Sundhedsudvalget 2009-10
SUU alm. del Bilag 517
Offentligt

Alzheimer's Disease
International

World Alzheimer Report 2010

THE GLOBAL ECONOMIC IMPACT OF DEMENTIA

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The Global Economic Impact of Dementia

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Published by Alzheimer's Disease International (ADI) 21 September 2010

Acknowledgements

Professor Bengt Winblad (Karolinska Institutet, Stockholm, Sweden) and Dr Linus Jönsson (i3 Innovus and Karolinska Institutet, Stockholm, Sweden) have contributed significantly to the methodological development in the cost estimates.

Swedish Brain Power (SBP) provided unrestricted financial support for the work of Anders Wimo for this study.

Alzheimer's Association (US) for support with reviewing and launching this Report.

Photos: Cathy Greenblat – www.cathygreenblat.com

Design: Julian Howell

ADI would like to thank those who contributed financially:
Vradenburg Foundation
Geoffrey Beene Foundation – www.geoffreybeene.com/alzheimers.html
Alzheimer's Association – www.alz.org
Alzheimer's Australia – www.alzheimers.org.au
Alzheimer's Australia WA – www.alzheimers.asn.au
Alzheimer Scotland – www.alzscot.org
Alzheimer's Society – www.alzheimers.org.uk
Association Alzheimer Suisse – www.alz.ch
Alzheimerföreningen i Sverige – www.alzheimerforeningen.se
Deutsche Alzheimer Gesellschaft – www.deutsche-alzheimer.de
Stichting Alzheimer Nederland – www.alzheimer-nederland.nl

Cover image
Ana de Jesus de Bido, a pastor and geriatrician, and her physician husband run a care facility in the Villa Francisca barrio in Santo Domingo, Dominican Republic. Here she was on a home visit with 82-year-old Ana Luisa Candelario, who cares for her 92-year-old husband. Ana Luisa takes little care of herself, often not eating, and Pastor Ana consoled her and explained the importance of caregivers taking care of themselves.

ALZHEIMER'S DISEASE INTERNATIONAL

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As Mandakini became more confused, it was clear that she could no longer live alone. Two of her sons indicated that they could not take care of her because they had young children. Her son Satish and his wife Neha, who also had young children, brought her to their home, where they take care of her with the assistance of a professional caregiver. Eight-year old Srushti has found ways to relate to her grandmother, and her two-year-old sister shows no fear. Though Mandakini speaks very little, Srushti has found that her grandmother enjoys the religious chants that have been important to her throughout her life. Now Srushti leads and they chant together.

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Foreword

In the World Alzheimer Report 2010, we build upon the findings detailed in the World Alzheimer Report 2009, to explore the cost of dementia to our societies. The Report contains an explanation of the methods used, detailed results for different economic and geographic regions, and we offer conclusions and recommendations in the final section.

As you will see, the figures are cause for great concern and we hope that this Report will act as a call to action for governments and policy makers across the world. It is vital that they recognize that the cost of dementia will continue to increase at an alarming rate and we must work to improve care and support services, treatment and research into dementia in all regions of the world. Lower income countries face a severe lack of recognition of dementia, placing a heavy burden on families and carers who often have no understanding of what is happening to their loved one. High income countries are struggling to cope with the demand for services, leaving many people with dementia and caregivers with little or no support. Consequently, we urge key decision makers to take notice of this very important document and to work with Alzheimer associations and with ADI to make dementia a national and global health priority.

We would like to thank a number of people for their hard work on the development of this Report. We are grateful to the Report's authors, Prof Anders Wimo and Prof Martin Prince, for their tireless efforts and dedication, and Niles Frantz and MaryKate Wilson from the Alzheimer's Association in the USA for their valuable input. Thank you also to the sponsors who made the Report possible and to those who took the time to review the contents: the Organisation for Economic Co-operation and Development (OECD) in Paris, the Alzheimer's Association in the USA and Glenn Rees at Alzheimer's Australia. Finally, we would like to thank Cathy Greenblat for her photographs.

Daisy Acosta
Chairman
Alzheimer's Disease International

Marc Wortmann
Executive Director
Alzheimer's Disease International

Contents

Executive Summary

The total estimated worldwide costs of dementia are US$604 billion in 2010.

About 70% of the costs occur in Western Europe and North America.

Costs were attributed to informal care (unpaid care provided by family and others), direct costs of social care (provided by community care professionals, and in residential home settings) and the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care).

Costs of informal care and the direct costs of social care generally contribute similar proportions of total costs, while the direct medical costs are much lower. However, in low and middle income countries informal care accounts for the majority of total costs and direct social care costs are negligible.

Background

- Dementia is a syndrome that can be caused by a number of progressive disorders that affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.
- Dementia mainly affects older people, although there is a growing awareness of cases that start before the age of 65. After age 65, the likelihood of developing dementia roughly doubles every five years.
- In last year's World Alzheimer Report, Alzheimer's Disease International estimated that there are 35.6 million people living with dementia worldwide in 2010, increasing to 65.7 million by 2030 and 115.4 million by 2050. Nearly two-thirds live in low and middle income countries, where the sharpest increases in numbers are set to occur.
- People with dementia, their families and friends are affected on personal, emotional, financial and social levels. Lack of awareness is a global problem. A proper understanding of the societal costs of dementia, and how these impact upon families, health and social care services and governments may help to address this problem.
- The societal cost of dementia is already enormous. Dementia is already significantly affecting every health and social care system in the world. The economic impact on families is insufficiently appreciated.
- In this World Alzheimer Report 2010, we merge the best available data and the most recent insights regarding the worldwide economic cost of dementia. We highlight these economic impacts by providing more detailed estimates than before, making use of recently available data that considerably strengthens the evidence base.
  - The World Alzheimer Report 2009 provides the most comprehensive, detailed and up-to-date data on the prevalence of dementia and the numbers of people affected in different world regions.
  - The 10/66 Dementia Research Group's studies in Latin America, India and China have provided detailed information on informal care arrangements for people with dementia in those regions.
  - For this Report, Alzheimer's Disease International has conducted a global survey of key informants regarding the extent of use of care homes in different world regions.

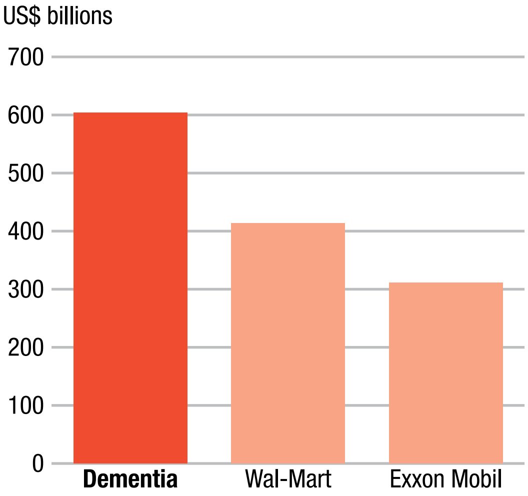
Methods

- Different methods can be used to estimate the cost of an illness. The base approach in this Report is a societal, prevalence-based gross cost of illness study. Annual costs per person with dementia for each country have been applied to the estimated number affected in that country, and then aggregated up to the level of World Health Organization regions, and World Bank income groupings.
- The costs considered include informal (family) care as well as 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.
- For informal care, we estimated how much time family caregivers spend caring, including time spent with basic activities of daily living (such as eating, dressing, bathing, toileting and grooming) and with instrumental activities of daily living (such as shopping, preparing food, using transport and managing personal finances).
- The costs in this Report, as well as the prevalence of dementia, reflect estimates for 2010 and are expressed as US dollars. To permit aggregation across countries, and comparisons between countries and regions, costs were converted to US dollars from local currencies based on current exchange rates.
- Cost of illness studies depend on a set of sources and assumptions. We have conducted comprehensive sensitivity analyses in which we use different source data or vary assumptions to see how this would affect the results ("Sensitivity analyses" on page 28).

Results

- The total estimated worldwide costs of dementia are US$604 billion in 2010.
- These costs account for around 1% of the world's gross domestic product, varying from 0.24% in low income countries, to 0.35% in low middle income countries, 0.50% in high middle income countries, and 1.24% in high income countries.
- If dementia care were a country, it would be the world's 18th largest economy, ranking between Turkey and Indonesia. If it were a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US$414 billion) and Exxon Mobil (US$311 billion) (figure 1).
- Costs of informal care (unpaid care provided by families and others) and the direct costs of social care (provided by community care professionals and in residential home settings) contribute similar proportions (42%) of total costs worldwide, while direct medical care costs are much lower (16%).
- Low income countries accounted for just under 1% of total worldwide costs (but 14% of the prevalence), middle income countries for 10% of the costs (but 40% of the prevalence) and high income countries for 89% of the costs (but 46% of the prevalence). About 70% of the global costs occurred in just two regions: Western Europe and North America.

Figure 1 **Cost of dementia compared to company revenue**



- These discrepancies are accounted for by the much lower costs per person in lower income countries – US$868 in low income countries, US$3,109 in lower middle income, US$6,827 in upper middle income and US$32,865 in high income countries.
- In lower income countries, informal care costs predominate, accounting for 58% of all costs in low income and 65% of all costs in lower middle income countries, compared with 40% in high income countries. Conversely, in high income countries, the direct costs of social care (professional care in the community, and the costs of residential and nursing home care) account for the largest element of costs – nearly one half, compared with only one tenth in lower income countries.

Conclusions

- The scale of the global cost of dementia is explainable when one considers that 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 instrumental activities of daily living (such as cooking or shopping), to full personal care and round the clock supervision.
  - In some high income countries, between one third and one half of all people with dementia live in resource- and cost-intensive residential or nursing home care facilities.
  - Medical care costs also tend to be relatively high for people with dementia, particularly in high income countries with reasonable provision of specialist care services.
- Costs are lower in developing countries, both per person and societally (as a proportion of GDP). In these regions, there is a much greater reliance on the unpaid informal care provided by family and others.
  - While wage levels are low, these are increasing rapidly, and hence the opportunity cost or replacement cost of these informal inputs is set to rise.
  - In our key informant survey, we estimated that in low and middle income countries only 6% of people with dementia live in care homes. However, this sector is expanding rapidly, particularly in urban settings in middle income countries, boosted by demographic and social changes that reduce the availability of family members to provide care.
  - Medical help-seeking is relatively unusual in low and middle income countries, where dementia is often viewed as a normal part of ageing. Demand for medical care is likely to increase in the future, with improved awareness, better coverage of evidence-based interventions, and, possibly, more effective treatments.
- Worldwide, the costs of dementia are set to soar. We have tentatively estimated an 85% increase in costs to 2030, based only on predicted increases in the numbers of people with dementia. Costs in low and middle income countries are likely to rise faster than in high income countries, because, with economic development, per person costs will tend to increase towards levels seen in high income countries, and because increases in numbers of people with dementia will be much sharper in those regions.
- 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. Only by investing now in research and cost-effective approaches to care can future societal costs be anticipated and managed. Governments and health and social care systems need to be adequately prepared for the future, and must seek ways now to improve the lives of people with dementia and their caregivers.

Recommendations

1 **Alzheimer's Disease International calls on governments to make dementia a health priority and develop national plans to deal with the disease.**

2 **Alzheimer's Disease International reminds governments of their obligations under the UN Convention on the Rights of People with Disabilities, and the Madrid International Plan for Action on Ageing to ensure access to healthcare. It calls on governments to fund and expand the implementation of the World Health Organization (WHO) Mental Health Gap Action Plan, including the packages of care for dementia, as one of the seven core disorders identified in the plan.**

3 **Alzheimer's Disease International requests that new investment in chronic disease care should always include attention to dementia. For example, the WHO Global Report on 'Innovative Care for Chronic Conditions' alerts policymakers, particularly those in low and middle income countries, to the implications of the decreases in communicable diseases and the rapid ageing of populations. Healthcare is currently organized around an acute, episodic model of care that no longer meets the needs of patients with chronic conditions. The WHO Innovative Care for Chronic Conditions framework provides a basis on which to redesign health systems that are fit for their purpose.**

4 **Alzheimer's Disease International calls on governments and other major research funders to act now to increase dementia research funding, including research into prevention, to a level more proportionate to the economic burden of the condition. Recently published data from the UK suggests that a 15-fold increase is required to reach parity with research into heart disease, and a 30-fold increase to achieve parity with cancer research. International coordination of research is needed to make the best use of resources.**

5 **Alzheimer's Disease International calls on governments worldwide to develop policies and plans for long-term care that anticipate and address social and demographic trends and have an explicit focus on supporting family caregivers and ensuring social protection of vulnerable people with dementia.**

6 **Alzheimer's Disease International supports HelpAge International's call for governments to introduce universal non-contributory social pension schemes[i].**

7 **Alzheimer's Disease International calls on governments to ensure that people with dementia are eligible to receive and do receive disability benefits, where such schemes are in operation.**

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[i] http://www.helpage.org/Researchandpolicy/Socialprotection

Introduction

Alzheimer's Disease International's first World Alzheimer Report, released on 21 September 2009, provided up-to-date information on the prevalence and impact of dementia from a global perspective(1). We estimated 35.6 million people living with Alzheimer's disease and other dementias worldwide in 2010, increasing to 65.7 million by 2030 and 115.4 million by 2050. We highlighted that nearly two-thirds of all people with dementia lived in low and middle income countries, this proportion being set to grow because the sharpest increases in the numbers of people with dementia will be in rapidly developing regions including Latin America, China and India. People with dementia, their families and friends are affected on personal, emotional, financial and social levels. In the 2009 Report, we advocated for greater awareness, more services, more funding for research and, ideally, national dementia strategies in every country worldwide(1).

In this World Alzheimer Report 2010, we focus on the economic impact of dementia, again providing the latest and most reliable estimates possible from the available evidence. Lack of awareness is a global problem, leading to common misunderstandings about Alzheimer's disease and other forms of dementia:

- It is not a very common problem.
- It is a normal part of ageing.
- Nothing can be done.
- Families will provide care – it is not an issue for health care systems or for governments.

A proper understanding of the societal costs of dementia, and how these impact upon families, health and social care services and governments may help to correct these misapprehensions. Dementia is already significantly affecting every health system in the world, and large amounts of money are spent in caring for people with dementia. The aim of this Report is to highlight these economic impacts so that governments, health and social care systems are adequately prepared for the future, and can seek ways to improve the lives of people with dementia and their caregivers now.

Cost of illness (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 between different countries and regions can also be estimated and compared. CoI studies can also be used to describe or (with less certainty) predict changes in the extent or distribution of costs over time. While 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 healthcare should be determined by the relative incremental cost-effectiveness of available interventions, rather than the burden of the disease(2). Transparency is crucial with regard to the assumptions underlying any cost calculations and comparisons.

WHAT IS DEMENTIA?

Dementia is a syndrome that can be caused by a number of progressive illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. The boundaries between the types are not clear, and a mixture of more than one type is common. Dementia mainly affects older people, although there is a growing awareness of cases that start before the age of 65. After age 65, the likelihood of developing dementia roughly doubles every five years. A detailed overview of dementia can be found in the World Alzheimer Report 2009, available from www.alz.co.uk/worldreport.

Previous evidence

Cost of illness studies for dementia have already been carried out for some regions and countries, mainly from high income parts of the world: for example, Europe(3), United Kingdom(4), Sweden(5), Australia(6), the USA(7) and Canada(8). All these reports have shown that Alzheimer's and other dementias are 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).

Previously, three papers that highlight the global economic burden have been published(13-15). These reports were, at the time of their publication, based on the best available data for Alzheimer's and dementia. Cost estimates were generated from the Dementia Worldwide Cost Database (DWCD) a continuously updated resource maintained at the Karolinska Institutet Alzheimer's Research Center, Stockholm, Sweden. The most recent of these three reports 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 four years(15). US$312 billion per year (74% of the worldwide total) is contributed by countries designated by the UN as more developed regions and 110 billion (26% of the total) by less developed regions.

One major limitation of these papers was that the DWCD contained very few data from low and middle income countries 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). While we still have incomplete data, the evidence-base has been strengthened in three respects:

1. The World Alzheimer Report 2009 provides the most comprehensive, detailed and up-to-date data on the prevalence of dementia and the numbers of people affected in different world regions(1).
2. The 10/66 Dementia Research Group's studies in Latin America, India and China have provided detailed information on informal care arrangements for people with dementia in those regions(1,16).
3. Alzheimer's Disease International has conducted a global survey of key informant opinions regarding the extent of use of care homes in different world regions.

In this Report, we are merging the best available data and the most recent insights regarding the worldwide cost of Alzheimer's and other dementias. Clearly, the societal cost of dementia is already enormous. With the forecast growth in disease prevalence(1), costs will rise further, particularly in low and middle income countries. 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. Only by investing now in research and cost-effective approaches to care can future societal costs be anticipated and managed.

When a caregiver in a Kyoto group home embraced this resident everyone around smiled. Although it is widely held that touching is not appropriate in Japanese culture, Dr Yoshio Miyake explained that 'In Japan, training courses for professional caregivers of people with dementia take place in many and different settings, where non-verbal communication with them, including touch or physical contact, is emphasised very often.'

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Methods

Ten years ago, when Vijay was 52, he and Anu were told that his increasing problems were due to early onset Alzheimer's. They were not prepared for this news, but Anu managed the family life and become the sole earner. She pursued many avenues to find what Vijay needed. Anu also sought out and benefited from advice and assistance from others and she joined a support group. She loves Vijay very much and benefits from the assistance of Mr Deepak, a caregiver seen here feeding Vijay. Anu now offers support and advice to other caregivers through ARDSI and she willingly shares her story through the mass media to create better understanding and fight stigma.

Methods

Key design issues for cost of illness studies

Prevalence versus incidence approaches

CoI studies can either be prevalence or incidence based. With the prevalence approach, the average costs are computed from all people in a population found to be affected at a specified time, with data collected in a cross-sectional survey; people with dementia will include some recently incident cases, and others at varying stages in the disease course(1,2). The rate at which the costs are observed to occur are then applied to a given period, typically one year, to compute the annual cost of illness, either as an average for each person with dementia or, by multiplying by the total numbers affected, for a whole country or region. An alternative approach is to use longitudinal data (in which people with assumed newly diagnosed dementia (incident cases) have been followed up over time) to estimate the typical costs of illness over the disease course, as annual costs and the future (discounted) costs during the expected or calculated survival period. This approach can also be applied, although less accurately, to cross-sectional data. The choice of approach depends on the purpose of the study; if the idea is to estimate the aggregated economic societal burden of a condition for a country or region, the prevalence approach is suitable. If the aim is to illustrate the economic consequences of evolving and cumulative care needs within individuals over time, then the longitudinal approach is preferable.

Top-down versus bottom-up approaches

In a 'top-down' analysis, the total costs for a specific resource (for example, health care costs or social sector costs) are distributed appropriately to different conditions. Such studies are often based on data from local or national registers of service users. With the 'bottom-up' method, detailed cost data from a defined sub-population (often from a local area) are extrapolated to the 'total' dementia population in a given country or region. One limitation of this approach is that not all costs linked to people with dementia may be directly attributable to that condition. Comorbidity with other chronic diseases (such as stroke, heart disease or arthritis) is relatively common. However, recently published analyses from the 10/66 Dementia Research Group studies in Latin America, India and China demonstrate that for older people, at the population level, dementia is overwhelmingly the leading contributor among chronic diseases to disability(3) and needs for care(4). It was also demonstrated that for people with dementia, it was the severity of dementia (as opposed to comorbid stroke, number of physical impairments or depression) that was the major contributor to hours of ADL care(5). However, the 'net' costs of healthcare (costs that only depend on dementia as opposed to other comorbid conditions) are often difficult to estimate.

Which costs are to be included, and how should they be computed?

Care resources are generally scarce, so the use of a resource in one way will result in a loss of benefits somewhere else(6). Opportunity cost is the value of a resource in its best alternative use(7), and this is the approach recommended by most economists. Ideally, opportunity costs are based on market prices. However, with respect to care, market prices are not easy to identify and collect.

Costs of illness are often sub-classified as direct medical costs, direct social care costs and indirect costs. Direct cost calculations are typically based on the value of resources used while indirect costs are based on resources lost.

Direct medical costs refer to the medical care system, such as costs of hospital care, drugs and visits to clinics.

Direct social care costs arise from formal services provided outside of the medical care system; for example, community services such as home care, food supply ('meals on wheels') and transport, and residential or nursing home care. Depending on how care is organized, it may be difficult to make a clear distinction between social and medical care, and some 'social care' costs may still relate in part to medical care services, for example home nursing or nursing and medical care provided to care home residents.

Indirect costs usually refer to production losses linked to the person with the illness (arising from impaired productivity while working, sick leave, early retirement, or death). This type of indirect cost is generally less relevant in the context of dementia, where most of those affected are older people who would in most cases be retired. The costs of informal care, arising from the unpaid inputs of family caregivers, friends and others (see below) are more often considered as indirect costs, but this is a complicated issue(8,9).

The viewpoint

Any analysis of health economics has a viewpoint, even if this is not always made explicit. With a societal viewpoint, which is recommended in most cases, all relevant costs and outcomes should be included(10). However, the focus can be upon the contributions of different payers; for example, local or national government, an insurance company, caregivers or patients (the latter referred to as 'out of pocket costs'). Above all, it is essential that there is transparency regarding the viewpoint adopted.

The representativeness of data sources on resource utilization

Studies on resource utilization and costs associated with dementia typically use one of two main approaches for sampling: representative samples from population-based studies or 'convenience' samples of those receiving help from dementia care services or Alzheimer associations. Studies are sometimes labelled as 'population-based' even if the recruitment process for the study is more or less based on clinical service contact. Naturally, 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 more likely to have accessed and to have used more health and community support services. If the aim is to characterise people affected by the disease to the extent that they need and have sought formal care ('users' of care), then clinical-based study populations are sufficient. However, if the aim is to describe all people with the illness, then population-based studies including both those who use formal care and those that do not are needed, otherwise average and total costs may be overestimated. Since many reports, particularly those with a top-down design, include many sources, it is not easy to judge whether the underlying sources in this Report are population based or clinical/user based. Of the 42 studies that are used in this Report for estimating the costs of informal care, we regard 11 studies as having population based designs (cohort studies, case control studies) or including controls (people without dementia). For the direct costs, the corresponding figures are 11 out of 31 studies.

The ideal scenario for computing cost of illness … and the reality

An ideal worldwide CoI study has a societal viewpoint including comprehensive accounting of informal care, direct medical and social care costs. Precise data on the prevalence of dementia and resource utilization 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 for different countries.
- Data on dementia prevalence (the proportion of the older population affected) applied to the total population size to estimate the numbers of people with dementia is not available for all countries(5).
- Most studies of care arrangements and resource utilization for people with dementia use convenience rather than representative population-based samples. Many of the estimates come from small studies and, hence, may be imprecise. Many studies are not recent, and care arrangements and patterns of healthcare utilization may change over time. For many countries, there are few or no studies available, but informal care arrangements are likely to be highly dependent on culture and place.
- Many basic indicators, for example demographic and macroeconomic data, are not yet provided for 2010. However, projections can be found in online databases.

For all of the above reasons, it is necessary to rely on some degree of imputation (making an educated and informed estimate when precise data are not available) and a range of assumptions. The CoI figures that are presented here must be regarded as estimates rather that exact calculations.

Methods used in our cost of illness analyses

Summary

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 (5)), and aggregated up to the level of WHO regions (see box), and World Bank country income-level groupings.

- Most of the source papers (see below) providing evidence on direct medical and social care, and informal care, have a bottom-up design. Most used convenience sampling, although some data were derived from more representative population-based surveys.
- The costs in the current Report (as well as the prevalence of dementia) reflect estimates for 2010 and are expressed as US dollars. Costs estimates based on previous years are inflated to 2010 using relevant country-specific data from the International Monetary Fund (IMF) or World Economic Outlook (WEO)[i], or if lacking from those sources, from the World Bank[ii] or World Fact Book[iii]. Data on per capita Gross Domestic Product (GDP) was obtained in a similar way.
- To permit aggregation across countries, and comparisons between countries and regions, costs are expressed as US dollars converted from local currencies based on current exchange rates. An alternative approach based on purchasing power parity (PPP) was used in the sensitivity analysis (see page 28 for further details).

To facilitate comparisons with previous studies, we also present data according to current World Bank classifications. Based on its Gross National Income (GNI) per capita, every economy is classified as low income, middle income (subdivided into lower middle and upper middle), or high income. Economies are divided according to 2009 GNI per capita calculated using the World Bank Atlas method[iv]. The groups are: low income, $995 or less; lower middle income, $996 – $3,945; upper middle income, $3,946 – $12,195; and high income, $12,196 or more.

CLASSIFICATION OF COUNTRIES

In this Report, countries are classified according to the system that will be used in future Global Burden of Disease reports from the World Health Organization (WHO). A similar approach was used in the World Alzheimer Report 2009. The classification is principally geographic, with seven sub-regions in Asia (Australasia, Asia Pacific High Income, Asia Central, Asia East, Asia South, Asia Southeast and Oceania), three in Europe (Europe Western, Europe Central, Europe Eastern), six in the Americas (North America, Caribbean, Latin America Andean, Latin America Central, Latin America Southern, Latin America Tropical), and five in Africa (North Africa / Middle East, Sub-Saharan Africa Central, Sub-Saharan Africa East, Sub-Saharan Africa Southern and Sub-Saharan Africa West).

The evidence on the prevalence of dementia, and numbers affected worldwide

For the World Alzheimer Report 2009 (5), we conducted a systematic review of the global prevalence of dementia, identifying 147 studies in 21 Global Burden of Disease (GBD) world regions. Previous estimates of numbers of people with dementia worldwide, published in *The Lancet* in 2005 (11), were based on expert consensus. A large number of new studies unearthed in the systematic review, particularly from low and middle income countries, enabled us to conduct quantitative meta-analyses in 11 of the 21 GBD world regions. The new estimates showed that age standardised prevalence (for those aged 60 years and over) did not vary much between world regions, with between 5% and 7% affected in most regions. The exceptions were the four sub-Saharan African regions where between 2% and 4% were affected. When compared with our earlier ADI/*Lancet* consensus estimates, those for

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[i] World Economic Outlook Database [database on the Internet]. IMF. 2010 [cited 2010-02-07]. Available from: http://www.imf.org/external/pubs/ft/weo/2010/01/weodata/weoselgr.aspx

[ii] Data Research [database on the Internet]. World Bank. 2010 [cited 2010-06-07]. Available from: http://econ.worldbank.org/WBSITE/EXTERNAL/EXTDEC/0,,menuPK:476823~pagePK:64165236~piPK:64165141~theSitePK:469372,00.html

[iii] World Fact Book [database on the Internet]. 2010 [cited 2010-05-30]. Available from: https://www.cia.gov/library/publications/the-world-factbook/

[iv] http://data.worldbank.org/about/country-classifications/world-bank-atlas-method

three regions were higher – western Europe (7.3% vs. 5.9%), south Asia (5.7% vs. 3.4%) and Latin America (8.5% vs. 7.3%). Those for east Asia were lower (5.0% vs. 6.5%).

Having applied these prevalence proportions to the United Nations estimates of the total older population, we estimate 35.6 million people with dementia in 2010, with the numbers nearly doubling every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. These figures represented a 10% increase on the figures published in *The Lancet* in 2005. 58% of all people with dementia worldwide live in low and middle income countries, rising to 71% by 2050. Proportionate increases over the next twenty years in the number of people with dementia will be much steeper in low and middle compared with high income countries. We forecast a 40% increase in numbers in Europe, 63% in North America, 77% in the southern Latin American cone and 89% in the developed Asia Pacific countries. These figures are to be compared with 117% growth in east Asia, 107% in south Asia, 134-146% in the rest of Latin America, and 125% in north Africa and the middle East. Given that the new figures published in last year's World Alzheimer Report are based on the most up to date and comprehensive review of the evidence base, we believe these to be the most robust and valid figures currently available.

Table 1 **Total population over 60, crude estimated prevalence of dementia (2010), estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010-2030 and 2010-2050) by GBD world region**

GBD Region	**Over 60 population (millions)**	**Crude estimated prevalence (%)**	**Number of people with dementia (millions)**			**Proportionate increases (%)**	
	2010	**2010**	**2010**	**2030**	**2050**	**2010-2030**	**2010-2050**
ASIA	**406.55**	**3.9**	**15.94**	**33.04**	**60.92**	**107**	**282**
Australasia	4.82	6.4	0.31	0.53	0.79	71	157
Asia Pacific	46.63	6.1	2.83	5.36	7.03	89	148
Oceania	0.49	4.0	0.02	0.04	0.10	100	400
Asia, Central	7.16	4.6	0.33	0.56	1.19	70	261
Asia, East	171.61	3.2	5.49	11.93	22.54	117	311
Asia, South	124.61	3.6	4.48	9.31	18.12	108	304
Asia, Southeast	51.22	4.8	2.48	5.30	11.13	114	349
EUROPE	**160.18**	**6.2**	**9.95**	**13.95**	**18.65**	**40**	**87**
Europe, Western	97.27	7.2	6.98	10.03	13.44	44	93
Europe, Central	23.61	4.7	1.10	1.57	2.10	43	91
Europe, East	39.30	4.8	1.87	2.36	3.10	26	66
THE AMERICAS	**120.74**	**6.5**	**7.82**	**14.78**	**27.08**	**89**	**246**
North America	63.67	6.9	4.38	7.13	11.01	63	151
Caribbean	5.06	6.5	0.33	0.62	1.04	88	215
Latin America, Andean	4.51	5.6	0.25	0.59	1.29	136	416
Latin America, Central	19.54	6.1	1.19	2.79	6.37	134	435
Latin America, Southern	8.74	7.0	0.61	1.08	1.83	77	200
Latin America, Tropical	19.23	5.5	1.05	2.58	5.54	146	428
AFRICA	**71.07**	**2.6**	**1.86**	**3.92**	**8.74**	**111**	**370**
North Africa / Middle East	31.11	3.7	1.15	2.59	6.19	125	438
Sub-Saharan Africa, Central	3.93	1.8	0.07	0.12	0.24	71	243
Sub-Saharan Africa, East	16.03	2.3	0.36	0.69	1.38	92	283
Sub-Saharan Africa, Southern	4.66	2.1	0.10	0.17	0.20	70	100
Sub-Saharan Africa, West	15.33	1.2	0.18	0.35	0.72	94	300
WORLD	**758.54**	**4.7**	**35.56**	**65.69**	**115.38**	**85**	**225**

Figure 2 **Estimated prevalence of dementia for those aged 60 and over, standardised to Western Europe population, by GBD region (%)**

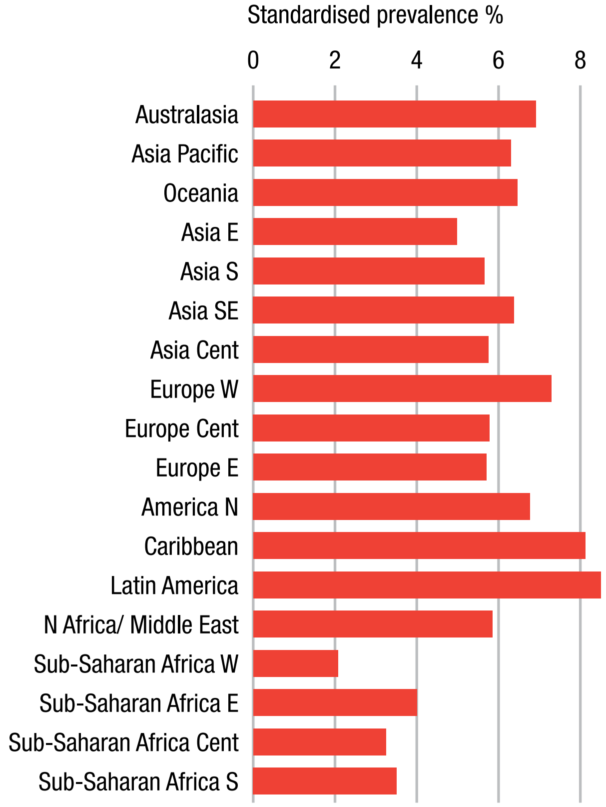
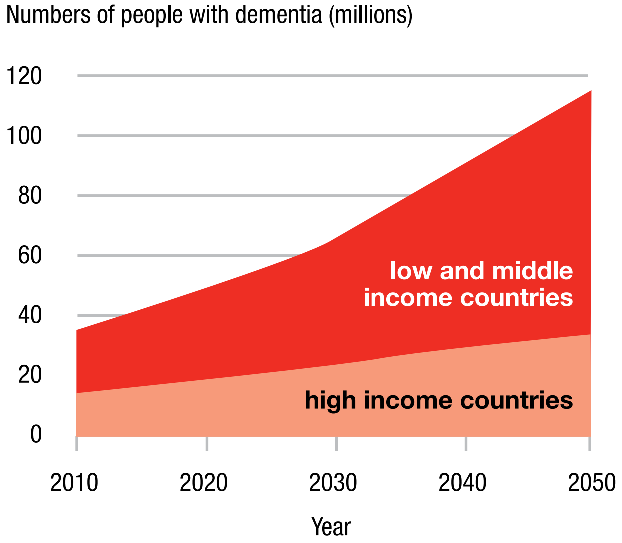


Figure 3 **The growth in numbers of people with dementia in high income countries and low and middle income countries**



The evidence on the utilization of medical and social care, and informal care

SEARCH STRATEGY

For the previous Cost of Illness (CoI) estimates for 2005 and 2009 (12,13), a comprehensive literature search was done. The resulting database has been updated and refined for the present Report. For the cost data, we focused on papers and reports no older than 2000, although older studies were considered for countries where there was no newer data. Older studies were also accepted regarding the amount of informal care. The key criterion was that direct and indirect costs as well as amounts of informal care could be identified. The search was done in PubMed/Medline, Ingenta, Cochrane Library, NHSEED/HTA, HEED, EMBASE, Current contents, PsycINFO, ERIC, Societal services abstracts and Sociological abstracts. The search terms (MESH/Subheadings when appropriate) were dementia/Alzheimer's disease/Alzheimer disease combined with cost and/or economic and informal care. Two recent systematic reviews comprising published papers between 1969 and 2008 with at least an abstract in English were also included (14,15). Secondary papers from reference lists were considered for inclusion. Another source was various reports that were not found in scientific databases, such as reports from governmental authorities and Alzheimer associations.

IMPUTATION APPROACHES

Our general aim was to generate evidence-based estimates of resource utilization for each country. Where more than one estimate was available for a given country we selected the one that we regarded to be the most appropriate study. Where no estimate was available we first used estimates from other similar countries within the same region, or, failing that, adjacent regions. For particular resources, for certain regions, more complex procedures were used and these are described in the relevant section.

DIRECT COSTS

Data on direct costs were available from 21 countries representing 49% of the worldwide dementia population (Argentina, Australia, Belgium, Canada, China, Denmark, Finland, France, Germany, Hungary, Ireland, Israel, Italy, Korea, New Zealand, Norway, Spain, Sweden, Turkey, UK and USA). For many countries, there were no available data on direct costs. For each country, we sought to estimate both total direct costs and the distribution between direct medical and social care costs. Regional imputation from local similar countries was possible for a further 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, no data was available even from neighbouring countries. From macro-economic research it is known that there is a strong correlation at country-level between per capita expenditure on health care and per capita Gross Domestic Product (GDP). This relationship can be used to impute direct care costs by assuming that these costs per person with dementia as a proportion of GDP per capita for the countries and regions where imputation is necessary are similar to the proportions in the countries for which cost data are available(12). In a simple linear regression model, the relationship between the costs per person with dementia and year and the GDP per person and year was tested. Based on this model (derived from 31 papers(16-46)), for each US$1 increase in annual per capita GDP the annual cost per person with dementia increased by US$0.37 ($p<0.001$, $r^2=0.43$, 95% confidence interval 0.22-0.51). The regression approach did not work well for the estimation of the distribution between direct medical and direct non medical costs, and so the percentage distribution observed in one country (China) was used to specify the likely distribution for all countries within the Asian and African regions for which these data were not directly available.

INFORMAL CARE

Family members, friends and others who take on caring roles are likely to experience role strain, negative impacts on their physical and mental health, and their quality of life, and consequent changes to their social network(47-51). Their inputs have an important influence on the societal costs of dementia, since they are producers of an extensive amount of unpaid informal care(52-57). However, translating this contribution into economic costs is not straightforward.

First, quantifying caregiver time is problematic. The inputs most commonly assessed are:

- Assistance with basic activities of daily living (ADL), such as eating, dressing, bathing, toileting, grooming, and getting around – sometimes referred to as personal care.
- Assistance with instrumental activities of daily living (IADL), such as shopping, preparing food, using transport, and managing personal finances.
- Supervision to manage behavioural symptoms or to prevent dangerous events(53).

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 the performance of these activities, for example shopping (referred to as 'joint production').

Second, costing informal care is also complicated and controversial(8,58-64). Two methods are frequently used, the 'opportunity cost' and the 'replacement cost' approaches. Informal care is unpaid. In some high income countries there are systems to compensate or remunerate family caregivers, but the amounts concerned are relatively small. However, whether a caregiver is paid or unpaid does not affect the economic valuation of their inputs. Payments and other transfers have an impact on the distribution of the economic burden but not on the total societal cost. To calculate the opportunity cost it is first necessary to identify the possible alternative use of the caregiver's time. If the alternative is working on the labour market – as may be the case, especially for younger caregivers who often give up or cut back on work to provide care – then the cost for informal care should be valued according to the production loss due to absence from work. More challenging is the costing of caregiver time for retired people (as is often the case with spouses of people with dementia). There is no obvious answer to how this should be calculated, since there are no obvious market prices(62). 'Willingness to pay' approaches may be an option(65, 66). The replacement cost approach assumes that the informal caregiver's inputs should be calculated according to the cost of replacing them with a professional caregiver.

Third, some people with dementia live in care homes, where professional staff provide most care, and informal care is less relevant. These may be residential care homes (providing low intensity care, with few trained staff), or nursing homes (providing high intensity care with more trained nursing and medical staff), or specialist facilities for dementia care. There are few reliable estimates of the proportion of people with dementia living in these facilities, as opposed to their own homes in the community. Estimates for the United Kingdom vary between 35 and 50%(36,67,68), while for Canada the estimate was 45-50%(16,69). In settings in high income countries, people with dementia residing in care homes contribute a substantially higher amount to the total cost of illness than in low and middle income countries. In low and middle income countries, anecdotal information suggests that few such facilities exist, and that the large majority of people with dementia are cared for, informally, in the community. In order to estimate total 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 residential or nursing home care facility. In most countries, there is no published data on this. So, for the purpose of this Report, ADI commissioned a worldwide questionnaire survey of key informants (including Alzheimer association staff, ADI's Medical and Scientific Advisory Panel members and 10/66 Dementia Research Group principal investigators) to provide more information on this issue. Informants were asked, in their opinion, what proportion of people with dementia resided in care homes, in both city areas and rural areas. The questions had fixed 10% point range response intervals (and one 100% option). The range of estimates is wide from some countries, since several respondents had answered. Extreme outliers (8 respondents out of 86) were excluded. Two trends are obvious: the proportion of people with dementia residing at home is higher in low income countries and higher in rural areas (table 2). In high income countries, the mean proportion living at home is 66% (95% confidence interval 64%-68%), while in low and middle income countries 94% of people with dementia live at home (95% confidence interval 92%-96%).

For the estimates in the cost model, we used the central values (after excluding outliers). Imputation was used for nearby countries with similar care structures. From a UN demographic database we gathered information on the rural-urban population distributions for all relevant countries[i], which combined with the results from the ADI questionnaire

Table 2 **Estimated proportion of people with dementia that are living at home (%).**

Source: ADI survey (unpublished)

Country	**Urban areas**	**Rural areas**
ASIA		
Armenia	50-59%	50-59%
China	70-99%	80-94%
India	90-94%	95-99%
Japan	60-79%	70-79%
Jordan	95-99%	95-99%
Pakistan	100%	100%
Nepal	100%	100%
Singapore	90-99%	100%
Sri Lanka	70-99%	95-100%
Thailand	80-89%	95-99%
Turkey	70-79%	90-94%
AFRICA		
Egypt	100%	100%
Mauritius	80-89%	80-89%
Nigeria	80-89%	90-94%
South Africa	90-94%	100%
Zimbabwe	70-79%	95-99%
AMERICAS		
Argentina	50-89%	70-94%
Aruba	80-89%	80-89%
Bahamas	95-99%	95-99%
Bolivia	70-94%	90-99%
Brazil	70-94%	90-99%
Dominican Republic	90-94%	95-99%
Honduras	95-99%	100%
Jamaica	70-79%	70-79%
Mexico	80-99%	95-100%
Peru	90-94%	95-99%
Puerto Rico	70-79%	70-89%
Venezuela	90-94%	95-99%
United States	70-79%	80-89%
EUROPE		
Belgium	50-59%	70-79%
Croatia	80-89%	95-99%
Cyprus	70-79%	95-99%
Germany	50-59%	60-69%
Greece	80-89%	95-99%
Ireland	60-69%	60-69%
Israel	80-89%	80-89%
Italy	50-59%	50-59%
Macedonia Former Yugoslav Rep. of	50-59%	90-94%
Netherlands	60-69%	70-79%
Poland	80-89%	95-99%
Romania	80-89%	100%
Serbia	95-99%	100%
Slovakia (Slovak Republic)	80-89%	90-94%
Slovenia	40-49%	60-69%
Sweden	50-59%	50-59%
Switzerland	60-69%	50-59%
United Kingdom	50-94%	50-94%
AUSTRALASIA		
Australia	50-69%	50-69%

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[i] World Urbanization Prospects The 2009 Revision [database on the Internet]. UN. 2009 [cited 2010-05-25]. Available from: http://esa.un.org/unpd/wup/index.htm

gave a weighted proportion of people with dementia living at home in the community, and hence likely to be in receipt of informal care.

Based on our review of the international literature, we identified:

- 10 appropriate studies where time spent assisting with basic ADLs was quantified, covering 25 countries representing 63% of the worldwide dementia population(5,32,33,37,38,56,70-73).
- 42 papers or reports with time spent assisting with basic ADLs and IADLs combined, covering 30 countries representing 73% of the worldwide dementia population(5,21,30-33,35-38,41,43,44,46,52,54-57,70-92).
- 13 papers or reports with estimates of time spent in supervision, covering 25 countries representing 63% of the worldwide dementia population(5,30,31,33,38,52,56,71-73,79,88,89).

Regional imputation was carried out for the remaining countries according to the procedures previously described (page 16). However, for all African regions, global average figures were used. Although the degree of imputation required was quite substantial, this still represents a considerable advance on the evidence base available for previous reports, since to a large extent we were able to use region-specific figures. The detailed estimates from six Latin American countries, India and China, where research is being done by the 10/66 group, provided important data from low and middle income countries for this review, which was not available for previous worldwide cost estimates.

Table 3 **WHO-region specific figures of informal care inputs (hours per day)**

WHO region **(red=imputed)**	**Basic ADL**	**Combined ADL**	**Super-vision**
Australasia	2.0	3.3	2.6
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
All	**2.0**	**3.6**	**2.6**

The WHO-region specific estimates for informal care inputs are summarised in table 3. Despite the problems, noted above, in quantifying caregiving time spent assisting with IADL, we used the combined ADL figures (combining basic ADL and IADL care inputs) as the base option for calculating the costs of informal care. Our justification was that support for IADLs is an important part of the caregiver's life with a person with dementia, and that there are many more papers describing combined ADLs than those covering only basic ADL care inputs. Cost estimates generated only from assistance with basic ADLs (personal care), and from all categories of informal care (assistance with basic ADLs, IADLs and supervision) are part of the sensitivity analysis.

The base option for costing informal care for this Report uses the opportunity cost approach, valuing informal care by the average wage for each country[i]. Since not all average wage figures were expressed as an hourly rate, a division factor of 8 was used for daily wage figures, 40 for weekly and 172 for monthly wage figures. Average wage figures were available for 131 countries, covering 96% of people with dementia worldwide. This method may, arguably, overestimate costs arising from the contributions of those who would not normally form part of the labour force, for example retired spouses. However, from a global viewpoint, it is necessary to use sources that are globally available, in this case the International Labour Organisation (ILO) / Laborsta database. In this database, income data is available for different periods (for example, International Standard Industrial Classification of all Economic Activities (ISIC) rev 2, rev 3) and for different sectors (such as agriculture, manufacturing) as well as a 'Total' estimate representing all sectors economic activity. Not all of these data were available for all countries. If

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[i] Laborsta Internet [database on the Internet]. ILO. 2010 [cited 2010-02-23]. Available from: http://laborsta.ilo.org/STP

Table 4 **Comparisons between different average wage alternatives**

1999-2008	ISIC categories	Number of comparisons	Mean ratio	95% CI for ratio
Total (ISIC rev 2 and 3)	ISIC rev 2: 2-9	17	1.08	1.03-1.12
Total (ISIC rev 2 and 3)	ISIC rev 3: C-Q	250	1.03	1.02-1.03
Total (ISIC rev 2 and 3)	Manufacturing (ISIC rev 2 and 3)	383	1.00	0.98-1.02

a 'Total' estimate was not provided, we used different summaries representing many, but not all sectors (including sectors 2-9 with ISIC rev 2 and sectors C-Q for ISIC rev 3), and if those were lacking, we used data for the manufacturing sector (sector 3 with ISIC rev 2 and sector D with ISIC rev 3). To assess the possible effect of using different data sources to estimate average wage, we estimated the ratio between earnings per month calculated from 'Total' (all sectors), most sectors (C-Q from ISIC rev 3 or 2-9 from ISIC rev 2) or manufacturing only (both ISIC rev 2 and 3), for countries where each of these data sources was available (table 4). Our conclusion is that adjustments are not necessary.

For some countries, particularly in Africa, there were no figures about hourly wage available at all. For these countries, imputation was done, based on countries where hourly wage figures were available from the same WHO region. The imputation was adjusted according to the GDP per person from countries in the same WHO region with as similar GDP figures per person as possible. This imputation is examined in the sensitivity analysis.

Table 5 **Sex of caregivers, by WHO region**

WHO region (red=imputed)	Proportion (%) of caregivers that are female
Australasia	72%
Asia Pacific High Income	81%
Oceania	**55%**
Asia Central	**71%**
Asia East	55%
Asia South	77%
Asia Southeast	86%
Europe Western	66%
Europe Central	74%
Europe Eastern	82%
North America High Income	71%
Caribbean	80%
Latin America Andean	85%
Latin America Central	82%
Latin America Southern	74%
Latin America Tropical	91%
North Africa / Middle East	71%
Sub-Saharan Africa Central	**81%**
Sub-Saharan Africa East	**81%**
Sub-Saharan Africa Southern	**81%**
Sub-Saharan Africa West	81%
All	**67%**

Table 6 **Sex differences in average wage in different WHO regions**

WHO region (red=imputed)	Men vs All	Women vs All	Women vs Men
Australasia	**1.08**	**0.89**	**0.83**
Asia Pacific High Income	1.11	0.67	0.60
Oceania	**1.08**	**0.84**	**0.78**
Asia Central	1.24	0.71	0.58
Asia East	1.20	0.80	0.67
Asia South	1.04	0.84	0.81
Asia Southeast	1.08	0.84	0.78
Europe Western	1.08	0.89	0.83
Europe Central	1.07	0.93	0.87
Europe Eastern	1.17	0.85	0.72
North America High Income	1.03	0.89	0.87
Caribbean	1.03	0.97	0.94
Latin America Andean	**1.10**	**0.82**	**0.74**
Latin America Central	1.10	0.82	0.74
Latin America Southern	**1.10**	**0.82**	**0.74**
Latin America Tropical	1.08	0.88	0.82
North Africa / Middle East	1.02	0.90	0.88
Sub-Saharan Africa Central	**1.04**	**0.99**	**0.96**
Sub-Saharan Africa East	1.04	0.99	0.96
Sub-Saharan Africa Southern	1.11	0.83	0.75
Sub-Saharan Africa West	**1.04**	**0.99**	**0.96**
All	**1.06**	**0.85**	**0.80**

Since, in many countries, average wages for women are lower than those for men, we needed to determine the cost of care by male and female caregivers separately. In our review of the literature regarding care arrangements for people with dementia (25 studies representing countries with 78% of the global dementia population) we found that a woman was identified as the main informal caregiver for 55-91% of people with dementia (table 5)(5,21,26,37,38,42,45,72,84,92-107).

We looked at the ILO database[i] to assess the magnitude of average wage differences between men and women (table 6), which, when applied to the proportion of caregivers of each sex allowed us to calculate an appropriately weighted hourly cost for each WHO region. For some regions, imputation was used with data from the nearby WHO region.

We have also included an option in the sensitivity analysis, varying the opportunity costs of caregiver inputs where care is provided by spouses, since they might be assumed often to be retired or otherwise not usually economically active. For these sensitivity analyses, on an ad hoc basis, we valued these inputs at 25% and 50% of the average wage, applied to other non-spouse caregivers. From the caregiver literature(5,21,26,30,31,37,38,42,45,49,55,57,72,84,89,92,93,96-102,108-112) spouses are the main caregivers for around 40% of people with dementia, but with important regional differences as seen in table 7.

Table 7 **Relation of informal caregiver to person with dementia by WHO region**

WHO region (red=imputed)	**Proportion (%) of main caregivers that are spouses of the person with dementia**
Australasia	43%
Asia Pacific High Income	36%
Oceania	41%
Asia Central	38%
Asia East	40%
Asia South	24%
Asia Southeast	8%
Europe Western	48%
Europe Central	36%
Europe Eastern	36%
North America High Income	52%
Caribbean	18%
Latin America Andean	15%
Latin America Central	8%
Latin America Southern	46%
Latin America Tropical	54%
North Africa / Middle East	38%
Sub-Saharan Africa Central	41%
Sub-Saharan Africa East	41%
Sub-Saharan Africa Southern	41%
Sub-Saharan Africa West	41%
All	**41%**

Sensitivity analysis

Since CoI studies depend on a set of sources and assumptions, there are always uncertainties in CoI estimates. To consider the impact of the significant uncertain background factors, we have conducted a comprehensive set of sensitivity analyses in which we use different source data or vary assumptions to see how this would have affected the results. 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 and how to do it, for example regarding informal care. There are several presentations in the sensitivity analysis to facilitate comparisons with other studies and approaches.

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[i] Laborsta Internet [database on the Internet]. ILO. 2010 [cited 2010-02-23]. Available from: http://laborsta.ilo.org/STP

References for Methods are combined with references for Results, page 34

World Alzheimer Report 2010

Results

At the Alzheimer's Cote d'Azur Christmas party, Amelia and her son Pierre listened to the singers with interest. Pierre is not married and lives next door to his mother, who he adores.

Results

Results of base option

The total estimated worldwide costs of dementia are US$604 billion in 2010 (table 8). About 70% of the costs occur in Western Europe and North America (table 9). Costs of informal care and the direct costs of social care generally contribute similar proportions of total costs, while the direct medical costs are much lower (table 10). However, in low and middle income countries direct social care costs are negligible and informal care costs predominate. The results of the base option are seen in tables 8–15.

The cost per person with dementia is highest in North America (US$48,605 – table 11) and lowest in the South Asia region (US$903 – comprising countries such as India and Bangladesh) and Western Sub Saharan Africa (US$969). The cost per person with dementia is therefore more than 50 times higher in the richest world regions than in the poorest.

The differences between developed and developing countries are even more obvious when the World Bank classification is applied (tables 12-15). Low income countries, where 14% of people with dementia reside, contribute less than 1% of the total costs (table 13).

The costs of informal care constitute the majority of costs in the low income and lower middle-income countries while the direct costs of social care have a much larger role in the high income countries (table 14), probably due to the costs of long term residential and nursing home care in these countries.

The total cost per person with dementia is 38 times higher in high income countries than in low income countries, and the direct costs of social care are 120 times higher (table 15).

Table 8 **Aggregated costs in each WHO region (billions US$)**

	Number of people with dementia	Informal care (all ADLs)	Direct costs		Total costs	Percent of GDP
			Medical	Social		
Australasia	311,327	4.30	0.70	5.07	10.08	0.97%
Asia Pacific High Income	2,826,388	34.60	5.23	42.29	82.13	1.31%
Oceania	16,553	0.07	0.02	0.01	0.10	0.46%
Asia Central	330,125	0.43	0.28	0.24	0.94	0.36%
Asia East	5,494,387	15.24	4.33	2.84	22.41	0.40%
Asia South	4,475,324	2.31	1.16	0.57	4.04	0.25%
Asia Southeast	2,482,076	1.77	1.48	0.73	3.97	0.28%
Europe Western	6,975,540	87.05	30.19	92.88	210.12	1.29%
Europe Central	1,100,759	8.59	2.67	2.94	14.19	1.10%
Europe Eastern	1,869,242	7.96	3.42	2.94	14.33	0.90%
North America High Income	4,383,057	78.76	36.83	97.45	213.04	1.30%
Caribbean	327,825	1.50	0.78	0.71	2.98	1.06%
Latin America Andean	254,925	0.35	0.31	0.28	0.93	0.43%
Latin America Central	1,185,559	1.58	2.61	2.37	6.56	0.37%
Latin America Southern	614,523	2.36	1.42	1.29	5.07	1.02%
Latin America Tropical	1,054,560	2.17	2.67	2.42	7.26	0.42%
North Africa / Middle East	1,145,633	1.90	2.05	0.54	4.50	0.16%
Sub-Saharan Africa Central	67,775	0.04	0.02	0.01	0.07	0.06%
Sub-Saharan Africa East	360,602	0.28	0.08	0.04	0.40	0.17%
Sub-Saharan Africa Southern	100,733	0.52	0.11	0.06	0.69	0.24%
Sub-Saharan Africa West	181,803	0.11	0.04	0.02	0.18	0.06%
Total	**35,558,717**	**251.89**	**96.41**	**255.69**	**603.99**	**1.01%**

Table 9 **The contribution of each WHO region to the global prevalence of dementia, and to global costs (informal care, direct medical and social care costs, and total costs)**

	Proportion of people with dementia	Informal care (all ADL)	Direct costs		Total costs
			Medical	Social	
Australasia	0.9%	1.7%	0.7%	2.0%	1.7%
Asia Pacific High Income	7.9%	13.7%	5.4%	16.5%	13.6%
Oceania	0.0%	0.0%	0.0%	0.0%	0.0%
Asia Central	0.9%	0.2%	0.3%	0.1%	0.2%
Asia East	15.5%	6.1%	4.5%	1.1%	3.7%
Asia South	12.6%	0.9%	1.2%	0.2%	0.7%
Asia Southeast	7.0%	0.7%	1.5%	0.3%	0.7%
Europe Western	19.6%	34.6%	31.3%	36.3%	34.8%
Europe Central	3.1%	3.4%	2.8%	1.1%	2.3%
Europe Eastern	5.3%	3.2%	3.6%	1.2%	2.4%
North America High Income	12.3%	31.3%	38.2%	38.1%	35.3%
Caribbean	0.9%	0.6%	0.8%	0.3%	0.5%
Latin America Andean	0.7%	0.1%	0.3%	0.1%	0.2%
Latin America Central	3.3%	0.6%	2.7%	0.9%	1.1%
Latin America Southern	1.7%	0.9%	1.5%	0.5%	0.8%
Latin America Tropical	3.0%	0.9%	2.8%	0.9%	1.2%
North Africa / Middle East	3.2%	0.8%	2.1%	0.2%	0.7%
Sub-Saharan Africa Central	0.2%	0.0%	0.0%	0.0%	0.0%
Sub-Saharan Africa East	1.0%	0.1%	0.1%	0.0%	0.1%
Sub-Saharan Africa Southern	0.3%	0.2%	0.1%	0.0%	0.1%
Sub-Saharan Africa West	0.5%	0.0%	0.0%	0.0%	0.0%
All	**100%**	**100%**	**100%**	**100%**	**100%**

Table 10 **Aggregated cost types as percentages of total costs in the different WHO regions**

	Informal care (all ADL)	Direct costs		Total costs
		Medical	Social	
Australasia	42.7%	7.0%	50.3%	100%
Asia Pacific High Income	42.1%	6.4%	51.5%	100%
Oceania	74.7%	16.9%	8.4%	100%
Asia Central	45.2%	29.5%	25.2%	100%
Asia East	68.0%	19.3%	12.7%	100%
Asia South	57.1%	28.7%	14.2%	100%
Asia Southeast	44.4%	37.2%	18.4%	100%
Europe Western	41.4%	14.4%	44.2%	100%
Europe Central	60.5%	18.8%	20.7%	100%
Europe Eastern	55.6%	23.9%	20.5%	100%
North America High Income	37.0%	17.3%	45.7%	100%
Caribbean	50.3%	26.1%	23.7%	100%
Latin America Andean	37.5%	32.7%	29.7%	100%
Latin America Central	24.1%	39.8%	36.1%	100%
Latin America Southern	46.6%	28.0%	25.4%	100%
Latin America Tropical	29.9%	36.8%	33.4%	100%
North Africa / Middle East	42.3%	45.7%	12.0%	100%
Sub-Saharan Africa Central	60.0%	26.8%	13.2%	100%
Sub-Saharan Africa East	70.1%	20.0%	9.9%	100%
Sub-Saharan Africa Southern	75.3%	16.5%	8.2%	100%
Sub-Saharan Africa West	62.8%	24.9%	12.3%	100%
All	**41.7%**	**16.0%**	**42.3%**	**100%**

Table 11 **Cost per person with dementia in each WHO region (US$)**

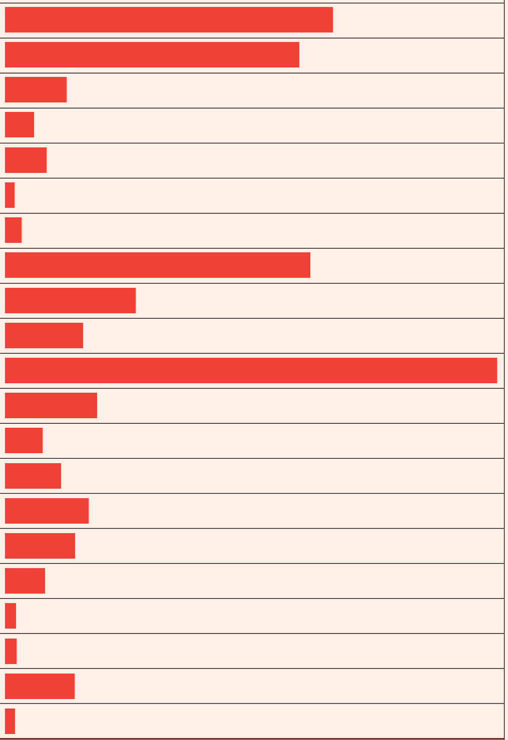
	Informal care (all ADL)	Direct costs		Total costs	
		Medical	Non-medical		Total costs
Australasia	13812	2262	16296	32370	
Asia Pacific High Income	12243	1852	14963	29057	
Oceania	4526	1026	508	6059	
Asia Central	1295	845	723	2862	
Asia East	2774	788	517	4078	
Asia South	515	259	128	903	
Asia Southeast	711	595	295	1601	
Europe Western	12479	4328	13315	30122	
Europe Central	7801	2423	2667	12891	
Europe Eastern	4261	1832	1573	7667	
North America High Income	17968	8403	22233	48605	
Caribbean	4570	2371	2151	9092	
Latin America Andean	1375	1200	1089	3663	
Latin America Central	1335	2202	1999	5536	
Latin America Southern	3838	2309	2095	8243	
Latin America Tropical	2057	2529	2295	6881	
North Africa / Middle East	1660	1794	472	3926	
Sub-Saharan Africa Central	648	289	143	1081	
Sub-Saharan Africa East	787	224	111	1122	
Sub-Saharan Africa Southern	5149	1127	558	6834	
Sub-Saharan Africa West	609	241	119	969	
All	**7084**	**2711**	**7191**	**16986**	

Table 12 **Aggregated costs in different World Bank income groups (billions US$)**

	Number of people with dementia	Informal care (all ADL)	Direct costs		Total costs	Percent of GDP
			Medical	Non-medical		
Low income	5036979	2.52	1.23	0.62	4.37	0.24%
Lower middle income	9395204	18.90	6.74	3.57	29.21	0.35%
Upper middle income	4759025	13.70	10.44	8.35	32.49	0.50%
High income	16367508	216.77	78.00	243.14	537.91	1.24%
All	**35558717**	**251.89**	**96.41**	**255.69**	**603.99**	**1.01%**

Table 13 **Aggregated costs in different World Bank income groups, as percentages of total global costs**

	Prevalence	Informal care (all ADL)	Direct costs		Total costs
			Medical	Social	
Low income	14.2%	1.0%	1.3%	0.2%	0.7%
Lower middle income	26.4%	7.5%	7.0%	1.4%	4.8%
Upper middle income	13.4%	5.4%	10.8%	3.3%	5.4%
High income	46.0%	86.1%	80.9%	95.1%	89.1%
All	**100%**	**100%**	**100%**	**100%**	**100%**

Table 14 **Aggregated cost types as percentages of total costs in different World Bank income groups**

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

Table 15 **Costs per person with dementia in different World Bank income groups (US$)**

	Informal care (all ADL)	Direct costs		Total costs	Care costs 🟧 Informal 🟦 Medical 🟩 Social
		Medical	Social		
Low income	500	244	124	868	
Lower middle income	2,012	717	380	3,109	
Upper middle income	2,879	2,194	1,755	6,827	
High income	13,244	4,766	14,855	32,865	
All	**7,084**	**2,711**	**7,191**	**16,986**	

Sensitivity analyses

For the estimation of costs in the base case, we made several assumptions, regarding, for example, the appropriate method for comparing costs between countries, the types of informal care that should be included in cost estimations, the hourly costs to be attached to informal caregiver inputs, and the relative cost of inputs from different types of caregiver. In order to understand the effect of these assumptions on the cost estimations, we carried out sensitivity analyses in which we varied these assumptions. The base case options and the sensitivity analysis options are summarized in table 16.

Table 16 **Summary of sensitivity analysis options**

Consideration	**Base case option**	**Sensitivity analysis option(s)**
How should we compare costs between countries, using a single cost metric?	According to the exchange rate with US dollar	According to purchasing power parity (PPP)
Which informal care inputs should be included?	Assistance with both basic and instrumental ADL (referred to as combined ADL), but not time spent supervising	1 Assistance with basic ADL only 2 Assistance with combined ADL and time spent supervising
How should we cost the inputs of informal caregivers?	At the average wage for that country based on manual imputation	1 A regression model of average wage as a function of GDP per person 2 At replacement cost (the average wage for a social care professional)
	Equally for spouses and non-spouses	1 Spouse caregiver inputs should be costed at 25% of the average wage 2 Spouse caregiver inputs should be costed at 50% of the average wage

How should we compare costs between countries, using a single cost metric?

There are essentially two approaches: through exchange rates (as used in the base option) or through purchasing power parity (PPP). One US dollar exchanged into Indian rupees and spent in India would have more purchasing power in India than it would in the USA. The PPP approach uses an international dollar as the standard metric, equalizing the purchasing power of different currencies for a given basket of goods.

Using a PPP basis is arguably more useful than exchange rates when comparing generalized differences in living standards between nations because PPP takes into account the relative cost of living and the inflation rates of the countries, while exchange rates may distort real differences in income. For our purposes, the PPP estimates take into account the local value of the costs incurred, as opposed to their value on the international money markets. If PPPs are used for the estimates instead of exchange rates, the total worldwide costs are 7.4% higher. However, PPP is most useful when comparing costs between countries and regions, particularly those with widely differing levels of economic development. In relative terms, the contribution from lower income countries is more substantial (table 17). Under the base case option, low income countries accounted for just 0.7% of total worldwide costs, middle income countries for 10.2% and high income countries for 89.1%. Using PPP, these proportions are 2.1% for low, 20.0% for middle income and 77.9% for high income countries.

The costs of dementia as a proportion of GDP are scarcely affected by the choice of exchange rates or PPP-based approaches, since both the numerator and the denominator are increased in lower income countries. Using PPP, this proportion varied from 0.25% in low income countries to 0.37% in lower middle to 0.54% in upper middle to 1.25% in high income countries.

Table 17 **Sensitivity analysis: Costs estimates based on PPPs (billions US$)**

Regions	**Informal care (all ADL)**	**Direct costs**		**Total costs PPPs**	**Total costs (base case)**
		Medical	**Non-medical**		
Australasia	3.94	0.71	5.08	9.73	10.08
Asia Pacific High Income	33.00	5.29	42.78	81.08	82.13
Oceania	0.12	0.02	0.01	0.15	0.10
Asia Central	0.75	0.48	0.41	1.64	0.94
Asia East	27.16	9.66	5.90	42.71	22.41
Asia South	6.95	3.47	1.72	12.13	4.04
Asia Southeast	3.89	3.12	1.55	8.56	3.97
Europe Western	76.10	27.03	83.69	186.81	210.12
Europe Central	12.11	3.99	4.25	20.35	14.19
Europe Eastern	13.92	5.72	4.91	24.56	14.33
North America High Income	78.72	36.83	97.42	212.98	213.04
Caribbean	1.81	0.91	0.83	3.55	2.98
Latin America Andean	0.87	0.53	0.48	1.88	0.93
Latin America Central	2.97	3.49	3.16	9.62	6.56
Latin America Southern	4.68	2.26	2.05	8.99	5.07
Latin America Tropical	7.07	2.88	2.61	12.56	7.26
North Africa / Middle East	3.39	3.05	1.03	7.47	4.50
Sub-Saharan Africa Central	0.05	0.03	0.02	0.10	0.07
Sub-Saharan Africa East	0.79	0.15	0.07	1.02	0.40
Sub-Saharan Africa Southern	1.06	0.21	0.11	1.38	0.69
Sub-Saharan Africa West	0.21	0.09	0.04	0.35	0.18
Low income	7.70	3.86	1.95	13.51	4.37
Lower middle income	36.13	14.90	7.88	58.92	29.21
Upper middle income	36.47	18.66	15.41	70.54	32.49
High income	199.24	72.50	232.88	504.63	537.91
Worldwide (all)	**279.55**	**109.93**	**258.12**	**647.6**	**603.99**

Which informal care inputs should be included?

For the base case option, we costed time spent by informal caregivers assisting with basic ADL (personal care) and instrumental activities of daily living. Inclusion of time spent assisting with IADL may be problematic given that the ingredients of this component of care may vary substantially across cultures, and that estimates between studies tend to vary substantially depending partly on the methods used to quantify it. On the other hand, a relatively high proportion of studies included in our systematic review provided estimates of time spent assisting with both types of ADL combined. Time spent generally supervising the person with dementia is even more difficult to quantify, and hence estimates are highly variable. Nevertheless, both IADL assistance and supervision are generally considered important and time-consuming aspects of informal care, and a focus on personal care alone is likely to seriously underestimate the extent of informal care inputs and associated costs. Thus, to highlight the complexity in caregiving and estimates of caregiver time, we also include basic ADLs (representing a minimum level) and combined ADLs and supervision together (representing a maximum level) as options for the cost estimates of informal care.

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 (table 18) while they are 30% higher if combined ADLs and supervision are included. Compared with the total worldwide cost estimate of US$604 billion in the base case, these sensitivity analyses provide a lower bound estimate of US$470 billion (basic ADLs only) and an upper bound estimate of US$783 billion (including assistance with basic ADLs and IADLs, and supervision). The proportions of total costs accounted for by informal care are highest in low income and lower middle income countries, particularly in the combined ADLs and supervision alternative (68-73%).

How should we cost the inputs of informal caregivers?

Not only the quantification of informal care but also the costing is crucial for the final estimated total costs. In the approach used in the base case, the inputs of informal caregivers were costed as the average hourly wage for that country with an adjustment for the difference in the average wage earning potential of men and women. These estimates could therefore be considered to represent

Table 18 **Sensitivity analysis**

Costs of informal care, and informal care costs as a % of total costs when informal care inputs are considered as a) basic combined ADL and IADL (the base case), b) basic ADL assistance only and c) combined ADL assistance and supervision (billions US$)

	Base case (combined basic ADL and IADL assistance)		**Basic ADL assistance only**		**Combined ADL assistance and supervision**	
Regions	**Costs of informal care**	**% of total costs**	**Costs of informal care**	**% of total costs**	**Costs of informal care**	**% of total costs**
Australasia	4.30	42.7%	2.59	31.0%	5.84	50.3%
Asia Pacific High Income	34.60	42.1%	19.40	29.0%	46.16	49.3%
Oceania	0.07	74.7%	0.06	70.1%	0.09	78.8%
Asia Central	0.43	45.2%	0.20	28.0%	0.99	65.6%
Asia East	15.24	68.0%	11.82	62.3%	20.35	74.0%
Asia South	2.31	57.1%	1.14	39.6%	3.62	67.6%
Asia Southeast	1.77	44.4%	0.88	28.5%	2.55	53.6%
Europe Western	87.05	41.4%	23.19	15.9%	162.51	56.9%
Europe Central	8.59	60.5%	3.63	39.3%	15.73	73.7%
Europe Eastern	7.96	55.6%	3.84	37.6%	14.48	69.5%
North America High Income	78.76	37.0%	41.59	23.6%	135.91	50.3%
Caribbean	1.50	50.3%	1.50	50.3%	2.75	65.0%
Latin America Andean	0.35	37.5%	0.35	37.5%	0.66	53.1%
Latin America Central	1.58	24.1%	1.58	24.1%	4.25	46.0%
Latin America Southern	2.36	46.6%	1.56	36.6%	3.96	59.4%
Latin America Tropical	2.17	29.9%	2.16	29.8%	4.38	46.3%
North Africa / Middle East	1.90	42.3%	1.48	36.3%	5.40	67.6%
Sub-Saharan Africa Central	0.04	60.0%	0.02	45.4%	0.07	71.0%
Sub-Saharan Africa East	0.28	70.1%	0.16	56.5%	0.46	79.3%
Sub-Saharan Africa Southern	0.52	75.3%	0.29	62.8%	0.85	83.3%
Sub-Saharan Africa West	0.11	62.8%	0.06	48.3%	0.18	73.4%
Low income	2.52	57.6%	1.30	41.2%	3.90	67.8%
Lower middle income	18.90	64.7%	13.92	57.4%	28.09	73.2%
Upper middle income	13.70	42.2%	9.30	33.1%	26.27	58.3%
High income	216.77	40.3%	92.98	22.5%	372.93	53.7%
All (informal care)	**251.89**	**41.7%**	**117.50**	**25.0%**	**431.20**	**55.0%**
All (total costs)	**603.99**		**469.60**		**783.29**	

theoretical lost productivity, assuming that, if they were not providing informal care for a person with dementia, the caregivers might all form part of the labour force and contribute to GDP. In the base option, imputation for missing data was made from nearby countries with similar GDP per person and assumed similar care patterns. This approach may include bias. Another option is to make a regression model with average wage as the dependent variable and GDP per person as the explanatory variable. This regression model showed that a change of GDP per person by US$1 will change the hourly average wage per hour by US$0.000263 (95% confidence interval 0.000214-0.000312; $p<0.0001$, $r^2=0.48$). If this model is applied for missing data (table 19), the results are very similar to the base option. Data from countries with imputed data represented in most cases low income countries with relatively small populations of people with dementia.

However, a substantial proportion of caregivers are spouses (generally around 40%, but between 15% to 51% by region – see table 7) and most, but not all, could be assumed to be beyond the usual working age. For the sensitivity analyses, we recalculated informal care and total costs valuing the care inputs of spouse caregivers at 50% and 25% of the average wage, and applying this reduced wage to the estimated proportion of caregivers in each country that were spouses. This 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

Table 19 **Sensitivity analysis (billions US$)**

Total costs using a regression based model for imputation of missing data for costs of informal care

Regions	Base case	Regression model	Lower bound of the 95% confidence interval	Upper bound of the 95% confidence interval
Australasia	10.08	10.08	10.08	10.08
Asia Pacific High Income	82.13	80.78	80.54	81.03
Oceania	0.10	0.09	0.09	0.09
Asia Central	0.94	0.93	0.93	0.93
Asia East	22.41	22.36	22.34	22.38
Asia South	4.04	4.03	4.03	4.03
Asia Southeast	3.97	3.83	3.80	3.86
Europe Western	210.12	210.00	209.95	210.05
Europe Central	14.19	14.19	14.19	14.19
Europe Eastern	14.33	14.27	14.25	14.28
North America High Income	213.04	213.04	213.04	213.04
Caribbean	2.98	3.00	2.92	3.08
Latin America Andean	0.93	0.93	0.93	0.93
Latin America Central	6.56	6.44	6.42	6.46
Latin America Southern	5.07	5.07	5.07	5.07
Latin America Tropical	7.26	7.24	7.24	7.25
North Africa / Middle East	4.50	4.19	4.11	4.27
Sub-Saharan Africa Central	0.07	0.07	0.06	0.07
Sub-Saharan Africa East	0.40	0.26	0.24	0.28
Sub-Saharan Africa Southern	0.69	0.68	0.68	0.68
Sub-Saharan Africa West	0.18	0.16	0.15	0.17
Low income	4.37	4.19	4.16	4.22
Lower middle income	29.21	28.87	28.80	28.93
Upper middle income	32.49	32.20	32.04	32.35
High income	537.91	536.38	536.05	536.71
All	**603.99**	**601.63**	**601.06**	**602.21**

when costed at 50% of the average wage) and to US$520 billion (a 14% reduction when costed at 25% of the average wage).

Another way of looking at care inputs is that the value to society is the same regardless of whether the care is provided by women or men, or by younger and potentially economically active or older and retired caregivers. This is the implicit viewpoint when assessing 'replacement costs', namely the cost to society of replacing the informal caregiver with a paid social care professional. We estimated the average wage of a social care professional from the Laborsta database (health and social work)[i] where the average wage in the health and social sector was available and applied this to all informal care inputs.

Comparison of this Report with previous worldwide cost estimates of dementia

In 2007, the worldwide costs of dementia were estimated as US$315 billion(12), later updated to US$422 billion for 2009(13). The basic assumptions in these papers were different from those in this Report. Firstly, only basic ADL assistance rather

Table 20 **Sensitivity analysis (billions US$)**

Total costs, with the costs of informal care calculated a) with different assumptions regarding hourly wage cost for spouse caregivers, and b) as replacement costs

Regions	Base case (retired spouse proportion valued at 100% of average wage)	Spouse caregiving valued at 50% of average wage	Spouse caregiving valued at 25% of average wage	Replacement cost (average wage for a social care professional)
Australasia	10.08	9.15	8.69	10.22
Asia Pacific High Income	82.13	75.98	72.91	86.07
Oceania	0.10	0.08	0.08	0.06
Asia Central	0.94	0.86	0.82	0.82
Asia East	22.41	19.37	17.86	17.11
Asia South	4.04	3.76	3.62	4.02
Asia Southeast	3.97	3.90	3.86	5.02
Europe Western	210.12	190.63	180.89	218.17
Europe Central	14.19	12.51	11.67	14.51
Europe Eastern	14.33	12.89	12.17	14.92
North America High Income	213.04	192.43	182.13	218.81
Caribbean	2.98	2.84	2.78	3.21
Latin America Andean	0.93	0.91	0.89	0.82
Latin America Central	6.56	6.49	6.45	6.83
Latin America Southern	5.07	4.52	4.25	4.08
Latin America Tropical	7.26	6.67	6.38	7.08
North Africa / Middle East	4.50	4.14	3.95	4.02
Sub-Saharan Africa Central	0.07	0.06	0.06	0.07
Sub-Saharan Africa East	0.40	0.35	0.32	0.28
Sub-Saharan Africa Southern	0.69	0.58	0.53	0.44
Sub-Saharan Africa West	0.18	0.15	0.14	0.17
Low income	4.37	4.04	3.87	4.36
Lower middle income	29.21	25.73	23.98	22.94
Upper middle income	32.49	30.09	28.89	31.65
High income	537.91	488.44	463.70	557.75
All	**603.99**	**548.29**	**520.44**	**616.71**

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[i] Laborsta Internet [database on the Internet]. ILO. 2010 [cited 2010-02-23]. Available from: http://laborsta.ilo.org/STP

than combined basic ADL and IADL assistance were included in the base option 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 uniform across the world in the 2005 and 2009 estimates (1.6 hours per day). However, in the sensitivity analyses for these earlier estimates, options similar to those applied in the current Report were included, making more direct comparisons possible. When doing so, it is clear that the costs per person with dementia are very similar, particularly for the combined ADLs (table 21). If the approach in the 2005 estimates had been used for 2010, the cost of illness with combined ADLs would actually have been somewhat higher (US$668 billion). However, this figure cannot be interpreted as a decrease in costs; it just highlights methodological issues (for the 2010 estimate we have more inputs of population based data, see comment on page 13). The number of people with dementia increased by 18% between 2005 and 2010.

Table 21 **Comparisons with current cost estimates and previous reports with similar assumptions**

	Base case	**Wimo et al, 2010**	**Wimo et al, 2007**
Year	**2010**	**2009**	**2005**
Unadjusted cost of illness estimate in study	US$604.0 billion	US$421.6 billion	US$315.4 billion
Number of people with dementia as estimated in study	35,558,717	34,376,044	29,336,448
Cost of illness including combined (all ADLs) (PPPs, inflated to 2010, prevalence of 2010)*	US$647.6 billion	US$645.3 billion	US$668.3 billion
Cost of illness including core (basic) ADLs (PPPs, inflated to 2010), prevalence of 2010)*	US$509.3 billion	US$447.2 billion	US$465.1 billion
Total cost per person with dementia including all (combined) ADLs (PPPs, inflated to 2010)*	US$18,212	US$18,147	US$18,796
Total cost per person with dementia including core (basic) ADLs (PPPs, inflated to 2010)*	US$14,322	US$12,577	US$13,079

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

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Conclusions and recommendations

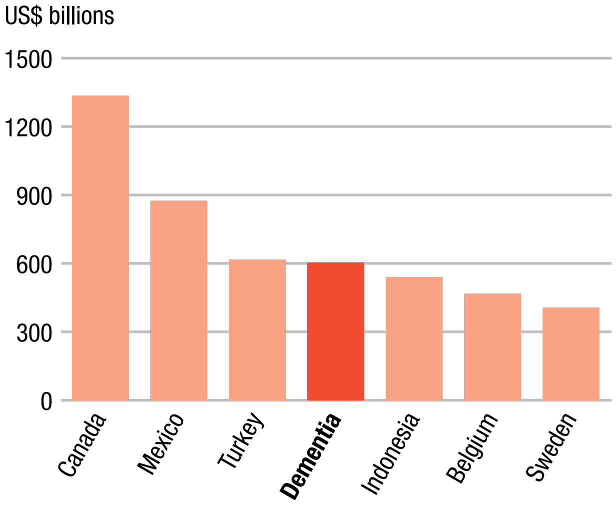
As her cognitive difficulties increase, Maria is finding it more difficult to continue to live in her small home in the Villa Francisca barrio in Santo Domingo, Dominican Republic. She is coming to realise the necessity of moving to a rural area where she has family, but the idea of moving is painful.

Conclusions and recommendations

The estimated annual worldwide cost to society of dementia, US$604 billion, highlights the enormous impact that dementia has on socio-economic conditions worldwide. It is difficult to envisage so large a sum, but it amounts to around 1% of the world's gross domestic product. If dementia care were a country, it would be the world's 18th largest economy, ranking between Turkey and Indonesia (figure 4)[i]. 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)[ii].

The scale of these costs is explainable when one considers that, according to our estimates in the World Alzheimer Report 2009, 35.6 million older 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 instrumental activities of daily living (such as cooking or shopping), to full personal care and round the clock supervision. In some high income countries, between one third and one half of all people with dementia live in resource- and cost-intensive residential or nursing home care facilities. Medical care costs also tend to be relatively high for people with dementia, particularly in high income countries with reasonable provision of specialist care services(1). In many such studies, the greater number of comorbid medical conditions accounts for the higher use of medical care resources by people with dementia.

Figure 4 **Cost of dementia compared to national economies**



It is very difficult to make an accurate projection of future costs, since there are so many things that are difficult to predict. Future costs could be influenced by macroeconomic factors (for example, the pace of economic development) and by dementia-specific factors. These would include changes in the incidence and prevalence of dementia, in patterns of help seeking, in the availability of health and social care services, and changes in care systems and care conditions. The availability of new and more effective treatments for dementia might on the one hand increase medical care costs, but on the other reduce the needs for social care. 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 in last year's World Alzheimer Report, then by 2030 worldwide societal costs will have increased by 85%.

Strengths and weaknesses

The accuracy of any estimate of the worldwide costs of dementia depends critically upon the quality of the data used to estimate it. These comprise:

- The prevalence of dementia.
- The resources used with respect to direct medical care, social care and informal care.
- The costs attached to the resources used.

Ideally, these data should be up to date, available for all countries worldwide, and in appropriately fine-grained detail.

This Report is based on much better underlying sources than previous worldwide cost estimates. Estimates of the prevalence and numbers of people with dementia were obtained from the World Alzheimer Report 2009, following a fully systematic review of the literature from around the world. The review identified 135 publications, with a large recent increase in the prevalence survey evidence-base covering low and middle income countries. However, a relatively high proportion of studies were conducted more than 10 years previously, particularly those from high income countries. The methodological quality of many studies also left much to be desired. Only in two countries, the USA and Canada, had nationally representative surveys been conducted.

Data on resource utilization is also more extensive than previously available, particularly with respect to informal care provision in low and middle income countries. The 10/66 Dementia Research Group studies in Latin America, India and China provide

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[i] World Bank - Gross domestic product 2009 http://siteresources.worldbank.org/DATASTATISTICS/Resources/GDP.pdf

[ii] Wikipedia – list of companies by revenue http://en.wikipedia.org/wiki/List_of_companies_by_revenue

recent estimates of caregiver characteristics, and of average time spent assisting with basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and time spent supervising, all from representative population-based samples of people with dementia. This adds significantly to the pre-existing database generated from a systematic review of 53 economic studies of formal and informal care, which was heavily skewed to European and North American studies. Based on our comprehensive review of the international literature, we identified estimates of assistance with basic ADLs for 25 countries, representing 63% of the worldwide dementia population, and data on assistance with combined ADLs from 30 countries representing 73% of the worldwide dementia population. Data on supervision were available for 25 countries representing 63% of the worldwide dementia population. For other countries it was necessary to make imputations based on available figures from nearby countries or in some cases from regional or global estimates. The regression-based imputation models showed similar results. However, although this Report is based on better data than previous reports, it is important to acknowledge the limitations with the current evidence base. The majority of resource utilization studies have been carried out on ‘convenience samples’ of those who have accessed services or contacted Alzheimer associations, and are hence skewed towards those with more advanced disease and greater needs for care, which may result in an overestimate of costs. Generalizing from one sample, in one treatment facility, usually in a major city, to the population of the country as a whole is clearly problematic. Sample sizes are often small, and often based on urban areas, leading to imprecise estimates. Many of the studies are not recent and since care patterns and care systems change, there is a need for a continuous update of such figures.

The most significant limitation is in the estimation of direct costs of both medical and social care. In this study, these figures are partly based on imputation from nearby countries but also estimated with a regression model, mainly based on high income countries, although cost figures from Turkey, China, Argentina and Hungary are available. Even if the estimates of direct costs and the distribution between direct medical and non-medical costs are the best possible, these figures must be interpreted with caution. While estimates of use of medical care services from the 10/66 Dementia Research Group studies in Latin America, India and China add significantly to our understanding of resource utilization in this domain, we considered that the global coverage of such data was still insufficient to replace the imputed approach. It is particularly important that medical and social care utilization data is up to date and locally relevant in order to reflect:

- Cultural differences in help-seeking.
- National differences in health and social care systems.
- Secular changes in patterns of help-seeking linked to changes in awareness, availability of specific services, promotion of early diagnosis, and access to benefits linked to diagnosis.

The results from the ADI worldwide survey of key informants regarding placement in residential care is also a great advance from previous studies. The survey showed that there are differences between rural and urban areas as well as between high and low income countries.

A general limitation is that our global cost of illness estimates rely on studies of dementia prevalence and dementia-related resource utilization that are unequally distributed worldwide, with data lacking from many countries. There is a particular lack of relevant studies from the continent of Africa, the Middle East, and from Eastern Europe. The extensive sensitivity analysis we have conducted indicates the degree of uncertainty in the cost estimates, and we consequently use the concept of ‘cost estimates’ rather than ‘cost calculations’.

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 costed. The several presentations in the sensitivity analysis facilitate comparisons with other studies and approaches.

The regional distribution of global costs

We have estimated that 89% of total global societal costs of dementia are incurred in high income countries, 10% in middle income countries, and less than 1% in low income countries. However, the minority (46%) of people with dementia live in high income countries, 39% in middle income, and 14% in low income countries. There is therefore a clear inequity in the global distribution of morbidity and attendant costs, which requires explanation.

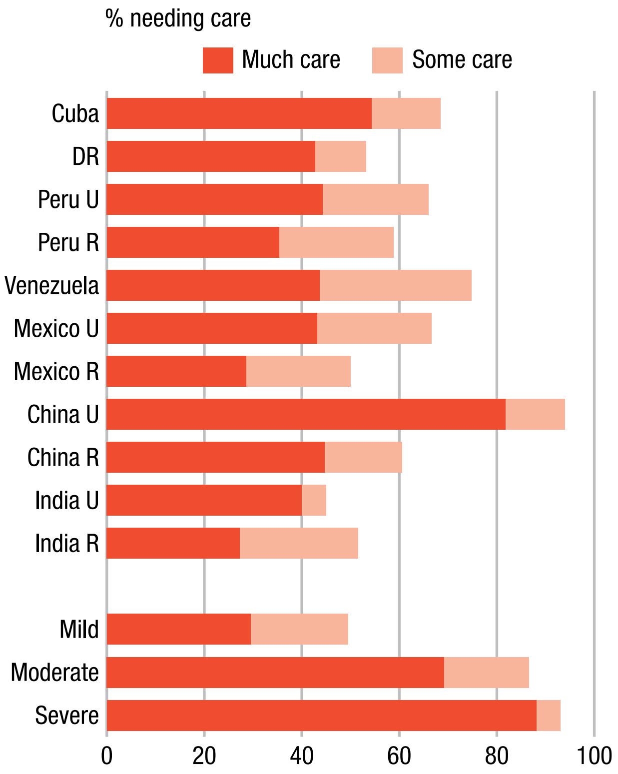
The use of exchange rates to provide a standard metric for comparing costs across countries may have underestimated costs in lower income countries, relative to higher income countries. When the PPP approach is used instead, 78% of total global costs are incurred in high income countries, 20% in middle income and 2% in low income countries.

In low and middle income countries (LMIC), informal care costs predominate (accounting for around two thirds of all costs, compared with around 40% in high income countries), whereas in high income countries (HIC), direct social care costs account for nearly half of all costs, compared with only one tenth in lower income countries. Since average wages (used to estimate informal care costs) are much lower in LMIC, this has an important impact on comparative total costs. Also, direct social care costs generally exceed those of informal care, because of the fixed structural costs involved in employing and managing community social care staff, and maintaining residential care premises. For example, in the recent Dementia UK report(2), while the average annual cost per person with dementia was £25,472, costs ranged from £14,540 for somebody with mild dementia living in the community to £20,355 for moderately severe dementia living in the community to £31,263 per year for those living in care homes.

There are surprisingly few reliable estimates of the proportions of people with dementia living in care homes, and none at all from low and middle income countries. In the five regional centres surveyed in the early 1990s for the UK Medical Research Council Cognitive Function and Ageing Study, 34% (95% confidence interval 30%-39%) of people with dementia lived in care homes(3). This figure is very close to the 37% that was subsequently estimated for the UK as a whole in the Dementia UK report(2). However, another recent estimate from the UK, based upon care home market survey data suggested that as many as 54% of all those with dementia resided in care homes(4). This second figure is very close to that estimated in the Canadian Study of Health and Ageing(5), which is, to date, the only nationally representative survey of dementia to have sampled separately private households and institutional care settings. In the Dementia UK report, the proportion of those with dementia living in care homes rose with age, from 27% of those aged 65-74, to 28% of those aged 75-84, to 41% of those aged 85-89, to 61% of those aged 90 and over(2). This is understandable in the context of the greater severity of dementia among the oldest old, and the relative paucity of informal support among older people, who are more likely to have been widowed and to have lost many of their friends through bereavement.

In our analyses, the extent of informal care may have been overestimated in HIC relative to LMIC, since most HIC estimates in our database derived from convenience rather than representative population-based studies, which, as we have seen, are likely to be biased towards the inclusion of more advanced cases, needing more care. Conversely, the LMIC estimates were based largely on the 10/66 population-based studies in Latin America, India and China. In most 10/66 study sites, between 30% and 50% of those with dementia were rated as needing 'no care'. Only 30% of those with mild dementia were rated as needing 'much care', compared with 69% of those with moderate dementia, and 88% of those with severe dementia. Needs for care were less evident in rural sites in Latin America and China, and in India, where traditional extended family living circumstances still prevailed. In those settings, most older people lived with and were materially supported by their children. Instrumental activities of daily living (cooking, shopping, cleaning, managing

Figure 5 **The prevalence of needs for care among people with dementia, by research site and severity of dementia (10/66 Dementia Research Group population-based studies, data release 2.2)**



household budgets) would not be part of the normal roles and responsibilities even of fit and healthy older adults, who to that extent were 'cared for' by their children. Under such circumstances, dependence, beyond cultural norms, might only become apparent with more advanced dementia(6).

These observations regarding possible explanations for the inequitable distribution in dementia costs between world regions have important implications for future trends. These will inevitably tend towards 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 are likely to be driven by several underlying factors:

1 Increases in numbers of people with dementia will occur much more rapidly in low and middle income countries, because of the more rapid pace of demographic ageing in those regions. Thus, in the World Alzheimer Report 2009, we forecast a 40% increase in numbers in Europe over the 20 years from 2010 to 2030, a 63% increase in North America, 77% in the southern Latin American cone, and 89% in the developed Asia Pacific countries(7). These figures for more developed regions are to be compared with 117% growth in east Asia, 107% in south Asia, 134-146% in the rest of Latin America, and 125% in north Africa and the middle East.

2 With economic development, average wages, used here to calculate the opportunity cost or replacement cost of informal care, will rise particularly rapidly in low and middle income countries.

3 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, and supply of such care.

Health care expenditure is lower than it should be in all world regions. Evidence-based interventions, including caregiver support and training, and respite care should be being routinely provided, but are not, even in high income countries(8). 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; fewer than 10% of recruits to a widely advertised trial of a caregiver intervention in Goa, south India, had received any prior medical attention(9). The World Health Organization's Mental Health Gap Action Plan aims explicitly to close this gap in LMIC by boosting the coverage of evidence-based 'packages of care'(10) delivered in a cost-effective manner by non-specialist health workers in general healthcare settings. The guidelines (including recommendations for dementia case finding, diagnosis, caregiver education, training and support, and cognitive stimulation for people with dementia) are due to be piloted and evaluated in the context of scaling up in up to 12 target LMIC from 2011. This initiative, if successful, could bring about a step change in patterns of medical care utilization in resource poor countries. The cost of such interventions, which rely mainly on human resources, will vary between countries according to their wage levels. However, the cost of drugs that are still on patent tend to be quite similar worldwide (as was recently reported for acetylcholinesterase inhibitors for Alzheimer's disease(11)), and hence relatively unaffordable in low and middle income countries.

Alzheimer's is currently a very active field for drug development(12). Any new disease-modifying agent would have a huge potential market in LMIC, raising important ethical and practical challenges, arguably meriting a global response on the scale of the Global Fund and PEPFAR initiatives for HIV/AIDS.

Residential care and community social care systems (home care) are well developed in many high income countries, but scarce in low and middle income countries where there is still a strong reliance on traditional, informal family care arrangements. However, it seems likely that the need for high quality community and residential care will grow in LMIC, and with it the direct costs of dementia care. This has certainly been the case in HIC such as the United Kingdom and the USA, which were among the first to experience the dementia epidemic. In many developing countries traditional family and kinship structures are under threat from the demographic, social and economic changes that accompany economic development and globalisation(13). First, 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. Second, populations are increasingly mobile as education, cheap travel and flexible labour markets induce children to migrate to cities and abroad to seek work. Finally, declining fertility in the last stage of the demographic transition leaves increasing numbers of older people, particularly those with no son, lacking family support. Its effects will be most evident in China, where the baby boom encouraged by Mao was sharply reversed by the introduction of the one-child family law in 1978. Over the next twenty years, the parents of these only children will be reaching old age, and the period of greater risk for dementia and dependence.

Some governments in low and middle income countries have sought to encourage or coerce families to shoulder their responsibility for the financial support and care for older parents (14). For example, the Indian parliament passed a law in 2007 requiring children to support their parents, with those who fail to do so facing a three-month prison term with no right of appeal. The Social Justice Minister, Meira Kumar was quoted as saying:

> 'This bill is in response to the concerns expressed by many members over the fate of the elderly. With the joint family system withering away, the elderly are being abandoned. This has been done deliberately as they (the children) have a lot of resources which the old people do not have.'

The legislation also provides for the state to set up old age homes that the minister said should be the 'last resort for the poor and the childless'. While such policies are understandable in the context of the very real social problem identified by Indian lawmakers, they seem destined to fail in the longer-term. Care homes are already proliferating in major cities in countries such as India and China, catering to the affluent middle classes. In Beijing, the 10/66 Dementia Research Group survey highlighted that more than half of those with dementia were being cared for, at least in part, by paid caregivers. This is largely a by-product of economic development: when urban salaries exceed the cost of purchasing care by an adequate margin, then families are likely to opt for this rather than giving up work to care. In Japan, a high income country with a similarly strong Confucian tradition of honouring and caring for the elderly, the government felt obliged, on 1st April 2000, to implement a long-term care insurance plan entitling those eligible to services worth 365,400 yen per month (US$3,840), with the obligation of a 10% co-payment (15). Despite initial public misgivings regarding its cultural appropriateness (15), the new system has proved popular with families and care-providing entrepreneurs alike (16), and has been helpful in alleviating caregiver strain (17).

Table 22 **Annual costs per person with dementia derived from previously published cost of illness studies (figures recalculated when necessary to facilitate direct comparison)**

Project	**Costs per person with dementia (US$ – all inflated to 2010)**
USA (21)	60,090
Sweden (22)	49,413
Australia (23)	34,552
EuroCoDe for EU27 (20)	31,939
Canada (24)	30,812
UK (2)	30,805
EuroCoDe for the whole of Europe (20)	25,222
DWCD for Europe (18;19;25)	24,850
Hungary (26)	24,544
European Brain Council project (27)	16,585
Argentina (28)	4,012
Turkey (29)	3,393
China (30)	2,641

Comparisons with other estimates of the cost of dementia

The previously estimated worldwide CoI of dementia – US$315 billion for 2005 (18) and US$422 billion for 2009 (19) may at a first glance be significantly lower than the cost figure in the current paper, US$604 billion. However, our sensitivity analyses (table 20, page 32) showed that the differences were mainly accounted for by the exclusion of assistance with IADLs from the computation of informal care inputs, and by the increases in numbers of people with dementia over time.

There are also some previous aggregated costs estimates for Europe. In the EuroCoDe project (20), the estimated cost of dementia in the European Union (EU27) was €160.3 billion in 2008 or €22,194 per person with dementia, which corresponds to US$225.9 billion/US$31,281 in 2008 and US$228.5 billion/US$31,633 if inflated to 2010. If we extract the cost figures for EU27 from our current study, these are slightly lower – US$212.3 billion or US$27,698 per person with dementia (20). The cost estimates from the European Brain Council (EBC) are considerably lower than other estimates.

In table 22 we have summarised annual per person costs derived from previously published cost of illness studies in different countries and world regions. All costs are expressed in US dollars, and have been inflated to 2010 to facilitate direct comparison. Nevertheless, different studies have used different sources of information for their cost estimates and applied different assumptions. This will account for some of the observed variation. However, it is obvious that the largest single determinant of the scale of the costs is the level of economic development of the country or region concerned. The per person annual costs in table 22 are in general quite consistent with those estimated in our current report – US$868 in low income countries, US$3,109 in low middle income countries, US$6,827 in upper middle income countries and US$32,865 in high income countries.

There have been many studies of the cost of dementia in high income countries. In the United Kingdom, the results of an economic analysis commissioned by the Alzheimer's Society for the Dementia UK report indicated a total annual cost of £17 billion in 2005(2) (US$25.5 billion), updated by the Alzheimer Research Trust to £19.7 billion (US$29.6 billion) for 2010(31). Informal care accounted for just over one third of the total. The single largest cost driver was the cost of institutional care in care homes (contributing 41% of the total costs). The cost of social care (community care plus care homes) dominates direct costs, accounting for 56% of total costs, while health service costs accounted for only 8% of the total. In high income countries, costs tend to rise as dementia progresses. When people with dementia are cared for at home, informal care costs may exceed direct formal care costs. As the disease progresses, and the need for professional caregivers and specialist medical care arises, so the direct social and health care costs will increase. Thus, in the Dementia UK report, while the average annual cost per person with dementia was estimated as £25,472 (US$38,208), this varied from £14,540 (US$21,810) for a person with mild dementia living in the community (where informal care makes the largest contribution) to £20,355 (US$30,534) for a person with moderate dementia living in the community, to £31,263 (US$46,895) for a person with dementia living in a care home(2).

Similarly, in a Swedish CoI study(22) the costs of residence in care homes constituted about two-thirds of the societal costs, estimated as SEK 50 billion in 2005 (US$7.0 billion in 2010) or US$49,413 per person per year. The cost estimates from the UK and Sweden illustrate two patterns from 'welfare' states: first, that societal costs are very high, and second that the costs of long-term residential care are prominent.

There are several CoI studies from the US with a great range in the cost estimates, illustrating perhaps the heterogeneity of dementia care in the US but also heterogeneity in study populations and costing methods. The Alzheimer's Association estimated in their 2010 Alzheimer's Disease Facts & Figures report(21) that the total direct costs of Alzheimer's disease and other dementias were US$172 billion in 2010 and the costs of informal care were US$144 billion (2009), resulting in a total societal cost of US$316 billion. The Alzheimer Society of Canada has estimated a total national societal cost of 14.9 billion Canadian Dollars (US$14.1 billion) for 2008, arising from 481,000 people with dementia, with a tenfold increase, to 153 billion over the thirty years to 2038(24).

From Australia, there are three reports with diverging cost estimates; two studies(32,23) showed similar results, while a report from Australian Institute of Health and Welfare(33), computed significantly lower costs, based upon a smaller estimated number of people with dementia, and using a net costs approach.

Very little detailed work has been done on evaluating the economic costs of dementia in low or middle income countries. There are several reasons for this, including a shortage of trained health economists, the low priority given to dementia, and the poorly developed state of services for people with dementia. However, the fundamental obstacle has been the absence of available data sets(34). Given that the needs of frail older people will soon come to dominate health and social care budgets in these regions, more data is needed, urgently. In Denizli, Turkey a cost analysis was carried out on 42 patients with dementia(29). In Turkey, only 1% of older people live in residential care, so families provide most of the care. The average annual cost of care (excluding hospitalisation) was US$1,766 for mild dementia and US$4,930 for severe dementia. While most costs increased with the severity of the disease, out-patient costs declined. In Argentina(28), the annual direct costs of the disease increased with disease severity, from US$3,420 in mild to US$9,658 in severe Alzheimer's disease, and with institutionalisation (US$3,189 for community dwelling and US$14,448 for institutionalised). Most direct costs were paid for by the family.

In a study from China(30), costs from 67 people with Alzheimer's disease were collected. Direct costs constituted US$1,068 (44%) and costs of informal care US$1,326 (56%) with increasing costs due to severity. In another study from China(35), amount and costs of informal care in terms of basic ADLs, instrumental ADLs (IADLs) and supervision was measured in 71 people with dementia using the RUD instrument(36). Cost in terms of IADL was the biggest proportion (US$4,111 per year) followed by supervision (US$2,841 per year) and basic ADLs (US$2,723 per year).

There are also very few studies from Eastern and Central Europe. ICTUS is a clinical based project and includes several European countries, including Romania(37). There is a range in annual costs per person with dementia (2006 cost level) between €6,063 (Northern Europe) and €8,279 (Western Europe). As part of the EuroCoDe project(20) a separate report from Hungary(26) included resource utilization and cost data on 74 people with mild cognitive impairment or dementia, ranging from €358 per month (MCI) to €885 (severe dementia). In both the ICTUS and Hungarian project, the RUD (resource utilization dementia) instrument(36) was used for data collection.

Comparison with the cost of other chronic diseases

It is difficult to compare our estimates of the global societal costs for dementia with those for 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 UK, a recent report commissioned by the Alzheimer's Research Trust (Dementia 2010) focused upon the economic burden of dementia and other chronic diseases, and sought to compare like-for-like disease costs with national expenditure on research(31). 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(31). The annual per capita costs were estimated at £27,647 for dementia, £5,999 for cancer, £4,770 for stroke and £3,455 for heart disease. However, Government and charitable spending on dementia research was 12 times lower than on cancer research. £590 million was spent on cancer research each year, while £50 million was invested in dementia research. Heart disease received £169 million per year and stroke research £23 million. Clearly, investment in research did not match the relative burden of these different chronic diseases. In fact, for every £1 million in care costs arising from the disease(31):

- £129,269 was spent on cancer research.
- £73,153 on heart disease research.
- £8,745 on stroke research.
- £4,882 on dementia research.

In a paper from Sweden(22), the costs of dementia were compared with other estimates for chronic disorders. The annual costs of dementia (50 billion 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. While, 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.

The World Alzheimer Report 2009 highlighted the discrepancies in the burden arising from different chronic diseases, depending upon whether ranking is determined according to their contributions to disability or mortality(7). The diseases that contribute most to years lived with disability (dementia, arthritis, stroke and sensory impairments) contribute least to mortality (where the effects of cardiovascular disease and cancer predominate), and vice versa. Recently published findings from the 10/66 Dementia Research Group show clearly that dementia is the leading chronic disease contributor to both disability(38) and needs for care(39). However, most analyses of the way that chronic diseases are prioritised suggest that for clinicians, policymakers and researchers what matters most is the quantity rather than the quality of life. In the USA also, the National Institutes of Health spend 14 times more on research into cancer, and five times more is spent on research into cardiovascular disease, than is spent on research into dementia[i]. Worldwide, in the last 10 years, there were 16 times as many research publications on cancer, and 11 times as many on heart disease(7). Health care expenditure is also skewed towards cancer and heart disease.

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[i] National Institutes of Health Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) http://report.nih.gov/rcdc/categories/

Alzheimer's Disease International's recommendations

Globally, dementia costs around 1% of GDP, this figure varying between around 0.24% in low income countries and 1.24% in high income countries. While the health care costs for dementia are currently comparatively modest, these are more than made up for by the very high costs of informal care (unpaid care provided by families), community social care and, in some developed countries, residential care homes.

In high income countries (for example the United Kingdom, where such a comparison was recently published (31)) it is likely that the societal costs of dementia already exceed those of other chronic conditions such as cancer, heart disease or stroke that are accorded relatively greater priority.

The relatively low medical care costs for dementia are explained first by low levels of awareness and help-seeking. Raising awareness and the promotion of early diagnosis is now a key priority, and countries such as the UK, France and Australia are focusing on this as part of their national dementia strategies. However, this is a particular problem for low and middle income countries, where resources for specialist care are also very limited.

There is also evidence to suggest that dementia is currently under treated, even in high income countries (8). While the efforts of the WHO to increase the coverage of basic packages of care will focus on non-specialists in resource poor settings, the evidence-based dementia care guidelines are equally applicable to high income countries, where, for example, few caregivers receive education, training and support (8).

Many governments already commit funds for dementia care, but lack strategic awareness of it and of the hidden costs and the pressure that dementia puts on health systems. Currently there are national plans to improve dementia care in only a few countries. There is no strategy to deal with increases in the future, which current health systems are not equipped to deal with.

1 Alzheimer's Disease International calls on all governments to make dementia a health priority and develop national plans to alleviate the burden of the disease.

2 Alzheimer's Disease International reminds governments of their obligations under the UN Convention on the Rights of People with Disabilities, and the Madrid International Plan for Action on Ageing to ensure access to healthcare. It calls on governments to fund and expand the implementation of the WHO Mental Health Gap Action Plan, including the packages of care for dementia, as one of the seven core disorders identified in the plan.

3 Alzheimer's Disease International requests that new investment in chronic disease care should always include attention to dementia. For example, the WHO Global Report on 'Innovative Care for Chronic Conditions' (40) alerts policymakers, particularly those in low and middle income countries, to the implications of the decreases in communicable diseases and the rapid ageing of populations. Healthcare is currently organized around an acute, episodic model of care that no longer meets the needs of patients with chronic conditions. The WHO Innovative Care for Chronic Conditions framework (41) provides a basis on which to redesign health systems that are fit for their purpose.

Medical care costs remain low because there are currently no pharmacological treatments that have proven to be effective in preventing or modifying the course of the disease. In addition, psychosocial interventions are also greatly under-researched, and they are under-promoted when found to be effective.

4 Alzheimer's Disease International calls on governments and other major research funders to act now to increase funding for research into prevention treatment and care. to a level more proportionate to the economic burden of dementia. Recently published data from the UK (31) suggests that a 15-fold increase would be required to reach parity with research into heart disease, and a 30-fold increase to achieve parity with cancer research. International coordination of research is needed to make the best use of resources.

The costs of chronic diseases to society are driven mainly by long-term disability and dependence, and the resulting costs of social care. Currently, these are largely met by unpaid family caregivers. While governments may regard family care as 'free', they do so at their peril. The major driver of the need for formal community and residential care (counted as direct social care costs in this Report) is likely to be the dependency ratio, defined as the number of dependent people divided by the size of the working age population. Declining fertility and increasing longevity mean that this is increasing in almost all world regions; from 7% now to 10% by 2050 in high income countries (but to 13% in Japan); from 8% to 14% in China (16–17% in the Hong Kong and Macau special administrative regions); and from 9% to over 12% in India(42). Under the most pessimistic scenario, by 2050 the dependency ratio will have reached 20% in China(42).

As the capacity of the informal care system is exceeded, current indirect costs are likely to translate into increased direct costs. In high income countries, direct social care costs are generally subsidized to varying degrees and hence impose a significant cost burden on the national exchequer. This, coupled with the high cost of residential care, accounts explicitly for the focus in recent national dementia strategies to 'invest to save': reducing costs to government by investing in improved early diagnosis and caregiver support, hence delaying or preventing institutionalisation(8).

Families worldwide need and deserve support, and for this the state is the ultimate guarantor. The WHO policy document 'Towards an International Consensus on Policy for Long-Term Care of the Ageing'(43) describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of countries at different levels of development. There is wide variation between countries and cultures in the responsibilities of individuals, families and the state for long-term care. However, the WHO recommends that each community could and should determine transparently the types and levels of assistance needed by older people and their caregivers, and the eligibility for and the financing of this long-term care(43). In practice, governments have not heeded this call, and relatively few, particularly in low and middle income countries, have comprehensive policies and plans(44).

Studies from the 10/66 Dementia Research Group have highlighted the social vulnerability of older people with dementia in Latin America, India and China(45). Social protection is hard to define, depending on an interaction between health status and dependence on the one hand, income sufficiency and secure living arrangements. In the Dominican Republic, rural Peru and Mexico, rural China and in India, pension coverage was low and many people with dementia were significantly reliant on family cash transfers. Almost nobody with dementia reported receiving disability benefits, even in countries where such schemes existed. In contrast with developed countries, it is relatively unusual for people with dementia to live alone or just with their spouse; living with children or children-in-law is the norm, and three generation households (including children under 16) are relatively common. Nevertheless, around one-fifth of people with dementia (10% to 37% by centre) were classified as having potentially vulnerable living circumstances (living alone or with a spouse). In most places between 5% and 25% of people with dementia had no children available for support, because of infertility or migration.

5 Alzheimer's Disease International calls on governments worldwide to develop policies and plans for long-term care that anticipate and address social and demographic trends and have an explicit focus on supporting family caregivers and ensuring social protection of vulnerable people with dementia.

Social pensions (universal non-contributory pension schemes) address these concerns directly, providing insurance against the risks that older people face, including uncertainty over how long they will live, how long they will remain healthy, whether they can count upon the support of others if they need it, and how long they can earn an income. Where they have been introduced, these pensions have been shown to play a significant role in alleviating chronic poverty at household and community level(46-48). Further, they serve to reinforce reciprocal family ties, changing the perspective from one in which older people are seen as expending household resources to one in which they can be properly valued for their non-economic as well as their economic contributions. Dependent older people would be particularly likely to benefit – informal care would be bolstered and paid care would be more affordable. There may also be a role for targeted disability pensions and caregiver benefits, although eligibility testing would impose costs and potential bureaucratic delays.

6 Alzheimer's Disease International supports HelpAge International's call for governments to introduce universal non-contributory social pension schemes[i].

7 Alzheimer's Disease International calls on governments to ensure that people with dementia are eligible to receive and do receive disability benefits, where such schemes are in operation.

Helen Sr. has been experiencing moderate dementia for the past ten years. She was a prolific artist, even through the early stages of her dementia, until she lost her eyesight. Her oil paintings adorn the walls of Helen Jr's home as well as those of many family members, friends, and the people who purchased her artwork at the many shows she participated in from the 1960s through the 1980s. For the past three years Helen Sr. has been living at a small, private, residential group home for people with dementia near Washington DC. Her daughter, Helen Jr., and other family members live in the area and visit regularly. They feel that at Victoria House every person, from residents to family members and caregivers are 'family'.

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[i] http://www.helpage.org/Researchandpolicy/Socialprotection

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Glossary

ADL

Basic activities of daily living (ADL), such as eating, dressing, bathing, toileting, grooming, and getting around – sometimes referred to as personal care.

CI / confidence interval

The 95% confidence intervals give a range of plausible values in the real world for what is being observed in the study sample, given the sample size and the likely play of chance. This could be the prevalence or incidence of dementia, or an odds ratio or relative risk for an association between a risk factor and dementia. So, a prevalence of 6.0% with 95% confidence intervals of 4.5%-7.5% would mean that, given the likely imprecision of the estimate, the true prevalence in the general population could be as low as 4.5% or as high as 7.5%, but would be unlikely to lie outside of these limits. A simple interpretation would be that there would be a 95% probability that the true figure would lie somewhere between these intervals.

CoI

Cost of illness. Cost of illness (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.

Comorbidity

The presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases.

Heterogeneity

When summarizing findings across studies (whether regarding the prevalence of dementia, or associations between dementia and other factors) the results may be similar (homogeneity) or different (heterogeneity). When the results are similar, this adds to our confidence. When different, this may be explained by a real difference in what one is measuring, or by the different research methods used in different studies.

HIC

High income countries. Based on its Gross National Income (GNI) per capita, every economy is classified as low income, middle income (subdivided into lower middle and upper middle), or high income. Economies are divided according to 2009 GNI per capita calculated using the World Bank Atlas method. The groups are: low income, US$995 or less; lower middle income, US$996 – US$3,945; upper middle income, US$3,946 – US$12,195; and high income, US$12,196 or more.

IADL

Instrumental activities of daily living, such as shopping, preparing food, using transport, and managing personal finances.

Imputation

To impute is to substitute an educated and informed estimate when a value is not available for an item in a set of data. For example, if no value for average medical costs was available for a country, that value could be imputed based on similar countries nearby.

Incidence

Incidence is the rate at which new cases occur within a defined population. It is usually quoted in terms of x cases per 100, per 1,000, or per 10,000 per year. The incidence of dementia increases exponentially with age, so age-specific rates are usually reported. Incidence rates can be used to calculate the numbers of new cases over a given period.

LMIC

Low and middle income countries. See also HIC.

Morbidity

Morbidity refers to the extent or distribution of disease within a population.

Mortality

Mortality refers to the extent or distribution of deaths within a population.

Prevalence

Prevalence is defined as the proportion of people in a defined population that has the disease at a defined time point or period. It is usually quoted as a percentage. In the field of dementia, prevalence is often expressed as proportion of people with dementia in different age groups.

Jody Ross, a laughter yoga teacher in Minneapolis, USA, visited Lakeview Ranch to lead a session with residents, staff, and a few visitors. Elsie agreed to participate, but at first all her grimaces indicated that she knew she would not have a good time. Soon, however, she changed into an active and enthusiastic participant. The session ended with this hug. Everyone was delighted and Elsie and the other residents asked to have more such sessions.

Alzheimer's Disease
International

Alzheimer's Disease International

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 73 members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI's vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to build and strengthen Alzheimer associations and raise awareness about dementia worldwide. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organization.
- Bring Alzheimer organizations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.

Key activities

- Raising global awareness through World Alzheimer's Day™ (21 September every year).
- Providing Alzheimer associations with training in running a non-profit organization through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.

ADI is based in London and is registered as a non-profit organization in the USA. ADI was founded in 1984 and has been in official relations with the World Health Organization since 1996. You can find out more about ADI at www.alz.co.uk.

Muriel, in the foreground, has recently been diagnosed with early onset Alzheimer's. An emergency room nurse, she now finds herself, at 58, the recipient of a different form of care delivery. Muriel participates in a research and action programme run by the Centre for Memory Resources and Research (CMRR) in Nice, France. Here she is walking with Nathalie, a psychologist, during an excursion to a local park.

Alzheimer's Disease International:
The International Federation
of Alzheimer's Disease and
Related Disorders Societies, Inc.
is incorporated in Illinois, USA,
and is a 501(c)(3) not-for-profit
organization

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