

Economic costs of dementia in 11 countries in Europe: Estimates from nationally representative cohorts of a panel study



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Summary

Background With population aging, the economic burden of dementia is growing in Europe. Understanding the economic costs of dementia provides an important basis for prioritization in public health policy and resource allocation.

Methods We calculate the economic costs of dementia, including both direct medical and social care costs and indirect costs of informal care, for 11 countries in Europe. Costs are estimated using population-representative data from the Survey of Health, Ageing, and Retirement in Europe from 2004 to 2017, supplemented with external information about wages of care workers, dementia prevalence, and fraction of direct costs paid by other sources. We report overall costs for persons, both living and deceased with dementia and also isolate the costs attributable to dementia by estimating regression models that relate a given cost component to dementia while controlling for coexisting conditions and demographics. We make the monetary data comparable by adjusting for inflation and Purchasing Power Parity to 2018 euros.

Findings Average annual direct out of pocket costs that can be attributed to dementia vary between EUR 253 (95% CI: -17 to 522) and EUR 859 (95% CI: -587 to 2306) across countries, but are not statistically significant after adjustment for multiple testing. Average annual hours of informal care that can be attributed to dementia vary between 163 (95% CI: 27–299) and 1051 (95% CI: 15–2086) annual hours across countries, and are statistically significant in all countries before adjustment for multiple testing, and in seven out of 11 countries after this adjustment. Combining these estimates with external wage information in each country implies a burden between EUR 2687.4 (95% CI: 704.5 to 4670.3) and EUR 15,468 (95% CI: 8088.1 to 22,847.9) per individual with dementia per year depending on the country. When combined with external estimates of the fraction of direct costs covered by other payment sources (insurance, government) and numbers of individuals with dementia, estimates of the total costs of dementia at the country level vary from EUR 162.9 million (95% CI: 56.3 to 269.5) in Estonia to EUR 32,606.9 (95% CI: 13,893.9 to 51,319.9) in Germany. Informal care costs account for the largest proportion of costs attributable to dementia in all European countries, varying between about 50% and about 90%.

Interpretation The economic burden of dementia on families in terms of direct out-of-pocket and informal care costs varies greatly by country, depending on the health and social care systems. Informal care costs accounts for the largest proportion of costs, requiring policy attention to dementia care provision and costs.

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Introduction

Dementia imposes a large burden on health and social care systems around the world, and this burden will rise over the next three decades. In Europe, the number of

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Research in context

Evidence before this study

Dementia is a public health priority in an increasing number of countries. As populations age, the number of people affected by dementia is growing, and in Europe, the number of dementia cases is estimated to increase from 7.7 million in 2001 to 15.9 million in 2040. Accordingly, the costs of dementia are forecasted to also rise. The total economic impact of dementia on the patients' families and society overall goes beyond the direct cost of care, as family members often provide care themselves. In 2010, Alzheimer's Disease International (ADI) provided the first global and regional (grouping Europe to Western, Central, and Eastern) estimates of the economic impact of dementia. A prevalence-based approach was taken, estimating the economic costs to society during one year by applying country-specific per capita costs to country-specific prevalence estimates. Economic costs included both direct medical (i.e., dementia care provided in primary and secondary healthcare settings) and social care (i.e., paid and professional home care and residential and nursing home care) costs and unpaid informal care costs. Estimates of annual direct costs per person were gathered from available studies, which in most cases had not been carried out using population-representative samples, and applied to the estimated number of persons with dementia in each country. For the estimation of informal care costs, hours of informal care were obtained from country-specific studies and valued at the average wage for each country. In countries where no data on direct or informal costs were available, they were imputed using estimates from neighboring countries. The resulting estimates of economic costs have been widely used to appraise the impact of dementia at the societal level, guiding policymakers. Recently, the World Health Organization estimated the economic costs of dementia based on the 2019 prevalence estimate from the Global Burden of Disease for the entire European region, without analyzing variations within Europe. There have also been several country-specific studies based on small clinical samples that may not be population-representative, as well as a handful of country-specific studies that have updated cost estimates based on population-representative data.

Added value of this study

Based on the most up-to-date estimates of the number of persons with dementia from the 2019 Alzheimer Europe Report, we estimate the economic costs of dementia in 11 countries in Europe. Our estimates of the annual cost per person are based on population-representative data from the Survey of Health, Ageing, and Retirement in Europe and account for the costs attributable to both persons living with dementia and those who died with dementia. In estimating the economic costs to society during one year as a function of the prevalence of dementia, most prior literature has accounted for only the economic costs incurred by

persons with dementia, not including the costs attributable to the people who died with dementia during the same time period. This can lead to an underestimation of the economic costs of dementia, as the costs can be higher during the last year of life, when symptoms are often more severe and use of inpatient care tends to increase.

Implications of all the available evidence

The costs attributable to dementia are high and set to increase with the rising number of dementia cases in Europe. They are, however, considerably lower than those reported by the Alzheimer's Association, which estimated the average costs incurred by people with dementia without adjusting for costs associated with coexisting conditions. As people with dementia often suffer from other chronic health problems such as diabetes and cardiovascular diseases, accounting for the costs associated with coexisting conditions is important in calculating costs attributable to dementia. We found significant cross-country differences in costs attributable to dementia both in terms of per capita costs and the share of direct out-of-pocket and informal care costs. Informal care costs accounted for the largest proportion of costs attributable to dementia in all European countries.

dementia cases is projected to increase from 7.7 million in 2001 to 15.9 million in 2040.¹ Understanding the economic consequences of dementia provides an important basis for prioritization of resources in public health policy development.² At a national and international level, strategic planning of health and social policy requires an understanding of the magnitude of different diseases. Estimates of the economic effects of dementia on households and society at large can guide policymakers in assessing the magnitude of the challenge that dementia presents and compare it to that of other diseases. As supporting carers of dependent individuals is an explicit policy goal for many European governments, estimates of the burden borne by informal carers are important inputs for designing policies addressing this issue.

In 2010, Alzheimer's Disease International (ADI) provided the first global and regional (grouping Europe into Western, Central, and Eastern) estimates of the economic impact of dementia.³ Economic costs included both direct medical and social care costs as well as unpaid informal care costs. Cost estimates were obtained from country-specific studies, which in most cases were not based on population-representative samples. ADI updated these estimates in 2015 to reflect changes in prevalence.⁴ Most recently, In 2021, the World Health Organization reported the global and regional (grouping Europe as a whole) estimates of the economic impacts of dementia based on prevalence estimates from the 2019 Global Burden of Disease, data from a systematic literature review and other sources

like OECD.⁵ There have also been several country-specific studies based on small clinical samples that may not be population-representative, including a 2011 study in Germany and two 2015 and 2016 studies in Spain,^{6–8} as well as a handful of country-specific studies that have updated cost estimates based on population-representative data.^{9–12}

In this paper, we calculate the economic cost of dementia in 11 countries in Europe using the most up-to-date prevalence estimates from Alzheimer Europe (2019) and further improving the methodological approach to estimating costs.¹³ Using the most up-to-date prevalence estimates is important to capture secular trends in dementia prevalence rates.¹⁴ In the past two decades, a declining trend in dementia prevalence rates has been observed in some countries,^{9,15,16} while prevalence rates have remained stable or even increased in other countries.^{17,18}

The Survey of Health, Ageing, and Retirement in Europe (SHARE) provides rich data on adults ages 50 and older in all 27 countries of the European Union, Switzerland, and Israel.¹⁹ Its goal is to provide a multidisciplinary data resource on the influence of health and socioeconomic factors on aging at the individual and societal levels, eliciting information about demographics, health, cognition, health care use and costs, formal and informal care, income, and assets. Using the rich microdata on out-of-pocket health and social care and unpaid informal care provision from SHARE, we estimate average direct out-of-pocket costs and informal costs per person with dementia.

In estimating the annual economic costs of dementia to society, the prior literature has accounted for only the annual economic costs incurred by persons with dementia who were alive at the time of the survey, not including the costs incurred by persons who died with dementia during the year of their death. This can lead to an underestimation of the economic burden of dementia, as costs can be higher during the last year of life, when symptoms are often more severe and use of inpatient care increases. In this paper, we estimate the direct out-of-pocket costs and informal costs attributable to both persons living with dementia and persons who died with dementia. To estimate the latter, we use data from the SHARE end-of-life interviews with next-of-kin of deceased respondents, which collect rich data on medical and social care utilization and informal care in the last year of life. We apply this average cost per person who died with dementia to the number of deaths related to Alzheimer's disease or related dementias using the estimate from the age-group specific dementia prevalence rates from Alzheimer Europe and the number of deaths per age group from Eurostat.^{13,20}

In estimating the economic costs of dementia, we first calculate the total costs, assessing the overall economic burden of supporting persons with dementia. We then estimate the costs *attributable* to dementia

alone, as persons with dementia might have other coexisting conditions, which also incur costs. Most of the prior cost of illness studies tend to report the total costs without consideration of the costs stemming from these comorbidities, with some exceptions.^{9,21} Globally, Pedroza and colleagues estimated that about 45% (95% CI, 29–62%) of the direct costs of health care for persons with dementia were attributable to dementia, with 55% attributable to other health conditions.²¹ Taking it all together, we provide the most up-to-date, comprehensive estimates of the economic costs of dementia in 11 European countries based on microdata from population-representative cohorts.

Methods

Overview and data sources

We calculate the economic costs of dementia in 11 countries in Europe. To do so, we first estimate the average annual direct out-of-pocket medical care costs, direct out-of-pocket social care costs (including paid and professional home care and residential and nursing home care), and indirect costs of informal care per person living with dementia and per person who died with dementia in the last year.

We then apply the average annual cost per person living with dementia to the most up-to-date, country-specific estimates of the number of persons living with dementia, obtained from Alzheimer Europe (2019).¹³ Alzheimer Europe's estimates are based on the most recent population-level data and utilize population figures from the 2018 United Nations World Population Prospects at the country level. They constitute a major update since the EuroCoDe project's prevalence estimation more than a decade ago. It should be noted that Alzheimer Europe did not provide confidence intervals for their estimates.

We apply the average annual cost per person who died with dementia to the number of persons who died with dementia in each country, obtained by combining five-year age-specific dementia prevalence rates from Alzheimer Europe (2019) and the number of deaths in each age group, based on estimates for 2018 from Eurostat.^{13,20}

Microdata on direct out-of-pocket medical and social care costs, as well as hours of informal care, are obtained from the Survey of Health, Ageing, and Retirement in Europe (SHARE), a cross-national panel study of people ages 50 and older and their partners in all 27 countries of the European Union, Switzerland, and Israel.¹⁸ We used the data from six panel waves of SHARE (waves 1, 2, 4–7), as well as the end-of-life interviews that were conducted with next-of-kin of deceased respondents, restricting attention to individuals age 65 and older. Out of 27 EU countries included in SHARE, we excluded from the analysis 11 countries for which

the only data available came from a wave that collected retrospective life histories but no information on dementia status or other key variables such as formal and informal care utilization. A further 5 countries were excluded because sample sizes in the core data were too small to yield reliable estimates. The remaining 11 countries included in our analysis were Austria, Belgium, Czechia, Denmark, Estonia, France, Germany, Italy, Slovenia, Spain, and Sweden. Sample sizes range from 2841 individuals in Slovenia to 5487 individuals in Spain in the core waves, with up to five follow-up interviews, generating a number of person-year observations ranging from 5104 in Slovenia to 13,033 in Spain (see Appendix A). The sample size is much smaller for the end-of-life interviews, ranging from 194 in Germany to 784 in Spain. Therefore, we conduct country-specific analyses using the core data but pooled analyses to estimate the costs for the deceased, combining the observations from all countries. To obtain country-specific estimates of the costs in the end-of-life period, we multiplied the pooled end-of-life estimate by the ratio of the country-specific and pooled core estimate. Specifically, let \hat{K}_c be a cost estimate per individual with dementia for country c from the core data, \bar{K} the corresponding estimate pooling all countries from the core data, and \bar{E} the corresponding pooled estimate from the end-of-life data. Then our estimate of the corresponding country-specific estimate per individual with dementia for the end-of-life period is $\hat{E}_c = \hat{K}_c(\bar{E}/\bar{K})$. See further details of the core data in Appendix A and end-of-life interview data in Appendix B. The methodology for combining the two sources is outlined below and in more detail in Appendix C.

SHARE started asking whether the respondent had been diagnosed with Alzheimer's disease or dementia in 2006 (Wave 2), as part of the core interviews. Each country team drew its own sample under the guiding principle of national representation, but inclusion/exclusion of the institutional population in the initial sampling frame varies across countries. Once selected into the sample, all respondents are followed up in longitudinal interviews as they move into institutional settings. Barczyk and Kredler concluded that individuals living in institutions are underrepresented in SHARE and constructed an adjustment to the sampling weight to correct that, using OECD's institutionalized population statistics drawn from aggregate government data.²² We adapted their methodology to create sample weights that reflect the proper fraction of institutionalized individuals and applied those weights in our estimation (see Appendix A for a detailed description).

Direct costs

Medical and social care costs are divided between costs paid by service users (direct out-of-pocket costs) and costs paid by public or private health insurance and

long-term care insurance. SHARE asks respondents to separately report on utilization of and expenditures on a wide range of health and social care types in the past 12 months, including hospital stays, nursing home stays, doctor visits and outpatient care, home care services (i.e., professional and paid nursing care received at home), professional and paid help for domestic tasks, and dental care. For medical and social care, SHARE asks about whether the cost was publicly funded or covered by insurance and how much was paid out-of-pocket. We calculate annual out-of-pocket costs by adding up all out-of-pocket expenses. We report monetary amounts in Purchasing Power Parity (PPP)-adjusted 2018 Euros at the country level, using the PPP conversion rates supplied with the SHARE data.

A substantial fraction of the direct costs of dementia is covered by public or private health insurance and long-term care insurance. To estimate total direct costs, we divided the country-specific estimates of total out-of-pocket costs, obtained from SHARE and external data on dementia prevalence, by the country-specific ratio of household out-of-pocket payments to total expenditures on health and long-term care, calculated from statistics provided by the Joint OECD, Eurostat, and WHO Health Accounts.²³ See Appendix C for details. This approach is based on the assumption that the fraction paid out of pocket does not differ by dementia status, which is an important caveat in interpreting the total cost estimates.

Informal care costs

The inputs most commonly assessed to measure informal caregiving hours are time spent providing assistance with ADLs, time spent providing assistance with IADLs, and time spent in supervision.³ The type of information on caregiving inputs available in the core SHARE data varies between waves. The most extensive version asks about help provided by up to three helpers from outside the household and up to three from within the household. No information about frequency and hours of care was asked for helpers from within the household. For helpers from outside the household, SHARE asks how frequently they helped and, in early waves, how many hours of help per day they provided, although it is not possible to identify the care recipient if there is more than one individual in the household, as informal care questions were asked at the household level. In the end-of-life data, SHARE separately asks about caregiving for ADLs and IADLs. For individuals who received only formal care or only informal care, the frequency and hours of care are observed. For those who received both types of care, SHARE asks about total care hours, so the split between formal and informal hours is not observed. Neither the core nor the end-of-life SHARE data provide any explicit information on time spent on supervisory tasks. Therefore, the procedure to quantify informal caregiving uses as inputs

time spent assisting with ADLs and time spent assisting with IADLs, and is thus comparable to the baseline specification in previous ADI reports.^{3,4} To obtain measures of informal care hours received in the core data, we used available information in SHARE as follows. We started by first allocating couple-level informal care to the spouse who had ADL or IADL limitations for couples in which one of them did and the other did not. For couples in which both or neither had limitations, we assigned half of the informal care to each spouse. We then imputed missing information. Imputations were done by country and wave when possible, and otherwise by country using the closest wave(s) with the relevant information as estimation sample. Using this strategy, we obtained hours of informal care from individuals outside the household, hours of formal care, and bounds on the hours of informal care from household members (e.g., zero if the individual did not receive informal care from within the household, and between zero and 24*365 minus the other hours of care if they did). This then resulted in a lower and upper bound of the total hours of care. We then used a model for total hours of care estimated on the end-of-life data to impute total hours of care in the core data, respecting the calculated bounds. This then implied the imputed hours of informal care from within the household and the total hours of informal care. We then estimated the fraction of total care hours received that were provided by informal care and used this fraction to allocate the total hours of care in the end-of-life data to informal care and formal care. The imputation strategy used to quantify time spent on informal care in the core interviews is described in detail in Appendix A, and that used for end-of-life data is described in Appendix B.

In valuing informal care, a systematic literature review identified the replacement cost method and the opportunity cost approach as the two most common approaches.²⁴ The replacement cost approach assigns values for informal care hours based on the market wage paid to formal caregivers with the rationale that if the informal caregiver were unavailable, the respondent could hire a formal caregiver as a “replacement.” In this study, we have taken a “replacement” approach, valuing informal care time based on the wages of social service workers providing non-residential care, obtained from Eurofound.²⁵ The wages of social services workers ranged from 63% to 93% of mean earnings in each country.

The two prior ADI reports (2010, 2015) used an opportunity cost approach, valuing informal care by the average wage for each country.^{3,4} For comparability, we also valued informal care hours at the mean wage in each country. The opportunity cost estimates are presented in Appendix D. An alternative valuation method based on minimum wage has been also used, as the best valuation of informal care remains debatable.²⁶

Costs attributable to dementia

Persons with dementia are older on average and have more coexisting conditions than those without dementia, and those conditions also incur costs. Most of the prior cost of illness studies tend to report total costs without consideration of costs due to coexisting conditions, with few notable exceptions.^{9,21} To isolate the costs attributable to dementia, we estimated regression models that relate a given cost component to dementia while controlling for coexisting conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychiatric problems, arthritis, hip replacements, and hip fractures). In order to differentiate between the costs incurred to treat and care for individuals with dementia and those incurred to treat other conditions, we controlled for common health conditions among older persons. We also controlled for demographic characteristics such as age, education level, sex, marital status, household income, and household wealth, as these characteristics are associated with health and care utilization. We took a similar approach to estimate the costs attributable to dementia for deceased persons. In both cases, the estimated attributable costs are the regression coefficients of the dementia indicator.

Combining costs for the living and costs for the deceased

Previous studies that have estimated costs of dementia using microdata have used population-representative surveys similar to the core SHARE survey. Doing so understates the costs of dementia at the population level. This is most easily illustrated with an example. Consider a sample consisting of everyone alive at a specific date (say, January 1, 2019) and containing information about the costs incurred in the previous year. Such a sample omits the costs incurred by individuals during the year of interest (2018 in the example) who died before the sampling date. We used the SHARE end-of-life data to estimate the costs attributable to individuals who died with dementia during the previous year. Because the end-of-life data ask about costs in the last 12 months of life, simply adding the costs from the end-of-life interviews would overestimate the costs incurred by deceased individuals in the year of interest (for example, only one-fourth of the end-of-life costs of an individual who died in March 2018 were incurred during the period of interest). On average, an individual who died during the period of interest would live half this period, and thus, if costs are incurred proportionally during the last year of life, half of the reported costs should be counted toward the annual costs at the population level. This is what we have done for the direct costs. For the informal care costs, the end-of-life data contain information about the number of months during which these were incurred, and we have taken this into account, with the assumption that these were the last months of

life (it turned out that this resulted in a ratio relative to the 12-months cost that was close to half as well). Appendix C describes these considerations and the methodology used in more detail.

Target years

The SHARE data were collected between 2004 and 2017, with different countries present in different years (waves). We have made the monetary data comparable across time by adjusting for inflation and Purchasing Power Parity (PPP) adjustments to 2018 euros. We also report the PPP unadjusted estimates in Appendix E. Analogously, we valued informal care hours by the wages of long-term care workers in 2018.²⁵ For estimates of costs at the country level, we have used estimates of the numbers of individuals with dementia for 2018 as well.⁵ All analyses were performed in Stata version 15 (StataCorp, 2017).

Confidence intervals

For the main analyses for direct out-of-pocket costs, we estimated the regressions in 2018 euros and multiplied estimates and confidence intervals by the PPP adjustment factor afterward. For the main analyses for informal care hours, the confidence intervals were taken directly from the Stata regression output, after setting up the data as multiply imputed survey data with the appropriate sampling weights, defining the household as the clustering unit. For the analyses in the core data that pool the data for all countries (the estimates denoted by \hat{K} above, which are used in the formula for estimating the costs at the end of life, as discussed there and in Appendix C), we made a few adjustments in the data before estimation. To convert the country-specific estimates and confidence intervals for informal care

hours to informal care costs, we multiplied them by these same hourly costs afterward. The standard errors for the end-of-life data were taken directly from the regression output after preparing the data analogously to the pooled analyses in the core. We computed standard errors for the estimates that combined the core estimates and end-of-life estimates using the delta method, using the simplifying assumption that the component estimates (\hat{K}_c , \hat{E} , and \hat{K} in the formula above) were stochastically independent; see Appendix C for details. Confidence intervals for these combined estimates were computed as estimate plus or minus 1.96 times the standard error.

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Results

Table 1 presents country-specific estimates of dementia prevalence among living individuals ages 65 and older in 2018, as well as the number of people aged 65 and older living with dementia and the number of people aged 65 and older who died during the year. The prevalence of dementia among those age 65+ ranges from 6.9% in Czechia to 9.1% in Spain.

The first column of Table 2 presents the mean annual direct out-of-pocket costs per individual living with dementia. Significant cross-country variations in costs are observed. Out-of-pocket direct costs were the lowest in Czechia at €705 (PPP-adjusted 2018 Euros), followed by Denmark (€941) and Sweden (€949). At

	Dementia prevalence among age 65+ (% of total population) ¹	Total number of people with dementia among age 65+ ¹	Estimated number of people who died with dementia at age 65+ ²
Austria	8.45	139,129	13,866
Belgium	8.60	183,307	18,353
Czechia	6.86	139,999	14,423
Denmark	7.41	82,682	8185
Estonia	8.42	21,768	2158
France	8.91	1,172,387	107,327
Germany	8.54	1,511,869	150,320
Italy	8.98	1,225,853	115,633
Slovenia	8.02	32,198	3130
Spain	9.06	811,310	76,234
Sweden	7.99	160,288	15,886

Table 1: Total number of people with dementia and dementia-related death for individuals ages 65+ in 2018.

Source:

¹ Dementia in Europe Yearbook 2019.¹³

² Authors' calculations based on Alzheimer's Europe¹³ and Eurostat.²⁰

Country	Average annual direct out-of-pocket costs for persons living with dementia (95% CI)		Average annual direct out-of-pocket costs attributable to dementia after adjusting for demographics and coexisting conditions (95% CI)		Holm-Bonferroni corrected p-value
Austria	1552	(1044 to 2059)	452	(-46 to 949)	0.58
Belgium	1561	(936 to 2186)	415	(-201 to 1030)	0.80
Czechia	705	(370 to 1040)	253	(-25 to 531)	0.51
Denmark	941	(594 to 1287)	370	(21 to 718)	0.45
Estonia	1326	(482 to 2170)	774	(1 to 1547)	0.50
France	1391	(183 to 2599)	647	(-447 to 1740)	0.73
Germany	1555	(309 to 2801)	739	(-519 to 1998)	0.87
Italy	1233	(907 to 1560)	285	(-42 to 612)	0.52
Slovenia	1255	(-529 to 3040)	859	(-587 to 2306)	0.49
Spain	1015	(736 to 1294)	319	(39 to 600)	0.33
Sweden	949	(707 to 1192)	253	(-17 to 522)	0.55

Table 2: Direct out-of-pocket costs per person living with dementia and average annual direct out-of-pocket costs attributable to dementia after adjusting for demographic and coexisting conditions (2018 PPP-Adjusted Euros).

Source: SHARE Wave 1, 2, 5, 6, and 7, Harmonized SHARE and Harmonized SHARE End-of-Life Data.

the other extreme, the direct costs were over €1500 in Austria, Belgium, and Germany. The second column of Table 2 presents estimates of the costs attributable to dementia. As expected, these are noticeably smaller than the average costs per individual with dementia. Although the point estimates are always positive, the dementia-attributable direct costs in the core data are not statistically significantly different from zero at the 5 percent level in most countries. Moreover, the Holm-Bonferroni corrected *p*-values presented in the third column, which account for the multiple significance tests,

are always above the 5 percent level. Thus, there is weak evidence that dementia increases direct costs slightly, but in general, the direct out-of-pocket costs incurred by individuals with dementia are similar to direct costs they would have incurred if they did not have dementia. Examination of selected percentiles of the distributions of out-of-pocket cost for individuals with and without dementia show no statistical differences except at the 90th percentile. There, direct out-of-pocket costs are higher for individuals living with dementia (see Appendix F, Figure 1).

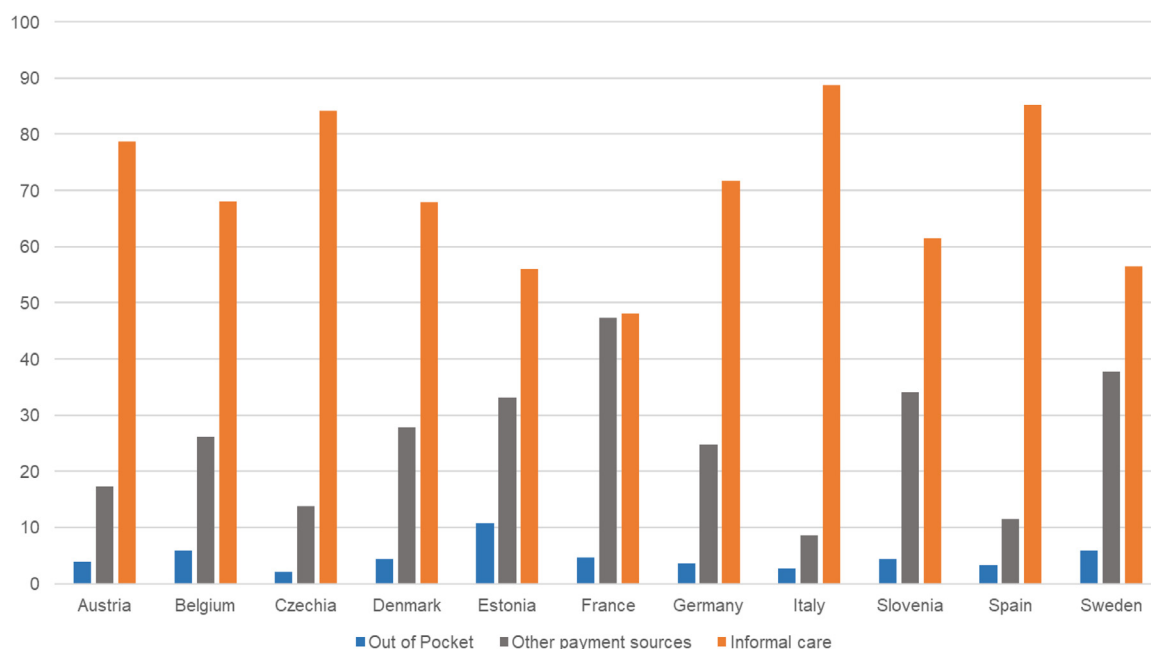


Figure 1. Share of direct out-of-pocket, informal care, and direct public and private health and LTC insurance costs of dementia in 2018.

The mean direct out-of-pocket costs in the last year of life for individuals who died with dementia were €2866 (95% CI, €2058–€3674), and the estimates of the end-of-life costs that are attributable to dementia were €450 (95% CI, -€922–€1821). There were no appreciable differences in the distributions of direct out-of-pocket costs for individuals with and without dementia at any of the percentiles considered (see Appendix F, Figure 2).

We conducted several robustness checks. First, we estimated regression models without covariates. As expected, these estimates, which capture the difference in costs between people with and without dementia without adjusting for differences in socioeconomic characteristics across the two groups, were typically larger than the regression models with covariates (see Appendix E for details). We also examined potential interaction effects between age and dementia status, as the cost of dementia might increase with age, reflecting increases in dementia severity. The interaction terms were not statistically significant in most countries (see Appendix E).

The first column of Table 3 shows the average informal care hours per individual living with dementia. Significant cross-country variation was also observed in this case, with average annual hours ranging from 323 hours (equivalent to 0.9 hours per day) in Sweden to 1809 hours (5.0 hours per day) in Italy. The dementia-attributable informal care hours, shown in the second column of Table 3, were also much smaller than the average informal care hours among individuals with dementia, but they remained substantial, ranging from 163 annual hours (0.4 hours per day) in Sweden to 1051 annual hours (2.9 hours per day) in Slovenia. All point estimates were statistically significant at the 5 percent level, and the Holm-Bonferroni-corrected *p*-values, shown in the third column of Table 3, were below the 5 percent level for all countries except Denmark, Sweden,

Estonia, and Slovenia. The percentile graphs of the distributions of informal care hours for individuals with and without dementia show individuals with dementia receiving substantially more hours of care starting at the 75th percentile (see Appendix D Figure 3).

The mean informal care hours in the last year of life for the deceased were 3047 (95% CI, 2606–3488), and the informal care hours attributable to dementia after accounting for other coexisting conditions were 1142 (95% CI, 821–1463). Comparing the distributions of mean informal care hours received by deceased individuals with and without dementia in the last year of life shows substantially higher hours received by those with a dementia diagnosis starting at the 50th percentile (see Appendix E, Figure 4).

The first two columns of Table 4 show the annual attributable direct out-of-pocket costs and informal care costs for individuals living and deceased with dementia at the country level. Column 3 presents the sum of the annual attributable costs from columns 1 and 2, capturing the household burden attributable to dementia, and Column 4 presents the per-capita household burden. Finally, Column 5 shows the projected total costs of dementia. All estimates are in millions of PPP-adjusted 2018 euros. The point estimates of the attributable direct out-of-pocket costs are all positive, but they are not statistically significant in most cases. In contrast, the attributable informal care costs are all positive, and they are statistically significantly different from zero at the 5 percent level for all countries. Not surprisingly, the annual household burden attributable to dementia is higher for larger countries, ranging from €108.8 million in Estonia to €24.6 billion in Germany. Significant cross-country variation remains after adjusting for population size, with the per-capita household burden ranging from €2687 per person with dementia

Country	Average annual informal care hours for persons living with dementia (95% CI)		Average annual informal care hours attributable to dementia after adjusting for demographics and coexisting conditions (95% CI)		Holm-Bonferroni corrected <i>p</i> -value
Austria	1042	(746–1337)	567	(276–858)	0.002
Belgium	736	(550–923)	327	(124–530)	0.02
Czechia	1785	(1240–2330)	1015	(447–1583)	0.01
Denmark	459	(156–762)	286	(23–549)	0.33
Estonia	1404	(829–1979)	553	(22–1085)	0.34
France	872	(622–1121)	506	(286–725)	0.0001
Germany	1286	(800–1772)	812	(383–1241)	0.001
Italy	1809	(1489–2129)	870	(563–1,176)	<0.0001
Slovenia	1604	(681–2528)	1051	(15–2086)	0.46
Spain	1693	(1446–1940)	790	(456–1124)	<0.0001
Sweden	323	(191–455)	163	(27–299)	0.24

Table 3: Average annual informal care hours per person living with dementia and average annual informal care hours attributable to dementia after adjusting for demographic and coexisting conditions.

Source: SHARE Wave 1, 2, 4, 5, 6, and 7, Harmonized SHARE and Harmonized SHARE End-of-Life Data.

Country	Direct Out-of-Pocket Costs	Informal Care Cost	Household Burden ¹	Per capita Household Burden	Total Costs ²
Austria	65.6 (-6.5 to 137.6)	1335.9 (661.9 to 2009.9)	1401.5 (723.7 to 2079.4)	9595.4 (4954.6 to 14,236.2)	1696.5 (914.7 to 2478.3)
Belgium	79.4 (-31.8 to 190.5)	925.0 (362.4 to 1487.6)	1004.4 (430.9 to 1577.8)	5218.1 (2238.9 to 8197.3)	1360.3 (530.9 to 2189.7)
Czechia	37.0 (-3.9 to 77.9)	1467.1 (674.3 to 2259.8)	1504.1 (710.2 to 2297.9)	10217.2 (4824.6 to 15,609.8)	1743.6 (894.0 to 2593.2)
Denmark	31.9 (1.6 to 62.2)	498.3 (65.8 to 930.7)	530.2 (96.6 to 963.7)	6109.6 (1113.8 to 11,105.5)	734.3 (247.3 to 1221.3)
Estonia	17.6 (-0.1 to 35.2)	91.2 (12.6 to 169.8)	108.8 (28.2 to 189.3)	4762.0 (1236.4 to 8287.5)	162.9 (56.3 to 269.5)
France	788.6 (-539.4 to 2116.7)	8089.2 (4587.0 to 11,591.3)	8877.8 (5132.3 to 12,623.3)	7241.0 (4186.1 to 10,295.9)	16,830.6 (1699.0 to 31,962.2)
Germany	1166.2 (-693.8 to 3026.2)	23,381.9 (11,818.4 to 34,945.3)	24,548.1 (12,836.0 to 36,260.2)	15,468.0 (8088.1 to 22,847.9)	32,606.9 (13,893.9 to 51,319.9)
Italy	364.1 (-54.6 to 782.7)	12,165.2 (7847.1 to 16,483.2)	12,529.2 (8190.9 to 16,867.6)	9760.5 (6380.8 to 13,140.1)	13,710.1 (9040.8 to 18,379.3)
Slovenia	28.8 (-19.8 to 77.5)	403.6 (14.3 to 792.9)	432.4 (40.1 to 824.8)	12,808.1 (1187.2 to 24,429.1)	655.8 (79.2 to 1232.4)
Spain	269.8 (31.6 to 508.0)	7047.5 (4266.5 to 9828.6)	7317.3 (4526.1 to 10,108.5)	8614.4 (5328.4 to 11,900.4)	8268.5 (5285.8 to 11,251.3)
Sweden	42.3 (-2.2 to 86.7)	409.8 (79.2 to 740.5)	452.1 (118.5 to 785.7)	2687.4 (704.5 to 4670.3)	726.1 (257.2 to 1194.9)

Table 4: Costs of dementia in 2018: total costs for persons living and the deceased with dementia (Millions of PPP-Adjusted 2018 Euros, except per capita, which is in PPP-Adjusted 2018 Euros).

Note:

¹ Household Burden includes direct out-of-pocket and informal care costs.

² Projected total costs based on household burden and the country-specific ratio of household out-of-pocket payments to total expenditures on health and long-term care (OECD, 2021). See Appendix C for further details for the projection methodology.

Source:

1. SHARE Wave 1, 2, 4, 5, 6, and 7; Harmonized SHARE and Harmonized SHARE End-of-Life Data.

2. OECD. Health expenditure and financing, 2021. <https://stats.oecd.org>.

in Sweden to more than €15,000 in Germany. The projected total costs attributable to dementia are once again related to country size, ranging from €162.9 million for Estonia to €32.6 billion for Germany.

We conducted a number of sensitivity analyses for these results. We estimated per capita total costs separately in two subperiods, 2004–2014 and 2015–2017 (see Appendix G). Although sample sizes become too small to draw strong conclusions, we observed significant cross-country variation, with no clear pattern suggesting an upward or downward trend in per capita costs. For comparability, we also computed the dementia-attributable costs using an opportunity cost approach (see Appendix D Table D.1). Those cost estimates are somewhat higher because they value informal care hours at the country's average wage, which is higher than the average wage of social service workers in all cases.

The shares of direct out-of-pocket costs, direct costs paid by other sources such as government and insurance, and informal care costs, shown in Figure 1, vary substantially across countries. In all countries, informal care costs accounted for the largest share of dementia costs (ranging from 48.1% in France to 88.7% in Italy), while direct out-of-pocket costs accounted for the smallest share. The costs paid by governments and insurance ranged from 8.6% in Italy to 47.3% in France.

Discussion

We estimated the economic costs attributable to dementia in 11 countries in Europe using nationally representative data for both direct out-of-pocket costs and informal care for persons living with dementia and those who died with dementia. As persons with dementia often suffer from other coexisting conditions (e.g., heart diseases, diabetes, cancer), we isolated the costs attributable to dementia after controlling for coexisting conditions and demographic characteristics. The costs attributable to dementia were about 23.1% to 68.5% of the direct out-of-pocket costs and about 39.4% to 65.5% of the informal care costs before adjustment.

This result is in line with prior literature.^{9,11,21} At the global level, Pedroza and colleagues estimated that about 45% of the direct costs were attributable to dementia using data from the Global Burden of Diseases 2019 study.²¹ Using records from the Danish National Patient Registry, Frahm-Falkenberg and colleagues identified persons with dementia.¹¹ Compared to randomly chosen controls matched for sociodemographic characteristics, the direct costs for persons with dementia were about 50% higher. Therefore, in estimating the economic costs of dementia, it is important to note whether the cost estimate refers to the average costs incurred by people with dementia without explicit consideration of the costs due to other coexisting

conditions or to the costs attributable to dementia after accounting for other conditions.

When comparing the average cost estimates for persons with dementia before adjusting for coexisting conditions, our estimates are consistent with country-specific estimates reported in France, Germany, and Italy for informal care hours.^{27–29} Our estimate is also in line with ADI's estimates based on prior literature, which reported averages of 3.5 hours per day for help with ADLs and IADLs in Western Europe, and 4.4 hours per day in Central and Eastern Europe.⁴ While average hours of daily care seem modest, they hide great heterogeneity, with a large share of carers providing a limited number of hours and others providing the equivalent of a working day in hours of care (see Appendix F Figure 3). Once adjusted for other coexisting conditions, informal care hours attributable to dementia were down to 39% to 66% of the average informal care hours. Our estimates are, however, lower than other cost estimates based on clinical samples.²⁸ For example, Homerová et al. estimated an average of 2976 hours of informal care per patient in the Czech Republic, significantly higher than our estimate of 1785 average hours per year.³⁰

Significant cross-country variation was observed both in the dementia-attributable household burden ranged from €2687 in Sweden to €15,468 in Germany. The heavy social and economic burden of dementia in Germany has been stressed in previous literature, which found the societal cost of dementia to be higher in people living at home compared to those hospitalized, due to the high cost of informal care.²⁸

Informal care costs accounted for the largest share of the total costs of dementia. Previously, ADI estimated informal care costs accounted for 37.6% to 61% in Western and Eastern Europe,³ and our country-specific estimates are similar in countries like Belgium, Estonia, France, and Slovenia, but higher in Italy, Spain, and Czechia, where informal care costs are over 80% of the dementia-attributable costs. Prior studies for countries such as Germany and Spain had also found that informal care costs exceeded direct costs.^{7,28} For example, Michalowsky et al. reported a ratio of one to ten between formal and informal care costs for dementia in Germany, resulting from the high reliance on informal carers in the country (85% of care services for dementia).²⁸ Low direct costs for dementia can be explained by a mix of factors, including low availability of formal care and community care services and high reliance on informal care, low availability of and access to care providers, differences in quality of care, and the general availability of free or heavily subsidized healthcare.³¹

Large cross-country variations were also observed in the previous literature.³² This most likely reflects differences in the hourly cost assigned to informal care, but

also cross-country differences in health and long-term care structure, for example, high reliance on informal caregivers in Southern Europe. On the other end, the estimated low indirect informal care cost of dementia in Sweden can be explained by the comprehensive care system available in the country. The Swedish system includes several care services for people with dementia and offers dementia-specific programs as part of day care services. Dementia care in Sweden also relies very little on informal carers, with only 4% of the adult population providing informal care on a daily basis.³³ While determining the sources of cross-country differences is beyond the scope of this paper, it remains a key challenge for future research.

A globally aging population and a rise in the diagnosis of dementia are calling for urgent action from policy-makers. Ensuring that people living with dementia have a good quality of life and receive adequate and affordable care is crucial today more than ever. Calculating and benchmarking the cost of dementia across countries can provide relevant information around the affordability of care. This paper builds the estimates of the direct and informal care cost of dementia upon SHARE interviews of older people with dementia (ages 65 and over) as well as end-of-life care interviews with relatives of the decedents. This method allows us to include the costs borne by both people who died with dementia and people who were diagnosed with dementia but were still alive at the time of the interview, reducing underestimation.

This paper is nonetheless subject to a number of caveats. First, our estimates for the end-of-life expenses are based on the pooled data, as the sample size for the deceased was too small to warrant country-specific estimates. Second, in quantifying informal care hours, our estimates are based on only the care hours for ADLs and IADLs. This estimate does not include informal care hours associated with supervision and, therefore, can be considered as a lower bound of the costs. Third, our estimate for the direct costs paid by public or private health insurance and long-term care insurance is based on country-specific estimates of household out-of-pocket payments as a share of total expenditure on health and long-term care. This means that our estimates assume that the share of direct out-of-pocket costs does not vary by dementia status. Fourth, some of the key measures in the analysis are based on self-reports. Self-reports of dementia diagnoses in SHARE have not been validated against clinical diagnostic criteria, and self-reports of informal care receipt and out-of-pocket health care spending may be less reliable for individuals with cognitive impairment whose interview was not obtained by proxy than for those without cognitive impairment or with proxy interviews. Finally, our estimates are confined to the population ages 65 and older and therefore not including the costs of early onset of dementia.

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Data sharing statement

The authors used publicly available data.

Declaration of interests

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Supplementary materials

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