

The economic burden of dementia in Europe: COIN-Eu dementia

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Abstract

Background: Dementia, with Alzheimer's disease as its most common underlying cause, is a major contributor to disability, dependency, and death, imposing significant societal and economic burdens across Europe. Despite its growing prevalence, cross-country cost estimates remain scarce and highly heterogeneous, limiting comparability.

Objective: To estimate country-level societal costs of dementia in Europe and to derive aggregate European cost estimates, including direct costs, indirect costs (productivity losses), and informal care costs.

Methods: A standardized review of dementia cost assessments conducted in Europe was performed. Heterogeneous cost-estimation approaches were harmonized using pooling and health-economic imputation techniques to address data gaps and generate country-level estimates. All cost estimates were converted to 2019 euros using Consumer Price Indices and Purchasing Power Parities (PPP). Informal care costs were analyzed separately to reflect their complexity and substantial contribution to total costs.

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Results: Forty-five studies were identified. Annual societal costs of dementia in high-income European countries totaled €221.4 billion (€PPP, 2019; €25,218 per patient) for 8.8 million people with dementia. Informal care and direct costs accounted for 58% and 42% of total costs, respectively. Indirect costs contributed minimally to total costs. Substantial variation in per patient costs across countries was observed.

Conclusions: Dementia care imposes substantial societal burdens, largely driven by informal care. Owing to data availability, estimates were limited to high-income European countries. Future research should focus on standardizing cost assessment methods, improving informal care valuation, expanding evidence from low- and middle-income countries, and evaluating the financial impact of emerging treatments and prevention strategies.

Keywords

Alzheimer's disease, cost of illness, dementia, economic burden, health economics, informal care

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Introduction

Dementia is a progressive neurodegenerative disorder that primarily affects older adults and impairs cognitive domains, including memory, executive function, language, attention, and visuospatial skills.¹ As their condition advances, people living with dementia (PwD) experience difficulties performing daily activities, leading to disruptions in their social, occupational, and overall quality of life.² These progressive deficits increase dependence on both formal and informal caregivers and long-term care support.

The Global Burden of Disease Study (GBD) 2021 reported that over 52 million individuals worldwide were living with dementia in 2019, with more than 12 million PwD in Europe alone.³ Dementia was the seventh leading cause of death globally and the third in the European Region, according to the World Health Organization (WHO) regional classifications. Among individuals aged 55 years and older, dementia is the seventh primary cause of disability-adjusted life years worldwide and the fourth in Europe.³

The economic burden of dementia affects healthcare systems, informal caregivers, and society at large, leading to substantial costs in medical care, long-term support, and productivity losses. The advent of biological disease-modifying therapies may initially increase costs and shift resource needs towards early diagnosis, biomarker assessment, treatment delivery, and monitoring.^{4–6} Economic models of specific and hypothetical disease-modifying treatments suggest that slowing disease progression may reduce some care costs in later disease stages, although real-world effects on healthcare utilization and societal costs remain uncertain.^{6–9}

Previous research has shown the significant costs of dementia to society. For example, in 2010, the global and European costs were estimated at US-\$604 billion and US-\$239 billion, respectively.¹⁰ By 2015, these figures had increased to US-\$818 billion globally and US-\$301.1 billion in Europe.¹¹ Subsequent assessments in 2019 further indicated a rise in the worldwide economic burden, reaching US-\$1313 billion.¹² Moreover, a European study that used a different costing approach from the previously cited

publications, which were based on broadly similar methodological frameworks with incremental refinements, and treated informal care as part of direct non-medical costs, reported that the cost of dementia, adjusted for purchasing power parity (PPP) in 2010, was €105.2 billion.¹³

Projections expect a significant global increase in the prevalence of dementia in the coming decades,¹⁴ as well as its accompanying economic burden.¹⁵ Aging societies such as Europe face a growing epidemiological and financial burden due to dementia. Assessing the societal costs of this condition is essential for understanding its economic impact, as a substantial proportion of dementia-related costs falls outside the healthcare sector,¹² such a comprehensive perspective supports public awareness, guides research priorities, and informs policy-making. This study aimed to estimate the epidemiologic burden of dementia and its direct, indirect, and informal care costs to society for each of the 47 member countries of the European Academy of Neurology (EAN).

Methods

This burden of disease study is part of a larger analysis on the economic burden of 12 neurological disorder groups in Europe, conducted within the WHO-defined European region, under the *Cost of Illness in Neurology in Europe* (COIN-Eu) project. The methodological framework used both in this analysis and the COIN-Eu project is described in the following sections, with further details provided in Supplemental Material 1. Four methodological steps were implemented in this study: (1) assessment of epidemiological data to reflect the size of the respective populations, (2) assessment of economic input data, (3) data synthesis and imputation, and (4) expert validation.

Target region and population

This investigation assesses the country-specific annual costs of dementia in the 47 EAN member countries (see

Supplemental Material 2), covering a population of 917 million persons.³ The focus was on the adult population (aged 20 years or older), totaling 704 million individuals.³ Although dementia primarily affects older adults and cost assessments tend to focus on this age group, including young adults in our calculations allowed us to estimate indirect costs (defined in this study as productivity losses of PwD). The reference year of 2019 was selected for the estimates because it preceded the global coronavirus disease 2019 (COVID-19) pandemic, which may have disrupted regular incidence and treatment patterns.

This research utilized publicly available data without collecting individual patient data for the analysis. Thus, it did not meet the regulatory definition of human participant research and was exempt from institutional review board review.

Epidemiological data

Epidemiological data on prevalence across countries were sourced through the GBD 2021 study via its online results tool (<https://vizhub.healthdata.org/gbd-results/>). Data were sourced for the adult (aged 20 years or older) and working-age populations (20–64 years). The working-age population data were explicitly used to estimate the indirect costs.

Economic data

Economic data were based on a standardized literature review covering the period from January 2010 to February 2023. A prevalence-based societal perspective was adopted, including direct (medical and nonmedical) costs, informal care costs as a distinct category,¹⁶ and costs due to productivity losses.¹⁷

Cost and related cost estimation approaches were derived from a standardized literature review in PubMed combining disease-specific and cost-of-illness terms using MeSH and title-based queries to identify information on dementia costs (see Figure 1 and Supplemental Material 3). All costs were transformed to cost per patient and year and entered as such into our cost database. For details of the literature review, see Supplemental Material 1.

Relevant information from the identified articles was extracted into a structured assessment form. Pivotal fields included country, publication details, cost year, currency of reported costs with or without purchasing power adjustment, and detailed breakdowns of direct medical, nonmedical, indirect, and informal care costs; publications reporting only total overall costs without differentiating cost categories were excluded (see Supplemental Material 4).

Data synthesis and analytic procedures

For data synthesis, the annual cost per patient extracted from country-specific cost assessments was inflated to the

index year 2019 using the Consumer Price Index (CPI) from the World Bank (<https://data.worldbank.org/indicator/FP.CPI.TOTL.ZG>) and converted into the common currency Euro (€) using PPP from the World Bank (<https://data.worldbank.org/indicator/PA.NUS.PPP>) and from the Organization for Economic Co-operation and Development (OECD; <https://data.oecd.org/conversion/purchasing-power-parities-ppp.htm>).

Where direct costs reported by studies covered only direct medical costs, missing direct nonmedical costs were imputed using median nonmedical costs from other studies from the same country, if such data were available.

For the imputation of cost data, missing for countries where cost assessments were lacking, we followed an approach previously applied by Begley et al.¹⁸ and imputed data after stratifying the 47 EAN member countries according to the World Bank's four gross national income (GNI) categories (<https://datatopics.worldbank.org/world-development-indicators/the-world-by-income-and-region.html>) in 2019 (low-income, lower-middle income, upper-middle income, and high-income; see Supplemental Material 2 for more details). This categorization intends to reflect the economic context and important healthcare dissimilarities among countries. Within each GNI category, observed median costs by cost category (i.e., direct, informal care, and indirect) were further weighted to derive country-level imputed estimates using country-specific 2019 World Bank indicators, that is, health expenditure as a share of Gross Domestic Product (GDP) for direct and informal care costs, and GDP per capita for indirect costs. For details, see Supplemental Material 1.

Briefly, to derive the annual costs for each specific country, the assessed annual cost per patient in this country was multiplied by the number of prevalent cases reported for the country in our epidemiological database (<https://vizhub.healthdata.org/gbd-results/>). To estimate the relative economic burden of each disorder per country, the total annual cost of each disorder was divided by the country's GDP in 2019 (<https://data.worldbank.org/indicator/NY.GDP.MKTP.CD>). A detailed description of the approach can be found in Supplemental Material 1. The per capita cost was calculated by dividing the total costs by each country's population size according to the GBD 2021 study.

Expert validation of the economic data

Four EAN neurology experts (CB, GD, TB, PB) validated the plausibility of each disorder's country-level costs, both at the per patient and national levels, including imputed data to identify implausible input parameters or results. The panel followed a four-step approach using evaluation matrices, which involved reviewing total costs, analyzing cost subcategories (direct, informal care, and

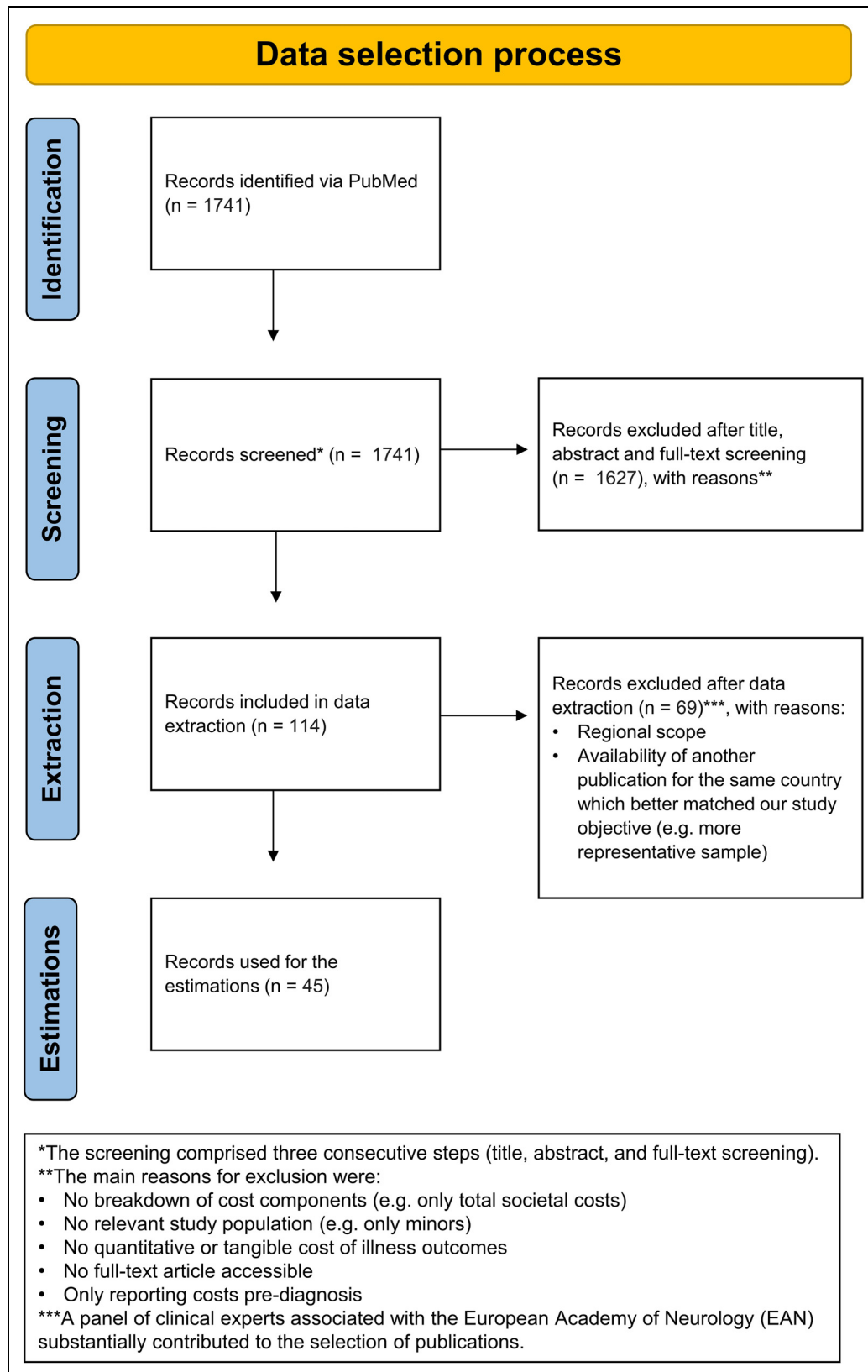


Figure 1. PRISMA 2020 flow chart illustrating the search strategy. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.¹⁴

indirect), and resolving inconsistencies within direct medical and non-medical costs.¹⁹ This collaborative approach aimed to achieve an agreement regarding data that required reassessment to correct extraction errors and to refine methodological or inclusion considerations (see Supplemental Material 5).

Reporting

The PRISMA flow diagram presents the results of the standardized literature review.²⁰ Economic findings are shown in tables and bar charts. In line with the Consolidated Health Economic Evaluation Reporting Standards 2022 (CHEERS 2022) Statement,²¹ disaggregated results are reported by country and cost type.

Results

A total of 45 cost assessments were identified. The following results focused on the 30 high-income member countries of the EAN, where the necessary data were available in the literature. We were not able to identify cost data from upper-middle- or lower-middle-income countries, which prevented cost estimations or imputations for these income categories.

Dementia prevalence across Europe

The GBD 2021 study reported a prevalence of 12.3 million PwD across the 47 EAN member countries, corresponding to 1754 cases per 100,000 adults. Categorized according to the World Bank's GNI categories for 2019, high-income countries accounted for 8.8 million PwD (2093 per 100,000), upper-middle-income countries accounted for 2.9 million (1298 per 100,000), and lower-middle-income countries accounted for 0.7 million (1098 per 100,000).

Among the 30 high-income countries examined, the five most populous countries (France, Germany, Italy, Spain, and the United Kingdom) accounted for 66% of the cases (5.8 million PwD) within this income group.

Economic data sources

Of the 45 cost assessments retrieved from the literature review, 23 focused on Alzheimer's disease, and 22 addressed dementia in general. Sample sizes varied widely, ranging from 54 PwD in a German subsample that was part of a more extensive investigation involving seven other European countries²² to 78,715 PwD in Denmark, where data from 1997–2009 were extracted from the Danish National Patient Registry—a comprehensive national database covering all inpatient and outpatient contacts in the country.²³ In addition, a study with estimates

for the UK with a sample size greater than 688,300, established with literature-based calculations, was also included.²⁴ Supplemental Material 6 provides details on the sample sizes, extracted data, and individual methodological decisions for each economic study included in the calculations.

The literature review yielded 220 data points across all 47 EAN member countries. Although publications up to 2023 were screened, all included cost estimates referred to pre-2019 costing years, with the latest underlying cost year being 2018. Individual data points may come from multiple countries or cover various cost types (direct, indirect, or informal care) within a single publication. Germany had the most data extracted, with 16 data points, followed by France, Spain, Sweden, and the United Kingdom, each with nine data points. Informal care costs were extracted 79 times, followed by direct medical, direct nonmedical, indirect, and total direct costs (when disaggregation was impossible), with 61, 57, 17, and six cases, respectively. Supplemental Material 7 documents the availability and origin of data by country.

Approaches to estimating informal care in the literature. Out of the 45 cost assessments analyzed, 35 addressed informal care costs, though methodological heterogeneity was evident. Two primary methods emerged: the replacement cost method, which estimates costs based on hiring a formal caregiver, and the opportunity cost method, which assigns value to the caregiver's foregone income or time spent on caregiving. The opportunity cost method was applied in 17 studies, while ten used the replacement cost method. Two combined both approaches, three presented data using multiple methods, and three opted for alternative methodologies (see Table 1).

In terms of evaluated components, 19 studies considered both activities of daily living (ADLs) and instrumental activities of daily living (IADLs), while 13 studies included ADLs, IADLs, and supervision. Three studies used different methodologies. Additional details regarding the methods, evaluated components, and specific remarks for each source can be found in Supplemental Material 8.

Economic burden of dementia per patient in high-income European countries

The weighted average total annual cost per patient was €25,218, and the median was €22,589. The median informal costs, direct costs, and indirect costs were €12,242, €9093, and €43, respectively. Country-level costs ranged from €10,136 in Hungary to €45,474 in the Netherlands.

The costs varied significantly among countries, with a range of €35,338, an interquartile range (IQR) of €14,935, and a standard deviation (SD) of €8979 for total costs. Despite clustering cases around the mean, some countries presented high costs without extreme outliers.

Table 1. Methods used to estimate the informal care costs of dementia in the literature. Note: Combination indicates that both the replacement and opportunity cost methods were applied with the same framework. Conversely, separate refers to studies that reported estimates based on multiple approaches independently. See Supplemental Material 6 for further details and source-specific information.

Cost assessment method	n
Opportunity cost method	17
ADLs and IADLs	12
ADLs, IADLs, and supervision	5
Replacement cost method	10
ADLs and IADLs	5
ADLs, IADLs, and supervision	5
Combination: Opportunity cost and replacement method	2
ADLs and IADLs	1
ADLs, IADLs, and supervision	1
Separate: Opportunity cost and replacement cost method	1
ADLs, IADLs, and supervision	1
Separate: Replacement cost method and contingent valuation method	1
ADLs, IADLs, and supervision	1
Separate: Opportunity cost method, replacement cost method, and contingent valuation method	1
Other	1
Contingent valuation method	1
ADLs and IADLs	1
Other methods	2
Total	35

The 25th and 75th percentiles were €14,960 and €29,895, respectively, reflecting the heterogeneity of results across countries. For additional information on the distribution of total, direct, informal care, and indirect costs per patient, refer to Supplemental Material 9.

Although Germany, Italy, UK, France, and Spain contributed significantly to the overall economic burden (as shown in Table 2), they did not rank among the top five for the highest costs per patient. However, the UK (€29,444), Spain (€28,723), Germany (€27,143), Italy (€23,486), and France (€22,980) all exceeded the median. The highest total costs within the 90th percentile were the Netherlands (€45,474), Denmark (€37,924), Switzerland (€36,931), and Luxembourg (€36,796).

Informal care costs per patient ranged from €4991 in Sweden to €26,618 in Greece. The median, SD, and IQR were €12,242, €5,721, and €7,821, respectively. Some countries had high costs without outliers. The 75th percentile was €16,670, including Italy (€18,314) and Spain (€17,766). The Netherlands had 29.2% informal costs (€13,286), the second lowest, with direct costs at 70.7%. Greece had the highest costs, followed by Denmark (€24,421) and Czechia (€21,959) in the 90th percentile (€21,752).

Direct costs varied widely, reporting a median of €9,093, and a SD of €6424. The 25th percentile was €6,311, and the 75th percentile was €12,743. The Netherlands had an extreme value of €32,129, and Sweden had a value of €25,014.

Indirect costs were low, with a median of €43, an SD of €134, and an IQR of €42. Three outliers were Denmark (€719), Germany (€314), and Luxembourg (€164).

Total societal costs of dementia in high-income European countries

The costs reached €221.4 billion (adjusted to €PPP in 2019). This value comprises €128.1 billion allocated to informal care, €93.2 billion to direct costs, and €59 million to indirect costs, corresponding to 57.9%, 42.1%, and 0.03% of the total costs, respectively (see Figure 2).

In terms of total annual costs by country, costs for Germany were €51.8 billion, followed by Italy (€32.8 billion), the United Kingdom (€26.1 billion), France (€20.6 billion), and Spain (€19.6 billion). These five countries collectively contribute 68.1% of the estimated economic burden in the considered EAN member countries (see Table 2).

Distribution of dementia cost by category in high-income European countries. Informal care costs imposed the highest burden, representing 57.9% of total costs (€128.1 billion). However, this proportion varied among the 30 examined countries, ranging from 16.6% for Sweden to 89.2% for Greece. Despite its low proportion of informal care costs, Sweden had higher informal care costs in absolute values than did twelve of the 30 studied countries.

In contrast, direct costs presented an inverse distribution to informal care costs, with their share ranging from 10.6% in Greece to 83.4% in Sweden, followed by the Netherlands with 70.7% and Estonia with 69.6%. However, despite having remarkably fewer prevalent PwD compared to the five countries with the highest total costs, the Netherlands presented the fourth highest direct costs, with €8.6 billion, surpassing Spain (€7.4 billion) and Italy (€7.2 billion).

Impact of dementia costs in relation to the gross domestic product. The total dementia cost of the entire analyzed region in relation to GDP was 1.6%, with 0.9% allocated to informal care and 0.7% to direct costs. The total cost to GDP ranged from 4.4% in Greece to 0.4% in Luxembourg. In Greece, the burden of informal care costs (€5.6 billion) was significant, representing 89.2% of its total costs (€6.2 billion) and accounting for 3.9% of GDP; this figure is in sharp contrast to the other 29 countries, since Italy, for instance, which ranked second among the countries with the highest percentage of informal care costs relative to GDP, reported costs of 1.8%.

Table 2. Prevalence of dementia and annual costs per patient, country, and percentage to gross domestic product (in € PPP 2019) broken down by cost category. Alongside each country's name, the imputed costs are indicated in parentheses (a, total direct costs; b, informal care costs; c, indirect costs); Prevalence (Prev.); Gross Domestic Product (GDP); Purchasing Power Parity (PPP); Blanks in the economic data show that no data were found in the literature and could not be imputed (see Supplemental Material 5).

Country	Annual costs per prevalent patient (€ PPP 2019)				Epidemiological data			Annual costs per country (million € PPP 2019)				Annual costs related to GDP (% of GDP 2019)			
	Total direct costs		Indirect costs		Total costs	Prev. (working age)	Prev. (age)	Total direct costs		Informal care costs		Total indirect costs		Total direct costs	Total indirect costs
	(a)	(b)	(c)	(c)				(a)	(b)	(b)	(c)	(c)	(c)	(a)	(c)
Albania						26,861	3676								
Armenia						28,090	3857								
Austria	10,467	14,769	9	25,245		140,123	9685	1467	2069	<1	3536		0.5	0.7	<0.001
Azerbaijan						46,068	10,932								
Belarus						112,675	13,344								
Belgium	8513	12,640	48	21,200		195,870	12,961	1667	2476	<1	4144		0.4	0.7	<0.001
Bosnia and Macedonia						17,059	2801								
Norway(a,c)	9672	8661	100	18,433		70,646	5538	683	612	<1	1296		0.2	0.2	<0.001
Poland(a,b,c)	5926	7802	21	13,750		489,880	53,446	2903	3822	1	6727		0.7	0.9	<0.001
Portugal	11,484	10,666	49	22,199		196,786	12,005	2260	2099	<1	4359		1.4	1.3	<0.001
Republic of Moldova						38,295	4757								
Romania	5281	6952	17	12,250		261,193	25,061	1379	1816	<1	3196		0.8	1.0	<0.001
(a,b,c)															
Russian Federation						1,592,386	203,421								
Serbia						110,026	11,617								
Slovakia(a,b,c)	6397	8422	26	14,844		58,913	6980	377	496	<1	873		0.5	0.7	<0.001
Slovenia(a,c)	7836	12,227	34	20,097		32,251	2921	253	394	<1	647		0.7	1.0	<0.001
Spain	10,923	17,766	33	28,723		681,574	49,120	7445	12,109	2	19,556		0.8	1.2	<0.001
Sweden	25,014	4991	65	30,070		178,769	10,657	4472	892	<1	5365		1.2	0.2	<0.001
Switzerland(c)	20,515	16,305	111	36,931		137,184	9274	2814	2237	1	5052		0.6	0.4	<0.001
Turkey						660,007	95,249								
Ukraine						523,428	61,884								
United Kingdom	14,256	15,119	69	29,444		887,877	58,393	12,658	13,424	4	26,085		0.6	0.7	<0.001
Uzbekistan						107,889	25,254								

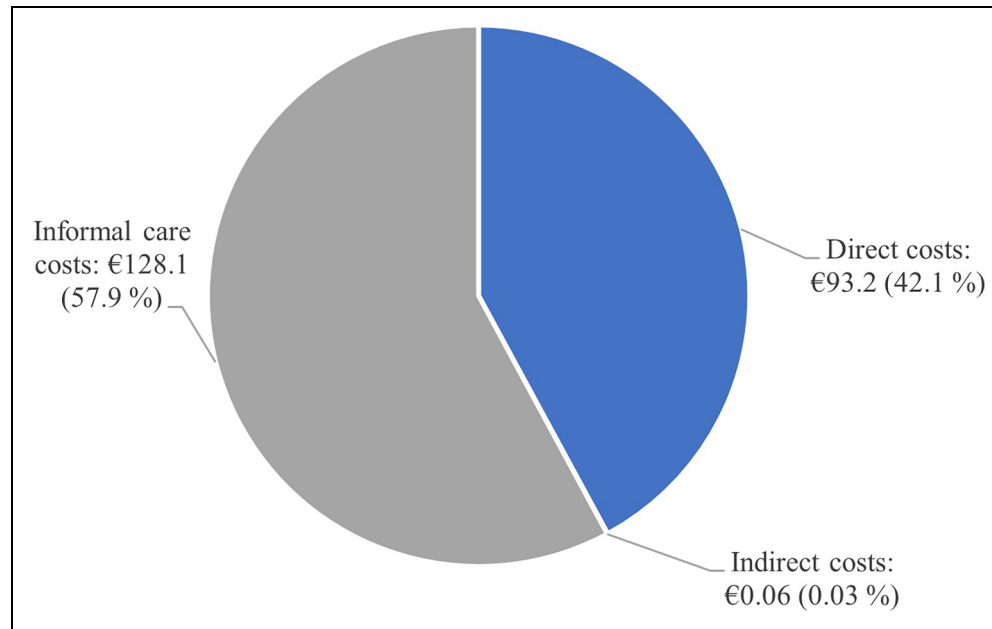


Figure 2. Cost distribution of dementia among high-income EAN member countries (in million € PPP 2019).

Economic burden of dementia per capita in high-income European countries

The median per capita cost was €314, ranging from €139 in Israel to €710 in the Netherlands. Informal care costs had a median of €178, while direct costs reached €131. No country reported a median indirect cost exceeding €1 (see Figure 3).

Discussion

The total societal cost of dementia for the 30 high-income EAN member countries was estimated at €221.4 billion. With aging populations and the associated increases in dementia prevalence,¹⁴ research into the economic burden of dementia is critical. Furthermore, Pedroza et al.¹⁵ forecasted that global dementia-related healthcare spending would reach US\$594 billion by 2050. Wittenberg et al.²⁵ estimated that dementia cases in England will double between 2015 and 2040, with costs more than tripling. Similar projections were projected for the United States,²⁶ the Netherlands,²⁷ and China.²⁸

Approximately 68% of the economic burden was concentrated in the five most populous, high-GDP countries—Germany, Italy, UK, France, and Spain—amounting to €150.8 billion. However, countries such as the Netherlands, Denmark, Switzerland, Luxembourg, Czechia, Finland, Sweden, and Greece presented higher costs per patient but accounted for 13% of the region's prevalent cases and 17.7% (€39.1 billion) of total regional costs. These variations in the costs per patient arose from differences in healthcare systems, resource utilization, demographics, and

the origin of our reported data, as explained in the methods section and Supplemental Material 1.

Comparison with previous estimations

Our research estimated dementia costs that were significantly higher than the €118.3 billion (€PPP, adjusted to 2019 using the Euro area harmonized index of consumer prices; https://ec.europa.eu/eurostat/databrowser/view/prc_hicp_midx_custom_15199656/default/table) reported by Gustavsson et al.¹³ This discrepancy partly stemmed from epidemiological differences and included data sources. Gustavsson et al. estimated 14% fewer cases in 2010 for the same region than did the GBD 2021 study. The results also varied by country since the latter reported 73% more cases in Germany and 24% fewer in France.

According to Gustavsson et al., costs were distributed at 16% for direct healthcare and 84% for direct nonmedical costs—informal care being included in the latter. Our study treated informal care costs as a distinct category, considering their relevance to the economic burden of dementia.

The substantial difference between the two studies is explained by: a) disparities in sources and approaches to estimate the prevalence; b) data imputation techniques, as Gustavsson et al.¹³ also emphasized when comparing their results to those of similar studies¹²; c) a greater number of literature sources providing more recent country-specific estimates (15 versus 45 in our study); d) the significant methodological differences in evaluating informal care within cost-of-illness literature,²⁹ even when the same umbrella term for a specific approach is used

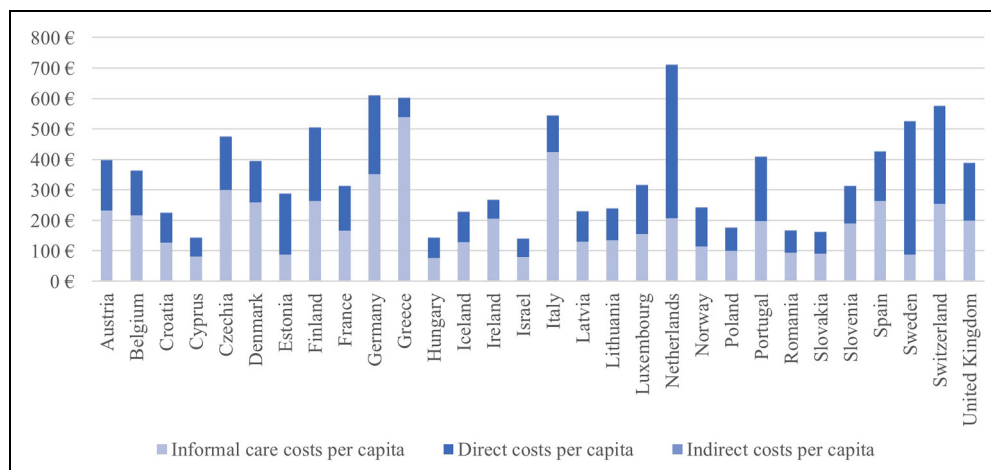


Figure 3. Average annual per capita costs of dementia per country (in alphabetical order; cost in € PPP 2019).

in two different publications, in this context, our study highlights informal care as a distinct cost category, which ultimately accounted for 57.9% of the total economic burden; and e) the inherent uncertainties associated with the available and utilized data.

Wimo et al.¹² estimated the global dementia costs at US\$1313 billion in 2019 (€814.98 billion, adjusted to €2019 PPP), with €604.09 billion in high-income countries, 49.6% for informal care, 34.2% in the direct social sector, and 16.2% in the direct medical costs. Informal care costs were based on the opportunity cost approach and time contributions documented in the literature, including ADLs, IADLs, and supervision. Although it is not possible to distinguish costs solely for EAN member countries or Europe, the cost per patient for high-income countries is similar to that in this study for informal care (€12,524 versus our estimated cost of €12,242).

Informal care costs for dementia patients and their estimation challenges

Estimating informal care costs is particularly critical for dementia due to its significant caregiving burden, but the absence of a market price leads to methodological heterogeneity in valuation methods.³⁰

The implementation of the replacement cost method or the opportunity cost method varies. Earlier reviews noted the predominance of the replacement cost method³¹ and that most studies in North America and Europe used this approach or did not specify the method.³² Recent findings have indicated that the opportunity cost method is favored in Europe, whereas the replacement cost method is preferred in North America, and the latter generally results in higher estimates.²⁹ For example, this discrepancy was highlighted in a Spanish study comparing three valuation approaches (i.e., the replacement cost method, the

opportunity cost method, and the contingent valuation method), suggesting that the choice of a technique is not neutral.³³ In this regard, our findings aligned with those of Engel et al.²⁹ in Europe, particularly in the predominance of the opportunity cost method. Methodological diversity poses challenges for cross-study comparisons, such as that of Wimo et al.,¹² which excluded supervision of the calculations and relied on the opportunity cost method.

Each approach reflects a distinct assumption: the replacement cost method estimates the economic impact on the formal care system if informal care is absent, whereas the opportunity cost method captures personal sacrifices, such as lost income or lifestyle changes. The choice of method has implications for interpreting and reporting results, particularly in cross-country contexts where sociocultural norms vary widely, as monetizing informal care implies standardizing outcomes.

Informal caregiving imposes significant stress, strain, and healthcare challenges on caregivers, underscoring its substantial but often overlooked economic and personal burden.

Indirect costs of dementia

Productivity losses are generally not estimated for dementia, as its primary impact is on individuals over 65 years old, who are typically no longer part of the workforce. This study included 17 data points on indirect costs from three studies: a) productivity losses due to mortality and morbidity for 15 countries³⁴; b) a German study with 2.2% of the sample reporting indirect costs³⁵; and c) a Danish analysis estimating forgone earnings related to reduced labor supply.²³ These publications illustrated the low burden of productivity losses related to dementia, with Denmark and Germany reporting the highest costs per patient (€719 and €314, respectively) compared with our median cost of €43. At the country level, these costs

were minimal, reflecting the low prevalence of dementia in the working-age population (see Table 2).

However, our methodology likely underestimates indirect costs due to the limited availability of sources on productivity losses of the PwD related to dementia, as reflected in our results. Further research, particularly on cases such as young-onset dementia, is needed to deepen our understanding of productivity-related losses. Although studies in this area remain scarce, exploring indirect costs could provide valuable insights, despite their relatively small contribution to the overall economic burden.

Strengths and limitations

This study has several key strengths. First, it implements a systematic and transparent approach to data synthesis and imputation, integrating diverse cost assessment methods from recent literature into a unified framework.¹⁹ Second, it addresses data gaps in regions with incomplete or limited information. Third, it incorporates a comprehensive range of payer perspectives and cost categories. Fourth, it treats informal care costs as a distinct category, acknowledging their central role in dementia's economic burden while also analyzing methodological trends in their estimation. Finally, a plausibility assessment by clinical experts enhances the validity of the results.

However, data limitations and the challenge of integrating heterogeneous sources constrain the generalizability of our estimates. Imputation methods relied on GNI-based stratification as a pragmatic proxy and on country-specific economic weighting, which may oversimplify complex differences in health systems. As such, the results of this study should be interpreted as the best possible approximations based on the currently available evidence. Similarly, because this GNI-based classification required at least one country within the same income category to perform imputations, our cost estimations were restricted to high-income countries.

Pragmatic decisions were made due to methodological heterogeneity among sources, which introduced potential biases in the interpretation of results. For example, deviations in study populations from the hypothetical average patient, including the use of Alzheimer's disease-specific and broader dementia samples, or the inclusion of all-cause costs rather than dementia-attributable costs, which were rarely reported in the literature, were considered acceptable. As detailed in Supplemental Material 6, these choices may lead to cost overestimation, as the data often reflect more severe cases. Similarly, despite systematic conversion and harmonization, the included studies remained methodologically heterogeneous, for example, in the valuation of informal care and the scope of cost components, which may have affected comparability. Additionally, the utilization of the GBD 2021 prevalence estimates at a country level assumes an ideal scenario where all PwD are diagnosed and receive extensive care.

Implications

The economic burden of dementia impacts not only healthcare systems but also PwD and their families, who face financial and emotional challenges. Accessible, affordable, and high-quality care services, including residential facilities where appropriate, may help reduce reliance on informal caregiving, while specialized facilities and trained personnel remain important for improving patient care and easing hospital strain.

Disease-modifying treatments may reduce care costs in later disease stages if they delay disease progression and care dependency; however, their overall impact on total societal costs remains uncertain and depends on treatment costs, duration of effect, delivery and monitoring requirements, eligible populations, and timely access.^{6–9,36} Researchers play a crucial role in developing insights that guide resource allocation and policy. In health economics, standardized and contextualized methods are necessary for valuing resource utilization, particularly informal care, to enhance comparability across studies and diseases.

Preventing measures targeting modifiable risk factors such as physical inactivity, obesity, smoking, and hypertension could reduce the prevalence of dementia. Lifestyle changes starting in midlife may delay or prevent the onset.³⁷

Policymakers should prioritize immediate and long-term strategies, such as building or improving care facilities and supporting caregivers (e.g., financial benefits, legal information about their rights, respite services, psychosocial support, or training and education).

Conclusion

Dementia poses a high economic burden in Europe and represents a multifaceted challenge requiring comprehensive strategies from all stakeholders, including healthcare systems and policymakers. As the population ages, dementia-associated costs are expected to increase considerably, and the findings of this research may help facilitate an understanding of this economic burden.

The development and adoption of new therapeutic options, care, and policy measures, especially in a cross-national collaborative manner, will be essential for managing dementia's future social and economic impact.

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Ethical considerations

Ethical approval by an Ethics Committee or Institutional Review Board was not required for this study, as it was based exclusively on published literature and publicly available data.

Consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contribution(s)

Mateo Montes-Martinez: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing.

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Data availability statement

The data underlying this study are derived from published literature and publicly accessible sources. Aggregated and harmonized datasets generated during the study are available from the corresponding author upon reasonable request.

Supplemental material

Supplemental material for this article is available online.

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