randomly selected for each case. The comparison group faced similar inclusion criterion; they had to be enrolled in Medicare Parts A and B for the 12 months before and one month after the diagnosis date of their matched case. Additionally, controls had no dementia diagnosis themselves or for a household member prior to or for the 72 months following the diagnosis date of their matched dementia case. This last criterion addresses the concern that the health and health care costs of these participants may have been influenced by their household member’s dementia diagnosis. Individuals who eventually received a dementia diagnosis were eligible to be controls at younger ages (at least 6 years prior to diagnosis). This was allowed to ensure comparable longevity spells between our cases and controls. Controls were given the diagnosis date of their assigned case to allow for a comparison of equivalent time periods.

Study procedures were approved by the Institutional Review Board at the University of Washington, the University of Pennsylvania, the HRS Restricted Data Applications Processing Center, and the Centers for Medicare and Medicaid Services (CMS) Privacy Board.

*Outcomes*

We measured expenditures covered under Medicare and Medicaid. We separately estimate total Medicare spending, total Medicaid spending, and spending by service component within each program: inpatient, prescription drugs, nursing home and home health, and all other spending, the largest component of which is physician services. We categorize expenditures based on the delivery location, but recognize the types of services covered in home health and nursing facilities differ– long-term care (Medicaid) vs. post-acute care (Medicare).

Monthly expenditures for the 12 months prior to and 60 months following the diagnosis date were calculated. We adjusted expenditures for inflation using the Personal Consumption Expenditures price index for health care and report all amounts in 2017 dollars.

*Statistical analysis*

To calculate the marginal effect of dementia on public expenditures, we used the estimator described by Basu and Manning (2010) for estimating costs under censoring.22 Censoring appears in our data for two reasons: individuals can switch out of traditional Medicare to Medicare Advantage, or their 60 month follow-up period can extend beyond 12/31/2015, the endpoint of our claims data. Estimation was done in several steps. First, costs were estimated using a two-part model due to the skewness in medical cost data; the first part of the model estimated the probability of any costs during each month using a logit model, while the second part estimated the magnitude of costs when costs were greater than zero using a generalized linear model with gamma family and log link. This two-step procedure is estimated on two separate samples when estimating Medicare expenditures, both total and by service component, and when estimating total Medicaid expenditures: (1) for all observed months prior to death or censoring, and (2) for the month in which death occurred. Due to small sample sizes when estimating Medicaid expenditures by service component, only one sample is used, combining all observed months including the month in which death occurred. Finally, an accelerated failure time model based on the lognormal distribution for time was used to estimate each subject’s survival function after accounting for censoring.

All models controlled for age, sex, race, marital status, education (< college, college+), quartile of total Medicare expenditures for the 12 months prior to the diagnosis date, and indicator variables for the following comorbid conditions: anemia, arthritis, chronic kidney disease, chronic obstructive pulmonary disease, depression, diabetes, heart disease (atrial fibrillation, ischemic heart disease, or heart failure), hypertension, and stroke. Additionally, models included time from diagnosis (in months), an interaction term for dementia status and time from diagnosis, indicators for years since diagnosis, and interactions between time since diagnosis and the year indicator variables. These terms allow for non-linearity in the relationship between time and costs, and for this relationship to differ based on the year from diagnosis.

The marginal effects from each of the models were estimated using recycled predictions for the dementia cases. Standard errors were obtained via bootstrapping with 1,000 iterations. All analyses were conducted in Stata 17 (StataCorp LP, College Station, TX).

**Results**

Table 1 presents the characteristics of the sample, comparing dementia cases (n=3,658) to the first matched control case. We match on sex, race/ethnicity and birth year, so we see no statistical differences in those characteristics by design. There are no statistical differences in marital status. However, there are differences in levels of education, with the dementia cohort being slightly less educated than their first control. Further, the dementia cohort is significantly sicker across the board, with every comorbidity more prevalent at baseline. This difference in baseline health helps to explain the difference in baseline Medicare expenditures between the two cohorts; Medicare spending on the dementia cohort is 193 percent higher than that of the controls before the dementia diagnosis. We adjust for these covariates in all regression models.

Insurance coverage varies between the cases and the first-matched control, with higher Medicaid and Part D coverage at baseline. While the Part D coverage difference disappears by the time of death among the deceased, the Medicaid coverage difference increases to where cases who have died are over 10 percentage points more likely to be covered by Medicaid at death than their first-matched controls.

Figure 1 presents the unadjusted average monthly expenditures to Medicare and Medicaid among those who have not died or been censored for both the dementia and control cohorts. Prior to diagnosis, the dementia cohort has a higher level of spending for both the Medicare and Medicaid programs, but the trends start roughly parallel prior to diagnosis. A few months before diagnosis, there are significant and substantial increases in spending for Medicare – which is consistent with 40 percent of the cohort first having diagnosis codes appear during an inpatient event (hospital or SNF setting). Medicare expenditures decline almost as quickly as they rose, and again appear to be stable one year after diagnosis. Medicaid expenditures increase at the time of diagnosis, although much less than Medicare expenditures, and maintain at this level for the first few years after diagnosis, while the control cohort’s Medicaid expenditures remain close to zero throughout.

Table 2 presents the regression-adjusted absolute and incremental costs of ADRD to the Traditional Medicare and Medicaid programs in the first 5 years from diagnosis. Medicare expenditures on the dementia cohort were $72,722 (95% CI: $70,701; $75,399) in the first 5 years after diagnosis. Our model predicts that if these individuals did not have dementia, their 5-year expenditures would be $57,091 (95% CI: $54,895; $59,214), for an incremental cost of $15,632 (95% CI: $12,780; $18,588) over 5 years. As was see in Figure 1, these costs are concentrated around diagnosis, with more than 55 percent of these costs being incurred within the first 2 years of diagnosis. When we eliminate the costs associated with the hospitalization or nursing facility stay within which the diagnosis first occurs, the first year’s incremental costs decreases to $7,314, and 69 percent of costs occur within the first two years (See Appendix Table A2). Further, we find that differential survival plays a role in the Medicare expenditures, albeit a relatively small one. If the dementia cohort had the same survival as the control cohort, incremental costs would be $7,825 (95% CI: -$9,198; -$6,476) higher over 5 years.

Medicaid expenditures on the dementia cohort overall are much lower than the Medicare expenditures within the first five years from diagnosis, totaling $12,395 (95% CI: $10,847; $13,981). However, the estimate of the incremental cost due to ADRD is only slightly lower in Medicare than Medicaid, at $8,833 (95% CI: $7,267; $10,509), since the model predicts that Medicaid would pay relatively little if the cohort did not have dementia. Differential survival again plays very little role in the incremental Medicaid costs. It is also worth noting that, unlike the unadjusted time trends shown in Figure 1, the adjusted Medicaid expenditures are fairly stable over time, ranging from $2,324 to $2,734. This is due to the fact that Medicaid coverage and expenditures are more prevalent near the end of the 5-year window, when more than 35 percent of the sample has already died.

It is important to note that these incremental costs are per person costs for the cohort as a whole, regardless of whether an individual is alive or, in the case of Medicaid expenditures, enrolled in Medicaid. Table 3 presents the average incremental Medicare and Medicaid expenditures for the cohort as a whole and conditional on survival and dual-eligibility status. For Medicare, the average incremental expenditures decrease when examining expenditures on survivors vs. the entire cohort, and the general pattern remains stable. For Medicaid, however, the interaction between living a long time with dementia and enrolling in Medicaid changes the time pattern of average incremental expenditures. Among survivors, average expenditures increase with time since diagnosis, and experiences exponential increases when conditioning on those who are both alive and enrolled.

Table 4 breaks down the public expenditures by payer into their cost components. Medicare expenditures on ADRD are driven by inpatient, SNF and home health care, which represent 95 percent of the incremental costs over the first five years after diagnosis. All are front-loaded; indeed, beneficiaries with ADRD are predicted to spend less on inpatient care five years after diagnosis. The level of the incremental costs due to prescription drugs (Part D) increases over time but remains relatively low, at $68-$269 annually. Medicaid expenditures on ADRD are also driven by long-term care (nursing homes and home health), accounting for 95 percent of Medicaid expenditures in the first five years. Prescription drug spending levels are also low within Medicaid, ranging from $38-$101 annually. All categories of spending except long-term care show a front-loaded pattern of expenditures.

**Discussion**

ADRD represents a considerable cost to the public purse. Over the first five years after diagnosis, we estimate that ADRD costs $24,465 per person, with a 64-36 split between Medicare and Medicaid. There are also different trajectories to this expenditure by insurance program and by expenditure type – Medicare costs are concentrated soon after diagnosis while Medicaid expenditures are relatively evenly distributed over the first five years. Inpatient expenditures within Medicare decrease starting five years after ADRD diagnosis. This could be due to decreased utilization since patients are increasing their SNF use, or due to less intense inpatient use, for example by foregoing elective procedures since their health trajectory is already being driven by their ADRD. The estimated Medicaid costs in year 5 among those who are dual-eligible are roughly equivalent to the Medicaid costs of a nursing home, suggesting that Medicaid is covering most, if not all, of the long-term care bill five years post-diagnosis.

These longitudinal patterns are important for understanding the future cost burden of the disease. Most current estimates of the cost of ADRD are based on prevalent cases, which can be used to forecast future costs as long as one assumes that costs are not dependent on the time since diagnosis. Our estimates suggest that this approach might give reasonable estimates for forecasting Medicaid expenditures since they are relatively constant over the first five years after diagnosis. However, the pronounced time-trend in Medicare expenditures makes prevalent case estimates particularly difficult to use in predicting future costs; the case-mix matters for Medicare costs.

The time-profile of the incremental costs of ADRD is also important for understanding the cost implications of new therapies for ADRD. Our estimates suggest that delaying the onset of the disease, without changing underlying survival, will have a larger impact on the present discounted value of expenditures for Medicare than for Medicaid, since these costs are concentrated in the first two years post-diagnosis. Interventions that change the progression of the disease would have larger impacts on Medicaid, since they are primarily long-term care expenditures.

This study has limitations. We rely on diagnosis of dementia in claims data, which is likely not sensitive to the true onset of disease symptoms. Indeed, over 40 percent of our sample is first diagnosed in an inpatient setting. We do not estimate the incremental costs to the Medicare Advantage program, which has been increasing its coverage rates over the last 20 years and may have very different spending patterns. These estimates are only the direct medical costs to the public purse (Medicaid and Medicare) and are far from a full accounting of the cost of illness, which would include out-of-pocket expenditures and the cost of caregiving. We are limited to estimating the incremental costs due to ADRD for the first five years after diagnosis due to data and sample size limitations, while survival after diagnosis can be over 20 years.

In conclusion, the incremental costs of ADRD to the US government are substantial. On average, each case of ADRD is costing the government $24,465 over the first five years after diagnosis. Most of the literature has focused on estimating the costs to Medicare, missing 36 percent of the incremental costs over the first five years after diagnosis. While incidence of ADRD is declining, prevalence is not. Our estimates show that as the case-mix of ADRD disease changes, so will the level and the distribution of costs.

**Table 1. Characteristics of dementia cases and the first matched control**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Participants with dementia diagnosis (N=3,653) | First matched control (N=3,653) | p-value |
| **Sociodemographic characteristics** |  |  |  |
| Age at diagnosis in years, mean (sd) | 79.9 (7.4) | 79.7 (7.4) | 0.230 |
| Male, % | 36.8 | 36.8 | 1.000 |
| Race, % |  |  | 0.178 |
| Non-Hispanic white | 79.3 | 79.3 |  |
| Non-Hispanic black | 13.2 | 12.7 |  |
| Hispanic | 6.3 | 6.2 |  |
| Non-Hispanic other | 1.2 | 1.8 |  |
| Marital status at diagnosis, % |  |  | 0.686 |
| Married | 38.2 | 38.9 |  |
| Separated/divorced | 6.7 | 7.4 |  |
| Widowed | 40.7 | 39.5 |  |
| Never married | 2.9 | 2.7 |  |
| Unknown marital status | 11.5 | 11.5 |  |
| Educational attainment, % |  |  | <0.001 |
| Less than high school | 37.9 | 33.1 |  |
| High school graduate | 33.9 | 34.3 |  |
| Some college | 15.8 | 17.5 |  |
| College and above | 12.4 | 15.1 |  |
| Veteran, % | 20.9 | 22.9 | 0.041 |
| **Health characteristics at baseline\*** |  |  |  |
| Comorbid conditions, % |  |  |  |
| Anemia | 40.0 | 21.7 | 0.000 |
| Arthritis | 37.3 | 28.1 | <0.001 |
| Atrial fibrillation | 13.5 | 8.3 | <0.001 |
| Cancer | 10.2 | 9.6 | 0.388 |
| Chronic kidney disease | 17.4 | 9.1 | <0.001 |
| COPD | 19.2 | 11.7 | <0.001 |
| Depression | 23.5 | 5.7 | 0.000 |
| Diabetes | 30.6 | 23.3 | <0.001 |
| Heart failure | 32.7 | 20.2 | <0.001 |
| Hyperlipidemia | 34.8 | 32.1 | 0.014 |
| Hypertension | 69.2 | 55.1 | <0.001 |
| Ischemic heart disease | 47.7 | 34.9 | <0.001 |
| Stroke/TIA | 15.0 | 3.3 | 0.000 |
| Total Medicare reimbursement, mean (sd) | 18,328 (30,397) | 9,517 (18,882) | 0.000 |
| **Insurance coverage at diagnosis** |  |  |  |
| Medicare Part D, % | 53.6 | 48.5 | 0.006 |
| Medicaid, % | 10.1 | 8.4 | 0.048 |
| **Insurance coverage at death\*\*\*** |  |  |  |
| Medicare Part D, % | 55.2 | 52.3 | 0.127 |
| Medicaid, % | 13.9 | 12.1 | 0.098 |

\* The baseline period was defined as the 12 months prior to the diagnosis date.

\*\* Among the sub-sample where death is observed in the data. N=2,947 and 2,385 in dementia and first matched control cohorts, respectively.

**Table 2. Period-specific absolute and incremental costs to FFS Medicare and Medicaid**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Total costs | | Incremental costs | | |
|  | Participants with dementia diagnosis | Predicted costs without dementia | Incremental costs if survival held constant | Incremental costs due to changed survival | Total incremental costs |
| FFS Medicare |  |  |  |  |  |
| Months 1-12\* | $24,501  (23,494; 25,477) | $15,213  (14,512; 15,928) | $10,093  (9,039; 11,183) | -$805  (-960; -665) | $9,288  (8,241; 10,357) |
| Months 13-24 | $15,709  (15,009; 16,449) | $11,481  (10,920; 12,063) | $5,646  (5,072; 6,264) | -$1,418  (-1,679; -1,173) | $4,229  (3,617; 4,850) |
| Months 25-36 | $12,723  (12,056; 13,382) | $10,642  (10,120; 11,201) | $3,796  (3,282; 4,337) | -$1,715  (-2,004; -1,416) | $2,081  (1,510; 2,653) |
| Months 37-48 | $10,986  (10,287; 11,663) | $10,401  (9,811; 11,028) | $2,534  (1,959; 3,147) | -$1,949  (-2,310; -1,614) | $585  (-103; 1,294) |
| Months 49-60 | $8,802  (8,160; 9,493) | $9,353  (8,792; 9,977) | $1,386  (716; 2,057) | -$1,937  (-2,294; -1,592) | -$551  (-1,337; 270) |
| Total | $72,722  (70,185; 75,399) | $57,091  (54,895; 59,214) | $23,456  (20,861; 26,188) | -$7,825  (-9,198; -6,476) | $15,632  (12,780; 18,588) |
| Medicaid |  |  |  |  |  |
| Months 1-12\* | $2,442  (2,113; 2,837) | $657  (521; 802) | $1,826  (1,468; 2,214) | -$41  (-56; -30) | $1,785  (1,429; 2,168) |
| Months 13-24 | $2,324  (2,006; 2,683) | $659  (526; 798) | $1,752  (1,442; 2,068) | -$87  (-114; -64) | $1,665  (1,347; 1,989) |
| Months 25-36 | $2,404  (2,066; 2,770) | $700  (564; 854) | $1,823  (1,502; 2,170) | -$119  (-156; -88) | $1,704  (1,378; 2,047) |
| Months 37-48 | $2,491  (2,112; 2,899) | $735  (588; 907) | $1,901  (1,542; 2,296) | -$145  (-191; -106) | $1,756  (1,390; 2,157) |
| Months 49-60 | $2,734  (2,285; 3,240) | $811  (631; 1,006) | $2,100  (1,637; 2,609) | -$177  (-232; -129) | $1,924  (1,444; 2,442) |
| Total | $12,395  (10,847; 13,981) | $3,562  (2,928; 4,292) | $9,402  (7,861; 10,981) | -$570  (-746; -421) | $8,833  (7,267; 10,509) |

Notes: \* Month 1 is the month in which the diagnosis date occurred

**Table 3. Cohort and Conditional Incremental costs of ADRD**

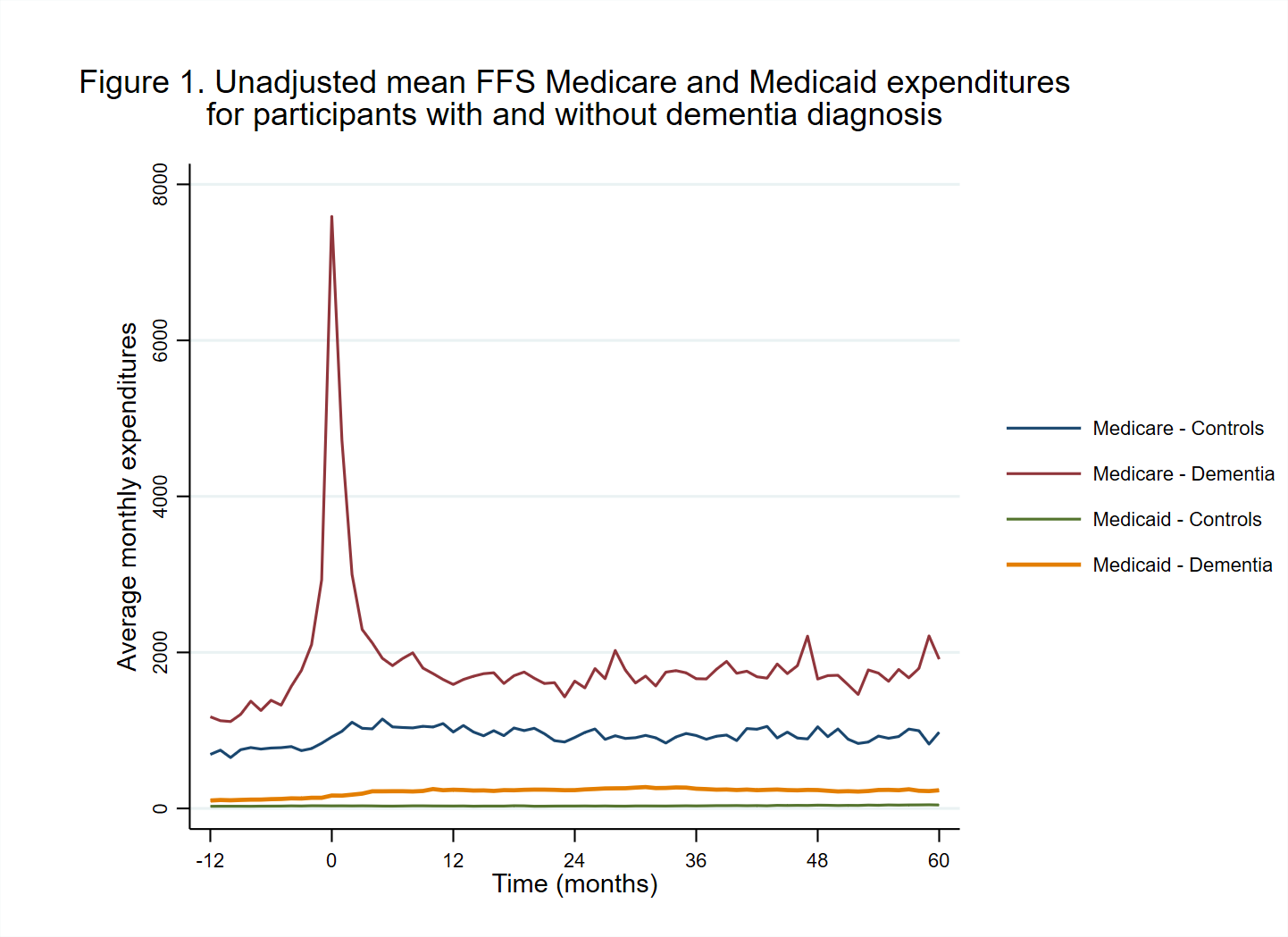
|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Medicare | | Medicaid | | |
|  | Cohort as a whole | Conditional on being alive | Cohort as a whole | Conditional on being alive | Conditional on being alive and enrolled | |
| Months 1-12\* | $9,288  (8,241; 10,357) | $12,133  (10,827; 13,437) | $1,785  (1,429; 2,168) | $2,282  (1,846; 2,773) | $36,006  (29,934; 42,832) | |
| Months 13-24 | $4,229  (3,617; 4,850) | $8,930  (7,988; 9,933) | $1,665  (1,347; 1,989) | $2,905  (2,394; 3,440) | $35,113  (29,878; 41,297) | |
| Months 25-36 | $2,081  (1,510; 2,653) | $7,345  (6,352; 8,436) | $1,704  (1,378; 2,047) | $3,739  (3,113; 4,470) | $42,935  (36,240; 50,479) | |
| Months 37-48 | $585  (-103; 1,294) | $5,806  (4,450; 7,204) | $1,756  (1,390; 2,157) | $4,629  (3,777; 5,554) | $47,279  (39,114; 56,672) | |
| Months 49-60 | -$551  (-1,337; 270) | $3,693  (1,960; 5,499) | $1,924  (1,444; 2,442) | $5,924  (4,592; 7,330) | $61,482  (49,268; 76,611) | |

Notes: \* Month 1 is the month in which the diagnosis date occurred

**Table 4. Period-specific incremental costs by payer and service type for the cohort as a whole**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Medicare | | | Medicaid | | |
|  | Inpatient | Prescription drugs | Skilled Nursing Facility and Home Health | Inpatient | Prescription drugs | Skilled Nursing Facility and Home Health |
| Months 1-12\* | $4,806  (4,158; 5,477) | $68  (-24; 161) | $4,546  (4,142; 4,926) | $17  (7; 27) | $101  (59; 145) | $1,415  (1,147; 1,716) |
| Months 13-24 | $1,576  (1,262; 1,882) | $97  (11; 174) | $1,978  (1,757; 2,200) | $10  (3; 16) | $81  (47; 117) | $1,369  (1,101; 1,664) |
| Months 25-36 | $459  (175; 765) | $139  (52; 226) | $1,298  (1,092; 1,517) | $7  (1; 13) | $65  (31; 99) | $1,415  (1,124; 1,730) |
| Months 37-48 | -$335  (-671; 4) | $193  (88; 307) | $748  (489; 1,011) | $4  (-3; 11) | $51  (14; 85) | $1,500  (1,197; 1,850) |
| Months 49-60 | -$826  (-1,182; -477) | $269  (126; 422) | $239  (-37; 520) | $2  (-7; 11) | $38  (-1; 78) | $1,597  (1,226; 1,989) |
| Total | $5,680  (4,178; 7,222) | $767  (301; 1,232) | $8,809  (7,667; 9,872) | $39  (9; 68) | $336  (171; 498) | $7,296  (6,039; 8,641) |

Notes: \* Month 1 is the month in which the diagnosis date occurred



**Table A1.** ICD-9-CM diagnostic codes used to identify subjects with dementia

|  |  |
| --- | --- |
| **Diagnosis code** | **Description** |
| 331.0 | Alzheimer’s disease |
| 331.11 | Pick’s disease |
| 331.19 | Other frontotemporal dementia |
| 331.2 | Senile degeneration of brain |
| 331.7 | Cerebral degeneration in diseases classified elsewhere |
| 290.0 | Senile dementia, uncomplicated |
| 290.10 | Presenile dementia, uncomplicated |
| 290.11 | Presenile dementia with delirium |
| 290.12 | Presenile dementia with delusional features |
| 290.13 | Presenile dementia with depressive features |
| 290.20 | Senile dementia with delusional features |
| 290.21 | Senile dementia with depressive features |
| 290.3 | Senile dementia with delirium |
| 290.40 | Vascular dementia, uncomplicated |
| 290.41 | Vascular dementia with delirium |
| 290.42 | Vascular dementia with delusions |
| 290.43 | Vascular dementia with depressed mood |
| 294.0 | Amnestic disorder in conditions classified elsewhere |
| 294.10 | Dementia in conditions classified elsewhere without behavioral disturbance |
| 294.11 | Dementia in conditions classified elsewhere with behavioral disturbance |
| 294.20 | Dementia, unspecified, without behavioral disturbance |
| 294.21 | Dementia, unspecified, with behavioral disturbance |
| 294.8 | Other persistent mental disorders due to conditions classified elsewhere |
| 797 | Senility without mention of psychosis |

**Table A2. Period-specific absolute and incremental costs to FFS Medicare, excluding diagnosis SNF/IP stay**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Total costs | | Incremental costs | | |
|  | Participants with dementia diagnosis | Predicted costs without dementia | Incremental costs if survival held constant | Incremental costs due to changed survival | Total incremental costs |
| FFS Medicare |  |  |  |  |  |
| Months 1-12\* | $22,034  (21,081; 22,958) | $14,720  (14,067; 15,394) | $8,124  (7,160; 9,085) | -$810  (-954; -661) | $7,314  (6,348; 8,232) |
| Months 13-24 | $15,216  (14,538; 15,953) | $11,609  (11,067; 12,173) | $5,049  (4,452; 5,648) | -$1,443  (-1,697; -1,190) | $3,607  (3,003; 4,210) |
| Months 25-36 | $12,567  (11,914; 13,244) | $10,685  (10,146; 11,227) | $3,615  (3,103; 4,155) | -$1,733  (-2,055; -1,441) | $1,882  (1,291; 2,501) |
| Months 37-48 | $11,071  (10,420; 11,775) | $10,372  (9,753; 11,013) | $2,655  (2,081; 3,296) | -$1,956  (-2,324; -1,615) | $700  (10; 1,406) |
| Months 49-60 | $9,025  (8,381; 9,752) | $9,239  (8,679; 9,816) | $1,711  (1,089; 2,417) | -$1,925  (-2,278; -1,603) | $-214  (-972; 564) |
| Total | $69,914  (67,449; 72,504) | $56,625  (54,443; 58,972) | $21,155  (18,481; 23,922) | -$7,866  (-9,318; -6,517) | $13,288  (10,325; 16,170) |

Statistical Analysis Appendix

Basu and Manning (2010)22 methodology for estimating costs under censoring. This is also presented in the appendix of White et al. (2019)18.

**Step 1**: Estimating costs in the time intervals prior to death

Part 1 of two-part model:

Only time intervals that were observed in their entirety were included in the model. Standard errors were clustered at the person-level.

where

Y*i* = a binary variable equal to 1 when costs are greater than zero

Dementia*i* = an indicator variable for dementia diagnosis for subject *i*

X*i* = a vector of covariates for subject *i*

Part 2 of two-part model:

Only time intervals that were observed in their entirety and where costs were greater than zero were included in the model. Standard errors were clustered at the person-level.

where

Y*i* = total costs in time interval for individual *i*

Dementia*i* = an indicator variable for dementia diagnosis for subject *i*

X*i* = a vector of covariates for subject *i*

ɛ*i* = error term

Recycled predictions: The dementia indicator was set to 1 for all individuals while keeping all other covariates constant and predictions made for the probability of any costs and for total costs, given any costs, for every time interval. This was repeated with the dementia indicator set to 0. Estimated costs for intervals prior to death were then calculated by multiplying the probability of any costs for time interval *j* with the estimated costs, given any costs, in time interval *j*.

**Step 2:** Estimating costs in the intervals of death

Only time intervals during which a subject died were included in the model. We used robust standard error estimates.

where

Y*i* = total costs in time interval for individual *i*

Dementia*i* = an indicator variable for dementia diagnosis for subject *i*

X*i* = a vector of covariates for subject *i*

ɛ*i* = error term

Recycled predictions: The dementia indicator was set to 1 for all individuals while keeping all other covariates constant and, for every time interval, cost predictions were made for every possible death time within the interval. A weighted average of the predictions was calculated using the observed distribution of death times over the interval. This was repeated with the dementia indicator set to 0.

**Step 3:** Estimating the survival function

,

where

T*i* = survival time for individual *i*

Dementia*i* = an indicator variable for dementia diagnosis for subject *i*

X*i* = a vector of covariates for subject *i*

ɛ*i* = error term

Recycled predictions: The dementia indicator was set to 1 for all individuals while keeping all other covariates constant and survival and cumulative survival probabilities were predicted for every time interval. This was repeated with the dementia indicator set to 0.

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