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Abstract

Introduction: Dementia is a leading cause of death and disability globally. Estimating total societal costs demonstrates the wide impact of dementia and its main direct and indirect economic components.

Methods: We constructed a global cost model for dementia, presenting costs as cumulated global and regional costs.

Results: In 2019, the annual global societal costs of dementia were estimated at US $1313.4 billion for 55.2 million people with dementia, corresponding to US $23,796 per person with dementia. Of the total, US $213.2 billion (16%) were direct medical costs, US $448.7 billion (34%) direct social sector costs (including long-term care), and US $651.4 billion (50%) costs of informal care.

Discussion: The huge costs of dementia worldwide place enormous strains on care systems and families alike. Although most people with dementia live in low- and middle-income countries, highest total and per-person costs are seen in high-income countries.

KEYWORDS
Alzheimer's disease, cost, cost-of-illness study, dementia, economics, informal care

Highlights

- Global economic costs of dementia were estimated to reach US $1313.4 in 2019.
- Sixty-one percent of people with dementia live in low-and middle-income countries, whereas 74% of the costs occur in high-income countries.
- The impact of informal care accounts for about 50% of the global costs.
- The development of a long-term care infrastructure is a great challenge for low-and middle-income countries.
- There is a great need for more cost studies, particularly in low- and middle-income countries.
- Discussions of a framework for global cost comparisons are needed.

1 | INTRODUCTION

Dementia is the seventh leading cause of death and a major cause of dependency and disability globally.[1] It is among the top 10 leading causes of years of healthy life lost due to disability in people aged ≥60 years.[2] The personal consequences of living with dementia can be harrowing for individuals and their families, and the social and economic consequences are challenging for all societies and care systems.[3] Data on resource use and costs in combination with prevalence figures offer indications of the scale of these challenges and can feed valuable information into the planning of future care infrastructure.

Previous work by Alzheimer's Disease International (ADI) estimated the global economic cost of dementia as US $604 billion in 2010,[4,5] and US $818 billion in 2015.[6,7]

Because the global dementia situation is dynamic, with changing prevalence patterns and care systems as well as preconditions for care,[2] we generated updated figures for 2019 as part of the World Health Organization's (WHO) Global Status Report on the public health response to dementia.[2] The cost estimates for all 194 WHO member states are assumed to reflect the global situation. The aim was to make a prevalence-based estimate of the global costs of dementia. To support global and local discussions of dementia policy and practice, we also analyze how costs are distributed by economic status and cost type.

RESEARCH IN CONTEXT

1. **Systematic Review**: As part of World Health Organization's Global Dementia Observatory project, this research is based on a systematic review of cost and cost-of-illness studies and papers describing the amount of informal care in the field of dementia.

2. **Interpretation**: The global costs of dementia are huge. Reliance on informal care is high, accounting for 50% of the societal costs. Costs are distributed disproportionately, as most people with dementia live in low- and middle-income countries, while the greatest proportion of costs are incurred in high-income countries.

3. **Future Directions**: Every society must have a plan for the expected huge increase in the numbers of people with dementia. There is a great need for cost studies, particularly in low-and middle-income countries. Discussions of a framework for global cost comparisons are needed.

2 | METHODS

In an "ideal" situation, estimation of the global economic impact of dementia would start with data that identified all people with dementia in every country, and the severity of their condition. Dementia-specific data on resource use and costs, disaggregated by severity, would be available for the same year in all countries and care systems. Registries with such data would be available and constructed in such a way that data extraction would be possible from all countries. Information would be available on all support contributions (hours and type of support) by family members and other people (distinguished by sex, age, co-residence status, and working situation). There would be agreement on how to assign monetary value to these families and other contributors. It would be possible to delineate dementia-specific costs from costs of comorbid conditions. The way that care is organized, financed, and reimbursed would also be known, to avoid double-counting and to separate transfer payments from real costs. With this ideal scenario, it would be straightforward to calculate total costs.

This, of course, is nowhere near the reality. For example, there are insufficient demographic data; data are collected in different years; country-specific prevalence information is missing; national data on care systems are incomplete; resource use patterns are often unknown; people with dementia are not identified, and studies rely instead on "clinical" or convenience samples rather than population-based data. In most countries, there is little or no information on the characteristics of family and other caregivers, or on the support tasks they provide. Estimation of the global economic costs is therefore hampered by many limitations, and therefore we use the term "estimate" to acknowledge that exact calculations are not possible. We also explore how sensitive our estimates are to some of the key assumptions made in generating them.

2.1 | Data collection

We used a range of approaches to obtain data on resource use and costs for the calculation of cost estimates. Details of the methods used are available in the supporting information.

2.1.1 | Systematic review

We carried out a systematic review to identify data sources. The methodological approach was similar to previous global cost studies.[3-11] We used separate searches for costs and informal care (i.e., support provided to a person with dementia by any unpaid caregiver, including family, friends, and neighbors) in PubMed, Embase, PsycINFO, HEED, Social Services Abstracts, and Sociological Abstracts. For cost studies, the following terms were used: ("Dementia"[Mesh] OR "Alzheimer Disease"[Mesh]) AND ("Costs and Cost Analysis"[Mesh] OR "Economics"[Mesh] OR "Cost of Illness"[Mesh]). For informal care, the search terms were: "Patient care"[Mesh Terms] OR "Informal care"[Text Word]) in combinations with ("Economics"[Mesh]), "Hours"[Text Word], "caregiving time"[Text Word]). The search covered the period between 2009 and January 2019: it was assumed that results from the search that generated the 2010 estimates were appropriate. We applied a stepwise process for identifying relevant papers: title screening, abstract screening, and full-text screening.[12]

Additional studies identified from reference lists were added if they were of good quality. Inputs were gathered from relevant indicators in WHO's Global Dementia Observatory (GDO), as well as from work by other institutions such as the World Bank (WB), International Monetary Fund (IMF), Organisation for Economic Co-operation and Development (OECD), International Labour Organization (ILO), Institute for Health Metrics and Evaluation (IHME), ADI, Inserm,[13] and the 10/66 Dementia Research Group.[14]

Both top-down and bottom-up data were used.[15] In addition to the prevalence sources, 165 studies were used for the worldwide cost estimates (of which 77 were used in the 2010 and 2015 estimates). See Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagrams in the supporting information.

2.1.2 | Prevalence sources

Estimates of global costs may be sensitive to assumptions regarding the prevalence of dementia. In our base-case estimates, we used age-specific prevalence data from the Global Burden of Disease (GBD) project by IHME.[16,17] Country- and age-specific population data were extracted from the World Population Prospects of the United Nations.[18] In sensitivity analyses, we applied prevalence estimates by King's College London (KCL)/ADI[6] and IHME's population data.[19]

2.2 | Costs

There are different ways to classify costs, and particularly for long-term care the classification varies between countries.[20] To be consistent with previous global cost estimates, the following cost concepts were used:

1. Direct medical costs refer to the formal medical care system, such as costs of hospital care, drugs, diagnostic tests, and visits to clinics.
2. Direct social costs (sometimes called "direct non-medical costs") arise from formal services provided outside of the medical care system, including care in residential or nursing homes or other long-term care facilities, community services such as home care, food supply, and transport.
3. Indirect costs refer to informal care provided by family members, friends, and others, and production losses by people with dementia.

There are various ways to attach a cost to informal care.[21] The base-case option drew on the previous studies found through the search to generate data on hours of care per day, separating female and male inputs for hours, as in previous work by ADI.[4,6] We did not use the figures for informal care *costs* from previous studies because costing methods are too heterogenous. Contributions (hours) by informal care-givers can be described in three domains: support in personal/basic activities of daily living (ADLs; such as eating, hygiene, toilet visits, and dressing), support in instrumental ADLs (IADLS; more complex activities such as shopping, preparing food, economic transactions), and supervision (to prevent, for example, dangerous events). In the base-

case calculations, the focus is on aggregated ADL and IADL support. Opportunity costs are estimated as earnings (average wage), with data derived from ILO[22] at country level. Finally, costs were calculated at country level for the proportions of people with dementia estimated to be living at home, and annualized and aggregated (regions, world).

2.2.1 | Dementia severity and costs

There is a close relationship between dementia severity and resource use and costs. IHME provided estimates of how dementia severity is distributed globally (percentages), which were applied on country-specific prevalence figures. In the final severity cost model, 56 studies were used: 18 with data both on costs and informal care, 32 with informal care data only, and 6 with cost data only. Studies describing economic aspects of dementia severity were different to the studies used for cost estimates without severity aspects, and therefore the cost estimates differ slightly.

2.2.2 | Currency and inflation

Costs are expressed in US $ (conversion by exchange rates, to be in line with base option in previous studies) and adjusted to 2019 in line with inflation and average consumer prices derived from IMF's World Economic Outlook database.[23]

2.3 | Population-based studies

Many studies are based on convenience or clinical samples, making their representativeness questionable. Register-based studies are often large but, by very definition, are restricted to individuals who are known to health or care systems. Generally, cost estimates based on samples that are not population based are potentially overestimating direct costs because people who are not known to services (and thereby have lower use of resources) are not included in such studies. These risks are lower in population-based studies or some top-down studies (in which data come mainly from over-arching or aggregated sources) or combined top-down and bottom-up studies (the latter relying on individual-level data) where the prevalence is known, and costs are distributed in that population. These options are presented in the sensitivity analyses. The drawback is that there are few such studies and most of them are from high-income countries (HIC; see supporting information).

2.4 | Coverage of input data

Although the systematic review produced a more complete set of inputs than previous studies, data were still incomplete or missing for many countries, particularly from low- and middle-income countries (LMIC). Various statistical approaches present different challenges in imputing resource use data.[24]

TABLE 1 Estimated worldwide costs of dementia in 2019 (billion US $), based on current World Bank country classification 2019

	Number of people with dementia[b]		Costs		Direct costs % of cumulated GDP	Number of countries
	Millions	%	US $ billion	%		
Low-income countries	1.4	2.5	3.5	0.3	0.11	29
Lower-middle-income countries	8.8	16.0	44.3	3.4	0.17	49
Upper-middle-income countries	23.6	42.8	293.2	22.3	0.42	56
Low-and middle-income countries[a]	33.8	61.3	341.0	26.0	0.37	134
High-income countries	21.4	38.7	972.3	74.0	1.00	60
All	55.2	100.0	1313.4	100.0	0.76	194

[a]Low- and middle-income countries = low-income countries + lower-middle-income countries + upper-middle-income countries.
[b]Numbers are based on Institute for Health Metrics and Evaluation's age-specific prevalence figures combined with United Nations population data.

In the base-case option, we used data on resource use and direct costs from each GBD region. The GBD country classification reflects both income level and cultural and organizational aspects. However, as there are country differences within GBD groups, cost estimates were adjusted: gross domestic product (GDP) per capita in a country in a particular GBD region was adjusted for population-weighted GDP per capita in that region.

This method based on GBD region designations was used as the base-case model, while a generalized linear mixed model (GLMM) with gamma distribution and log link was applied[25] in the sensitivity analysis, as it was deemed difficult to obtain data on relevant covariates across all countries worldwide. There is limited country-level information from a dementia care perspective; for example, in relation to countries' long-term care resources, health care organization, workforce capacity, and dementia diagnostic rates. Data such as GDP per capita, and sociodemographic and socioeconomic indices are also highly intercorrelated. For the GLMM, evidence from the literature search was used to establish GDP per capita, proportion of people aged over 65 years, and proportion of people with dementia living at home.

The imputation status at country level is summarized in the technical report.[26] Many countries completely lacked data (mainly LMIC, particularly from Africa).

2.5 | Statistical considerations

As the cost estimates are based on a mix of both bottom-up and top-down studies, confidence intervals or other measures of parameter uncertainty are not presented. Such measures could have been used if the cost estimates had been based solely on bottom-up studies with known sample sizes and variances.

2.6 | Sensitivity analyses

As the global cost estimates rely on several uncertainties and assumptions, these were explored in several one-way sensitivity analyses. The following parameters were explored: alternative prevalence estimates

and population data, alternative ways of quantification and costing of informal care, cost estimates from population-based studies, use of GLMM, and purchasing power parities (PPPs) instead of exchange rates.[27]

3 | RESULTS

3.1 | Global cost estimates

In the base-case option, the global cost of dementia for 55.2 million people living with dementia in 2019 was estimated at US $1313 billion (Table 1). HIC accounted for 74% of the costs even though 61% of people with dementia live in LMIC. Direct costs of dementia, as a proportion of global GDP, have increased from 0.59% in 2010 to 0.76% in 2019. That proportion is also associated with WB income classification for countries.

Between 2010 and 2019, the global costs of dementia increased by 62% (Table 2). There was also a shift in the distribution of costs from HIC to LMIC, partially reflected by an increase in the numbers of people with dementia in LMIC, mainly linked to more rapid population aging, but also on higher estimates for informal care. Also, the WB classification had changed by 2019, and many countries had been "promoted" upward in the classification due to economic growth, resulting in more people with dementia particularly in upper-middle-income countries.

As has been found previously, informal care constituted a major proportion of dementia care costs (about 50% globally, 65% in LMIC). In HIC, the costs in the social care sector are almost on the same level as the costs of informal care (Table 3). As was also found in the 2010 and 2015 estimates, the impact of informal care is greater than direct costs in LMIC (52% and 53%, respectively, when applied on the 2019 WB classification), but not as much as in the 2019 estimates (not in table).

As expected, costs per person with dementia were closely related to the WB income classification of countries (Table 4).

Of the 55.2 million people living with dementia worldwide, 26.9 million had mild, 14.9 million moderate, and 13.4 million severe dementia. Although total costs did not differ greatly between severity levels, per-person costs were very different: globally, annual cost per person

TABLE 2 Worldwide costs of dementia in 2010, 2015, and 2019 (billion US $), based on World Bank country classification for 2019, inflated to 2019

Basis for prevalence estimates	WAR 2010[4]				WAR 2015[6]				WHO 2019			
WB country classification year	2019				2019				2019			
	Numbers of people with dementia (millions)	US $ billion	%	Per person with dementia	Numbers of people with dementia (millions)	US $ billion	%	Per person with dementia	Numbers of people with dementia (millions)	US $ billion	%	Per person with dementia
Low-income countries[a]	0.6	1.0	0.1	1595	1.1	1.6	0.2	1518	1.4	3.5	0.2	2575
Lower-middle-income countries	6.9	16.2	2.2	2351	8.7	17.0	1.9	1952	8.8	44.3	3.2	5010
Upper-middle-income countries	12.2	113.8	15.4	9347	19.2	162.1	18.1	8444	23.6	293.2	20.8	12,414
Low-and middle-income countries[b]	19.7	131.0	17.7	6656	29.0	180.7	20.2	6232	33.8	341.0	24.2	10,083
High-income countries	15.8	608.3	82.3	38,582	17.6	714.6	79.8	40,492	21.4	972.3	75.8	45,500
All[c]	35.4	739.3	100.0	20,858	46.6	895.3	100.0	19,210	55.2	1313.4	100.0	23,796

[a]Sudan is not included in the 2010 and 2015 estimates due to a very high inflation rate. The costs of Sudan correspond to 0.03% of the total costs in 2019.
[b]Low- and middle-income countries = low-income countries + lower-middle-income countries + upper-middle-income countries. Note, WB country income classifications are variable over time (i.e., countries are promoted/demoted based on their gross national income).
[c]The countries at each year are not identical, because many small WHO members are included in the 2019 estimates. These countries correspond to 0.02% of the total costs in 2019.
Abbreviations: WAR, World Alzheimer Report; WB, World Bank; WHO, World Health Organization.

TABLE 3 Subcategory costs of dementia (billion US $ and percent of total cost) in 2019, by World Bank country classification

Cost subcategory	Direct medical costs		Direct social sector costs		Informal care costs		Total costs	
World Bank country classification 2019	US $ billion	%	US $ billion	%	US $ billion	%	US $ billion	%
Low-income countries	0.2	4.6	0.4	10.5	3.0	84.9	3.5	100
Lower-middle-income countries	4.8	10.9	5.8	13.2	33.6	75.9	44.3	100
Upper-middle-income countries	54.4	18.5	54.8	18.7	184.0	62.8	293.2	100
Low- and middle-income-countries[a]	59.4	17.4	61.0	17.9	220.6	64.7	341.0	100
High-income countries	153.9	15.8	387.7	39.9	430.8	44.3	972.3	100
All	213.2	16.2	448.7	34.2	651.4	49.6	1313.4	100

[a]Low- and middle-income countries = low-income countries + lower-middle-income countries + upper-middle-income countries.

with mild dementia was US $15,899, for moderate dementia it was US $26,859, and for severe dementia US $36,180 (Table 5). The weighted average annual cost per person with dementia was US $23,764.

3.2 | Sensitivity analyses

In the base-case option, the IHME age-specific prevalence estimates are combined with United Nations population data. If prevalence esti-

mates from KCL/ADI are applied,[6] the total numbers of people with dementia are somewhat higher (56.7 million), although the distributions in the different WB regions vary (greater proportions in LMIC if KCL/ADI prevalence estimates are used). Thus, global costs based on the KCL/ADI prevalence are slightly lower. If the IHME prevalence is combined with IHME population data, numbers (57.1 million) and costs are slightly higher (Table 6).

The valuation of informal care has a marked impact on the cost estimates. If a more restricted quantification is used (only basic ADLs),

TABLE 4 Subcategory costs of dementia as per person costs of dementia (US $) in 2019, by World Bank country classification

Cost subcategory World Bank 2019	Direct medical costs US $	Direct social sector costs US $	Informal care costs US $	Total costs US $
Low-income countries	118	270	2187	2575
Lower-middle-income countries	546	660	3804	5010
Upper-middle-income countries	2302	2321	7790	12,414
Low-and middle-income countries[a]	1755	1805	6523	10,083
High-income countries	7201	18,140	20,159	45,500
All	3864	8130	11,803	23,796

[a]Low- and middle-income countries = low-income countries + lower-middle-income countries + upper-middle-income countries.

TABLE 5 Worldwide costs (billion US $) in relation to dementia severity and type of care

Severity World Bank 2019	Mild			Moderate			Severe			Total costs		
	Numbers of people with dementia (millions)	US $ billion	US $ per person with dementia	Numbers of people with dementia (millions)	US $ billion	US $ per person with dementia	Numbers of people with dementia (millions)	US $ billion	US $ per person with dementia	Numbers of people with dementia (millions)	US $ billion	US $ per person with dementia
Low-income countries	0.7	1.5	2122	0.4	1.0	2836	0.3	1.5	4897	1.4	4.0	2942
Lower-middle-income countries	4.5	24.8	5486	2.3	17.2	7448	2.0	18.9	9385	8.8	60.9	6884
Upper-middle-income countries	11.8	99.7	8453	6.3	72.4	11,558	5.6	103.1	18,518	23.6	275.1	11,647
Low-and middle-income countries[a]	17.0	126.0	7405	8.9	90.6	10,150	7.9	123.4	15,654	33.8	340.0	10,052
High-income countries	9.9	302.5	30,445	6.0	309.2	51,869	5.5	359.9	65,749	21.4	971.6	45,464
All	26.9	428.5	15,899	14.9	399.7	26,859	13.4	483.4	36,180	55.2	1311.6	23,764

Note: The cost estimates are not identical to those in Tables 1–4 as another set of input studies was used.

[a]Low- and middle-income countries = low-income countries + lower-middle-income countries + upper-middle-income countries.

total costs are about 73% of the base option. If supervision is included, costs are about 33% higher. However, there were small differences between the base option and the replacement cost method, probably because no adjustment was made for non-working caregivers in the main option. When a lower economic value is used for informal care for spouses assumed to be retired, the cost is estimated to be 20% lower. By using minimum wage instead of average wage, the costs are about 30% lower than in the base option.

Using GLMM leads to slightly higher costs, with higher direct costs and lower costs of informal care. Using PPPs increased total costs by 39%, informal care by 50%, particularly informal care in LMIC (+117%) versus the base option.

4 | DISCUSSION

Our calculations show that the estimated total societal cost of dementia in 2019 was US $1313 billion, substantially greater than previous estimates.[6] The main reason, besides the increase in numbers of people with dementia, was a higher estimate of informal care costs. This is partially due to new evidence on provision of informal care in LMICs, which was previously lacking and which suggests higher rates and hours of informal caregiving in LMICs than in HICs. Thus, it is not easy to compare the trends in the different types of costs over time. National policy frameworks for health and social care, as well as local systems of treatment and support, are increasingly needed to pay greater attention to

TABLE 6   Summary of the one-way sensitivity analyses

Type of sensitivity analysis	Direct costs	Indirect costs (including informal care)	Total costs	Difference vs. base option
Base option	661.9	651.4	1313.4	
Alternative prevalence source: King's College London /Alzheimer's Disease International	606.4	601.8	1208.2	−8.0%
Alternative population source: Institute for Health Metrics and Evaluation	667.1	671.4	1338.5	1.9%
Informal care hours—more restrictive	661.9	303.2	965.2	−26.5%
Informal care hours—more inclusive	661.9	1079.2	1741.1	32.6%
Informal care: replacement cost	661.9	688.9	1350.8	2.8%
Informal care: adjustment for non-working caregivers	661.9	397.9	1059.8	−19.3%
Informal care: minimum wage	661.9	249.1	911.1	−30.6%
Population-based studies only	619.6	516.4	1135.9	−13.5%
Generalized linear mixed model (GLMM)	731.3	619.3	1350.6	2.8%
Purchasing power parities (PPPs) instead of exchange rates	843.5	977.6	1821.1	38.7%

the circumstances and needs of both people living with dementia and their families and other caregivers.

Global costs in 2019 were distributed disproportionately; about 74% of the cost was in HIC, but these countries have only 39% of the global dementia population. About half of the costs were related to informal care with a gradient in relation to country income level: 44% in HIC and 85% in low-income countries. This was reflected in the estimated costs in the social care sector: 40% of the costs in HIC and about 10% in low-income countries. Medical sector costs did not show this relationship to country income level. The largest social care cost was for residential, nursing homes, and other long-term care facilities. While the challenge in HIC is funding, the challenge in many LMICs is often much more fundamental: to establish a care infrastructure based on each country's own prerequisites and preferences. The funding of such an infrastructure in LMICs is likely to be linked to economic development.

Given the expected future increase in numbers of people with dementia[2,17]—combined with changes in family structure, migration, urbanization, demography, and female labor force participation rates—particularly in LMIC, it is unrealistic to expect that unpaid care can be a sustainable care option at the same level as today. Most informal caregivers are female (≈70% on average), but the proportion is higher in LMICs.[2] Although informal care is hugely valued by most people living with dementia,[3] it is expected that it will be increasingly difficult for families to provide this kind of support to older people in the coming decades.[3,4]

4.1 | Methodological issues and limitations

The greatest methodological challenge for this kind of study is still the lack of data from many parts of the world. Although there are more and better sources for the global cost estimates now than when pre-

vious studies were conducted,[6,7] there is still paucity of data. As the greatest proportion of costs occur in HIC, the imputed proportion of costs is just 13%, but data are lacking from 77% of countries, mainly LMICs (see details in the supporting information). This is a major issue that needs attention in future work. Imputation was therefore needed for most countries. Previous work by ADI and the 10/66 Dementia Research Group has produced valuable inputs on dementia care in LMICs.[28] Hopefully, the work of WHO's GDO and the Strengthening Responses to Dementia in Developing Countries (STRiDE) project will generate valuable data to reduce these gaps further.[29]

Another perennial challenge is under-reporting of dementia, both in registries and in clinical practice.[30–32] Globally, too many people with dementia are undiagnosed; consequently, costs can be underestimated if aggregated estimates are based only on registry-based studies. Many other studies use convenience or clinical samples, which are usually non-representative of the dementia population, since such studies only include people with access to care in some way. Population-based cohort studies with data on resource use and costs are rare, as are top-down studies of high quality, and for the moment, it is not possible to base cost estimates solely on such data.

The quantification and costing of informal care have major impacts on global cost estimates, as illustrated by how the informal care component varied in the sensitivity analyses. One issue is what kind of care domains should be considered. Support in basic ADLs should clearly be included. Support in IADLs is more complicated in both content and quantification,[33] as IADL-related activities depend to a great extent on local culture. Likewise, supervision by family members is a significant part of daily care for people with dementia but is complicated to assess without understanding the context, which is one reason estimates of informal care can vary greatly.[34,35] It is also challenging to decide which earnings indicators to use. We used average wage from the ILO database[22] as the opportunity cost in the base-case option, and while it is more common to use minimum wage,[36] only limited

global data on this were available. The opportunity cost approach may be preferable according to economic theory,[37] but replacement costs (assuming that informal care would be replaced by professional caregiver support in a 1:1 ratio) are often used as they are transparent and easy to apply.[21]

In the base-case option, costs for people with dementia were estimated "total costs"; that is, costs attributed to dementia were not separated from other costs. It should be emphasized that older people with dementia often have many co-occurring conditions that interact in complex ways. Attributing costs to a specific disorder for people with several comorbid conditions is thus methodologically challenging and perhaps conceptually questionable.

The PPP option results in higher costs. However, PPPs are useful for country-by-country comparisons, but if PPPs are used for global cost estimates, we implicitly assume that all countries have the same purchasing power as the United States, which is questionable.

Global cost comparisons are challenging with different prerequisites for different conditions. For example, in estimates of global costs of diabetes,[38] the major component in the indirect costs are production losses, in contrast to informal care in dementia. Discussions of a methodological framework for global cost comparisons are needed.

5 | CONCLUSIONS

Despite the multiple methodological challenges, we have been able to highlight the huge global economic costs of dementia—across the world and impacting all care systems. The contributions of unpaid caregivers, and the associated costs, are huge. There is also a substantial imbalance between how and where people with dementia live and the distribution of costs (and therefore the care resources made available to them). The potential (and still unknown) effects of prevention and disease-modifying treatments are beyond the scope of this paper but would be highly pertinent when future scenarios are discussed.

CONFLICTS OF INTEREST

Anders Wimo: The first author was commissioned by the World Health Organization to perform this study (agreement for performance of work, WHO registration 2017/761958-0). Katrin Seeher: staff member of the World Health Organization. Rodrigo Cataldi: consultant

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REFERENCES

1. The top 10 causes of death [Internet]. World Health Organization. 2021 [cited 27 November 2021]. https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death
2. WHO. *Global Status Report on the Public Health Response to Dementia.* Geneva; 2021.
3. WHO. *Dementia: A Public Health Priority.* WHO, ed. Geneva: WHO; 2012.
4. Wimo A, Prince M. *World Alzheimer Report 2010. The Global Economic Impact of Dementia.* London; 2010.
5. Wimo A, Jonsson L, Bond J, Prince M, Winblad B. The worldwide economic impact of dementia 2010. *Alzheimers Dement.* 2013;9(1):1-11.e3.
6. Prince M, Wimo A, Guerchet M, Ali GC, Wu Y-T, Prina M. *The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Costs and Trends.* Alzheimert's Disease International; 2015.
7. Wimo A, Guerchet M, Ali GC, et al. The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimers Dement.* 2016;13:1-7.
8. Wimo A, Jonsson L, Winblad B. An estimate of the worldwide prevalence and direct costs of dementia in 2003. *Dement Geriatr Cogn Disord.* 2006;21(3):175-181.
9. Winblad B, Wimo A, Jönsson L, editors. *The Worldwide Direct Costs and Costs of Informal Care of Dementia.* ICAD; 2006.
10. Wimo A, Jönsson L, Winblad B. An estimate of the total worldwide societal costs of dementia in 2005. *Alzheimers Dement.* 2007;3:81-91.
11. Wimo A, Winblad B, Jonsson L. The worldwide societal costs of dementia: estimates for 2009. *Alzheimers Dement.* 2010;6(2):98-103.
12. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc.* 2015;13(3):141-146.
13. Kenne Malaha A, Thébaut C, Achille D, Preux P-M, Guerchet M. Costs of dementia in low- and middle-income countries: A systematic Review. *J Alzheimers Dis.* 2022. doi: 10.3233/JAD-220239. Online ahead of print
14. Prince M, Ferri CP, Acosta D, et al. The protocols for the 10/66 dementia research group population-based research programme. *BMC Public Health.* 2007;7:165.
15. Berger ML, Bingefors K, Hedblom EC, Pashos CL, Torrance GW. *Health Care, Cost, Quality and Outcomes: ISPOR Book of Terms.* Ispor; 2003.
16. IHME. All dementia, GBD2019. In: *(IHME) Ifhmae,* editor. IHME; 2020.
17. GBD. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health.* 2022;7(2):e105-e125.
18. UN. File POP/7-1: Total population (both sexes combined) by five-year age group, region, subregion and country, 1950-2100 (thousands). Medium fertility variant.: United Nations; 2020 [cited 2020 Dec 14, 2020]. https://population.un.org/wpp/Download/Standard/Population/
19. Collaborators GBDD. Global age-sex-specific fertility, mortality, healthy life expectancy (HALE), and population estimates in 204 countries and territories, 1950-2019: a comprehensive demographic

analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020;396(10258):1160-1203.

20. OECD, Eurostat, WHO. *A System of Health Accounts 2011: Revised Edition*. OECD; 2017.

21. van den Berg B, Brouwer WB, Koopmanschap MA. Economic valuation of informal care. An overview of methods and applications. *Eur J Health Econ*. 2004;5(1):36-45.

22. ILO. ILOSTAT Geneva: International labour Organization (ILO); 2019. http://www.ilo.org/ilostat/faces/oracle/webcenter/portalapp/pagehierarchy/Page3.jspx?MBI_ID=435

23. IMF. World Economic and Financial Surveys. World Economic Outlook Database: International Monetary Fund (IMF); 2020. https://www.imf.org/en/Publications/WEO/weo-database/2020/October

24. Belger M, Haro JM, Reed C, et al. How to deal with missing longitudinal data in cost of illness analysis in Alzheimer's disease-suggestions from the GERAS observational study. *BMC Med Res Methodol*. 2016;16:83.

25. Casals M, Girabent-Farres M, Carrasco JL. Methodological quality and reporting of generalized linear mixed models in clinical medicine (2000-2012): a systematic review. *PLoS One*. 2014;9(11):e112653.

26. WHO. Global status report on the public health response to dementia-Web Annex-Methodology for producing global dementia cost estimates2021 [cited 2021] https://apps.who.int/iris/bitstream/handle/10665/344479/9789240033269-eng.pdf

27. Databank World Development Indicators [Internet]. The World Bank. 2022 [cited April 29, 2022]. https://databank.worldbank.org/reports.aspx?source=2&series=PA.NUS.PPPC.RF&country=#

28. ADI. *World Alzheimer Report 2009*. ADI; 2009.

29. Breuer E, Comas-Herrera A, Freeman E, et al. Beyond the project: building a strategic theory of change to address dementia care, treatment and support gaps across seven middle-income countries. *Dementia (London)*. 2021;21(1):114-135. doi:14713012211029105.

30. Olafsdottir M, Skoog I, Marcusson J. Detection of dementia in primary care: the Linkoping study. *Dement Geriatr Cogn Disord*. 2000;11(4):223-229.

31. Nygaard HA, Ruths S. Missing the diagnosis: senile dementia in patients admitted to nursing homes. *Scand J Prim Health Care*. 2003;21(3):148-152.

32. Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: the Canadian Study of Health and Aging. *J Am Geriatr Soc*. 2000;48(11):1430-1434.

33. Wimo A, Nordberg G. Validity and reliability of assessments of time. Comparisons of direct observations and estimates of time by the use of the resource utilization in dementia (RUD)-instrument. *Arch Gerontol Geriatr*. 2007;44(1):71-81.

34. McDaid D. Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. *Int J Geriatr Psychiatry*. 2001;16(4):400-405.

35. Costa N, Ferlicoq L, Derumeaux-Burel H, et al. Comparison of informal care time and costs in different age-related dementias: a review. *Biomed Res Int*. 2013;2013:852368.

36. ILO. *Care Work and Care Jobs for the Future Of Decent Work*. International Labour Organization; 2018.

37. Drummond MF, O'Brien B, Stoddart GL, Torrance GW. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford University Press; 1997.

38. Bommer C, Heesemann E, Sagalova V, et al. The global economic burden of diabetes in adults aged 20-79 years: a cost-of-illness study. *Lancet Diabetes Endocrinol*. 2017;5(6):423-430.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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