

Health Care Use and Out-of-pocket Spending by Persons With Dementia Differ Between Europe and the United States

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Background: Persons with dementia need much care, but what care is used and how the burden of financing is divided between persons with dementia, caregivers, and public programs may differ between countries.

Objective: The objective of this study was to compare how health care use and out-of-pocket (OOP) spending associated with dementia differ between the United States and Europe, with and without controlling for background characteristics.

Research Design: We use prospectively collected survey data from the United States-based Health and Retirement Study (n = 48,877) and the Survey of Health, Ageing, and Retirement in Europe (n = 98,971) including all adults over the age of 70 years. Dementia status is imputed using a validated algorithm. After first reporting the observed differences in care use, we analyze how care use is associated with dementia using multivariate regressions, controlling for other health conditions and background characteristics.

Results: Persons with dementia in the United States use 50% less formal home care per year than persons living with dementia in Europe [mean (SD) = 236.8 h (1047.4) vs. 463.3 h (1371.2)], but use more nursing home care [75.1 d (131.4) vs. 45.5 d (119.4)]. Dementia is associated with higher OOP spending in the United States than Europe [4406 USD (95% confidence interval, 3914–4899) vs. 246 USD (73–418)—2017 price levels].

Conclusions: Health care use and OOP spending differ between Europe and the United States. The far greater reliance on nursing home care in the United States likely causes much higher expenditures for people with dementia and insurance programs alike.

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Dementia severely limits a person's ability to live independently.¹ There is thus far no cure for dementia, but persons with dementia can receive help to cope with their functional impairments and can rely on medical care to deal with some of its symptoms and consequences. Worldwide ~46.8 million people had dementia in 2015² and the economic burden of dementia is already greater than that of heart disease, cancer, and other chronic conditions and it will be growing fast as the prevalence is expected to have tripled by 2050.³ Dieleman et al,⁴ for instance, estimated United States health care spending by health condition and identified dementia as the health condition with the largest out-of-pocket (OOP) spending in the United States.

It has long been established that persons with dementia have progressively intense care needs, and aggregate-level data suggest that there is considerable international variation in health care use and OOP spending.^{5,6} These differences may be explained by institutional and cultural differences that influence which types of care people with health problems receive and how this care is being paid for. In particular, health care systems differ in the type of services that are covered by public and private health insurance, how comprehensive this health insurance coverage is, both in terms of who is covered and how much cost-sharing there is (eg, through deductibles and co-payments), and what role informal caregivers play. In turn, these factors codetermine which care is available to whom. In particular, and most relevant for studying differences in dementia care, long-term care (LTC) provision differs substantially both within Europe and between Europe and the United States: the Northern and Western European countries have comprehensive, universal public LTC insurance programs, while the United States and many Southern and Eastern European countries only offer limited coverage for subgroups in the population (eg, Medicaid-only covers individuals with low income and wealth and Medicare-only covers postacute LTC for up to 100 d). Private insurance coverage rates for LTC are low everywhere. This has consequences for the access to LTC services, for the total amount of formal LTC that is used, and for the burden on informal caregivers. To illustrate the very wide differences: combined public and private expenditures on formal LTC

range from 3.7% of Gross Domestic Product in the Netherlands to 0.5% in the United States and 0.2% in Estonia.⁷

Hence, while Europe and the United States both face similar demographic shifts coupled with the rise of chronic diseases, including dementia, these trends may have different consequences depending on the health care systems in place. A careful examination of cross-country variation is critical for improved forecasting of how population aging may have different consequences—and thus require different responses—in different countries on a macro level.

To date, all individual-level studies on the costs of dementia focused on one country only and were mostly based on fairly small samples.^{8–15} These studies show how health care use and expenditures are associated with dementia in one particular country. For instance, Hurd et al⁹ show that the total financial burden of dementia care in the United States is \$41,689–\$56,290 depending on the method used to value informal care, and that LTC rather than medical care accounts for the bulk of these expenditures and that OOP expenditures are accounting for a large share of this. Other studies^{3,8,11,12,15,16} confirm these findings, both for the United States and other countries. However, nonrepresentative samples and varying methods to measure dementia across studies severely limit the cross-country comparability of these studies. Instead, all international comparative work is based on aggregate-level data and focuses on costs rather than use.^{5,6} These studies combine prevalence estimates with per-person cost-of-illness estimates taken from other studies.^{5,6}

Our analysis aims to answer 2 questions: How does health care use and OOP spending of persons with dementia differ between the United States and Europe? And how much of this health care use and spending is associated with dementia rather than with comorbidity? It is hence the first Europe-United States comparison of health care use and OOP spending by persons with dementia based on individual-level data. Our reliance on individual-level data analysis has the important advantage that we do not have to make assumptions regarding the relationship between dementia and care use which, as we highlight, varies a lot internationally.

METHODS

Data

We analyze data from 2 highly comparable surveys—the Survey of Health, Ageing and Retirement in Europe (SHARE) and the United States Health and Retirement Survey (HRS). These surveys prospectively collect data about health, health care use, socioeconomic status and social and family networks of individuals aged 50 years or older and their spouses sampled in the United States (HRS) and in 27 countries in Europe and Israel (SHARE).¹⁷ The HRS initially surveyed noninstitutionalized individuals only, but followed those who in consecutive waves moved into nursing homes; for SHARE the sampling criteria are country specific. We apply probability weights to ensure that the survey samples are representative of the population for each of the countries regarding the share of nursing home residents among older adults (Supplement 2 contains the details, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

From HRS, we use waves 6 (2002) to 13 (2016). From SHARE, we use waves 1–2 (2004/2005 and 2006/2007) and

4–7 (2010/2011, 2013, 2015, and 2017) for respondents from 17 countries for which the input data required for the algorithm were available. Wave 3 is a retrospective survey on people's life history and is therefore not part of our study. The following countries are included for Europe: Sweden and Denmark (Northern Europe), Austria, Germany, Luxembourg, The Netherlands, France, Belgium, and Switzerland (Western Europe), Poland, Estonia, Slovenia, Czech Republic, Italy, Spain, Portugal, and Greece. Next to comparing Europe to the United States, we specifically zoom in on Northern and Western Europe as these regions are most similar to the United States in terms of their Gross Domestic Product (GDP) and health care spending per capita.

As in the study by Hurd et al,⁹ only respondents older than 70 years were included in the study sample because Aging, Demographics, and Memory Study (ADAMS) that was used to determine the dementia status only included respondents older than 70 years. If respondents were not able to answer the questions themselves due to limitations, proxy respondent answers were used.

Dementia Status

Identifying whether a respondent has dementia from survey data is critical to accurately estimate the total health care use associated with it. Yet, identifying dementia status from survey data also presents a challenge because diagnosing a person with dementia typically requires a costly and lengthy examination by a medical specialist. Therefore, large-scale population surveys typically do not include the dementia status of respondents. To address this problem, Hurd et al⁹ have used the ADAMS survey, in which an in-home cognitive assessment was performed to diagnose dementia in a subsample of at-risk HRS respondents, to create a prediction algorithm based on information on cognitive and functional limitations and socioeconomic characteristics. This algorithm was then used to impute the dementia status to respondents of the HRS. To identify persons living with dementia and estimate their dementia-related medical care we make use of the similarity of the 2 surveys by applying an adjusted algorithm of the one developed by Hurd et al⁹ using the HRS.

Hurd and colleagues estimate separate algorithms for regular and proxy respondents. These algorithms are based on an ordered probit model with 3 outcomes: (1) having dementia; (2) having cognitive impairment but not dementia; or (3) aging without cognitive change—that makes use of the following predictor covariates: demographics, measures of (instrumental) activities of daily living, and cognitive functioning test scores. The algorithm has also been used in the study by Kelley et al³ who showed, using a set of sensitivity tests, that the results were robust to choices regarding the application of the algorithm. Information about the original algorithm, ordered probit estimation results, and within-sample fit of the model are in Supplement 3 (Tables 2–10, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

As no ADAMS-like study exists for other countries, we (slightly) adapt their original algorithms to impute dementia status for SHARE respondents to ensure that they only require the use of information that is also collected for SHARE respondents. The new algorithms match the performance of the

original United States algorithms. First, the weighted within-sample fit is 85%, while it was 86% in Hurd and colleagues; second, the χ^2 tests do not reject the null hypothesis that the predicted number of cases in each decile of the prevalence distribution of dementia are equal to the actual number of such cases, and this holds for both the original and adapted algorithms. Performance test results of the adapted algorithm can be found in Tables 4–7 in the Supplement (Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

Health Care Use

The SHARE and the HRS surveys collect comparable data on doctor visits, inpatient days, the number of hours of formal home care and informal care, nights spent in a nursing home and OOP spending on nursing home stays, drugs, and inpatient and outpatient days (all variable definitions can be found in Supplement 1, Table 1, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>). All OOP expenditure amounts have been converted into 2017 USD (Supplement 4, Tables 11, 12, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>). We impute missing information on hours of informal care and formal care in SHARE and ensure that the definitions of all variables are equal. A comprehensive explanation on how we imputed missing information and adjust variables for comparability between SHARE and HRS is given in Supplement 2 (Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

Analyses

Older adults, and especially persons with dementia, are likely to suffer from multiple health problems. To distinguish dementia-related health care use from care use related to other conditions, we proceed in 2 steps. We first present health care use of respondents with dementia compared with those who are aging without dementia. Second, we identify the share of total health care use and OOP spending associated with dementia rather than other conditions. To this end, we follow Hurd et al⁹ and control for demographic characteristics (age, household income, educational level, number of children, sex, and marital status) and coexisting conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, and arthritis) in multivariate regression analyses. We regress the 5 health care use variables and the aggregated OOP spending on the estimated dementia status of respondents (= 1 if identified as person with dementia using the algorithm; = 0 otherwise) using a pooled ordinary least squares estimator, while controlling for the mentioned demographic characteristics and coexisting conditions. Robust SEs are clustered at the individual level because many respondents were surveyed in multiple waves.

This approach estimates the total difference in health care use and OOP spending associated with dementia. These total changes may consist of a direct effect of having dementia and, possibly, an indirect effect of dementia on health care use because it may influence how other conditions are treated. This total change in health care use is a relevant outcome because it demonstrates how dementia may change the financial burden on patients, informal caregivers, and society. In Supplement 7 (Tables 19–22, Supplemental

Digital Content 1, <http://links.lww.com/MLR/C217>), we disentangle the direct and indirect effects by including interaction terms between the dementia indicator and each of the 7 categories of chronic diseases.

RESULTS

Descriptive Statistics

Both in Europe and the United States, respondents with dementia are on average older than those who do not have dementia, have lower incomes, are more often female, are less often married, and have had fewer years of schooling (Table 1). Respondents with dementia also more often have experienced a stroke, have diabetes, or a heart disease but less often have cancer. These coexisting conditions are more common in the United States, both for people with dementia and without dementia.

Dementia prevalence in our selected age group is 13.7% in the United States, which is higher than the 11.1% in the European countries we selected, or the 9.0% and 7.5% in Western and Northern Europe. The United States figure is comparable to the estimate reported for this age group by the Alzheimer Association.¹⁸

Unadjusted Differences in Care for Persons With Dementia

Respondents with dementia use substantially more care than those without dementia, both in the United States and in Europe (Table 1). However, there are large differences in how much of each of the types of care is used between the United States and Europe. Respondents with dementia in Europe more often visit a doctor and spend more days in the hospital than their counterparts in the United States. Moreover, persons with dementia in Europe use more formal *and* informal care. However, persons with dementia in the United States stay on average 29.5 more nights per year in a nursing home compared with Europeans: 75.0 versus 45.5 nights. American persons with dementia also spend an 8 times higher amount on their health care OOP than their European counterparts: 6902 versus 846 USD.

Table 2 shows the difference between the United States and Northern and Western Europe, the 2 regions closest to the United States in terms of GDP per capita and health care spending levels. Most differences in care use between these regions and the United States are qualitatively similar to those between the United States and all European countries. The most important exception is that, unlike the overall average for Europe, people with dementia in Western Europe and Northern Europe report more nights in a nursing home than Americans (82.7 and 155.4 nights, respectively vs. 75.0 nights in the United States). While using less care, persons with dementia in the United States report much higher OOP spending (6902) than in Western Europe (964) and Northern Europe (1571).

Health Care Use Associated With Dementia

The multivariate regressions show that a sizable part of the total (unadjusted) differences in health care use and OOP spending between persons with dementia and other respondents are indeed associated with dementia rather than

TABLE 1. Descriptive Statistics for Europe and United States

Variables	Europe			United States			Comparison (Europe to United States)	
	Dementia [Mean (SD)]	Nondementia [Mean (SD)]	Difference to Nondementia [Mean (P)]	Dementia [Mean (SD)]	Nondementia [Mean (SD)]	Difference to Nondementia [Mean (P)]	Difference Dementia [Mean (P)]	Difference Nondementia [Mean (P)]
Sample size	10,989	87,982		6701	42,176			
Demographic characteristics								
Age (y)	85.0 (5.7)	77.9 (5.3)	7.0 (0.000)	84.7 (6.8)	77.8 (5.4)	6.9 (0.000)	0.3 (0.000)	0.2 (0.000)
Income (USD)	25,254 (45,560)	34,117 (57,842)	-8863 (0.000)	38,451 (117,589)	58,053 (98,389)	-19,603 (0.000)	-13,197 (0.000)	-23,936 (0.000)
Marital status								
Married	33.0%	55.5%	-22.5% (0.000)	36.6%	56.3%	-19.7% (0.000)	-3.6% (0.000)	-0.8% (0.006)
Sex								
Female	74.3%	57.8%	16.5% (0.000)	63.8%	56.5%	7.3% (0.000)	10.5% (0.000)	1.3% (0.000)
Education								
Less than high school graduate	80.1%	57.3%	22.7% (0.000)	40.9%	20.4%	20.5% (0.000)	39.2% (0.000)	36.9% (0.000)
High school graduate	15.1%	26.4%	-11.3% (0.000)	34.4%	37.2%	-2.9% (0.000)	-19.3% (0.000)	-10.8% (0.000)
No. children								
1 or 0 children	26.3%	27.7%	-1.4% (0.059)	21.0%	16.6%	4.4% (0.000)	5.3% (0.000)	11.1% (0.000)
2 children	30.7%	34.6%	-3.9% (0.000)	24.3%	25.1%	-0.8% (0.134)	6.4% (0.000)	9.5% (0.000)
Coexisting conditions								
Stroke	14.5%	5.0%	9.5% (0.000)	25.0%	8.4%	16.6% (0.000)	-10.5% (0.000)	-3.4% (0.000)
Diabetes	22.5%	16.7%	5.8% (0.000)	26.0%	22.7%	3.3% (0.000)	-3.5% (0.000)	-6.0% (0.000)
Heart disease	25.7%	18.6%	7.1% (0.000)	40.8%	34.0%	6.8% (0.000)	-15.1% (0.000)	-15.4% (0.000)
Hypertension	47.1%	48.8%	-1.7% (0.046)	66.3%	66.4%	-0.1% (0.172)	-19.2% (0.000)	-17.6% (0.000)
Lung disease	10.3%	7.7%	2.6% (0.000)	11.8%	12.1%	-0.3% (0.557)	-1.5% (0.003)	-4.4% (0.000)
Cancer	5.9%	6.7%	-0.8% (0.071)	19.5%	21.7%	-2.1% (0.297)	-13.6% (0.000)	-15.0% (0.000)
Arthritis	41.0%	32.3%	8.7% (0.000)	66.6%	70.4%	-3.9% (0.000)	-25.6% (0.000)	-38.1% (0.000)
Health care use in past 12 mo								
Doctor visits (n)	11.9 (14.1)	8.7 (10.3)	3.2 (0.000)	8.9 (12.5)	5.7 (7.9)	3.9 (0.000)	3.0 (0.000)	3.0 (0.000)
Hospital (nights)	6.00 (21.3)	2.5 (9.6)	3.5 (0.000)	3.4 (10.9)	1.7 (5.0)	2.1 (0.000)	2.6 (0.000)	1.2 (0.000)
Formal care (h)	463.3 (1371.2)	66.7 (391.1)	396.7 (0.000)	236.8 (1,047.4)	14.4 (204.4)	222.5 (0.000)	226.5 (0.000)	52.2 (0.000)
Informal care (h)	656.1 (1555.3)	98.9 (614.1)	557.2 (0.000)	537.7 (1,334.4)	38.8 (297.4)	499.0 (0.000)	118.4 (0.000)	60.1 (0.000)
Nursing home (nights)	45.5 (119.4)	7.4 (50.7)	38.1 (0.000)	75.1 (131.4)	2.6 (24.9)	72.5 (0.000)	-29.6 (0.000)	4.7 (0.000)
Out-of-pocket spending (USD)	846 (3345)	402 (1676)	443 (0.000)	6902 (19,129)	1461 (5116)	5,441 (0.000)	-6056 (0.000)	-1058 (0.000)

with other health conditions and sociodemographic characteristics. Figure 1 shows the coefficients for the United States, Europe, and the 2 European regions and Table 3 shows

whether the health care use and OOP expenditures associated with dementia are higher, lower, or at the same level in each of the European regions compared with the United States.

TABLE 2. Comparison of Health Care Use Between Northern and Western Europe and the United States

Variables	Northern Europe		Difference to United States	Western Europe		Difference to United States
	Dementia [Mean (SD)]	Difference to Nondementia [Mean (P)]	Dementia [Mean (P)]	Dementia [Mean (SD)]	Difference to Nondementia [Mean (P)]	Dementia [Mean (P)]
Sample size	939	11,647	6701	3480	35,222	6701
Health care use in past 12 mo						
Doctor visits (n)	6.4 (11.0)	1.5 (0.000)	-2.5 (0.000)	12.8 (14.3)	4.2 (0.000)	3.9 (0.000)
Hospital stays (nights)	4.1 (14.1)	2.4 (0.000)	0.7 (0.275)	7.4 (22.6)	4.5 (0.000)	4.0 (0.000)
Formal care (h)	222.3 (817.8)	196.2 (0.000)	-14.5 (0.731)	450.8 (1121)	378.2 (0.000)	214.0 (0.000)
Informal care (h)	410.5 (1455.6)	361.0 (0.000)	-127.2 (0.001)	610.0 (1498.1)	517.2 (0.000)	72.3 (0.243)
Nursing home (nights)	155.4 (178.8)	146.3 (0.000)	80.3 (0.000)	82.7 (151.1)	71.6 (0.000)	7.6 (0.000)
Out-of-pocket spending (USD)	1571 (2818)	974 (0.000)	-5332 (0.000)	964 (4540)	536 (0.000)	-5939 (0.000)

Complete descriptive statistics for all other variables for Northern and Western Europe and comparison to the United States are in Supplement 5 (Tables 13, 14, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

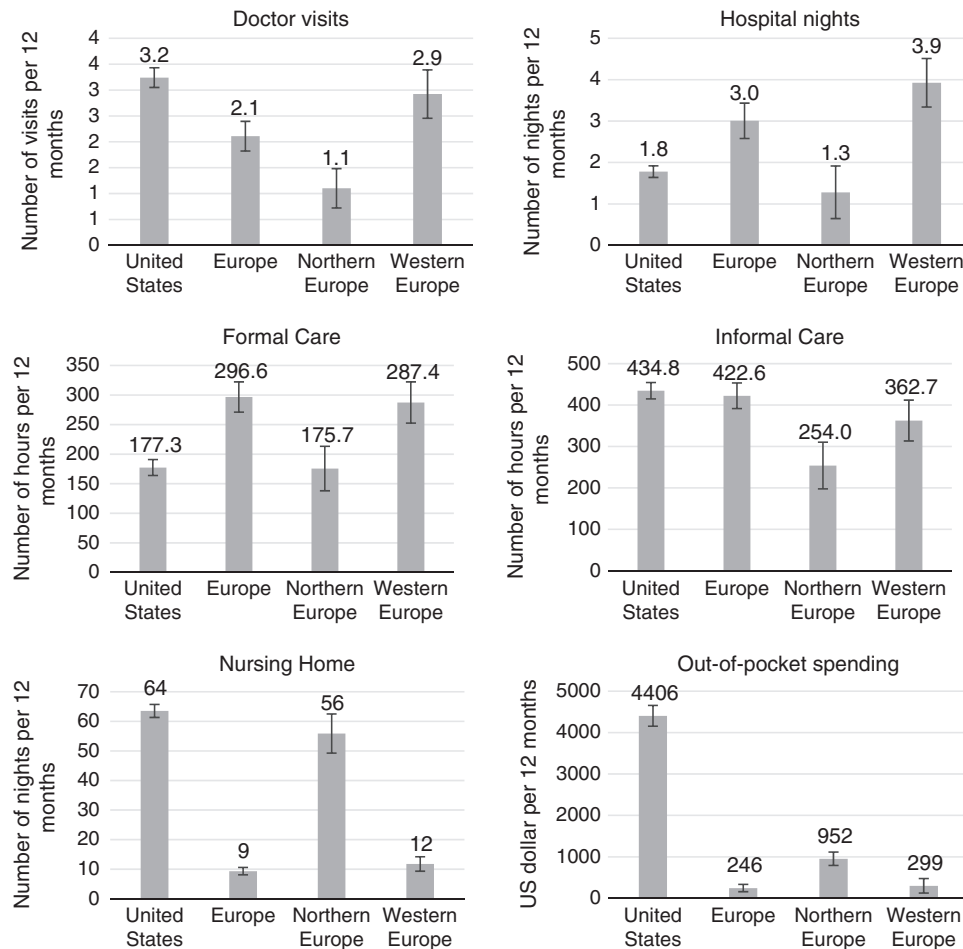


FIGURE 1. Regression results for health care use and out-of-pocket spending in the 12 months before the interview associated with dementia. The lines extending from the bars indicate 95% confidence intervals.

TABLE 3. Qualitative Summary of the Differences in Health Care Use Associated With Dementia Compared With the United States

Variables	Europe	Northern Europe	Western Europe
Doctor visits (per year)	-	-	0
Hospital nights (per year)	+	0	+
Formal care hours (per year)	+	0	+
Informal care hours (per year)	0	-	0
Nursing home nights (per year)	-	0	-
Out-of-pocket spending (USD)	-	-	-

Comparison of the coefficients from ordinary least squares regressions with cluster robust SEs (reported in parentheses); covariates include log of household income, whether married, age, age², female, less than high school education, high school graduate, 1 or no children, 2 children, with stroke, diabetes, heart disease, hypertension, lung disease, cancer, arthritis. Full regression results are in Supplement 6 (Tables 14–17, Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>).

0 indicates no statistically significant difference; -, less use in this region than in the United States; +, more use in this region than in the United States.

Medical Care Use

In the United States, dementia is associated with 3.2 [95% confidence interval (CI), 2.9–3.6] doctor visits and 1.8 (95% CI, 1.5–2.1) hospital nights per year. In Europe, dementia is associated with 2.1 (95% CI, 1.5–2.7) additional doctor visits and 3.0 (95% CI, 2.17–3.84) nights in the hospital.

Long-term Care Use

Formal care use associated with dementia is lower in the United States [177.3 h (95% CI, 150.8–203.9)] than in Europe [296.5 h (95% CI, 246.5–346.5)]. However, we observe wide variations within Europe: in Northern Europe dementia is associated with only 175.7 hours (95% CI, 101.9–249.5) of formal care, which is much lower than the overall European average, but similar to the United States estimates.

Informal care use associated with dementia is lower in the United States [254.0 h (95% CI, 143.4–364.6)] than in Europe [422.6 h (95% CI, 361.8–483.4)]. As with formal care use, there are large within-Europe differences in informal care use.

In Northern Europe dementia is associated with 434.8 hours of informal care (95% CI, 396.1–473.5), which is similar to the United States estimates.

The use of nursing home care associated with dementia is higher in the United States [63.5 nights (95% CI, 59.2–67.8)] than in Europe [9.3 nights (95% CI, 6.9–11.7)]. The level of nursing home use associated with dementia in Northern Europe [55.9 nights (95% CI, 42.9–68.8)] does not differ from the use in the United States, while use in the other European regions is much lower [eg, only 11.8 nights (95% CI, 6.96–16.56) in Western Europe].

Out-of-pocket Expenditures

The difference of OOP spending associated with dementia between Europe and the United States is large: Europeans pay 246 USD (95% CI, 73–418) OOP, Americans 4406 USD (95% CI, 3914–4899). In Northern Europe, OOP spending is higher than elsewhere in Europe [951.81 USD (95% CI, 634.7–1269)] but still much smaller than in the United States.

DISCUSSION

Persons living with dementia in Europe receive on average more medical care and formal and informal home care than persons with dementia in the United States, whereas the latter group spend more time in nursing homes. When confining attention to those countries in Europe that have GDP levels closer to the United States GDP level, the picture looks somewhat different. Persons in Northern Europe report less medical care and informal care use than persons in the United States. Moreover, persons with dementia in Western and Northern Europe report more nursing home stays than in America. Despite the higher nursing home use, average OOP spending is still much lower in these countries than in the United States.

Differences in the level of nursing home use have been linked to the financial burden of persons with dementia in the United States.¹⁶ Yet, the finding that the mean OOP spending is higher in the United States than in Europe while nursing home care use is lower does highlight the fact that raw cross-country differences in the *amount* of nursing home use cannot explain why persons with dementia in the United States have higher OOP spending than their European counterparts. Instead, the higher OOP spending is likely to be caused by less comprehensive public LTC coverage as discussed in the Introduction, leading to higher OOP spending per day for nursing home care in the United States. Indeed, according to Organisation for Economic Co-operation and Development (OECD) estimates, OOP spending accounts for a larger percentage of total nursing home care spending in the United States than in European countries.¹⁹

Controlling for comorbidities and background characteristics confirms that dementia is associated with large increases in health care use everywhere, and with LTC use in particular. The increase in formal care use and the number of nursing home nights is similar in the United States and in Northern Europe, while informal caregivers provide more dementia care in the United States than in Northern and Western Europe. The opportunity costs of informal care in terms of the labor market opportunities and the health and well-being of the caregiver may be substantial. Finally, OOP

spending associated with dementia is much higher in the United States, both in comparison to all European countries and to Northern and Western Europe. These last 2 findings suggest that the share of the total burden of dementia borne by family members and persons with dementia is much larger in the United States than in Europe.

A major strength of our dataset is that the results from all 18 countries are highly comparable, because we: (1) make use of one standardized questionnaire for 17 countries in Europe and the United States; and (2) use a rich set of variables and a validated prediction algorithm to impute dementia status rather than relying on a single proxy measure.

Our analysis has some limitations related to data and methods. First, the SHARE and HRS surveys do not contain a medical assessment to determine dementia status; instead, we impute dementia status based on the medical assessments in the ADAMS cohort. This means there may be measurement error in this variable. Nonetheless, the within-sample tests for the imputations of dementia status show a good fit. Second, all questions in the surveys are answered by respondents or proxy respondents and there may be differences among subgroups in how questions are answered, both within and across countries.^{20–24} Although such variation in reporting is arguably largest for subjective questions such as self-reported health, a similar issue may arise when reporting health problems, health care use, and OOP spending. Moreover, our analyses do not include people aged 70 years and younger, and thus do not represent a complete picture of health care use of persons with dementia. However, as dementia prevalence is very low for persons 70 years and younger, our study still captures the great majority of people with dementia. A final data-related limitation is that while the model by Hurd et al⁹ includes race and ethnicity as control variables, the SHARE survey does not collect these characteristics and hence they were not included in this analysis. The main limitation regarding the methods is that we control for 7 broad sets of other chronic illnesses but that: (1) there may be other health problems that are not included in the survey data used and (2) dementia may have an indirect effect if it influences the way in which other health problems are being treated. However, the interaction effects included in the regressions in Supplement 7 (Supplemental Digital Content 1, <http://links.lww.com/MLR/C217>) suggest that these indirect effects are rather small compared with the direct effect of dementia.

Our findings are relevant for health care financing policy because dementia prevalence rates are growing and thus health care use is expected to keep rising in the near future due to population aging. As dementia is already one of the highest cost conditions, this presents a major future policy challenge to all countries.⁴ However, the large discrepancies in health care use observed across countries suggest that neither the total amount of health care use associated with dementia nor how the burden is split across persons with dementia, relatives, and society at large are predetermined. Our results suggest that if current policies are continued in the near future, the United States can expect a far greater dementia burden than European countries. Moreover, persons at risk of acquiring dementia and their potential caregivers should hold much larger precautionary savings to pay for

OOP spending on health care and to compensate informal caregivers if they have to reduce their working hours to provide informal care.

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REFERENCES

- Dias A, Ferri C, Graham N, et al. Neurological disorders: a public health approach. 3.1 Dementia. *Epilepsy*. Geneva, Switzerland: World Health Organization; 2006:41–55.
- Organisation for Economic Co-operation and Development (OECD). *Health at a Glance: Europe 2016: State of Health in the EU Cycle*. Paris, France: OECD Publishing; 2016.
- Kelley AS, McGarry K, Gorges R, et al. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med*. 2015;163:729–736.
- Dieleman JL, Cao J, Chapin A, et al. US health care spending by payer and health condition, 1996–2016. *JAMA*. 2020;323:863–884.
- Wimo A, Jönsson L, Bond J, et al. The worldwide economic impact of dementia 2010. *Alzheimers Dement*. 2013;9:1.e3–11.e3.
- Wimo A, Guerchet M, Ali G-C, et al. The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimers Dement*. 2017;13:1–7.
- Organisation for Economic Co-operation and Development (OECD). Ageing and long-term care; 2020. Available at: www.oecd.org/els/health-systems/long-term-care.htm. Accessed November 3, 2020.
- Rice DP, Fox PJ, Max W, et al. The economic burden of Alzheimer's disease care. *Health Aff*. 1993;12:164–176.
- Hurd MD, Martorell P, Delavande A, et al. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368:1326–1334.
- Matthews FE, Arthur A, Barnes LE, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet*. 2013;382:1405–1412.
- Connolly S, Gillespie P, O'Shea E, et al. Estimating the economic and social costs of dementia in Ireland. *Dementia*. 2014;13:5–22.
- Holmerová I, Hort J, Rusina R, et al. Costs of dementia in the Czech Republic. *Eur J Health Econ*. 2017;18:979–986.
- Andersen CK, Andersen K, Kragh-Sørensen P. Cost function estimation: the choice of a model to apply to dementia. *Health Econ*. 2000;9:397–409.
- Belger M, Haro JM, Reed C, et al. Determinants of time to institutionalisation and related healthcare and societal costs in a community-based cohort of patients with Alzheimer's disease dementia. *Eur J Health Econ*. 2019;20:343–355.
- Wübker A, Zwakhalen SM, Challis D, et al. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *Eur J Health Econ*. 2015;16:689–707.
- Delavande A, Hurd MD, Martorell P, et al. Dementia and out-of-pocket spending on health care services. *Alzheimers Dement*. 2013;9:19–29.
- Börsch-Supan A, Brandt M, Hunkler C, et al. Data resource profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). *Int J Epidemiol*. 2013;42:992–1001.
- Alzheimer's Association Report. 2020 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2020;16:391–460.
- Colombo F, Llena Nozal A, Mercier J, et al. *OECD Health Policy Studies Help Wanted? Providing and Paying for Long-term Care: Providing and Paying for Long-term Care*. Paris, France: OECD Publishing; 2011.
- Bago d'Uva T, Van Doorslaer E, Lindeboom M, et al. Does reporting heterogeneity bias the measurement of health disparities? *Health Econ*. 2008;17:351–375.
- Grol-Prokopczyk H, Verdes-Tennant E, McEniry M, et al. Promises and pitfalls of anchoring vignettes in health survey research. *Demography*. 2015;52:1703–1728.
- Kapteyn A, Smith JP, Van Soest A. Vignettes and self-reports of work disability in the United States and the Netherlands. *Am Econ Rev*. 2007;97:461–473.
- Rossouw L, Bago d'Uva T, van Doorslaer E. Poor health reporting? Using anchoring vignettes to uncover health disparities by wealth and race. *Demography*. 2018;55:1935–1956.
- Van Soest A, Delaney L, Harmon C, et al. Validating the use of anchoring vignettes for the correction of response scale differences in subjective questions. *J R Stat Soc Ser A Stat Soc*. 2011;174:575–595.