The Incremental Effects of Dementia on Care Use and Financial Status:

Quasi-experimental Approach using Longitudinal Study

April 2023

HwaJung Choi, PhD hwajungc@umich.edu [a,b,c,d]

Kenneth M. Langa, MD, PhD klanga@med.umich.edu [a,b,c,d]

Edward C. Norton, PhD ecnorton@umich.edu [b,c,e]

Tsai-Chin Cho, MSc tccho@umich.edu [f]

Cathleen M Connell, PhD cathleen@umich.edu [c,g]

[a] Department of Internal Medicine, School of Medicine, University of Michigan

[b] Department of Health Management and Policy, School of Public Health, University of Michigan

[c] Institute for Healthcare Policy and Innovation, University of Michigan

[d] Institute for Social Research, University of Michigan

[e] Department of Economics, University of Michigan

[f] Department of Epidemiology, School of Public Health, University of Michigan

[g] Department of Health Behavior and Health Education, School of Public Health, University of Michigan

Corresponding author: HwaJung Choi, hwajungc@umich.edu. 2800 Plymouth Rd. NCRC Building 14, GR109, Ann Arbor, MI 48109, Tel. 734-936-4787

Funding Acknowledgement:

The Health and Retirement Study is funded by the National Institute on Aging (U01 AG009740) and performed at the Institute for Social Research, University of Michigan.

This research was supported by National Institute on Aging K01AG057820 and P30AG01284626.

ABSTRACT

Background: Estimating the incremental effects of dementia on care use and financial outcomes is timely, as the population with dementia will more than double in the next few decades.

Methods: To determine the extent to which dementia affects an older adult's care use and assess financial implications for individuals, families, and society, we used a quasi-experimental study design by performing rigorous propensity score-matching on national, longitudinal data. Extensive baseline variables were used for matching, including sociodemographic characteristics, economic status, family availability, health conditions, disability status, and survey design aspects. Outcome variables of care use included monthly care hours from family and unpaid helpers, in-home medical services, hospital stay, and nursing facility stay. Financial outcomes included out-of-pocket medical costs and wealth. The status of being on Medicaid was also examined. We followed the outcomes for eight years from the baseline.

Results: After matching, we had 2,249 adults aged 55 and older at baseline who would have dementia during the two-year follow-up ("dementia group") and 2,249 adults without dementia during the follow-up period but otherwise similar to the dementia group ("control group"). Care use was similar at baseline between the groups but was substantially greater for dementia vs. control group in subsequent years, especially during the two-year follow-up: 47 vs. 16 monthly care hours from family and unpaid helpers; 24% vs.15% using in-home medical care; 21% vs. 7% using a nursing facility. The increase in the percentage of using a nursing facility was especially high if family care availability was low at baseline. Over the eight-year follow-up, the two-year out-of-pocket medical costs increased from $4,443 to $10,356, median wealth was reduced from $81,088 to $33,405, and the percentage of being on Medicaid increased from 17% to 33% in the dementia group. No significant changes in financial outcomes were found in the control group during the follow-up period.

Conclusion: The incremental effects of dementia on long-term care and financial burden are substantial and long-lasting. Family care availability should be accounted for in a comprehensive assessment of predicting the impacts of dementia.

INTRODUCTION

Alzheimer's disease and related dementias (ADRD) are among the most expensive health conditions,[1] costing more than $387 thousand (in 2021 dollars) in the last five years of life for a person with dementia.[2,3] The number of ADRD cases is expected to more than double in the next few years, [4,5] leading to a dramatic increase in the total cost of dementia from $321 billion to nearly $1 trillion in 2050 (in 2022 dollars) in the U.S.[2]

Several studies have estimated the incremental costs attributable to dementia.[6–9] For example, the life-time care costs for a person with dementia were estimated to be greater than those without dementia by $184,500 (in 2015 dollars).[7] Another study found that the out-of-pocket care costs from age 65 to death were higher for those living with vs. without dementia by $38,540 (in 2014 dollars), primarily due to the cost of long-term residential care.[8] These studies provided important context to the care costs associated with dementia but have limitations in providing counterfactual inferences without using strictly controlled comparable samples. Other studies used propensity-score matching techniques to select comparable samples at baseline for dementia and control groups.[9,10] For example, one study using comprehensive baseline characteristics in the matching process found a substantial increase in Medicare expenditures among those in the dementia group by about $12,000 for the first 12 months while no increase was found in the control group.[9]

Our study also focused on counterfactual estimates in assessing incremental effects of dementia; i.e., estimates of what would have happened to those without dementia if they did have dementia, or vice versa. To date, there has been scant evidence to

examine broad healthcare outcomes and financial consequences based on a propensity score-matched, prospective cohort study. Prior studies using matched samples focused on specific healthcare costs such as Medicare expenditures.[9,10] To shed light on the implications related to dementia for individuals, families, and society, we examined broad outcomes including care use and financial status using a large longitudinal household survey of older adults. We employed a propensity score matching technique to select two comparable groups at baseline; the cognitive functioning status of one group transitioned to dementia during the two-year follow-up, while the other group did not during the observed follow-up period (up to 8 years) despite having the similar risk of dementia at baseline. Findings from our study clarify the potential effects of dementia on older adult's care use and financial consequences. Our study also enhances the evidence of the potential role of family availability in reducing or delaying the use of long-term institutional care (e.g., nursing home),[11] the most expensive type of dementia care.

METHODS

Data and Sample

The Health and Retirement Study (HRS) is a biennial longitudinal survey of approximately 20,000 U.S. adults over 50. It collects extensive information on sociodemographic characteristics, health, care use, care costs, and financial status.[12] The HRS was approved by the University of Michigan Institutional Review Board (IRB).

We first created a full dementia sample with the following inclusion criteria: 1) first-time dementia observed during 1998-2016; 2) community-dwelling two years before dementia; 3) 55 and older two years before dementia. We used the Langa-Weir

approach to determine whether a sample person had dementia.[15] Based on these criteria, we identified 4,092 persons in the full dementia sample.

For our primary analyses, we used a quasi-experimental research design by performing rigorous propensity score matching on the subsamples of HRS to select comparable prospective cohorts. We first estimated the propensity of having dementia using extensive sample characteristics including sociodemographic characteristics, economic status, family availability, and physical and cognitive functioning conditions, measured at baseline (Supplemental Methods for specific variables). We then selected matched pairs (one from the full dementia sample and one from the non-dementia sample for each pair) using one-to-one nearest neighbor matching with a caliper [13,14] to make sure the risk of having dementia was similar to each other within the pair and hence comparable between dementia and control groups. In summary, the dementia group included 2,249 adults whose cognitive status transitioned from not having dementia at baseline to having dementia during the two-year follow-up. The control group included 2,249 adults with characteristics similar to the dementia group at baseline but their cognitive functioning status had not transitioned to dementia during the follow-up period (up to 8 years).

By the study design, we had a balanced sample between baseline and two-year follow-up for each group, meaning no missing data at baseline and two-year follow-up. Both groups had high rates of attrition from the four-year follow-up, mainly attributable to high mortality rates (about 20% to 35% during four- to eight-year follow-up) and censored data meaning no further follow-up due to late entry (about 12% to 36% during four- to eight-year follow-up). However, the rates of mortality and missing data were

comparable between dementia and control groups (Supplemental Figure 1). The percentage of lost to follow-up was small (about 3 to 7% over the follow-up years).

Measures

To provide broad implications of dementia for individuals, family members, and society, we examined several measures of care use (home- and community-based care and institutional care), financial status (out-of-pocket medical costs, wealth) and reliance on Medicaid. Care hours from helpers were calculated as monthly average hours based on care received from family or other unpaid helpers who assisted with activities of daily living (ADL) such as walking across a room, dressing, bathing, eating, getting in/out of bed, or using the toilet. Zero values were assigned to those who reported receiving no help with ADLs. The measure of in-home medical care indicated whether the sample person reported using any home healthcare since the last interview. The measure of nursing facility stays indicated whether the sample person reported an overnight stay at a nursing facility since the last interview.

Out-of-pocket medical costs were the reported total out-of-pocket expenditures for services, including hospital, nursing facility, doctor visits, prescription drugs, home health care, and special facilities since the last interview. Wealth was the net value of all reported asset components (including second home) less all debt. We also used the measure of being on Medicaid, which is the primary insurer of long-term care. All financial outcomes were converted to 2019 dollars with the adjustment of a consumer price index.

To estimate propensity score for matching and to control for confounding factors in auxiliary analyses, we used extensive baseline variables of demographic

characteristics, socioeconomic status, family availability, health conditions, physical and cognitive functioning limitations, and survey aspects (Supplemental Methods for more detail). Spousal availability (no spouse, spouse with a disability, spouse without any disability) and adult child availability (no adult child, all adult children far, at least one adult child living close, at least one adult child coresident) measured at baseline were also used for our analysis assessing the role of potential family care resources in reducing the rate of nursing facility services.

Statistical Analysis

We provided the levels of and differences in the percentages between dementia vs. control group with a 95% confidence interval (CI) to overview the analysis samples and assess whether the matching process resulted in selecting similar groups over all covariates. To examine the change in underlying health and functioning associated with dementia, we summarized the incidence of having new health conditions and the prevalence of having difficulties with three or more ADLs or Instrumental ADLs (IADLs) over the two-year follow-up. The measures of IADLs included activities of managing money, taking medication, preparing hot meals, using phones, and doing groceries.

To calculate point estimates and CIs of the levels and rates of care use and financial status over the follow-up years, we used logit models for binary outcomes (nursing home stay, in-home medical care, insurance status), two-part models [16] for continuous outcomes with a large number of zeros (hours of care and out-of-pocket costs), and quantile regression for wealth to estimate the difference in median value. We included in the regression models the interactions between the dementia group indicator and dummy variables of follow-up years, as explanatory variables. To assess

the potential influence of family availability on using a nursing facility service, we estimated the outcome measured at the onset of dementia corresponding to each baseline level of family availability (e.g., spousal presence and disability status; adult child's presence and spatial proximity).

We conducted auxiliary analyses for related evidence and a robustness check. First, we examined the outcome of *moving* to a nursing facility which implied a permanent transition compared to the measure of any nursing facility stays. Second, we repeated the primary analyses using the full dementia sample (*N*=4,092) instead of the matched dementia sample (*N*=2,249). We used the same estimation models but included in each model the variables used for matching as control variables (Supplemental Table 1 for the list) and calculated predicted values by holding all covariates at the mean values same as the primary analysis sample (i.e., propensity-score matched dementia sample). All the analyses using the full dementia sample accounted for the complex survey design.

RESULTS

Baseline sample characteristics: Dementia vs. control groups

Among those in the dementia group, about sixty percent were female, 37% were racial/ethnic minority, 42% had education lower than high school, 16% were employed, about half didn't have a spouse, one in ten didn't have an adult child, and 22% had at least one adult child coresident, at baseline (Figure 1). About 25% of the dementia group had diabetes, one-third ever had a heart disease, 14% ever had a stroke, and 18% ever had a psychiatric problem, at baseline (i.e., two years before the onset of dementia). About 9% of the dementia group had difficulties with at least 3 ADLs, 6%

had difficulties with at least 3 IADLs, and 55% were cognitively impaired but did not have dementia, at baseline. The baseline characteristics of the control group were similar to those of the dementia group for all covariates (Figure 1), which suggests the matching was implemented successfully.

New health conditions and disability status during the two-year follow-up: Dementia vs. control groups

As demonstrated earlier, dementia and control groups had similar health conditions and functioning status at baseline (Figure 1). However, during the two-year follow-up (i.e., at the onset of dementia for the dementia group), a significantly greater share of dementia vs. control group had new hypertension (6.1% vs. 4.0%), new heart problem (7.2% vs. 3.9%), stroke (8.4% vs. 1.9%), and psychiatric problem (7.9% vs. 2.0%; Figure 2). The percentages having three or more limitations in ADLs or IADLs were also substantially greater in the dementia vs. control group during the two-year follow-up: 26.0% vs. 11.2% for ADLs; 33.6% vs. 5.9% for IADLs (Figure 2).

Care use at baseline and follow-up years: Dementia vs. control groups

As summarized in Figure 3, both groups had significant increases in monthly care hours during two-year follow-up but a substantially greater increase in the dementia vs. control group (by 32.8 hours vs. 7.8 hours). The rate of in-home care use in the dementia group was 11.7% at baseline (similar to the control group) but doubled during the two-year follow-up (i.e., at the onset of dementia), much higher than the control group (24.0% vs. 15.4%). About 35.1% of the dementia group reported at baseline that they had been hospitalized in the past two years (similar to the control group), but this rate increased to 46.7% during the two-year follow-up and then declined over the subsequent years

(Figure 3). There were no significant changes in the rate of hospital stay over time in the control group.

Both groups had a low rate of using a nursing facility at baseline (3.6-3.9%, Figure 3). However, more than 20% of the dementia group reported they stayed in a nursing facility at the onset and subsequent years of dementia. In the control group, there was a relatively moderate increase over the follow-up years (e.g., up to 8.6% at six-year follow-up). A significant share of adults in the dementia group moved to a nursing facility for a permanent residence (Supplemental Figure 2): None lived in a nursing facility at baseline but 12.5% at the onset of dementia and 19.2% four years after the onset. Few in the control group moved to a nursing home during the follow-up period (up to about 3%).

Focusing on the dementia group, we assessed the extent to which the rate of using a nursing facility differed by the baseline availability of a spouse and adult children (Figure 4). Results suggest there may be a profound influence of potential family care availability on nursing facility use. The substantial increase in the percentage of using a nursing facility over the past two years was mainly observed among those who had less family availability. For example, the percentage of using a nursing facility increased from 1.8% at baseline to 30.8% at the onset of dementia among those whose spouse had a disability and all adult children living far (Figure 4). In contrast, there was little increase in the percentage among those whose spouse did not have any disabilities and had at least one coresident adult child at baseline (from 2.7% to 5.6%).

The results based on the full dementia sample were generally consistent with the matched dementia sample in that the main increase in the percentage using care was

observed during the two-year follow-up (Supplemental Figures 3) and the percentage using a nursing facility varied substantially by the baseline family availability (Supplemental Figure 4). However, the elevated level of using in-home medical care, hospital stay, and nursing facility stay was more persistent in the full dementia sample compared to matched dementia sample.

Financial and Insurance status at baseline and follow-up years: Dementia vs. control groups

The average out-of-pocket medical costs in the past two years were just over $4K for both dementia and control groups, measured at baseline (Figure 5). While little change over time was observed in the control group, the out-of-pocket amount increased to more than double when measured at the onset of dementia ($8.5K) and to $10.1K in two years after the onset. The median wealth in the dementia group was reduced from $81.1K at baseline to $66.0K at the onset and further to $33.4K in the eight-year follow-up. In contrast, there were no significant changes in median wealth over time in the control group. The proportion of being on Medicaid in the dementia group increased from 14.6% at baseline to 20.2% at the onset and to 27.7% four years after the onset, while there was no increase in the control group. Results from the full dementia sample were generally consistent with the matched dementia sample (Supplemental Figure 5).

DISCUSSION

By carefully selecting a matched sample of people with dementia and a control group, this study provides important counterfactual evidence about the effects of dementia on broad aspects of care use and financial consequences. Findings suggest the incremental effects of dementia on home, community-based, and institutional care are

profound. The onset of dementia was associated with a dramatic increase in the number of care hours provided by family and other unpaid helpers and the rate of in-home medical service use and hospital and nursing facility stays, compared to those who had similar health conditions, sociodemographic status, and financial resources at baseline but did not have the onset of dementia during the follow-up period. The economic burden of dementia is also substantial by imposing high out-of-pocket medical costs on patients and families and creating a fiscal burden on society by accelerating reliance on Medicaid. Our study also highlights that without family members who are available and capable of providing care, older adults are substantially more likely to rely on long-term residential care at the onset of dementia, which needs to be reflected when developing long-term care policies.

There are several study limitations to bear in mind when assessing the findings. First, our rigorous matching strategy selected to provide the counterfactual scenario resulted in relatively more Black study participants, those employed at baseline, and those living with a spouse who did not have a disability at baseline, compared to the full dementia sample (Supplemental Table 1). The matched samples also had a greater proportion of those with normal cognitive function than the full dementia sample at baseline. While the matched dementia sample was similar in terms of other important contextual factors (e.g., age, gender, education, economic and insurance status, child availability, health conditions), extending the findings to the overall dementia population must be done with caution. Second, by focusing on survivors only, our study did not assess the potential influence of mortality on outcomes. While this is beyond the scope of the study, including mortality would be important for the development of a model to

predict the population-level care use and care costs attributable to dementia.

Despite the limitations, our findings contribute to a better understanding of the extent to which dementia affects older adults' formal and informal care use, financial status, and potential burden on Medicaid. Further investigations to identify factors reducing the risk of dementia and mitigating the adverse impact of dementia on people's lives would be timely and vital. For example, the dementia group in our study was less likely to have received elective surgery compared to the control group (17% vs. 22% over the past two years) at baseline (i.e., two years before the onset of dementia); this may imply a potentially significant role in screening and dementia risk reduction for mitigating dementia incidence and associated adverse impacts on health, healthcare, and private and public financial status. The stark difference between dementia and control groups in the level of care received from family and unpaid helpers persisted over the entire period of dementia we observed. This may be the result of both increased care provision for those with dementia living in a community setting[17] and continuing care involvement for those who transitioned to a nursing facility.[18] More nuanced evidence of care dynamics among family members and other unpaid helpers over the course of dementia is essential to inform the development of a more integrated, effective, and sustainable care system for people with dementia.[19–21]

REFERENCES

1. Alzheimer's Association. Costs of Alzheimer's to Medicare and Medicaid. 2022;Available from: https://portal.alzimpact.org/media/serve/id/62509c7a54845

2. Alzheimer's Association. 2022 Alzheimer's disease facts and figures. Alzheimers Dement J Alzheimers Assoc 2022;18(4):700–89.

3. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. Ann Intern Med 2015;163(10):729–36.

4. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. Neurology 2013;80(19):1778–83.

5. Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020–2060). Alzheimers Dement 2021;17(12):1966–75.

6. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. N Engl J Med 2013;368(14):1326–34.

7. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and family lifetime cost of dementia: implications for policy. J Am Geriatr Soc 2017;65(10):2169–75.

8. Hudomiet P, Hurd MD, Rohwedder S. The relationship between lifetime out-of-pocket medical expenditures, dementia, and socioeconomic status in the U.S. J Econ Ageing 2019;14:100181.

9. Lin P-J, Zhong Y, Fillit HM, Chen E, Neumann PJ. Medicare Expenditures of Individuals with Alzheimer's Disease and Related Dementias or Mild Cognitive Impairment Before and After Diagnosis. J Am Geriatr Soc 2016;64(8):1549–57.

10. White L, Fishman P, Basu A, Crane PK, Larson EB, Coe NB. Medicare expenditures attributable to dementia. Health Serv Res 2019;54(4):773–81.

11. Choi H, Heisler M, Norton EC, Langa KM, Cho T-C, Connell CM. Family care availability and implications for informal and formal care used by adults with dementia in the US. Health Aff Proj Hope 2021;40(9):1359–67.

12. Sonnega A, Faul JD, Ofstedal MB, Langa KM, Phillips JW, Weir DR. Cohort profile: the Health and Retirement Study (HRS). Int J Epidemiol 2014;43(2):576–85.

13. Leuven E, Sianesi B. PSMATCH2: Stata module to perform full Mahalanobis and propensity score matching, common support graphing, and covariate imbalance testing. 2003;Available from: https://ideas.repec.org/c/boc/bocode/s432001.html

14. Abadie A, Imbens GW. Large Sample Properties of Matching Estimators for Average Treatment Effects. Econometrica 2006;74(1):235–67.

15. Crimmins EM, Kim JK, Langa KM, Weir DR. Assessment of cognition using surveys and neuropsychological assessment: the health and retirement study and the aging, demographics, and memory study. J Gerontol B Psychol Sci Soc Sci 2011;66(suppl 1):i162–71.

16. Belotti F, Deb P, Manning WG, Norton EC. Twopm: two-part models. Stata J 2015;15(1):3–20.

17. Langa KM, Chernew ME, Kabeto MU, et al. National estimates of the quantity and cost of informal caregiving for the elderly with dementia*. J Gen Intern Med 2001;16(11):770–8.

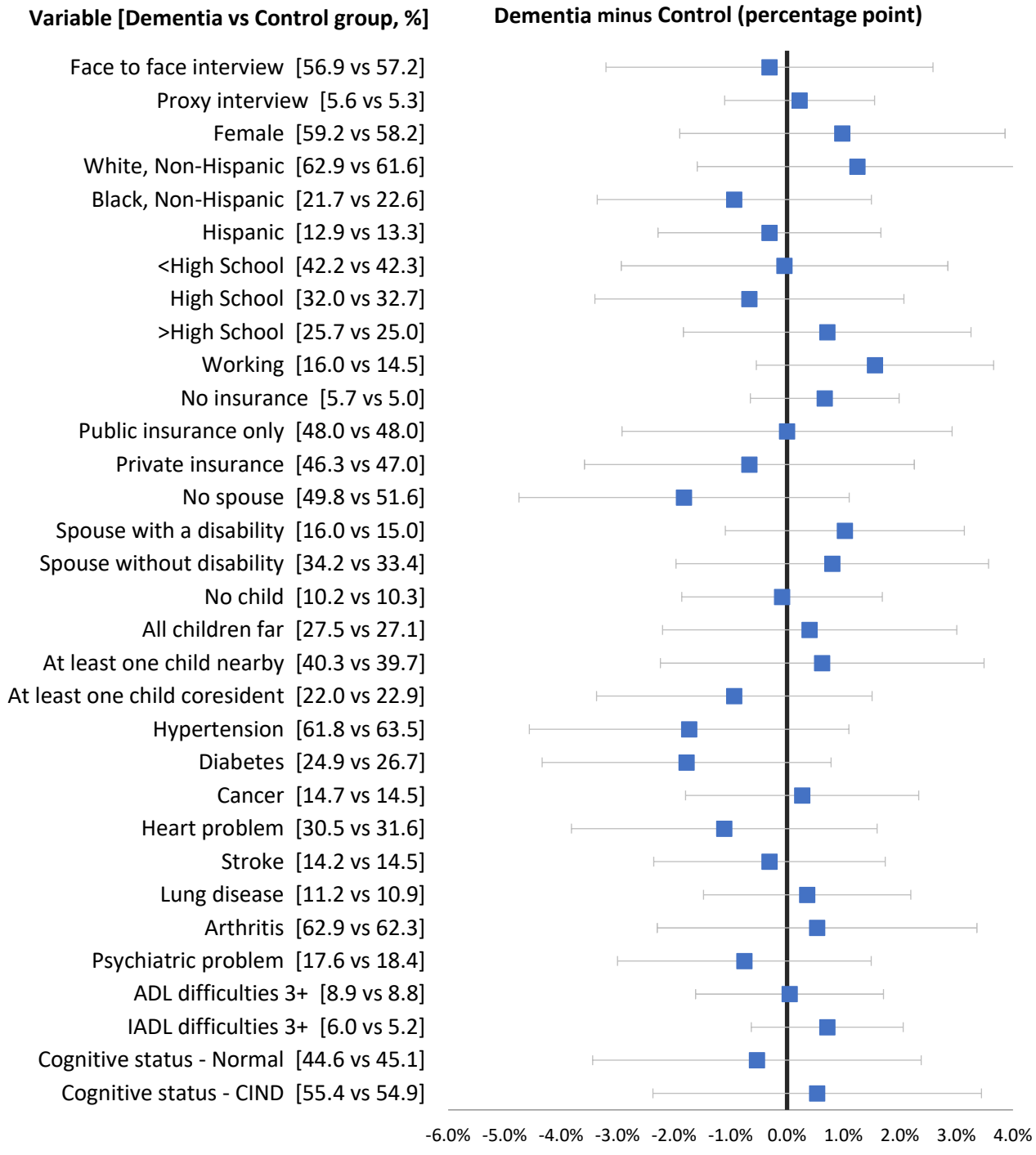
18. Coe NB, Werner RM. Informal caregivers provide considerable front-line support in residential care facilities and nursing homes. Health Aff (Millwood) 2022;41(1):105–11.

19. Van Houtven CH. Standing Up For My Sister. Health Aff (Millwood) 2022;41(10):1523–7.

20. Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. Palliat Support Care 2014;12(3):223–31.

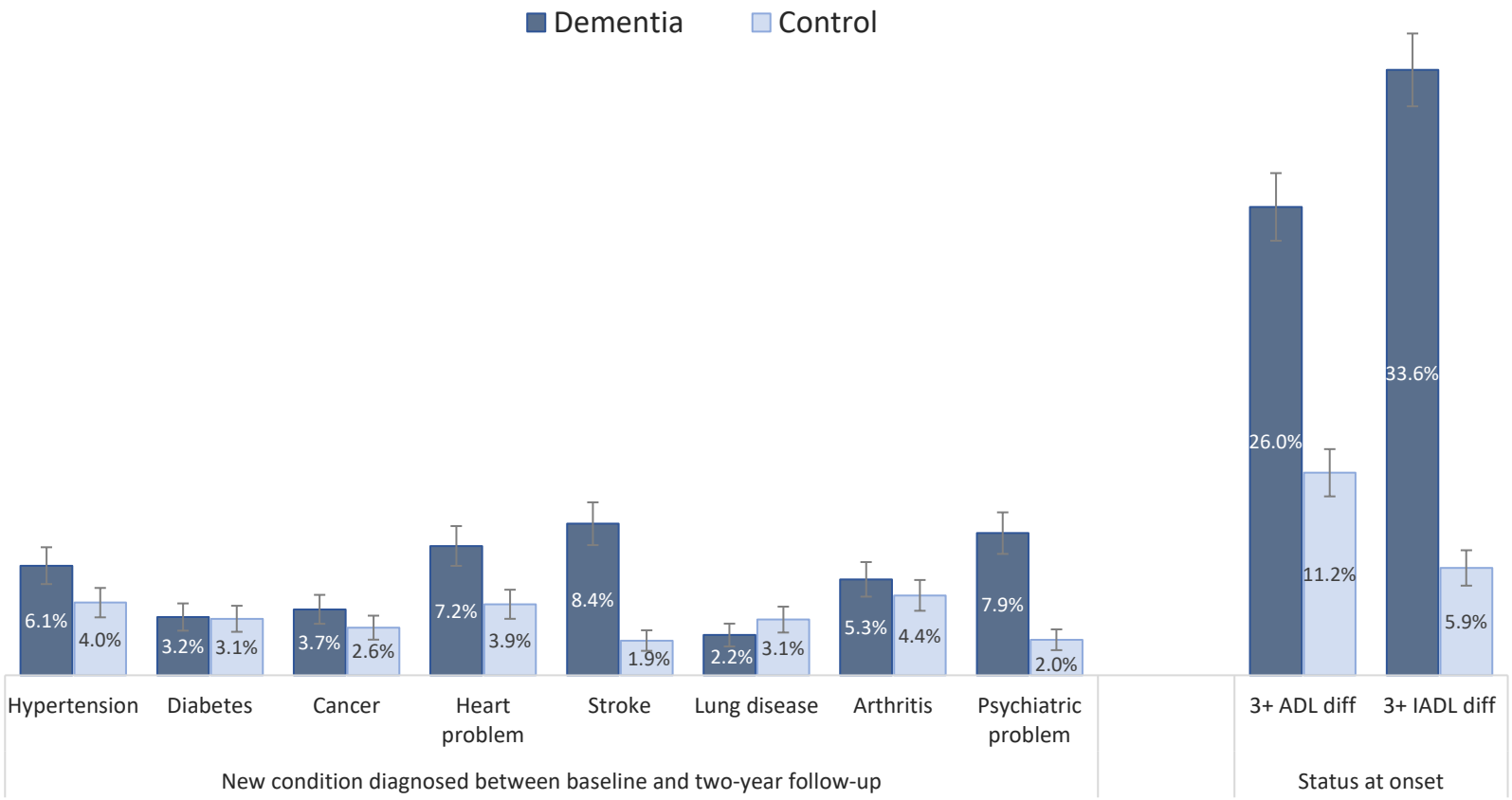
21. National Alliance for Caregiving, AARP. Caregiving in the U.S. 2020: A focused look at family caregivers of adults age 50+. 2020. Available from: https://www.caregiving.org/wp-content/uploads/2021/05/AARP1340_RR_Caregiving50Plus_508.pdf

Figure 1. Percentage of each covariate category in dementia vs. control sample, at baseline (N of persons: 2,249 for dementia group; 2,249 for the control group)



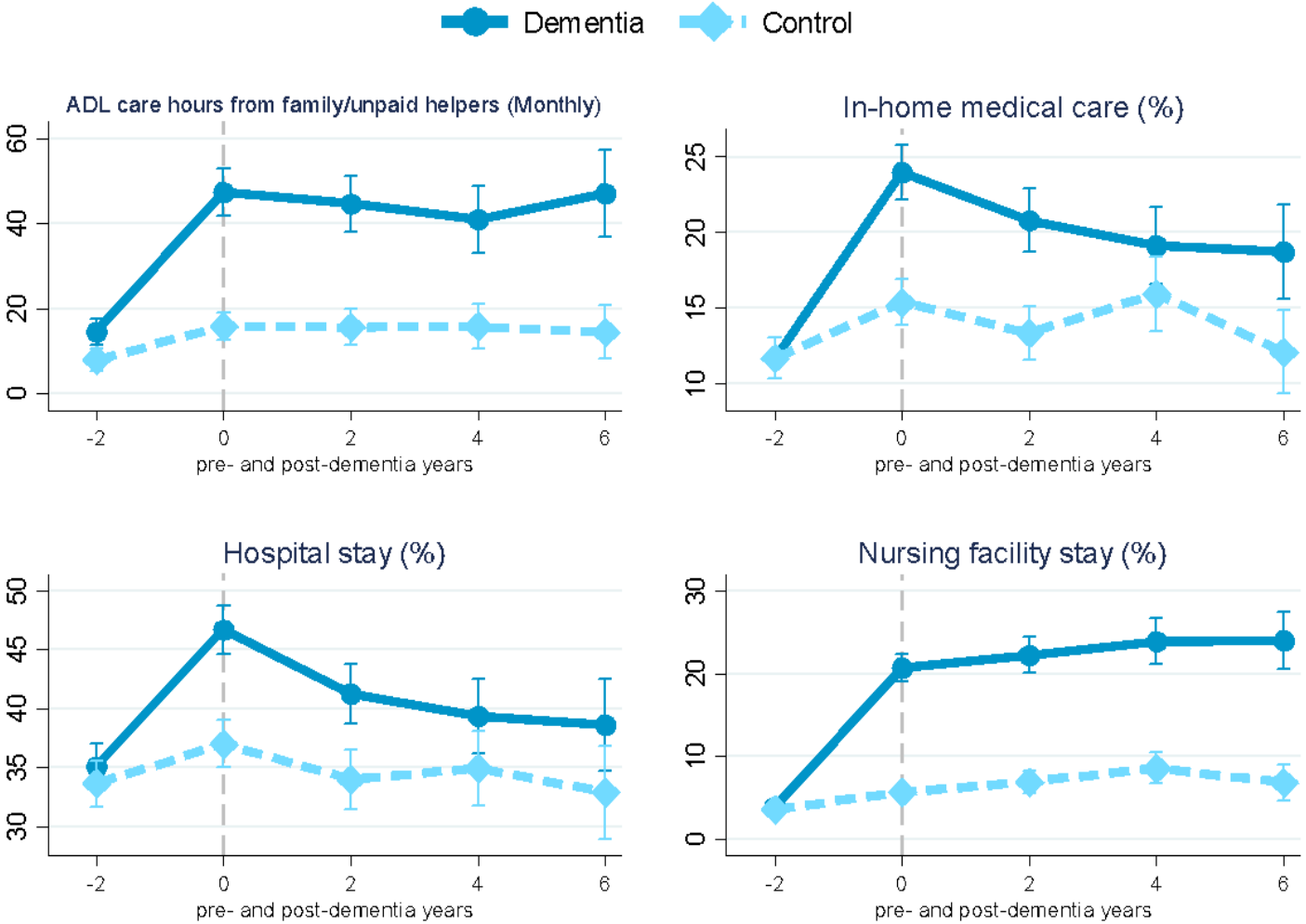
Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 were used to calculate the propensity score. Age, income, and wealth were also included in the matching and comparable between dementia and control group (Excluded in the plot due to unit differences).

Figure 2. New health conditions and disability status at the onset of dementia (N of persons: 2,249 for the dementia group; 2,249 for the control group)



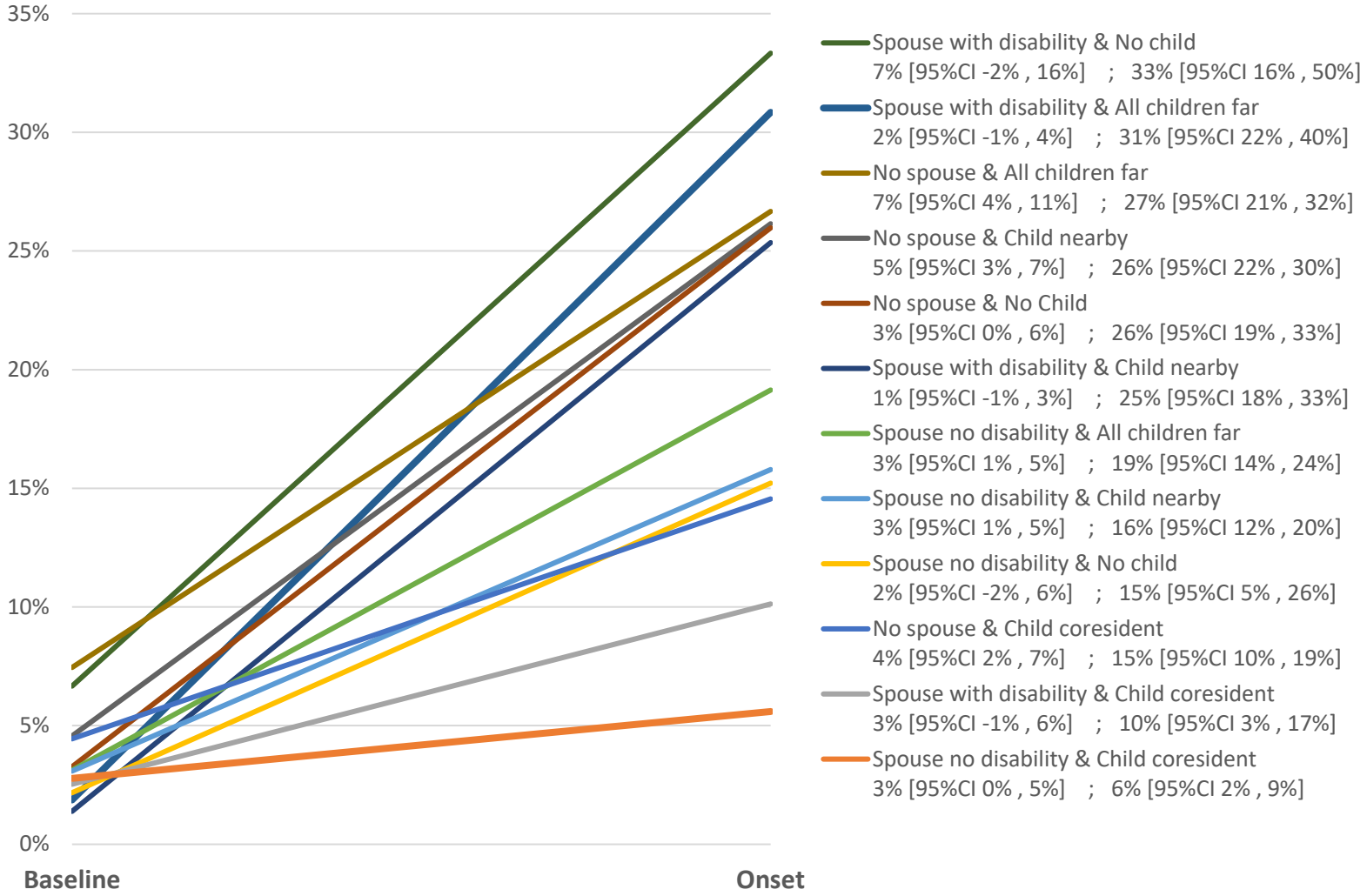
Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Figure 3. Care use at baseline and follow-up years for dementia and control groups
(N of persons: 2,249 for dementia group; 2,249 for the control group)



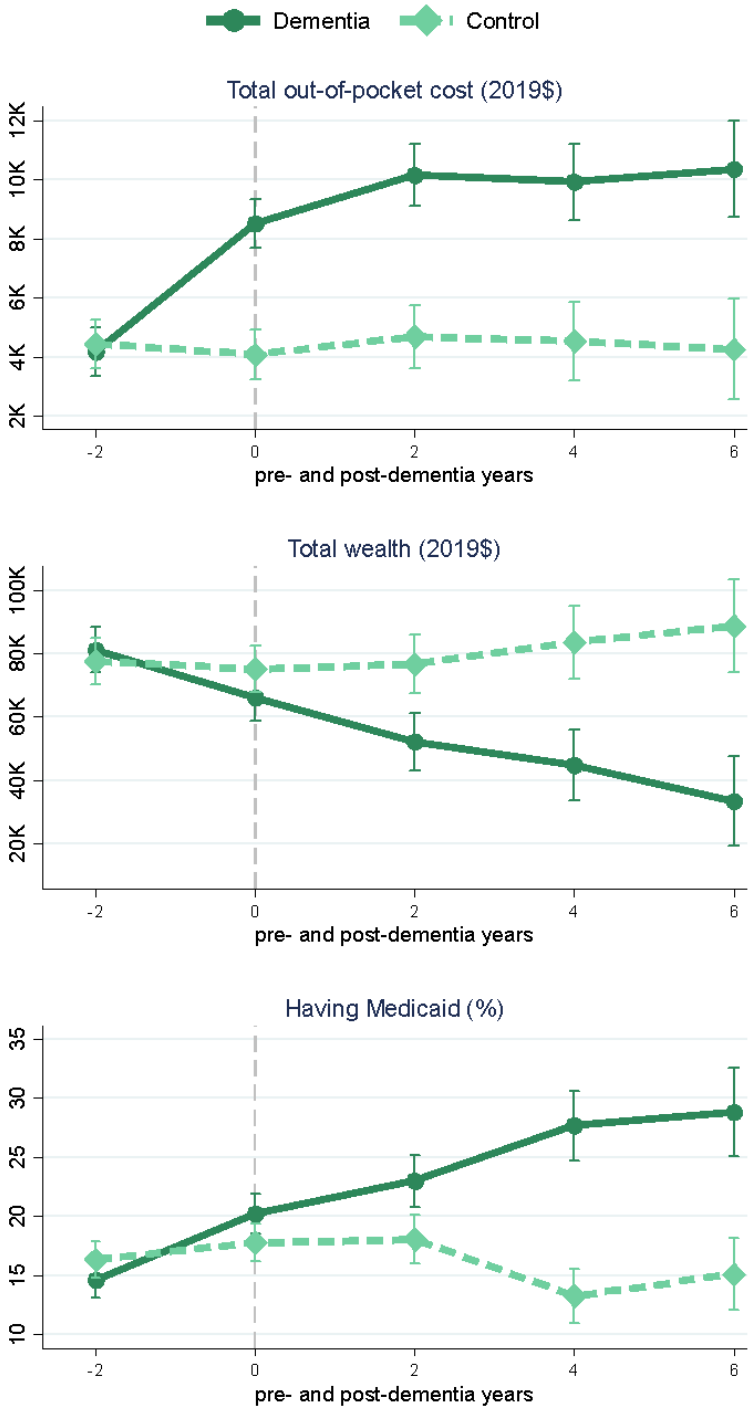
Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Figure 4. Percentage of those who stayed in a nursing facility at baseline and onset, by baseline family availability (N of dementia sample=2,249)



Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Figure 5. Financial status at baseline and follow-up years for dementia and control group (N of persons: 2,249 for the dementia group; 2,249 for the control group)



Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Supplemental Methods

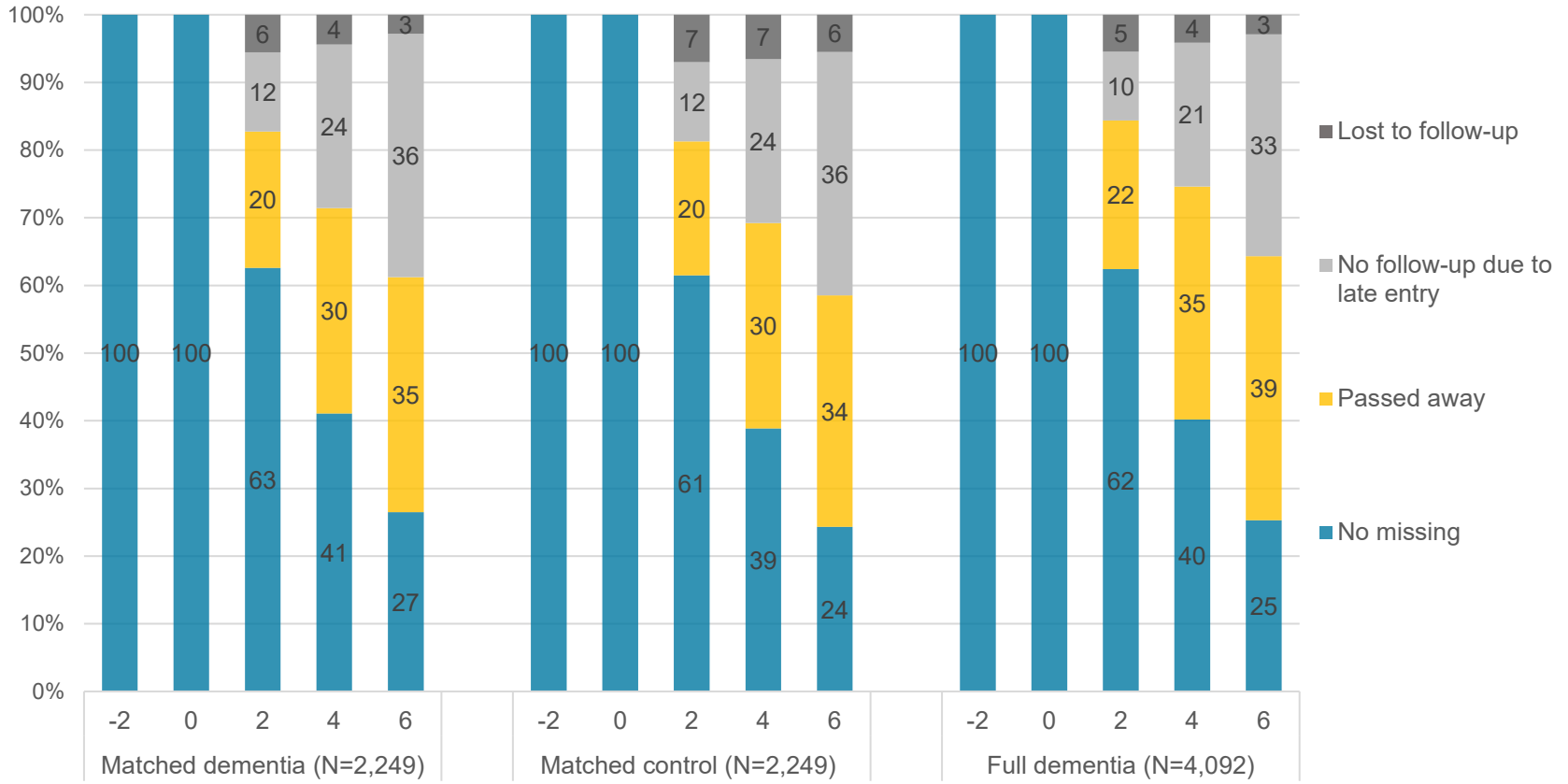
The variables used to match the dementia sample with the control sample at baseline were the following.

The survey aspect variables included survey year, survey mode (in-person or not), and proxy interview status. Demographic variables included age (55-64, 65-74, 75-84, 85+), gender (female or not), and race/ethnicity status (non-Hispanic white, non-Hispanic black, non-Hispanic others, and Hispanic). Socioeconomic variables included education (less than, equal to, or greater than high school), income (quartile), wealth (quartile), working status (currently working or not), and insurance status (no insurance, public insurance only, private insurance). The initial measure of income was the total income from a couple for those who were married (or partnered). We divided the income variable by the squat root of 2 for households with a couple before we determined income quartile groups. Wealth values were adjusted for household size by dividing by the squat root of the number of people in the household.

Family availability variables included spousal availability (no spouse, spouse with a disability, spouse without any disability) and adult child availability (no adult child, all adult children far, at least one adult child living close, at least one adult child coresident). The proximity of living close vs. far was determined based on the distance cut-point of 10 miles. Spousal disability was determined if the spouse had difficulty with at least one ADL or IADL due to a health problem. ADLs included walking across a room, dressing, bathing, eating, getting in/out of bed, or using the toilet, and IADLs included activities of managing money, taking medication, preparing hot meals, using phones, and doing groceries.

Health condition variables were measured based on respondents' reports of whether they were ever told by a doctor to have each of the following conditions: high blood pressure, diabetes, cancer, heart problems, stroke, lung disease, arthritis, psychiatric or emotional problems. We also included the number of ADLs and instrumental ADLs (IADLs) that they have difficulty with (0, 1, 2, 3+).

Supplemental Figure 1. Sample status over the follow-up period in matched dementia and control group and full dementia sample (%)



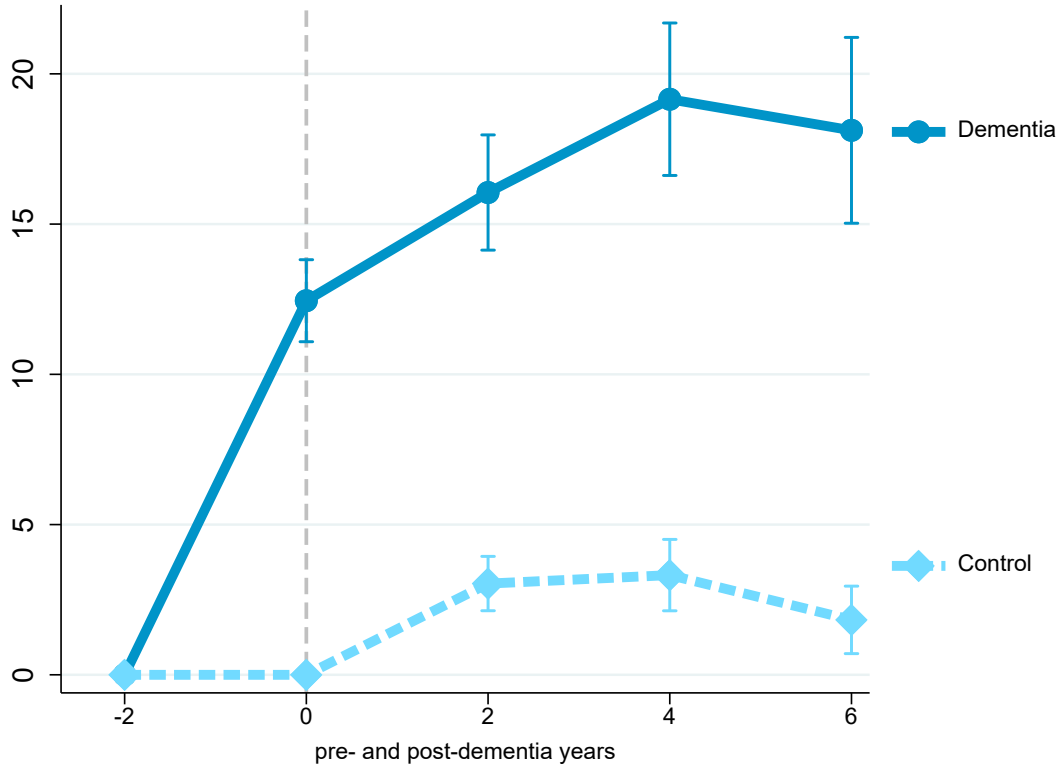
Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Supplemental Table 1. Summary of covariates at baseline using full and matched dementia sample

	Full dementia sample (weighted %; N=4,092) [95% CI]		Matched dementia sample (unweighted %, N=2,249) [95% CI]	
Face to face interview (%)	62.7	[61; 64.4]	56.9	[54.8; 58.9]
Proxy interview (%)	6.7	[5.6; 7.8]	5.6	[4.6; 6.5]
Age (mean)	75.0	[74.9; 75.9]	73.0	[72.9; 73.7]
Female (%)	60.2	[58.6; 61.8]	59.2	[57.1; 61.2]
White, Non-Hispanic (%)	69.5	[65.6; 73.3]	62.9	[60.9; 64.9]
Black, Non-Hispanic (%)	16.0	[14.1; 18]	21.7	[20.0; 23.4]
Other, Non-Hispanic (%)	2.9	[1.6; 4.3]	2.5	[1.9; 3.2]
Hispanic (%)	11.6	[8.3; 14.8]	12.9	[11.6; 14.3]
<High School (%)	44.6	[42; 47.3]	42.2	[40.2; 44.3]
High School (%)	30.2	[28.3; 32.1]	32.0	[30.1; 33.9]
>High School (%)	25.1	[22.9; 27.4]	25.7	[23.9; 27.6]
Household income (median)	21,471	[20759; 22183]	22,815	[21,917; 23,713]
Household asset (median)	81,088	[74409; 87767]	81,088	[72,804; 89,372]
Employed (%)	12.0	[10.8; 13.2]	16.0	[14.5; 17.5]
No insurance (%)	4.8	[3.9; 5.7]	5.7	[4.7; 6.6]
Public insurance only (%)	50.0	[47.3; 52.7]	48.0	[46.0; 50.1]
Private insurance (%)	45.2	[42.5; 47.9]	46.3	[44.2; 48.3]
No spouse (%)	58.4	[56.2; 60.5]	49.8	[47.7; 51.8]
Spouse with a disability (%)	13.4	[12.0; 14.7]	16.0	[14.5; 17.5]
Spouse without disability (%)	28.3	[26.8; 29.8]	34.2	[32.3; 36.2]
No child (%)	10.7	[9.5; 11.9]	10.2	[9.0; 11.5]
All children far (%)	29.7	[28.1; 31.3]	27.5	[25.6; 29.3]
At least one child nearby (%)	39.4	[37.2; 41.5]	40.3	[38.3; 42.4]
At least one child coresident (%)	20.3	[18.4; 22.1]	22.0	[20.3; 23.7]
Hypertension (%)	61.8	[60.2; 63.5]	61.8	[59.8; 63.8]
Diabetes (%)	25.1	[23.3; 26.9]	24.9	[23.1; 26.7]
Cancer (%)	14.9	[13.5; 16.2]	14.7	[13.3; 16.2]
Heart problem (%)	31.4	[29.7; 33.1]	30.5	[28.6; 32.4]
Stroke (%)	16.6	[15.4; 17.8]	14.2	[12.7; 15.6]
Lung disease (%)	10.6	[9.5; 11.7]	11.2	[9.9; 12.6]
Arthritis (%)	63.5	[61.7; 65.4]	62.9	[60.9; 64.9]
Psychiatric problem (%)	19.3	[17.7; 20.8]	17.6	[16.0; 19.2]
ADL difficulties 3+ (%)	11.3	[9.9; 12.7]	8.9	[7.7; 10.1]
IADL difficulties 3+ (%)	8.2	[7.0; 9.4]	6.0	[5.0; 6.9]
Cognitive status - Normal (%)	33.0	[31.4; 34.6]	44.6	[42.5; 46.7]
Cognitive status - CIND (%)	67.0	[65.4; 68.6]	55.4	[53.3; 57.5]

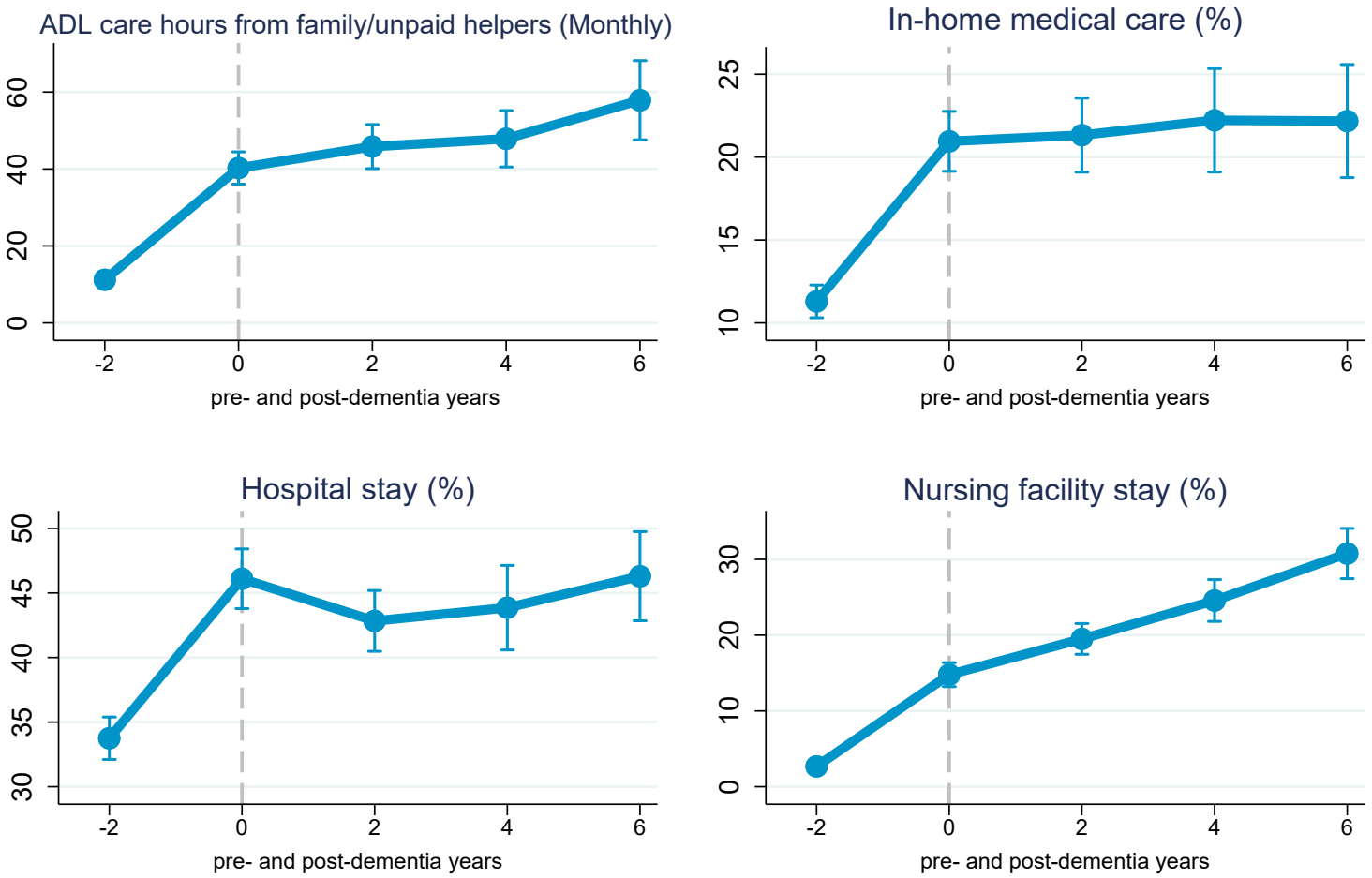
Supplemental Figure 2. Percentage of those who moved to a nursing facility

(N of persons: 2,249 for dementia group; 2,249 for control group)



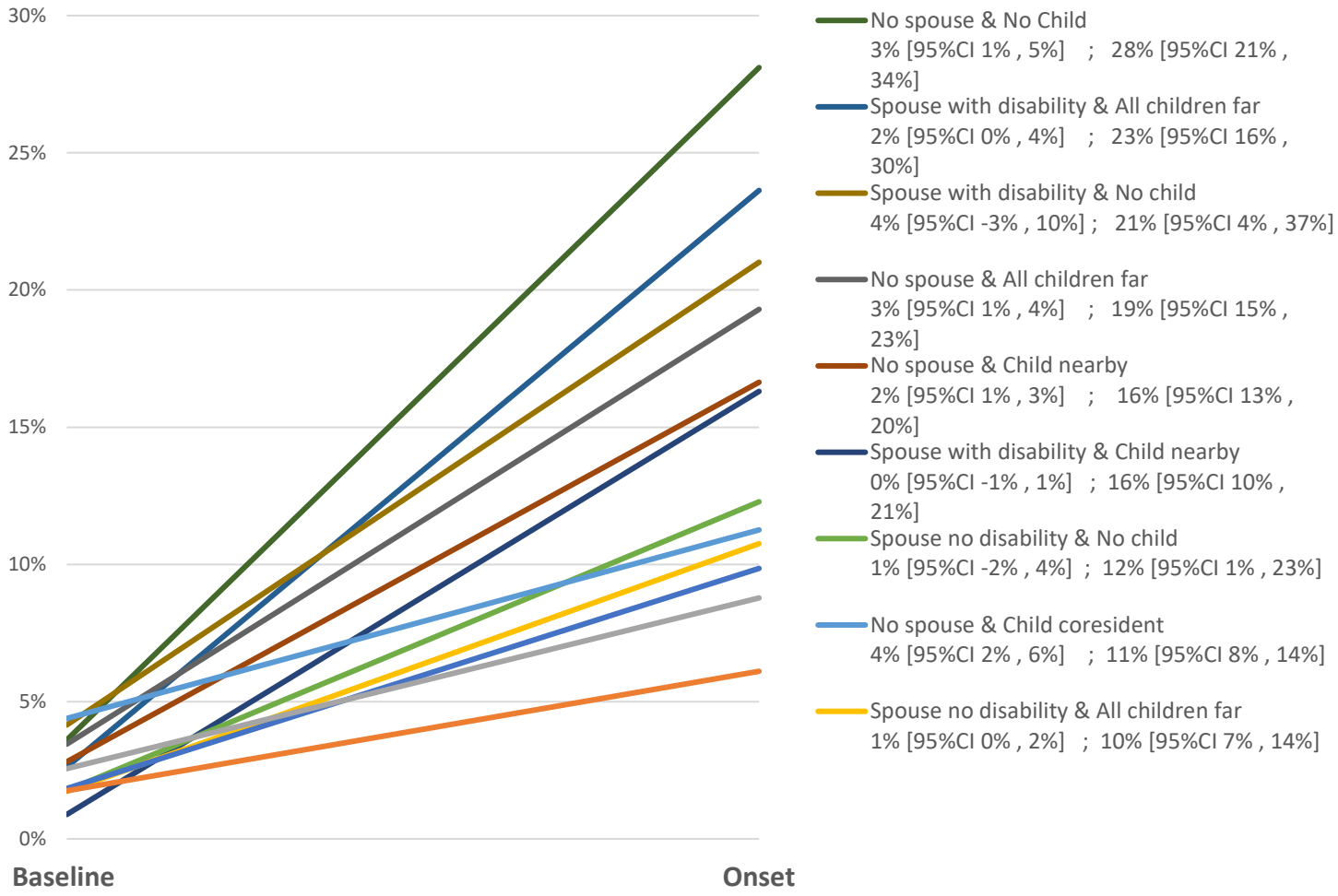
Note: Dementia and control groups were matched based on propensity score using one-to-one nearest neighbor matching with a caliper. All the variables listed in Figure 1 and age, income, and wealth were used for matching.

Supplemental Figure 3. Care use at baseline and follow-up years, using the <u>full dementia sample</u> (N of persons: 4,092)



Note: Multivariable analyses were used to adjust for baseline variables including demographic characteristics, socioeconomic status, health conditions, physical and cognitive limitations, and survey aspects. Predicted values were calculated by evaluating them at the same mean values of baseline covariates as the matched dementia group.

Supplemental Figure 4. Percentage of those who stayed in a nursing facility at baseline and onset, by baseline family availability using the full dementia sample (N of persons = 4,092)



Note: Full dementia sample was used, and sample weight and complex survey design were incorporated. Multivariable analyses were used to adjust for baseline variables, including demographic characteristics, socioeconomic status, health conditions, physical and cognitive limitations, and survey aspects. Predicted values were calculated by evaluating them at the same mean values of baseline covariates as the matched dementia group.

Supplemental Figure 5. Economic status at baseline and follow-up years, using the <u>full dementia sample</u> (N of persons = 4,092)



Note: Multivariable analyses were used to adjust for baseline variables including demographic characteristics, socioeconomic status, health conditions, physical and cognitive limitations, and survey aspects. Predicted values were calculated by evaluating them at the same mean values of baseline covariates as the matched dementia group. Baseline out-of-pocket medical costs, total wealth, and insurance status were excluded from the adjustments as they are part of the outcomes.