Supplementary Appendix

This appendix has been provided by the authors to give readers additional information about their work.

Supplement to: Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. N Engl J Med 2013;368:1326-34. DOI: 10.1056/NEJMsa1204629

On-Line Supplement

The Monetary Costs of Dementia in the United States

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Out-of-Pocket Spending

The HRS asks respondents if they utilized a particular type of health care, whether all of the cost of this care was covered by insurance, and if not how much they spent out-of-pocket (OOP) for this care. The 2002-2008 HRS waves asked questions about spending on the following services: (1) nursing home stays, (2) hospital stays, (3) doctor visits, (4) dental visits, (5) outpatient surgery, (6) home health care, (7) other "special" services, (8) prescription drugs and (9) dental services. Earlier waves had less detail and combined the questions on hospital and nursing home stays and also on outpatient services (dental visits, doctor visits, and outpatient surgery). For each of the HRS waves between 2000-2008, we computed total OOP spending by summing OOP spending by type of care. We also examined spending by type of care (data from the 2000 HRS was excluded for analyses of OOP spending on types of care that were combined).

We construct average annual OOP spending measures in the two years prior to the HRS interview by dividing the HRS variables on OOP spending on non-drug services by 2. Questions on OOP spending for prescription drugs ask about spending in the past month, so annual measures of OOP spending on drugs were generated by multiplying the monthly value by 12. All values are converted to 2010 dollars using the medical care CPI. The way the HRS questionnaire collects this information helps to reduce reporting error in several ways. First, separate questions are asked about spending on various services rather than a single question on total spending, and prior research has shown that a greater number of questions helps respondents recall incidents which may be forgotten with a single "catch-all" question (Bound, Brown, and Mathiowetz, 2001). Second, questions are asked using an "unfolding bracketing" method. Respondents who are unable or unwilling to provide an exact figure are presented with a series of questions such as "Was it more [or less] than $2,000?". Based on the responses to these questions, an exact dollar figure is imputed (details on the imputation procedure can be found in Cao, 2001). The bracketing procedure has been shown to reduce underreporting of economic concepts such as OOP spending (Hurd and Rodgers, 1998).

Nursing Home Costs

Our measure of nursing home spending uses self-reports of nights spent in a nursing home and information on average nursing home daily rates, and makes an adjustment for food and lodging provided by nursing homes that individuals would have to purchase in the community.

The core HRS interview asks respondents to report if they have ever had a nursing home stay in the past two years, and if they had, how many nights they had spent in a nursing home. Because the HRS asks about nursing home utilization over the two years prior to the current interview, we generated an annual measure by dividing the self-reported number of nights by two. Total average annual nursing home spending over this period was then computed by multiplying the number of nights in a nursing home with an estimate of the daily rate that they would face. For individuals covered by the Medicaid program, we use 2010 Medicaid nursing home rates (AHCA 2004; AHCA 2005; BDO Seidman and Eljay 2007; Eljay, 2008; Eljay, 2009; Eljay, 2010, Grabowski, 2004) and for other respondents we use 2010 average private pay nightly rates charged by nursing homes obtained from the 2010 MetLife Market Survey of Long-Term Care Costs (MetLife Mature Market Institute 2010). Medicaid and private pay rates are based on respondent state of residence.

Part of the nursing home nightly rate reflects expenses on food and housing that individuals would have to pay if they lived in the community. We approximated these expenses as 50 percent of mean per-person spending on food and rent among individuals age 71 and older in the CAMS supplement to the HRS (where rent was set to zero for individuals living in homes they owned). We scaled spending on food and rent to reflect the fact that nursing home housing and food are likely to be lower quality than what individuals receive in the community. For single individuals or married individuals whose spouse also was a nursing home resident, we computed net spending due to nursing home care by subtracting these costs from the nursing home nightly rate. On the other hand, we did not make this adjustment for individuals with a spouse living in the community, as the spouse would still incur costs for housing and food.

Since nursing home costs represent such a large share of total spending for dementia-related care, it is crucial that the self-reported data in the HRS accurately reflects nursing home utilization. We conducted several analyses comparing estimates of nursing home utilization from the HRS to similar estimates derived from other data sources to assess the validity of the self-reported nursing home data. Specifically, we compared the average number of nursing home nights per person, the percent of older adults living in the nursing home at time of interview, total number of nights spent in the nursing home among those currently in a nursing home, and the percent of older adults with at least one nursing home stay in the previous wave to existing estimates from the 2000 Census, Centers for Medicare and Medicaid Services (CMS, 2008), and the National Nursing Home Survey (CDC, 2008).

In 2007, the number of certified beds per 1000 population aged 65 and older in 2007 was 45.0 and the occupancy rate was 83.8% (CMS, 2008), indicating that 37.7 beds per 1000 were occupied on average per day (or .0377 per person). Over a year, those 65 and older spent 13.8 days (0.0377*365 days) on average in a nursing home. In the 2006 wave of HRS, respondents aged 65 and older spent on average 9.6 nights in a nursing home during the previous year (19.2 days in the previous two years). In the 2008 wave, respondents spent on average 8.9 nights in a nursing home in the previous year.

In the 2000 Census, 4.5 percent of individuals 65 years and older lived in nursing homes (Hetzel and Smith, 2001). In comparison, 3.9 percent of those 65 years and older lived in nursing homes at the time of the 2000 wave of the HRS. In the 2002 to 2006 waves, 4.0 percent of older adults lived in nursing homes. When comparing by age groups, in the 2000 Census, 1.1 percent, 4.7 percent, and 18.2 percent of those 65 to 74 years old, 75 to 84 years old, and 85 and older, respectively, lived in nursing homes. In the 2000 wave of the HRS, 0.7 percent, 3.5 percent and 19.5 percent of those 65 to 74 years old, 75 to 84 years old, and 85 and older, respectively, lived in nursing homes. Individuals 65 years and older who were living in nursing homes in 2004 had a mean length of time since admission among nursing home residents aged 65 and older in 2004 was 822 days (CDC, 2008). In the HRS, individuals 65 and older living in a nursing home at the time of interview spent on average 741 nights (2004) and 836 nights (2006) in the nursing home during the current and previous waves of data collection.

The percentage of older adults with at least one nursing home stay in 2007 was 7.4 percent for individuals 65 and older and 22.2 percent for those 85 and older (CMS, 2008). In the 2006 wave of the HRS, 7.4 percent of respondents 65 and older and 23.0 percent of respondents 85 and older had at least one nursing home stay in the previous two years.

Overall, we found that estimates based on the HRS were reasonably close to those derived from alternative data sources.

Spending by Medicare

Our source of Medicare spending comes from the administrative records of HRS respondents who provided their Medicare beneficiary ID number for research purposes. Overall, Medicare records are available for about 90 percent of HRS respondents who are 65 and older.

In this study we use the Beneficiary Annual Summary File (BASF), which contains summary information from the micro-level claims records. The BASF contains annual information for each individual on the number of months of enrollment in Medicare Part A, Part B, and non-fee for service plans. Spending is divided into 7 categories of care: skilled nursing facility, hospice, inpatient, outpatient, durable medical equipment, home health agencies and carrier (i.e., non-institutional medical care providers). All spending is converted to $2010 using the Medical care CPI.

The BASF has information on Medicare fee for service (FFS) claims. Almost all medical claims for services used by non-FFS Medicare patients are not observed in these data, so all analyses exclude an individual in a given year if they were enrolled in a non-FFS Medicare plan at any point during the year.

Informal and Formal In-Home Care

We used the HRS module on functional limitations and helpers for the 2000 through 2008 waves for information on in-home caregiving for assistance with ADL (eating, transferring, toileting, dressing, bathing, walking across a room) and IADL (preparing meals, grocery shopping, making phone calls, taking medications, managing money) limitations. Caregivers were classified as “informal” if they were related to the respondent or if they were unpaid nonrelatives not affiliated with any agency. All other caregivers were classified as “formal.”.

The number of weekly hours of informal care was calculated using the average number of days per week (in the prior month), and average number of hours per day that respondents reported receiving help from each informal caregivers. A respondent could receive care from more than one caregiver. Because data on hours per day of care were not collected for caregivers who helped less than once per week, hours values for these caregivers were assigned using a method of multiple imputation based on reported caregiver characteristics (helper sex, residential status, relationship to the respondent, and number of days per week of care). We imposed a limit of 16 hours of care per day for any individual caregiver to allow for 8 hours of sleep." We then summed hours provided over all caregivers to calculate total hours of caregiving.

Note that these measures only reflect caregiving for assistance with ADL and IADL limitations, and therefore are likely to be conservative estimates of total in-home caregiving. In particular, these measures exclude time spent by caregivers monitoring behavioral problems associated with dementia (e.g., wandering, paranoia), and also do not reflect the costs associated with shared housing and other living expenses (Langa et al., 2001).

Estimating the value of an hour of formal care is fairly straightforward because it is purchased in the market and hence prices for these services are observed. We used information from the 2010 MetLife Market Survey of Long-Term Care Costs on 2010 average hourly rates charged by home health agencies in the respondent's state of residence (MetLife, 2010).

We took two approaches to calculating the value of informal care: a "replacement cost" approach and a "foregone wage cost" approach. The **replacement cost** approach assigns values for informal care hours based on the market wage paid to formal caregivers. The rationale is that if the informal caregiver were unavailable, then the respondent could hire a formal caregiver as a "replacement." We assigned each respondent the average hourly private-pay rate of a home health aide in 2010 in the respondent's state of residence, published by MetLife in its 2011 Market Survey of Long-Term Care Costs. A home health aide is "trained to provide hands-on care and assistance to people in their homes who need help with ADLs (bathing, dressing, transferring, eating, toileting or continence)" and "are also able to help with needed tasks such as cooking, shopping and laundry" (MetLife, 2010). The average hourly cost was $21, with a range of $16 to $28 at the state level. We then multiply the average cost by the total hours of informal care provided to the respondent to compute the value of informal care.

The replacement cost approach is likely to overstate the value of informal care for at least three reasons. First, revealed preference implies that respondents who forgo formal care do so because it is not worth the cost to them. Thus, the formal care price likely overstates the value of care for the 95% of respondents who do not hire any formal caregivers. Second, because formal caregivers are typically trained and more experienced than informal caregivers, the quality of care provided by formal caregivers is likely higher than the quality of care provided informally. Finally, the MetLife costs do not subtract out the portion of costs, if any, covered by long term care insurance. However, out-of-pocket (OOP) costs more closely relate to the respondent's marginal willingness to pay for care.

The **foregone wage cost** approach answers the question, "If the informal caregiver were not providing care, what would she earn in the labor market?" Thus, we value each hour of informal care by calculating the caregiver's expected market wage – that is, the wage that the caregiver would earn if she reallocated those hours to the labor market times the probability that she would enter the labor market. In the HRS, we only observe the caregiver's wage if he or she is the spouse of the respondent. For this group, which accounts for about 8% of caregivers, we set the value of informal care equal to the reported market wage in 2010 dollars (using the consumer price index).

For the remaining 92% caregivers, we impute the wage based on age, sex and education. In particular, we divide age into 7 bands (<18, 18-34, 35-44, 45-54, 55-64, 65-74 and 75+) and education into four groups (less than high school, high school graduate or GED, some college or college graduate) and we impute the caregiver's potential wage by matching the average wage (the hourly rate for hourly workers, or the weekly rate divided by 40 for salaried workers) reported in the Current Population Survey (CPS) among workers in the same demographic group. To account for caregivers who choose not to work, we calculate the expected wage by multiplying the CPS average wage by the labor force participation rate in the same demographic group.

We do not observe the full set of demographic characteristics for approximately half of the caregivers, and for these individuals we must impute education, age and/or sex. HRS respondents who receive care report the sex for (almost) all caregivers, as well as the relationship of the caregiver to the respondent (e.g., spouse, child). However, age and education are only available for caregivers who are also crosslisted in the family structure module, and are missing for caregivers who are not close relatives or who are not related to the respondent. Finally, for individuals over age 30 education is only asked in the first wave the individual is mentioned, and even after attempting to cross-match between waves, education is missing for a large fraction (approximately 30%) of caregivers.

We impute the missing variables as follows. Where possible, we impute age of the caregiver using relationship to the respondent where we let 25 years equal a generation. For example, for caregivers who are spouses or siblings, we set age equal to the age of the respondent; for caregivers who are children (grandchildren) of the respondent, we subtract 25 (50) from the age of the respondent. Where sex is missing (less than 0.25% of cases) we assume the caregiver is female. Where we are missing only education, we match the education distribution of caregivers with nonmissing education conditional on age of the caregiver in the 2000 wave (which has the highest rate of nonmissing education data). Finally, if age and education are both still missing, we set them equal to the median age (55) and education (high school) among caregivers with nonmissing age and education in 2000.

Estimation of Dementia Status

The first step in estimating the likelihood of dementia among HRS respondents was to estimate a statistical prediction model of dementia using the ADAMS data. Therefore, we did not use any factors which might be affected by the onset of dementia (such as living arrangements, marital status, and income or asset levels) in the prediction model. Instead, predictions are based only on demographics such as age, gender and education, measures of Activity of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL) limitations, and cognitive functioning measured in prior waves of the HRS.[1] To reduce the noisiness introduced by measurement error in any given cognitive assessment and because the rate of decline in cognitive functioning might be predictive of the onset of dementia, we use both the level of cognitive functioning in the prior HRS wave as well as the change in cognitive scores between the prior two waves in the prediction model. Similarly, we also use the change in measures of ADL and IADL limitations between the prior two waves. Since the cognitive assessments differ for proxy and non-proxy respondents, we estimate separate models based on whether ADAMS subjects were

[1] The ADAMS dataset includes scores on the cognitive tests that are also administered in the HRS. However, we did not use these because small differences in the administration of the tests in ADAMS generate sizable differences in the distribution of scores relative to what is observed in the HRS, making it difficult to use the ADAMS variables to generate a prediction model for out-of-sample predictions.

proxy or non-proxy respondents in the prior HRS wave. For non-proxy respondents, the model is:

(1) $$Dementia_i=\beta_1 TICS_i + \beta_2 \Delta TICS_i + \beta_3 X_i + \varepsilon_i$$

where $Dementia_i$ is a categorical variable taking on three values (normal, CIND, demented) based on the ADAMS assessment, $TICS_i$ is a vector of cognitive items from the TICS assessment conducted in the HRS wave prior to the ADAMS assessment), $\Delta TICS_i$ is a vector containing the changes in the scores on the TICS items between the prior two HRS waves and X_i is a vector of economic and demographic characteristics including five-year age bands, education, gender, summary measure of ADLs and IADL and their changes between the prior two HRS waves. Table S1 provides the definitions of each of the TICS items along with means and standard deviations in the ADAMS sample, along with the mean of the ADL and IADL summary measures.

Equation (1) was estimated using an ordered probit model (Johnston and DiNardo, 1997). Ordered probit models can be used to examine how covariates are related to a categorical outcome variable, where the ordering of the categories of the outcome variable has real world interpretation. In the current study, the outcome variable is a three-category measure of dementia status, $Dementia_i$, which takes on values of 1, 2, and 3 for individual diagnosed as being demented, CIND, and normal cognitive functioning, respectively. Note that in this application (and in all ordered probit models), the actual values of the outcome are irrelevant, only their ordering matters.

An ordered probit model posits that the values of the categorical outcome variable are determined by an unobserved index variable, $y*$, which in our case can be thought of as cognitive functioning. Individuals with $y*$ below some cutoff, c_1, are classified as having dementia, those with $y*$ above some cutoff, c_2, are classified as having normal cognitive functioning, and those with $y*$ in between c_1 and c_2 are classified as being CIND. The ordered probit model further assumes that $y*=x$b +_e, where x is a vector of covariates used to predict dementia status and e is a random term distributed as a standard normal random variable. The vector of coefficients b and the cutoffs c_1 and c_2 are then estimated via maximum likelihood.

For proxy respondents, the model we estimate is:

(2) $$Dementia_i=\beta_1 IQCODE_i + \beta_2 \Delta IQCODE_i + \beta_3 PRIORPROXY_i + \beta_4 PRIORTICS_i + \beta_5 X_i + \varepsilon_i$$

where $IQCODE_i$ is the score on the Jorm IQCODE in the prior HRS wave, $\Delta IQCODE_i$ is the change in the Jorm IQCODE, $PRIORPROXY_i$ is an indicator for whether the respondent was a proxy respondent two waves prior to the ADAMS assessment, $PRIORTICS_i$ is a vector of cognitive variables two waves prior to the ADAMS assessment for respondents who were not proxy then, and X_i is defined as above. The vector of cognitive scores, ADLs and IADLs in Equations (1) and (2) both include a set of indicators for missing values. We estimate Equation (2) via ordered probit regression.

Ordered-probit estimates of Equations (1) and (2) are reported in Tables S2 and S3. As expected, age, cognitive scores, and ADL/IADL limitations are all strong predictors of dementia. This is true for both the proxy and self-respondent models. To judge the within-sample fit we assigned to each ADAMS respondent a dementia status according to the state that had the maximum predicted probability. We call this the maximum likelihood prediction. Of the 826 cases used in model estimation, our model classified 277 as demented whereas the ADAMS clinical evaluation classified 285 cases as demented. Of the 541 cases ADAMS classified as not demented our model classified 486 as not demented for a specificity of 89.8%. Of the 285 cases that ADAMS classified as demented, our model classified 222 as demented for a sensitivity 77.9%. Overall our model correctly classified 85.7% of the cases.

Our estimate of the percent of the population correctly classified is, itself, subject to uncertainty. To investigate this uncertainty we estimated via bootstrap methods the distribution of the percent correctly classified. The five percentile lower bound was 76.6% and the five percentile upper bound was 89.9%; that is, in 100 bootstrap simulations, five simulations had fewer than 76.6% correctly classified and five simulations had more than 89.9% correctly classified. The lower five percentile and upper five percentile of the sensitivity were 60.0% and 85.7% respectively, and the lower five percentile and upper five percentile of the specificity were 80.2% and 95.7%. We interpret these statistics to indicate that the model is robust to sample variation.

To examine the fit of the model throughout the distribution of the predicted probability of dementia (rather than just for population averages), we calculated the predicted probability that each individual had dementia. Then, we stratified the sample into 10 bins based on deciles of the predicted dementia probability. The following table shows for each bin the probability of dementia from the model, the actual frequency of demented cases from ADAMS, and the estimated and actual number of cases.

Bin	N	Fitted probability	Actual frequency	Estimated number of cases	Actual number of cases
1	83	0.001	0.000	0.06	0
2	83	0.007	0.000	0.61	0
3	82	0.025	0.024	2.05	2
4	83	0.060	0.024	4.99	2
5	82	0.127	0.171	10.44	14
6	83	0.230	0.241	19.06	20
7	83	0.432	0.482	35.86	40
8	82	0.653	0.598	53.57	49
9	83	0.908	0.916	75.38	76
10	82	0.999	1.000	81.89	82
Total or average	826	0.344	0.346	283.92	285

Note: estimated number of cases is N*(fitted probability)

We calculated a chi-square statistic for the null hypothesis that in each bin the estimated number of cases equals the number of actual cases. That statistic, which has 10 degrees of freedom, was 6.15 with a P-value of 0.80.

We conducted an additional validation exercise that consisted of doing an out-of-sample prediction. As part of the ADAMS data collection, a later dementia assessment (Wave C) was conducted for respondents who were still alive in 2006 and not previously diagnosed with dementia. A Wave C assessment was completed for 315 respondents between June 2006 and May 2008, with most of the assessments done in 2006 and 2007. Table S4 presents the transition rate of dementia status from baseline to follow-up. While about 69% of those respondents were classified as normal at baseline, this figure dropped to 50% at the follow-up: 30% of those who were normal became either CIND or demented at follow-up.

We used the prediction model described above and the 2006 HRS variables to predict the 2007 probability of dementia in 2007 for those 315 respondents.[2] We then compared the distribution of cognitive status based on our prediction and with that based on the wave C assessment in Table S5. It shows that both distributions are very similar. For example, the average predicted probability of dementia in this sub-sample is 13.9% (Table S5) compared to a 14.9% dementia prevalence based on the actual assessment (Table S4). Those figures are 30.8% and 34.9% respectively for CIND status. We further evaluate the concordance between the wave C assessment and the predictions by presenting the average predicted probability of cognitive status by follow-up status in Table S5.. It shows for example that the average predicted probability of being normal is 72% among respondents assessed as normal, while it is only 4% among those assessed as demented. Similarly, the average predicted probability of being demented is 19% among those who are assessed as normal and 43% among those who are assessed as demented.

We also used the maximum likelihood classification method discussed above to classify individuals as to demented or not demented. According to wave C, 47 cases had progressed to dementia status on follow-up; our maximum likelihood model classified 20 as demented for a sensitivity measure of 42.6%. Of the 267 cases that were not demented in wave C our maximum likelihood model classified 256 cases as not demented for a specificity measure of 95.9%. Of the 314 cases in wave C our ML model correctly classified 276 cases (87.9%).

Overall, all those empirical findings suggest that the model of dementia status has good out-of-sample predictive power.

Predictions of dementia status in the full HRS sample

The results of these models were then used to make predictions of dementia status in the full HRS sample among respondents age 70 and older. Because the ADAMS was conducted approximately one year after the prior HRS interview, predictions for a given HRS wave actually refer to predicted dementia status one year after the HRS interview. So for example, predictions for the 2000 HRS respondents were made using cognitive scores in the 2000 HRS, the change in cognitive scores between the 1998 and 2000 HRS, and the age the respondent will be one year after the 2000 HRS interview.

Costs Attributable to Dementia

To estimate the increase in OOP spending attributable to dementia, we control for observable characteristics available in the HRS dataset by estimating models of the form:

(3) $$Y_i = \theta P(Dementia_i) + X_i\beta + \varepsilon_i$$

where Y_i is a measure of OOP spending, $P(Dementia_i)$ is the respondent's estimated probability of dementia, X_i is a vector of controls for comorbidities and other confounders that could be correlated with dementia and also OOP spending, and ε_i is a random disturbance term.

[2] For 3 respondents where 2006 variables were missing, we use the 2004 HRS variables.

We estimate two different specifications of Equation (3). The first includes no other covariates aside from dementia status, and delivers the unadjusted correlation between dementia status and OOP spending. The second adjusts for demographic characteristics, economic factors, and comorbidities. Specifically, the models control for household income, age, race (indicators for white, Hispanic, with the remainder of individuals constituting the reference group), education (less than high school, high school, with more than high school as the reference group), marital status, number of living children (1 or no children, 2 children, 3 or more children as the reference group), and indicator variables for ever reporting having the following comorbid conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychological condition, and arthritis).[3]

All the regressions are weighted. HRS allocates a weight of zero to respondents in nursing home. To account for this population in our analysis, we use individual HRS weight for respondents who are not in nursing home, and the most recent non-zero HRS weight for respondents in nursing home (this procedure is suggested in the HRS documentation). All our estimations present bootstrapped standard errors to account for the fact that the probability of dementia is a predicted variable.[4]

The estimates from the regression models can be found in Tables S6-S10. For instance, the estimates in column 1 of Table S6 indicate that an increase in the probability of dementia from 0 to 1 is associated with an increase in total nursing home spending of nearly $23,000. Adjusting for demographic characteristics and comorbidities reduces this association to just under $21,000, or an 8 percent reduction. Other covariates that are associated with higher nursing home spending include being single and having one or zero living children, which may reflect the lack of individuals who can provide informal care. Indeed, the estimates in Columns 2 and 4 of Table S10 suggest that having one or zero living children is associated with increased levels of informal care.

To find the cost per case we sum the coefficients on *P(dementia)* from the cost regressions. To account for the fact that these coefficients are estimated over the same population, and, therefore, are not independent from each other, we performed 150 bootstrap estimations to calculate the standard error of total cost per case.

Total Monetary Costs

To calculate the total annual monetary cost of dementia in the population over age 70, we first obtain estimates of the number of individuals with dementia by multiplying age-

[3] Observations with missing data on comorbidities are coded as zeros; the models also include indicators for missing comorbidities.

[4] The standard errors were calculated as the standard deviation of the estimates of θ from 150 bootstrap iterations. Each iteration used different estimates of $P(Dementia_i)$ as the regressor to reflect the fact that the estimated probability of dementia is a predicted regressor. Specifically, we used a parametric bootstrap (Efron and Tibshirani, 1993) to generate separate new estimates of $P(Dementia_i)$ for each of the 150 bootstrap iterations. The parametric bootstrap involved using simulated values for dementia status as the outcome in a new ordered probit prediction model. The parameters from this new model were then used to generate new estimates of $P(Dementia_i)$ among ADAMS respondents. The simulated values of dementia were generated by drawing residuals from a standard normal distribution and using the estimated parameters obtained from the prediction model using the actual ADAMS data, combined with the assumption that the data generating process was ordered probit.

specific prevalence rates (71-75, 76-79, 80-84, 85-89, 90 and older) from ADAMS with projected population counts in these age bands (obtained from the Census population projections[5]). Summing across age bands yields the total number of expected cases of dementia among those age 71 and older. Multiplying this figure by estimates of per-individual costs (see Table 2 in the main text) generates an estimate of the total costs of dementia in the population. We also normalize total population costs by the projected population of individuals age 18 and older to control for the fact that total costs will rise simply because of population growth.

[5] http://www.census.gov/population/www/projections/downloadablefiles.html

Table S1

Cognitive variables	Description *	Mean	s.d.
Dates	Report "today's date," including the month, day, year, and day of week	3.31	1.05
Backward counting 20	Count backwards for 10 continuous numbers beginning with the number 20.	0.84	0.36
Serial 7	Subtract 7 from 100, and continue subtracting 7 from each subsequent number for a total of five trials.	2.46	1.94
Scissor	Object naming: "What do you usually use to cut paper?"	0.98	0.13
Cactus	Object naming: "What do you call the kind of prickly plant that grows in the desert?"	0.76	0.43
President	Name current president	0.86	0.35
Immediate recall	Recall as many words as possible from a list of 10 words in any order	3.7	1.87
Delayed recall	Approximately 5 minutes after, recall as many words as possible from the list of 10 words of immediate recall	2.44	2.13
Jorm IQCODE	Proxy respondents were asked 16 questions about the respondent's change in memory in the last two years for various types of information	4.14	0.73
Limitations			
ADLs	sum ADLs where respondent reports any difficulty (from 0 to 5)	1.08	1.6
IADLS	sum IADLs where respondent reports any difficulty (from 0 to 5)	1.31	1.83

* Source: Ofstedal et al. (2005)

Table S2 Predicting Dementia Status for Self-Respondents Using an Ordered Probit Model (dementia=1, CIND=2, normal=3)

	Coef.	Std. Err.
Age less than 75	(ref)	
75-79	-0.031	0.160
80-84	-0.634	0.154
85-89	-0.545	0.176
90+	-0.903	0.197
Less than HS	(ref)	
HS graduate	-0.452	0.145
More than HS	-0.221	0.151
Female	-0.075	0.116
ADL limitations	0.020	0.069
IADL limitations	-0.206	0.079
Change in ADL limitations	-0.063	0.068
Changes in IADL limitations	0.099	0.077
TICS items scores at previous HRS wave		
Dates	0.367	0.089
Backward counting 20	-0.337	0.197
Serial 7	0.119	0.045
Scissor	-0.740	0.448
Cactus	0.035	0.159
President	0.329	0.164
Immediate recall	0.235	0.063
Delayed recall	0.222	0.051
Change in TICS items scores between 2 previous HRS waves		
dates	-0.100	0.083
backward counting 20	0.530	0.202
serial 7	0.021	0.042
scissor	0.415	0.417
cactus	0.310	0.174
president	0.239	0.105
immediate recall	-0.098	0.048
delayed recall	-0.057	0.038
N	*657*	

The regression includes indicators for missing cognitive scores, ADLs and IADLS (not shown)

Table S3 Predicting Dementia Status for Proxy Respondents Using an Ordered Probit Model (dementia=1, CIND=2, normal=3)

	Coef.	Std. Err.
Age less than 75	(ref)	
75-79	-0.355	0.542
80-84	-1.418	0.508
85-89	-1.092	0.549
90+	-1.607	0.527
Less than HS	(ref)	
HS graduate	-0.085	0.455
More than HS	-0.721	0.672
Female	-0.192	0.357
ADL limitations	-0.066	0.163
IADL limitations	-0.319	0.170
Change in ADL limitations	0.112	0.152
Changes in IADL limitations	0.166	0.161
Jorm IQCODE at previous HRS waves	-1.912	0.489
Two waves prior to ADAMS		
Proxy respondents 2 waves prior	0.335	0.545
Change in Jorm IQCODE between 2 previous HRS waves	0.760	0.583
Dates 2 waves prior	0.155	0.220
Serial 7 2 waves prior	0.397	0.182
President 2 waves prior	-0.271	0.851
Immediate recall 2 waves prior	-0.003	0.216
Delayed recall 2 waves prior	-0.027	0.238
cut1	-7.673	1.858
cut2	-5.972	1.788
N	*169*	

Table S4: Transition Rates (in Percentage) from Baseline to Follow-up Assessment

		Wave C (follow-up) status		
Baseline status	N	Normal	CIND	Demented
Normal	216	68.5	25.9	5.6
CIND	99	10.1	54.5	35.4
Total	315	50.2	34.9	14.9

Table S5. Average Predicted Probability of Cognitive Status (in Percentage) by Follow-up Cognitive Status

	Dementia Status Predicted by Imputation Model		
Wave C status	Normal	CIND	Demented
Normal	71.8	24.2	4
CIND	47.1	37.0	15.9
Demented	18.9	38.4	42.7
Total	55.2	30.8	13.9

Table S6: Regression Results for Total Nursing Home Spending and Medicare Spending on Nursing Home Care

	Total Nursing Home Spending		Medicare Spending: Skilled Nursing Facilities	
Probability of Dementia	22734.87***	20906.00***	1859.68***	1100.99***
	[2727.89]	[2561.40]	[290.87]	[246.13]
Household Income		4.27		-2.28
		[8.90]		[2.64]
Married (Yes=1)		-1774.55***		-243.60***
		[165.08]		[58.28]
Age		52.69		38.45***
		[56.66]		[6.87]
White (Yes=1)		1971.20***		245.61**
		[367.22]		[81.10]
Hispanic (Yes=1)		-396.11		-66.01
		[389.23]		[117.31]
Female (Yes=1)		27.52		93.91
		[243.29]		[64.20]
Less than High School		-874.49*		59.11
		[357.46]		[74.52]
High School Graduate		-791.62**		-52.86
		[284.55]		[69.05]
1 or no Children		954.54***		100.28
		[252.17]		[74.60]
Two Children		-133.71		12.72
		[182.39]		[60.82]
Stroke		1521.21***		487.88***
		[334.64]		[106.98]
Diabetes		363.83		332.22***
		[223.02]		[86.74]
Heart Disease		-217.19		167.49**
		[154.71]		[57.50]
Hypertension		-551.67**		-59.77
		[194.58]		[55.27]
Lung Disease		64.41		74.93
		[245.56]		[86.05]
Cancer		-20.71		-13.96
		[192.99]		[65.31]
Psychological Condition		1546.97***		295.59**
		[379.32]		[109.86]
Arthritis		-316.43		105.74*
		[184.22]		[51.70]
Intercept	-72.7	-4862.05	318.91***	-3236.73***
	[174.34]	[4683.22]	[31.02]	[581.36]
Number of Obs	31756	31756	18398	18398

Note: * means significant at 0.05 level; ** means significant at 0.01 level; *** means significant at 0.001 level.

Table S7: Regression Results for OOP Spending on Nursing Home Care and Total OOP Spending

	Out-of-Pocket Nursing Home Spending		Total Out-of-Pocket Spending	
Probability of Dementia	6497.99***	5928.71**	6837.76***	6194.14***
	[658.75]	[631.01]	[991.69]	[835.83]
Household Income		14.40*		44.20***
		[7.16]		[12.49]
Married (Yes=1)		-526.58**		-562.25***
		[75.91]		[139.68]
Age		37.34*		46.09*
		[15.44]		[19.97]
White (Yes=1)		827.52**		428.84***
		[147.05]		[194.29]
Hispanic (Yes=1)		31.4		-38.48
		[153.14]		[219.85]
Female (Yes=1)		143.38		425.59**
		[89.69]		[138.25]
Less than High School		-465.14**		-1207.93***
		[126.08]		[200.93]
High School Graduate		-147.45		-769.53***
		[124.63]		[179.87]
1 or no Children		161.06		157.82
		[128.89]		[169.39]
Two Children		-23.67		228.78
		[128.45]		[156.46]
Stroke		241.57		1005.48***
		[175.59]		[243.91]
Diabetes		52.72		522.34**
		[94.03]		[179.54]
Heart Disease		-70.52		527.20**
		[83.74]		[161.14]
Hypertension		-215.95*		171.13
		[110.13]		[141.30]
Lung Disease		-134.44		42.65
		[100.72]		[200.84]
Cancer		-30		195.31
		[96.47]		[156.49]
Psychological Condition		574.66**		988.27***
		[183.31]		[246.37]
Arthritis		-279.63**		-73.5
		[82.73]		[142.50]
Intercept	-2.43	-3015.56*	2115.95***	-3283.42*
	[51.69]	[1204.21]	[92.39]	[1608.56]
Number of Obs	25596	25596	31936	31936

Note: * means significant at 0.05 level; ** means significant at 0.01 level; *** means significant at 0.001 level.

Table S8: Regression Results for Total Medicare Spending and Weekly Spending on Formal Home Care

	Total Medicare Spending		Total Formal Home Care (Weekly)	
Probability of Dementia	5225.81***	2752.31***	158.54***	125.32***
	[1069.70]	[818.38]	[23.44]	[19.29]
Household Income		-18.04		0.27
		[23.79]		[0.15]
Married (Yes=1)		-613.59		-9.83***
		[336.33]		[2.98]
Age		52.49		1.65***
		[30.53]		[0.47]
White (Yes=1)		-888.62		5
		[502.26]		[4.29]
Hispanic (Yes=1)		1818.81*		33.68***
		[769.64]		[9.35]
Female (Yes=1)		-38.45		4.75
		[384.14]		[3.74]
Less than High School		-493.16		-11.82**
		[414.98]		[4.47]
High School Graduate		-625.67		-11.87**
		[335.91]		[4.19]
1 or no Children		-162.77		4.21
		[377.14]		[4.24]
Two Children		241.97		3.24
		[352.52]		[3.60]
Stroke		3125.95***		23.56***
		[489.86]		[5.29]
Diabetes		2572.22***		1.87
		[423.63]		[3.26]
Heart Disease		4761.82***		7.27*
		[294.36]		[3.04]
Hypertension		206.5		-0.14
		[284.27]		[3.18]
Lung Disease		2086.28***		-1.3
		[487.46]		[3.77]
Cancer		3004.23***		8.85*
		[408.50]		[3.95]
Psychological Condition		1716.17***		20.59***
		[469.51]		[5.23]
Arthritis		1124.56***		-4.32
		[293.93]		[3.30]
Intercept	7175.35***	-472.17	8.55***	-128.34***
	[180.86]	[2567.63]	[1.90]	[37.45]
Number of Obs	18398	18398	31936	31936

Note: * means significant at 0.05 level; ** means significant at 0.01 level; *** means significant at 0.001 level.

Table S9: Regression Results for OOP Spending on Home Care and Medicare Spending on Home Health Agencies

	Out-of-Pocket Spending on Home Care		Medicare Spending on Home Health Agencies	
Probability of Dementia	259.19***	215.81**	1097.25***	622.38***
	[61.21]	[71.53]	[208.07]	[185.89]
Household Income		0.07		-2.6
		[0.49]		[2.09]
Married (Yes=1)		-36.16		-27.62
		[19.92]		[40.71]
Age		4.10*		21.85***
		[1.96]		[5.34]
White (Yes=1)		-2.92		-192.96**
		[31.16]		[73.07]
Hispanic (Yes=1)		-48.71**		400.11
		[18.15]		[209.89]
Female (Yes=1)		-8.91		142.25***
		[20.91]		[42.20]
Less than High School		-30.25		-0.07
		[27.52]		[44.93]
High School Graduate		-17.6		-28.78
		[20.16]		[39.11]
1 or no Children		-10.95		-79.42
		[18.54]		[44.45]
Two Children		-13.59		-5.28
		[14.59]		[41.79]
Stroke		-20.56		321.09***
		[19.01]		[64.72]
Diabetes		20.67		274.75***
		[32.25]		[67.76]
Heart Disease		11.6		184.24***
		[18.88]		[43.40]
Hypertension		-1.68		20.7
		[22.06]		[34.89]
Lung Disease		34.68		192.31***
		[34.09]		[54.20]
Cancer		8.42		17.37
		[13.99]		[42.61]
Psychological Condition		7.04		117.75
		[28.42]		[62.59]
Arthritis		-1.1		181.76***
		[12.89]		[33.03]
Intercept	22.62**	-232.63	310.67***	-1681.31***
	[6.98]	[142.63]	[23.01]	[412.87]
Number of Obs	25596	25596	18398	18398

Note: * means significant at 0.05 level; ** means significant at 0.01 level; *** means significant at 0.001 level.

Table S10: Regression Results for Valuation of Weekly Informal Care Usage

	Replacement Cost Valuation of Informal Care (Weekly)		Foregone Wage Cost Valuation of Informal Care (Weekly)	
Probability of Dementia	593.05***	534.40***	280.62***	253.62***
	[69.81]	[64.20]	[35.40]	[34.15]
Household Income		-0.34		0.15
		[0.41]		[0.18]
Married (Yes=1)		63.70***		-18.15***
		[6.97]		[3.56]
Age		1.98		-0.32
		[1.53]		[0.77]
White (Yes=1)		-50.47***		-40.25***
		[13.71]		[8.99]
Hispanic (Yes=1)		25.11		-3.94
		[22.19]		[13.99]
Female (Yes=1)		30.83***		16.35***
		[8.38]		[4.49]
Less than High School		39.55***		6.39
		[9.76]		[5.42]
High School Graduate		-2.14		-5.56
		[9.60]		[5.09]
1 or no Children		-27.76**		-22.58***
		[8.50]		[4.97]
Two Children		-4.53		-7.28
		[6.73]		[3.95]
Stroke		91.97***		39.82***
		[12.11]		[6.89]
Diabetes		46.74***		16.18***
		[8.64]		[4.58]
Heart Disease		19.05**		9.05**
		[5.84]		[3.22]
Hypertension		8.87		6.72*
		[5.70]		[3.33]
Lung Disease		61.59***		16.28**
		[9.03]		[5.62]
Cancer		10.97		7.63
		[7.50]		[4.13]
Psychological Condition		52.48***		20.87***
		[11.00]		[6.28]
Arthritis		10.02		3.54
		[5.90]		[3.45]
Intercept	53.12***	-180.92	20.26***	53.2
	[5.68]	[126.28]	[2.78]	[62.07]
Number of Obs	31936	31936	31936	31936

Note: * means significant at 0.05 level; ** means significant at 0.01 level; *** means significant at 0.001 level.

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