

Featured Articles

The worldwide economic impact of dementia 2010

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Abstract

Objective: To acquire an understanding of the societal costs of dementia and how they affect families, health and social care services, and governments to improve the lives of people with dementia and their caregivers.

Methods: The basic design of this study was a societal, prevalence-based, gross cost-of-illness study in which costs were aggregated to World Health Organization regions and World Bank income groupings.

Results: The total estimated worldwide costs of dementia were US\$604 billion in 2010. About 70% of the costs occurred in western Europe and North America. In such high-income regions, costs of informal care and the direct costs of social care contribute similar proportions of total costs, whereas the direct medical costs were much lower. In low- and middle-income countries, informal care accounts for the majority of total costs; direct social care costs are negligible.

Conclusions: Worldwide costs of dementia are enormous and distributed inequitably. There is considerable potential for cost increases in coming years as the diagnosis and treatment gap is reduced. There is also likely to be a trend in low- and middle-income countries for social care costs to shift from the informal to the formal sector, with important implications for future aggregated costs and the financing of long-term care. Only by investing now in research and the development of cost-effective approaches to early diagnosis and care can future societal costs be anticipated and managed.

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Keywords:

Alzheimer's disease; Dementia; Costs; Cost of illness

1. Introduction

Today, more than 35 million people live with dementia, 54% of whom live in countries with low or middle incomes (LMIC)[1–3]. Numbers affected are set nearly to double every 20 years, with the most rapid increases in LMIC.

A. W. had full access to all the data in the study and had the final responsibility for the decision to submit for publication. A. W., B. W., and L. J. are consultants to drug companies that are purchasing or developing drugs for treatment of Alzheimer's disease or other dementias (eg, Pfizer, Janssen-Cilag, Astra-Zeneca, Novartis, Merz, Lundbeck, Forest, GSK, Wyeth, Sanofi, Elan, Neurochem, Lilly, and BMS), but their occupation did not influence the work associated with this article, nor was there any financing received from these companies.

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Among older people, dementia is the leading chronic disease contributor to disability and need for care. Dementia is thus affecting every health system in the world significantly, and large amounts of resources and money are spent in caring for people with dementia. A proper understanding of the societal costs of dementia and how they affect families, health and social care services, and governments is fundamental to raising awareness, achieving proper prioritization, and focusing efforts to improve the lives of people with dementia and their caregivers. The aim of this article, summarizing the findings in the 2010 World Alzheimer Report [2] and parts of the World Health Organization (WHO) dementia report [4] is to highlight the economic impact of dementia worldwide so that governments and health and social care systems are better prepared for the future.

Cost-of-illness (CoI) studies for dementia have already been carried out for some regions and countries, mainly from high-income (HIC) parts of the world—for example, the whole of Europe [5], the United Kingdom [6], Sweden [7], Australia [8], the United States [9], and Canada [10]. The consensus is that dementia is already imposing huge societal economic burdens, both through direct (medical and social care) and indirect (unpaid caregiving by families and friends) costs. Evidence is just beginning to emerge of the extent of the economic burden in middle-income countries [9–12].

CoI studies are descriptive. They can be used to quantify the total societal economic burden of a health condition and can highlight the relative impact on different health and social care sectors. The distribution of costs among different countries and regions can also be estimated and compared. CoI studies can also be used to describe or (with less certainty) to predict the extent of changes in or distribution of costs over time. Although CoI studies conducted on different health conditions can be used to compare burden, some caution is needed in using these estimates to set priorities. The methods used, particularly the types of costs included or excluded, and the data used to estimate them may not be strictly comparable across different health conditions. Also, it has been argued that prioritization for investment in health care should be determined by the relative incremental cost-effectiveness of available interventions, rather than the burden of the disease [11]. Transparency is crucial with regard to the assumptions underlying any cost calculations and comparisons.

Previously, three articles that highlight the global economic burden have been published [12–14]. These reports were, at the time of their publication, based on the best available data for the prevalence of dementia and care inputs. The most recent of these updated previous estimates of global costs from US\$315 billion in 2005 to US\$422 billion in 2009, an increase of 34% (18% in fixed prices) in just 4 years. This update was based on the same database and the increase is mainly a result of an increase in numbers of people affected by dementia (from 29 million to 34 million). US\$312 billion per year (74% of the worldwide total) is contributed by countries designated by the United Nations as more developed regions and US\$110 billion (26% of the total) by less-developed regions. One major limitation of these reports is that they contained very few data on health and social care from LMIC and eastern Europe. Therefore, the cost models relied largely on extrapolation of economic conditions from higher to lower income countries, adjusted for gross domestic product (GDP) per person. Also, it was not possible to distinguish between direct medical costs (within the health care sector) and direct social care costs (within the community and care home sector). Because more articles are now published that at least overcome the limitations mentioned earlier in part, we are now merging the best available data regarding the worldwide cost of Alzheimer's disease and other dementias.

2. Methods

The estimated numbers of people affected by dementia worldwide and in different regions worldwide are based on the World Alzheimer Report 2009 [1], the WHO dementia report [4], and the joint article in this issue of *Alzheimer's & Dementia* [3]. We estimate that 35.6 million people lived with dementia in 2010.

2.1. Literature search for the CoI estimates

The search was done in PubMed/Medline, Ingenta, Cochrane Library, National Health Service Economic Evaluation Database/Health Technology Assessment Database, Health Economic Evaluations Database, Excerpta Medica base, Current contents, PsycINFO, Educational Resources Information Center, societal services abstracts and sociological abstracts. The search terms (Medical Subject Headings/Sub-headings when appropriate) were dementia/Alzheimer's disease/Alzheimer disease combined with cost and/or economic and informal care. Two recent systematic reviews [15,16] and secondary articles from reference lists were also considered for inclusion.

2.2. Key design issues

An ideal, worldwide CoI study has a societal viewpoint that includes comprehensive accounting of informal care, and direct medical and social care costs. Precise data on the prevalence of dementia and resource use should be derived from representative population-based studies. These data, and the unit costs applied to the resources used, should refer to the same index year. The same methods should be used to collect these data across all countries.

The reality is different:

- Estimates of the size of the older population are of variable quality.
- Data on dementia prevalence are not available for all countries [1].
- Most studies of care arrangements, informal care, and resource use for people with dementia use convenience rather than representative population-based samples. People identified through convenience sampling tend to have more advanced and severe dementia, their caregivers typically report higher levels of strain, and the families are likely to have accessed and to have used more health and community support services. Many of the estimates come from small studies and, hence, may be imprecise. Many studies are not recent, and care arrangements and patterns of health care use may change over time. For many countries, there are few or no studies available
- Most of the source articles have a bottom-up design. This means that CoI data from local studies are extrapolated to a greater population (eg, a country).

The costs (as well as the prevalence of dementia) reflect estimates for 2010. Cost estimates based on previous years are inflated to 2010, using relevant country-specific data from the International Monetary Fund or World Economic Outlook [17], or, if lacking from those sources, from the World Bank [18] or World Fact Book [19]. Data on per-capita GDP were obtained in a similar way. To permit aggregation across countries, and comparisons among countries and regions, costs are expressed as U.S. dollars, converted from local currencies based on current exchange rates. An approach based on purchasing power parity (PPP) was used in the sensitivity analysis.

With these limitations and assumptions in mind, our base case approach is a societal, prevalence-based gross CoI study in which country-specific annual per-capita costs (direct medical and social care costs, and informal care) have been applied to estimated numbers of people with dementia in each country (derived from the World Alzheimer Report 2009 [1]), and aggregated up to the level of WHO Global Burden of Disease (GBD) regions, and World Bank country income-level groupings (the income groups per annum are low income, \$995 or less; lower middle income, \$996–\$3945; upper middle income, \$3946–\$12,195; and HIC, \$12,196 or more). The assumptions for all the cost of illness estimates are summarized in Table E1.

2.3. Imputation approaches

Our general aim was to generate evidence-based estimates of resource use for each country. For all the reasons presented earlier, it was necessary to rely on some degree of imputation. When >1 estimate was available for a given country, we selected the one that we regarded to be the most appropriate study in terms of representativeness and sample size. When no estimate was available, we first used estimates from other similar countries within the same region or, failing that, adjacent regions.

2.4. Where do people with dementia live?

To estimate costs accurately and to apportion costs appropriately within sectors, it is crucial to estimate the relative proportions of people with dementia living at home or in a long-term care home. In HIC, people with dementia residing in care homes contribute a substantially greater amount to the total cost of illness than in LMIC, where anecdotal information suggests that few such facilities exist. The large majority of people with dementia are cared for, informally, in the community. Thus, Alzheimer Disease International (ADI) commissioned a worldwide questionnaire survey of key informants (eg, clinicians, social workers, Alzheimer associations representatives, policy-makers) who estimated what proportion of people with dementia resided in care homes, separately for urban and rural areas. From a United Nations database, we gathered information on the rural–urban population distributions [20] that, when combined with the results from the ADI questionnaire, gave a single weighted proportion of people

with dementia living in the community, and hence likely to be in receipt of informal care.

2.5. Informal care

The care input by family members, friends, and others has an important influence on the societal costs of dementia, since it is a producer of an extensive amount of unpaid informal care [21,e1–e5]. However, translating this contribution into costs is not straightforward. First, quantifying caregiver time is problematic. The inputs most commonly assessed are (1) assistance with basic activities of daily living (ADL), such as eating, dressing, bathing, toileting, grooming, and getting around—sometimes referred to as personal care; (2) assistance with instrumental activities of daily living (IADL), such as shopping, preparing food, using transport, and managing personal finances; (3) supervision to manage behavioral symptoms or to prevent dangerous events [21].

Personal care is relatively easy to assess and interpret across countries and cultures, but the nature and relative importance of IADLs are likely to be much more culture specific. Furthermore, the person with dementia and the caregiver may each contribute to these activities—for example, shopping (referred to as joint production).

Second, costing informal care is also complicated and controversial [22–29]. Two methods are frequently used: the opportunity cost approach and the replacement cost approach. To calculate the opportunity cost, it is first necessary to identify the possible alternative use of the caregiver's time. For caregivers who give up or cut back on work to provide care, the cost for informal care should be valued according to the production loss resulting from absence from work. More challenging is the costing of caregiver time for retired people. There is no obvious answer to how this should be calculated because there are no obvious market prices [27]. The replacement cost approach assumes that the informal caregiver's inputs should be calculated according to the cost of replacing their care input with those of a professional caregiver.

Based on our review of the international literature, we identified

- 10 appropriate studies in which time spent assisting with basic ADLs was quantified, covering 25 countries [1,e4,e6–e13] and representing 63% of the worldwide dementia population. The average caregiver input was 2.0 hours/day (range, 1.1–3.0 hours/day in WHO regions).
- 42 studies with time spent assisting with basic ADLs and IADLs combined, covering 30 countries and representing 73% of the worldwide dementia population [1,6,8,e1–e39] (average caregiver input, 3.6 hours/day; range, 1.4–4.7 hours/day).
- 13 studies with estimates of time spent in supervision, covering 25 countries and representing 63% of the worldwide dementia population [1,e1,e4,e7,e8,e10,

e12,e13,e19,e30–e33] (average caregiver input, 2.6 hours/day; range, 1.2–3.4 hours/day).

Regional imputation was carried out for the remaining countries according to the procedures described previously. However, for all African regions, in the absence of any regional data, worldwide average figures were used. Although the degree of imputation required was quite substantial, particularly in LMIC, this still represents a considerable advance on the evidence base available for previous reports because, to a large extent, we were able to use region-specific figures. The detailed estimates from six Latin American countries, India, and China from the 10/66 Dementia Research Group provided important data from LMIC.

We used the combined ADL figures (combining basic ADL and IADL care inputs) as the base option (Table E2). We then conducted sensitivity analyses using only basic ADLs (personal care) and all categories of informal care. Our justifications were that support for IADLs is an important part of the caregiver's life with a person with dementia, and that there are many more articles describing combined ADLs than those covering only basic ADL care input.

The base option for costing informal care uses the opportunity cost approach, valuing informal care by the average wage for each country [30]. Average wage figures were available for 131 countries, covering 96% of people with dementia worldwide. A woman was identified as the main informal caregiver for 55% to 91% of people with dementia (25 studies representing countries with 78% of the global dementia population) [1,e10–e12,e23,e26,e36,e40–e57], and the wage figures were adjusted according to gender differences in average wage. From the caregiver literature [1,31–36,e3,e5,e10–e12,e23,e26,e31–e33,e36,e40,e43–e51,e54], spouses are the main caregivers for 41% of people with dementia, but with regional differences. Different ad hoc costing approaches of the spouse input (25% and 50% of average wage) were tested in the sensitivity analysis.

2.6. Direct costs

Data on direct costs were available from 21 countries, representing 49% of the worldwide dementia population. For each country, we sought to estimate both total direct costs, and the distribution between direct medical and social care costs. Direct medical costs refer to the medical care system, such as costs of hospital care, medication, and visits to clinics. Direct social care costs are for formal services provided outside of the medical care system, including community services such as home care, food supply, and transport, and residential or nursing home care.

Regional imputation from local similar countries was possible for an additional 74 countries, representing 27% of the worldwide dementia population, mainly in Europe but also in Latin America. For the remaining 24% of the dementia population, in 97 countries mainly in Africa and Asia (mainly LMIC), no data were available even from neighboring countries. From macroeconomic research, it is known

that there is a strong correlation at country level between per-capita expenditure on health care and per-capita GDP. Similarly, a single linear regression model indicated a strong relationship between the costs per person with dementia and year and the GDP per person and year (derived from 31 articles [6–10,37–48,e7,e9,e11,e12,e23,e25,e32,e33,e37–e39,e48,e51,e54]); for each increase by US\$1 in annual per-capita GDP, the annual cost per person with dementia increased by US\$0.37 ($P < .001$, $r^2 = 0.43$; 95% confidence interval [CI], 0.22–0.51). This approach was used to estimate the total direct costs for the 97 countries with no data. However, regression did not work well for the estimation of the distribution between direct medical and social care costs because of the lack of data, and so the percentage distribution observed in one country (China) was used to specify the likely distribution. China represents a large proportion of the worldwide dementia population and even more of that from LMIC. From Chinese studies, there were also data for which it was possible to split direct costs into medical and social care costs. Thus, it was regarded as justified to use China as the key country for these estimates.

2.7. Representativeness

Of the 42 studies that were used for estimating the costs of informal care, we regard 11 studies as having population-based designs or including control subjects (people without dementia). For direct costs, the corresponding figures were 11 of 31 studies. Thus, there is still a risk that costs may be overestimated because part of the results are based on nonpopulation-based studies or studies without control subjects.

2.8. Sensitivity analysis

Because CoI studies depend on a set of sources and assumptions, there are always uncertainties in cost estimates. To consider the impact of the uncertain background factors mentioned earlier, we have conducted a comprehensive set of one-way sensitivity analyses in which we use different source data or varied assumptions. However, another component of the sensitivity analysis is to highlight the fact that there are different views of what should be included in a CoI estimate—for example, regarding exchange rates vs PPPs or informal care (quantification and costing).

An alternative to the regional imputation method for missing data of informal care is to regress average wage on GDP per person. This regression model showed that a change of GDP per person by US\$1 will change the average hourly wage by US\$0.000263 \$ (95% CI, 0.000214–0.000312; $P < .0001$, $r^2 = 0.48$).

Because a substantial proportion of caregivers are spouses and most, but not all, could be assumed to be beyond the usual working age, we recalculated informal care and total costs to value the care inputs of spouse caregivers at 50% and 25% of the average wage, and applied this reduced wage to the estimated proportion of caregivers in each country that were spouses.

Thus, in the sensitivity analysis, we compared (1) the types of informal care that should be included in cost estimations, (2) the hourly costs to be attached to informal caregiver inputs by regression, (3) the relative cost of inputs from different types of caregiver, (4) a replacement cost approach instead of an opportunity cost, and (5) the use of PPPs instead of current exchange rates.

3. Results

3.1. Results of base option

For the ADI worldwide questionnaire survey, we had data from 86 respondents in 48 countries (eight outliers were excluded because of a great discrepancy vs other responders from the same country). Two trends were obvious; first, the mean proportion of people with dementia residing at home from the survey was higher in LMIC (89%; 95% CI, 83–95) than in HIC (70%; 95% CI, 63–77). When the proportions for each country were applied to individual countries and aggregated up, we estimated 94% (95% CI, 92–96) living at home in LMIC and 78% (95% CI, 75–81) in HIC.

Second, the proportion of people with dementia that live at home was higher in rural than in urban areas: 86% (95%

CI, 81–91) or 92% (95% CI, 90–94) when extrapolated to the worldwide model for rural areas vs 78% (95% CI, 73–83) in the ADI questionnaire or 87% (95% CI, 85–89) when extrapolated to the worldwide model for urban areas.

The per-capita costs of dementia varied considerably by World Bank income classification, from US\$868 in countries with low incomes to US\$3109 in LMIC to US\$6827 in upper middle income countries to US\$32,865 in countries with high incomes (Table 1). When multiplied by the estimated numbers of people with dementia, this generated aggregated costs of US\$4.37 billion in countries with low incomes, US\$29.21 billion in LMIC, US\$32.39 billion in upper middle income countries, and US\$537.91 billion in countries with high incomes. The total estimated worldwide costs of dementia were US\$604 billion in 2010 (Table 1). It is clear, therefore, that the costs of dementia are distributed unevenly. About 70% of the global societal costs of dementia occur in just two WHO GBD regions—western Europe and North America—and 89% of the total costs are incurred in HIC. However, the minority (46%) of people with dementia live in HIC. Thirty-nine percent of people with dementia live in middle-income countries (where 10% of costs are incurred) and 14% live in low-income countries (<1% of the total costs; Table 2). The global societal cost corresponds to about 1% of the aggregated worldwide GDP (or 0.6% if

Table 1

Per capita (US\$) and aggregated costs of dementia (in billions of US\$) by World Health Organization global burden of disease region and World Bank income classification

WHO region	Per capita costs, US\$	People with dementia, n	Aggregated costs, billions of US\$					
			Total costs	Total costs as a% of GDP	Direct costs as a% of GDP	Informal care (all ADLs)	Direct medical costs	Direct social costs
Australasia	32,370	311,327	10.08	0.97	0.56	4.30	0.70	5.07
Asia Pacific high income	29,057	2,826,388	82.13	1.31	0.76	34.60	5.23	42.29
Oceania	6059	16,553	0.10	0.46	0.12	0.07	0.02	0.01
Asia, central	2862	330,125	0.94	0.36	0.20	0.43	0.28	0.24
Asia, east	4078	5,494,387	22.41	0.40	0.13	15.24	4.33	2.84
Asia, south	903	4,475,324	4.04	0.25	0.11	2.31	1.16	0.57
Asia, southeast	1601	2,482,076	3.97	0.28	0.15	1.77	1.48	0.73
Europe, western	30,122	6,975,540	210.12	1.29	0.75	87.05	30.19	92.88
Europe, central	12,891	1,100,759	14.19	1.10	0.44	8.59	2.67	2.94
Europe, eastern	7667	1,869,242	14.33	0.90	0.40	7.96	3.42	2.94
North America high income	48,605	4,383,057	213.04	1.30	0.82	78.76	36.83	97.45
Caribbean	9092	327,825	2.98	1.06	0.53	1.50	0.78	0.71
Latin America, Andean	3663	254,925	0.93	0.43	0.27	0.35	0.31	0.28
Latin America, central	5536	1,185,559	6.56	0.37	0.28	1.58	2.61	2.37
Latin America, southern	8243	614,523	5.07	1.02	0.54	2.36	1.42	1.29
Latin America, tropical	6881	1,054,560	7.26	0.42	0.29	2.17	2.67	2.42
North Africa/Middle East	3926	1,145,633	4.50	0.16	0.09	1.90	2.05	0.54
Sub-Saharan Africa, central	1081	67,775	0.07	0.06	0.02	0.04	0.02	0.01
Sub-Saharan Africa, east	1122	360,602	0.40	0.17	0.05	0.28	0.08	0.04
Sub-Saharan Africa, southern	6834	100,733	0.69	0.24	0.06	0.52	0.11	0.06
Sub-Saharan Africa, west	969	181,803	0.18	0.06	0.02	0.11	0.04	0.02
Low income	868	5,036,979	4.37	0.24	0.10	2.52	1.23	0.62
Lower middle income	3109	9,395,204	29.21	0.35	0.12	18.90	6.74	3.57
Upper middle income	6827	4,759,025	32.49	0.50	0.29	13.70	10.44	8.35
High income	32,865	16,367,508	537.91	1.24	0.74	216.77	78.00	243.14
Total	16,986	35,558,717	603.99	1.01	0.59	251.89	96.41	255.69

Abbreviations: GDP, gross domestic product; ADLs, activities of daily living; WHO, World Health Organization.

Table 2

The contribution of each World Bank income region to the global prevalence of dementia and to global costs (informal care, direct medical and social care costs, and total costs)

World Bank income region	Proportion of overall population, %	Proportion of people with dementia, %	Informal care (all ADLs), %	Direct costs, %		Total costs, %
				Medical	Social	
Low	30.6	14.2	1.0	1.3	0.2	0.7
Lower middle income	38.5	26.4	7.5	7.0	1.4	4.8
Upper middle income	13.0	13.4	5.4	10.8	3.3	5.4
High	17.8	46.0	86.1	80.9	95.1	89.1
Total	100	100	100.0	100.0	100.0	100.0

Abbreviation: ADLs, activities of daily living.

only direct costs are considered). The total cost, as a proportion of GDP, varied from 0.24% in low-income countries to 1.24% in HIC, with the highest proportions in North America (1.30%) and western Europe (1.29%) GBD regions. The distribution of total costs between sectors also varied markedly by country income level. In HIC, the costs of informal care (45%) and the direct costs of social care (40%) generally contribute similar proportions to total costs, whereas the proportionate contribution of direct medical costs (15%) are much lower (Table 3). However, in low-income and LMIC, direct social care costs are small and informal care costs predominate. Thus, although the total cost per person with dementia is 38 times higher in HIC than in low-income countries, the direct costs of social care are 120 times higher (Table 4).

3.2. Sensitivity analyses

If only basic ADLs are used for the costs of informal care instead of combined ADLs (basic ADLs and IADLs), the total costs are 22% lower, whereas they are 30% higher if combined ADLs and supervision are included. Compared with US\$604 billion in the base case, these sensitivity analyses provide a lower bound estimate of US\$470 billion (only basic ADLs) and an upper bound estimate of US\$783 billion (all informal care including assistance with basic ADLs and IADLs, and supervision).

If the regression model is applied for missing data of informal care, the results are similar to the base option. The use of alternative cost of inputs from different types of caregiver leads to a reduction in the total worldwide cost estimate from US\$604 billion in the base case to US\$548 billion (a 9% reduction) when cost at 50% of the average wage, and to US\$520 billion (a 14% reduction) when cost at 25% of the average wage.

With the replacement costs approach, based on the average wage of a social care professional from the Laborsta database (health and social work) [30], the total costs were slightly higher.

If PPPs are used for the estimates instead of exchange rates, the total worldwide costs are 7.4% higher (Table 5). Using the base-case option, low-income countries accounted for just 0.7% of total worldwide costs, middle-income countries for 10.2%, and HIC for 89.1%. Using

PPP, these proportions are 2.1%, 20.0%, and 77.9%, respectively.

3.3. Comparison with previous worldwide cost estimates of dementia

In 2007, the worldwide costs of dementia were estimated as US\$315 billion [13], and were later updated to US\$422 billion for 2009 [14]. The basic assumptions in these articles were different from those in this article. First, only basic ADL assistance rather than combined basic ADL and IADL assistance were included for estimating the costs of informal care, and PPPs instead of exchange rates were used for the currency transformations. The number of basic ADL hours per day was also somewhat lower and was assumed to be uniform across the world in the 2005 and 2009 estimates (1.6 hours/day). However, in the sensitivity analyses for these earlier estimates, options similar to those applied in this article were included, making direct comparisons possible. When doing so, it is clear that the costs per person with dementia are rather similar, particularly for the combined ADLs (Table 6).

4. Discussion

4.1. Impact of the results

The estimated annual worldwide cost to society of dementia—US\$604 billion—highlights the enormous impact that dementia has on socioeconomic conditions worldwide. It is difficult to envisage so large a sum, equivalent to around 1% of the world's GDP. If dementia care was a country, it would be the world's 21st largest economy,

Table 3

Aggregated costs types as percentages of total costs in the different World Bank income regions

World Bank income region	Informal care (all ADLs), %	Direct costs, %		Total costs, %
		Medical	Social	
Low	57.6	28.2	14.3	100
Lower middle	64.7	23.1	12.2	100
Upper middle	42.2	32.1	25.7	100
High	40.3	14.5	45.2	100
All	41.7	16.0	42.3	100

Abbreviation: ADLs, activities of daily living.

Table 4
Cost per person with dementia by World Bank income region

World Bank income region	Informal care (all ADLs), US\$	Direct costs, US\$		Total costs, US\$
		Medical	Social	
Low	500	244	124	868
Lower middle	2012	717	380	3109
Upper middle	2879	2194	1755	6827
High	13,244	4766	14,855	32,865
All	7084	2711	7191	16,986

Abbreviation: ADLs, activities of daily living.

ranking between Poland and Saudi Arabia. If it was a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion).

The scale of these costs is understandable when one considers that, according to our estimates in the World Alzheimer Report 2009 [1], 35.6 million people worldwide (around 0.5% of the world's total population) live with dementia. A high proportion of people with dementia need some care, ranging from support with IADLs (such as cooking or shopping), to full personal care and round-the-clock supervision. In some HIC, between one third and one half of all people with dementia live in resource- and cost-intensive residential or nursing home care facilities [6,49].

There is a clear imbalance in the global distribution of occurrence of dementia and costs. Although the majority of people with dementia live in countries with low or middle incomes, the much higher per-capita costs of dementia that prevail in countries with high incomes mean that 89% of global societal costs are currently incurred in those regions. This disparity arises, in part, because of the imbalance of costs between sectors. In low-income and LMIC, the formal social care sector (accounting for the direct costs of care in the community by paid social care professionals, and of care homes) is practically nonexistent. Therefore, responsibility falls largely on unpaid informal caregivers. In these regions, informal care costs predominate (accounting for around two thirds of all costs compared with around 40% in HIC), whereas in HIC the direct costs of social care account for nearly half of all costs, compared with only one

10th in lower income countries. Because average wages (used to estimate informal care costs) are much lower in LMIC, this has an important impact on comparative total costs.

4.2. Methodological issues

The accuracy of any estimate of the worldwide costs of dementia depends on the quality of the data used to estimate it. This article is based on better underlying sources than previous worldwide estimates, but there are, nevertheless, significant limitations. Because of the uncertainties, we consequently use the concept of cost estimates rather than cost calculations. Our global CoI estimates rely on studies of dementia prevalence and dementia-related resource use that are unequally distributed worldwide, with data lacking from many countries. Even with the recent large increase in population surveys conducted in LMIC, there is a particular lack of relevant studies from Africa, the Middle East, and from eastern Europe. Data on resource use are also more extensive than previously available, particularly with respect to informal care provision in LMIC. The 10/66 Dementia Research Group studies in Latin America, India, and China [1,e34] add significantly to the preexisting database, which was heavily skewed to European and North American studies. The results from the ADI worldwide survey of key informants regarding placement in residential care is also a great advance from previous studies. It should be noted that the majority of resource use studies have been carried out on convenience samples of those who have accessed services, rather than representative population-based studies, and hence are skewed toward those greater need for care, which may result in an overestimate of costs, particularly in HIC. The LMIC estimates of informal care were based largely on the 10/66 population-based studies in Latin America, India, and China [1], where in most study sites between 30% and 50% of those with dementia were rated as needing no care, whereas most HIC estimates are derived from convenience samples.

The most significant limitation is in the estimation of direct costs of both medical and social care. In this study, these

Table 5
Sensitivity analysis by World Bank income regions

One-way sensitivity analysis alternative	Low income	Lower middle income	Upper middle income	High income	All
Base case	4.37	29.21	32.49	537.91	603.99
Basic ADLs	3.16	24.23	28.09	414.13	469.60
All ADL + supervision	5.76	38.40	45.06	694.07	783.29
Regression model	4.19	28.87	32.20	536.38	601.63
Spouse caregiving valued at 50% of average wage	4.04	25.73	30.09	488.44	548.29
Spouse caregiving valued at 25% of average wage	3.87	23.98	28.89	463.70	520.44
Replacement cost (average wage for a social care professional)	4.36	22.94	31.65	557.75	616.71
PPPs	13.51	58.92	70.54	504.63	647.60

Abbreviations: ADLs, activities of daily living; PPPs, purchasing power parities.

Table 6
Comparisons with current cost estimates and previous reports with similar assumptions

Comparison approach	Base case	[5]	[7]
Year	2010	2009	2005
Unadjusted cost of illness estimate in study, US\$ in billions	604.0	421.6	315.4
People with dementia as estimated in study, n	35,558,717	34,376,044	29,336,448
Cost of illness including combined ADLs (PPPs, inflated to 2010, prevalence of 2010), US\$ in billions*	647.6	645.3	668.3
Cost of illness including basic ADLs (PPPs, inflated to 2010), prevalence of 2010 US\$ in billions*	509.3	447.2	465.1
Total cost per person with dementia including combined ADLs (PPPs, inflated to 2010, prevalence of 2010), US\$ in billions*	18,212	18,147	18,796
Total cost per person with dementia including basic ADLs (PPPs, inflated to 2010, prevalence of 2010), US\$ in billions*	14,322	12,577	13,079

Abbreviations: ADLs, activities of daily living; PPP, purchasing power parity.

*Costs inflated to 2010 by using average world inflation figures.

figures are based, in part, on imputation from nearby countries, but for many others were estimated with a regression model, based mainly on HIC data. These figures must be interpreted with caution. The use of exchange rates to provide a standard metric for comparing costs across countries may have underestimated costs in lower incomes relative to HIC. When the PPP approach was used instead, 78% of costs are incurred in HIC (instead of 89% as in the base case), 20% (instead of 10%) in middle-income countries, and 2% (instead of 1%) in low-income countries. The sensitivity analysis also reflects the fact that there are different opinions of what should be included in the cost estimates, particularly regarding informal care, and how these should be cost. The use of average wage for the costing of informal care may, arguably, overestimate costs arising from the contributions of those who would not normally form part of the labor force—for example, retired spouses. There may also be an impact of caregiving on the health of the informal caregivers [50] that, subsequently, may result in an increase in their use and costs of health services. However, because of the lack of data, it was not possible to include such costs in the cost model.

4.3. Future trends

It is very difficult to make projections of future costs. However, if we assume that all potential background factors remain unchanged, and we factor in only the increases in the number of people with dementia forecast, then by 2030 worldwide societal costs will have increased by 85%. The reality is more complicated. Future costs could be influenced by macroeconomic factors (for example, the pace of economic development) and by dementia-specific factors, including changes in the incidence and prevalence of dementia, in patterns of help seeking and trends toward earlier diagnosis, in the availability of health and social care services, changes in care systems and care conditions, and the availability of new and more effective treatments.

There are very few estimates of the extent of the treatment gap for dementia in LMIC, but it is likely to be much greater

than in better resourced settings [51]. However, the cost of drugs tend to be quite similar worldwide (as was recently reported for acetylcholinesterase inhibitors for Alzheimer's disease [52]), and hence relatively unaffordable in LMIC. Now the patents are going out, but it is, for the moment, difficult to estimate what the effects might be.

The current inequitable distribution in dementia costs among world regions will also have implications for future trends. These will inevitably tend toward more rapidly increasing per-capita and population costs in LMIC, in such a way that the global distribution of costs will come to resemble that of morbidity. Cost increases in LMIC countries are likely to be driven by several underlying factors. Despite the probability that economic development will change health care use in general, there are some factors that are more or less related to future cost estimates of dementia (and similar conditions in which informal care is a significant component). First, increases in numbers of people with dementia will occur much more rapidly in LMIC, because of the more rapid demographic aging in those regions. Thus, in the World Alzheimer Report 2009 [1], we forecast a 40% increase in numbers in Europe during the 20 years from 2010 to 2030, a 63% increase in North America, to be compared with 117% growth in east Asia, 107% in south Asia, 134% to 146% in parts of Latin America, and 125% in North Africa and the Middle East. Second, with economic development, average wages will increase particularly rapidly in LMIC. Third, if costs can be seen as a proxy for available resources, it is obvious that resources for dementia care, particularly formal medical and social care, are unequally distributed worldwide. With increased awareness will come increased demand for such care. Residential care and community social care systems are well developed in many HIC, but are scarce in LMIC, where there is still a strong reliance on traditional, informal family care arrangements. However, it seems likely that the need for community and residential care will grow in LMIC, and with it the direct costs. In many developing countries, traditional family and kinship structures are under threat from the demographic, social, and economic changes

that accompany economic development and globalization [53]. The education of women and their increasing participation in the workforce (generally seen as positive human development indicators), tend to reduce their availability for caregiving and their willingness to take on this additional role. Populations are also increasingly mobile as education, cheap travel, and flexible labor markets induce children to migrate to cities and abroad to seek work. Last, declining fertility in the last stage of the demographic transition leaves increasing numbers of older people lacking family support.

4.4. Comparisons with costs of other chronic conditions

It is difficult to compare our estimates of the global societal costs for dementia with those of other conditions because few such estimates exist, and there are problems with comparability in the way that societal costs were computed. In some countries, attempts have been made to study this issue using data that are more comparable. In the United Kingdom, a recent report commissioned by the Alzheimer's Research Trust (Dementia 2010) focused on the economic burden of dementia and other chronic diseases, and sought to compare like-for-like disease costs with national expenditure on research [e25]. The report's authors estimated the annual societal cost of dementia at £23 billion, £12 billion for cancer, £8 billion for heart disease, and £5 billion for stroke. The societal costs of dementia almost matched those of cancer, heart disease, and stroke combined. The annual per-capita costs were estimated at £27,647 for dementia, £5999 for cancer, £4770 for stroke, and £3455 for heart disease. However, investment in research did not match the relative burden of these different chronic diseases. For every £1 million in care costs arising from the disease, £129,269 was spent on cancer research, £73,153 on heart disease research, and £4882 on dementia research. In a article from Sweden [49], the costs of dementia were compared with other estimates for chronic disorders. The annual costs of dementia (50 billion Swedish Kronor [SEK]) was higher than for depression (32.5 billion SEK), stroke (12.5 billion SEK), alcohol abuse (21–30 billion SEK), and osteoporosis (4.6 billion SEK), but the distribution between the diseases and the types of costs differ. Although, for example, the direct costs of social care constituted the greatest cost component in dementia, indirect costs in terms of production losses dominated for depression.

4.5. Conclusion

The worldwide costs of dementia are enormous and inequitably distributed. Expenditures on medical care for dementia are also lower than they should be in all world regions. As shown in the World Alzheimer report 2011 [54], there are strong arguments in favor of early diagnosis

and interventions, even if there are several methodological obstacles to overcome. Evidence-based interventions, including caregiver support and training, and respite care should be being provided routinely, but are not, even in HIC [55]. Integrated multitargeted interventions including both nonpharmacological and pharmacological treatment approaches are rare. Prevention strategies, based on the potential link between cardiovascular risk factors and dementia (including Alzheimer's disease) found in epidemiological studies, need to be tested in controlled studies. There is an urgent need to develop cost-effective packages of medical and social care that meet the needs of people with dementia and their caregivers across the course of the illness, and evidence-based prevention strategies [56]. Only by investing now in research and cost-effective approaches to early diagnosis and care can future societal costs be anticipated and managed. Underdiagnosis, misdiagnosis, and undertreatment is not cost-effective. Governments and health and social care systems need to be prepared adequately for the future, and must seek ways now to improve the lives of people with dementia and their caregivers.

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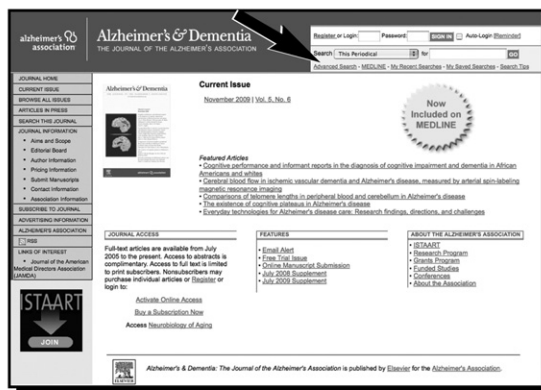
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Table E1

Assumptions for the base option in the cost-of-illness model

Item	Assumption
Numbers of people with dementia	Figures worldwide and in individual countries are based on ADI estimates
Costs	Costs expressed as US\$ in 2010, converted from local currencies based on current exchange rates
Living situation	The ADI worldwide questionnaire can be used for estimates of living situation (at home or institutionalized)
Informal care: types	Informal care can be described in terms of ADLs, IADLs, and supervision
Informal care (country level): hours, gender, relationship	Study data (hours, gender, relationship) are generalizable to the whole of this specific country
Informal care (imputation): hours, gender, relationship	Single country data are generalizable to similar countries/regions when data are missing
Informal care: costing	Average wage is a proxy for the opportunity cost of informal care
Direct costs, country level	Study data are generalizable to the whole of this specific country
Direct costs, imputation	Single country resource use and direct cost data are generalizable to similar countries/regions when data are missing
Direct costs, imputation	Single regression based on GDP per capita can be used to predict direct costs when similar country/region data are lacking
Direct costs: split into subtypes (imputation)	The split of direct costs into medical and social care costs from China can be used when data are missing and imputation is necessary

Abbreviations: ADI, Alzheimer Disease International; ADLs, activities of daily living; IADLs, instrumental activities of daily living; GDP, gross domestic product.

Table E2

WHO global burden of disease region-specific figures of informal care inputs (hours per day)

WHO region	Basic ADLs	Combined ADLs	Supervision
Australasia	2.0*	3.3	0.6*
Asia Pacific, high income	2.0*	3.6	2.6*
Oceania	3.6*	4.6*	1.2*
Asia, central	1.2*	2.7*	3.3*
Asia, east	3.6	4.7	1.2
Asia, south	1.3	2.7	2.6
Asia, southeast	1.3*	2.7*	2.6*
Europe, western	1.1	3.5	3.3
Europe, central	2.1	4.4	3.4
Europe, eastern	2.1*	4.4*	3.4*
North America, high income	2.1	4.0	2.8
Caribbean	3.0	3.0	2.1
Latin America, Andean	2.9	2.9	2.6
Latin America, central	1.9	1.9	3.1
Latin America, southern	2.9*	4.4	2.6*
Latin America, tropical	2.9*	2.9	2.6*
North Africa/Middle East	1.1	1.4	2.6*
Sub-Saharan Africa, central	2.0*	3.6*	2.6*
Sub-Saharan Africa, east	2.0*	3.6*	2.6*
Sub-Saharan Africa, southern	2.0*	3.6*	2.6*
Sub-Saharan Africa, west	2.0*	3.6*	2.6*
Total	2.0	3.6	2.6

Abbreviations: WHO, World Health Organization; ADLs, activities of daily living.

*Imputed figures.