Alzheimer's Disease International

World Alzheimer Report

2009

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Cover image
This participant in the ARDSI day care centre in Cochin, India, was diagnosed with dementia at age 68 and was initially taken care of at home by family and domestic servants. Her aggressive behaviour became problematic, and she was enrolled in the daycare centre. At the centre she chats, tells stories and benefits from trained staff members and volunteers, such as Geetha, who are understanding and kind.

ALZHEIMER'S DISEASE INTERNATIONAL

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Preface

Demographic ageing is a worldwide process that shows the successes of improved healthcare over the last century. Many are now living longer and healthier lives and so the world population has a greater proportion of older people. We all agree that ageing brings some challenges as well. Many international meetings have touched on this issue and adopted statements, for instance the Madrid International Plan of Action on Ageing from 2002.

A clearly negative effect of ageing is the significant increase in the number of people with Alzheimer's disease and related dementias. Alzheimer's Disease International (ADI) has commissioned this report in order to support Alzheimer associations around the world in working with their governments on strategies to improve the lives of people with dementia and their carers, and to increase research efforts. To encourage the development of those national strategies, it is very important that the World Health Organization makes dementia a global health priority. If a country is in the business of supporting or spurring medical research, its portfolio ought to include funding Alzheimer's disease research in a proportion that matches its burden to the country.

To make clear why this is important and why it is urgent, we wanted to put together updated information on the prevalence and impact of the disease and offer a framework for solutions. Some recent experiences have been very encouraging. In 2004, Australia was the first country to make dementia a national health priority, and national dementia strategies have been launched in France, South Korea, England, Norway and the Netherlands. We also want to highlight a very recent initiative from the European Commission as the first international action plan on dementia.

This report gives an overview and analysis of the situation, based on the currently available research data. The 2009 World Alzheimer Report confirms that there are many millions of people living with Alzheimer's or another dementia. This report and all earlier studies indicate that the current number of people living with dementia is expected to grow at an alarming rate. ADI believes this report provides the best available estimates of dementia prevalence at a worldwide level. The scientists working on behalf of ADI used meta-analyses that produce estimates for all the world regions in the way that is explained in the full version of the report. ADI does not present estimates for individual countries and understands that different studies may be preferred to determine national prevalence figures. ADI encourages national Alzheimer prevalence research in individual countries; the use of those local results may be more accurate.

It is clear that more research on the prevalence and impact of the disease is needed. ADI will therefore carry out follow up reports, beginning with economic data in 2010. We hope this will stimulate all those involved: governments, policy makers, healthcare professionals and Alzheimer associations, to work together on more and better solutions for dementia. With a new case of dementia in the world every seven seconds there is no time to lose.

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Key points

Jacqueline in a reminiscence therapy session, 2008, Nice, France. Reminiscence therapy is based on the evocation of older memories and autobiographies. The sharing of these memories, sometimes with the aid of photographs and other objects, in a group helps to promote social exchanges, and through this communication the quality of life of people with dementia and family carers is improved.

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BACKGROUND

What is dementia?

1 Dementia is a syndrome due to disease of the brain, usually chronic, characterised by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement.

2 While dementia mainly affects older people, there is growing awareness of cases that start before the age of 65 years. After 65, the prevalence (the proportion of people with the condition) doubles with every five-year increase in age. Dementia is one of the major causes of disability in later life.

3 Dementia syndrome is linked to a large number of underlying brain pathologies. Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia are the most common.

4 The boundaries between these subtypes are indistinct, and mixed forms may be the norm. The pathology (the changes that happen in the brain) with Alzheimer's disease develops over a long period of time, and the relationship between the severity of the pathology and the presence (or absence) of dementia syndrome is not clear. Other conditions that the person has, particularly cerebrovascular disease (disease of the blood vessels supplying the brain) may be important.

5 Clinicians focus their diagnostic assessments on impairment in memory and other cognitive functions, and loss of independent living skills. For carers, it is the behavioural and psychological symptoms (BPSD) linked to dementia, typically occurring later in the course of the disease, that are most relevant and have most impact on their quality of life. Behavioural and psychological symptoms are an important cause of strain on carers, and a common reason for institutionalisation as the family's coping reserves become exhausted.

6 Problem behaviours include agitation, aggression, calling out, sleep disturbance, wandering and apathy. Around one quarter of people with dementia exhibit apathy and a similar proportion show occasional signs of aggression. Common psychological symptoms include anxiety, depression, delusions and hallucinations. Around 25-40% have diagnosable affective disorder, and at least 10% have psychotic symptoms. The frequency and profile of these symptoms seems to be similar between developed and developing country settings.

7 Awareness of dementia, as an organic brain condition, is inadequate worldwide. The problem is stigmatised, so it is not discussed. If it is acknowledged then it is often dismissed as a normal part of ageing, or viewed as a problem for which nothing can be done. These three factors conspire to create a culture in which help is neither sought nor offered. Alzheimer's Disease International has identified raising awareness of dementia among the general population and health workers as a global priority.

8 The main risk factor for most forms of dementia is advanced age, with prevalence roughly doubling every five years over the age of 65. Onset before this age is relatively uncommon and, in the case of Alzheimer's disease, often suggests a genetic cause. Single gene mutations at one of three loci (beta amyloid precursor protein, presenilin1 and presenilin2) account for many of these cases.

9 For late-onset Alzheimer's disease both environmental (lifestyle) and genetic factors are important. A common genetic polymorphism, the apolipoprotein E (apoE) gene e4 allele, greatly increases risk of going on to develop dementia. Epidemiological studies partly support associations between limited education, head injury and depression, and both Alzheimer's disease and dementia, but it is not clear if these are causal.

10 The evidence for a causal role for cardiovascular risk factors and cardiovascular disease in dementia and Alzheimer's disease is very strong. Those with high cardiovascular risk scores (incorporating hypertension, diabetes, high cholesterol and smoking) have an increased risk for dementia incidence whether exposure is measured in midlife or a few years before dementia onset. Atherosclerosis (hardening of the arteries) and Alzheimer's disease may be linked disease processes with common underlying factors.

11 Unfortunately, attempts to modify cardiovascular risk exposure, by using cholesterol lowering drugs (statins) and antihypertensives, have so far been unsuccessful in reducing the incidence of dementia. This may well have been a case of 'too little, too late'. Hormone replacement therapy had an adverse effect, and a trial of non-steroidal anti-inflammatory drugs (NSAIDs) had to be stopped because of concerns regarding adverse effects.

12 Effective primary prevention of dementia is a realistic aspiration. However, much more research is needed to understand better how and when lifestyle factors influence the risk for developing dementia, informing more effective prevention strategies.

13 The principal goals for dementia care are:

- early diagnosis
- optimising physical health, cognition, activity and well-being
- detecting and treating behavioural and psychological symptoms
- providing information and long-term support to carers

The person with dementia needs to be treated at all times with patience and respect for their dignity and personhood. The carer needs support and understanding – their needs should also be determined and attended to. Both parties need to be supported to continue for as long as practicable with their lives and in their own communities – living well with dementia.

14 Currently, there are no treatments available that cure, or even alter the progressive course of dementia, although numerous new therapies are being investigated in various stages of clinical trials. When effective new therapies are developed, there will be enormous ethical and practical challenges with respect to making such treatments widely and equitably available, particularly to the two-thirds of people with dementia who live in low and middle income countries.

15 Partially effective treatments are available for most core symptoms of dementia. These treatments are symptomatic, that is they can improve a particular symptom, but do not alter the progressive course of the disease. Importantly, psychological and psychosocial therapies (sometimes referred to as 'non-pharmacological' interventions) may be as effective as drugs in many areas, but have been less extensively researched, and much less effectively promoted. The research evidence on dementia care comes, overwhelmingly, from high income countries.

16 People with dementia and their carers can be educated about dementia, countering lack of understanding and awareness about the nature of the problems faced. They can also be trained to better manage most of the common behavioural symptoms, in such a way that their frequency or the strain experienced by the carer is reduced. Above all, the person with dementia and the family carers need to be supported over the longer term.

CHAPTER 1

The global prevalence of dementia

1 We have conducted a new systematic review of the global prevalence of dementia, identifying 147 studies in 21 Global Burden of Disease (GBD) world regions.

2 We estimate 35.6 million people with dementia in 2010, the numbers nearly doubling every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

3 Previous ADI estimates, published in *The Lancet* in 2005, were based on expert consensus. A large number of new studies, particularly from low and middle income countries, have enabled us now to conduct quantitative meta-analyses in 11 of the 21 GBD world regions. Our new estimates are 10% higher. We believe these to be more robust and valid figures.

4 When compared with our earlier *Lancet*/ADI consensus estimates those for three regions were higher - Western Europe (7.29% vs. 5.92%), South Asia (5.65% vs. 3.40%) and Latin America (8.50% vs. 7.25%). Those for East Asia were lower (4.98% vs. 6.46%).

5 58% of all people with dementia worldwide live in low and middle income countries, rising to 71% by 2050.

6 Proportionate increases over the next twenty years in the number of people with dementia will be much steeper in low and middle income countries 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.

7 A recent marked increase in the number of studies from low and middle income countries has been accompanied by a sharp decline in prevalence research in high income countries. In many high income countries, the evidence-base is fast becoming out of date and more studies are needed.

8 The quality of many of the studies was relatively poor, although this is steadily improving. A particular concern is the 49% of all studies that used, but misapplied, a research design with two or more phases. This error is likely to lead to an underestimate of true prevalence. However, for two phase studies in general, a higher prevalence was observed, probably because of loss to follow-up in the interval between the screening and definitive diagnostic assessments. 57% of all studies lacked a properly comprehensive dementia diagnostic work up.

CHAPTER 2

The impact of dementia

1 According to the Global Burden of Disease report, dementia accounts for 4.1% of total disease burden (Disability Adjusted Life Years) among people aged 60 years and over, 11.3% of years lived with disability and 0.9% of years of life lost.

2 Among the other chronic non-communicable diseases, dementia accounts for 11.9% of years lived with disability (the second most burdensome chronic condition) and 1.1% of years of life lost. The leading causes of death are heart disease (32.9% of years of life lost) and cancer (22.5%). However, these are only 8th and 9th in the rank of disabling conditions.

3 Research from North America, and recent findings from the 10/66 Dementia Research Group's population-based studies in Latin America, India and China indicate, consistently, that dementia is the leading cause of dependency (needs for care) and disability among older people.

4 Among the chronic diseases, prioritisation seems to be determined more by contributions to mortality than to disability. Health spending and investment in research is very much higher for cancer and heart disease than for dementia and stroke. Chronic diseases that contribute most to mortality have the largest number of research papers focussed on them, but the chronic diseases that contribute most to disability are the subjects of the fewest research papers.

5 At some stage in the disease process, most if not all people with dementia require some form of care. In all parts of the world this is generally provided by informal (family) carers. According to the Alzheimer's Association's *2009 Alzheimer's Disease Facts and Figures*, it is estimated that almost 10 million Americans provide unpaid care for a person with Alzheimer's disease or another dementia.

6 While there are many positive aspects of caring, carers of people with dementia are very likely to experience strain. 40-75% have significant psychological illness, and 15-32% clinically diagnosable major depression. There may also be physical health consequences - strained carers have impaired immunity and a higher mortality rate.

7 Among carers in general, caring for a person with dementia is particularly stressful. Typically, they provide more intensive and extensive care, experience more strain, and have higher levels of psychological illness.

8 Carers and those who live with people with dementia are twice as likely as others to have significant psychological illness (controlling for the presence of other physical and mental disorders).

9 In high income countries, the direct costs of dementia care exceed informal care costs, with the cost of institutional care in care homes dominating in this category. In the United Kingdom, for example, residential care homes contribute 41% of the total costs, compared with 15% for care in the community, 8% for health care and 36% for informal care.

10 Worldwide, the annual economic cost of dementia has been estimated as US$315 billion. The total annual costs per person with dementia have been estimated as US$1,521 in a low income country, rising to US$4,588 in middle income countries, and US$17,964 in high income countries.

11 While only 38% of the people with dementia live in high income countries, 72% of the costs arise from these regions. Informal (family) care is more important in resource-poor countries, where there are few formal health or social care services available. Informal care accounts for 56% of costs in low income countries, 42% in middle income countries, and just 31% in high income countries.

12 In the United Kingdom, the societal cost of dementia (£17.0 billion/US$27.2 billion) exceeds that for stroke, heart disease and cancer combined when calculated on a like-for-like basis (£13.8 billion/US$22.0 billion), and is only a little less when the lost productivity from premature mortality linked to cancer, heart disease and stroke is included in the calculations (£19.9 billion/US$31.8 billion).

13 Demographic and social trends allow us to predict with reasonable certainty that the 'indirect' costs of care, effectively a subsidy provided by families, will increasingly be felt as 'direct' costs with real impacts on national budgets. This will particularly be the case for low and middle income countries, where dementia is not a priority and there are very few examples of national policies and plans for the financing or provision of long-term care.

CHAPTER 3

From recognition to action

1 Dementia is a challenge for governments throughout the world; it is also an opportunity to provide accessible, affordable and good quality services that meet the expectations and needs of people with dementia and their families.

2 For low and medium income countries there is the opportunity not to repeat the mistakes of high income countries that have become over dependent on institutional care.

3 Across the world there are immense disparities in healthcare expenditure and the distribution of doctors and nurses. This has an impact on the capacity of healthcare systems to respond to the growing number of people with dementia.

4 A seven stage model for planning dementia services is proposed. It reflects the progressive nature of dementia and includes:

- Pre-diagnosis awareness raising
- Diagnosis
- Post-diagnosis information and support
- Co-ordination and care management
- Community services to care for people with dementia in their own homes
- Continuing care
- End of life palliative care

5 A graduated approach for low and medium income countries is proposed which focuses attention first on:
- Awareness raising and understanding
- Capacity building
- Basic service development through enhancing primary care services

6 The visions for service development in all countries need to encompass public understanding and attitudes to dementia, skills and knowledge of the health and care workforce and their organisational infrastructure, and the equitable distribution of services.

7 Governments are urged to act now.

CHAPTER 4

Recommendations

1 The World Health Organization (WHO) should declare dementia a world health priority.

2 National governments should declare dementia a health priority and develop national strategies to provide services and support for people with dementia and their families.

3 Low and medium income countries should create dementia strategies based first on enhancing primary healthcare and other community services.

4 High income countries should develop national dementia action plans with designated resource allocations.

5 Develop services that reflect the progressive nature of dementia.

6 Distribute services with the core principle of maximising coverage and ensuring equity of access, to benefit people with dementia regardless of age, gender, wealth, disability, and rural or urban residence.

7 Create collaboration between governments, people with dementia, their carers and their Alzheimer associations, and other relevant Non-Governmental Organisations and professional healthcare bodies.

8 More research needs to be funded and conducted into the causes of Alzheimer's disease and other dementias, pharmacological and psychosocial treatments, the prevalence and impact of dementia, and the prevention of dementia.

World Alzheimer Report
Introduction

What is dementia?

Daphne and her grandmother, Lara, visited Lara's mother, Margie, for the Thanksgiving celebration at a Silverado Senior Living Alzheimer's community in Houston, Texas. Daphne was saddened by Margie's loss of verbal communication skills. Lara convinced Daphne to tell her about the piano recital she would give the next day. After the connection was made, Margie signalled non-verbally that she had heard her great-granddaughter's story.

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Definitions, pathology and clinical features

The definition of dementia

Dementia is a syndrome due to disease of the brain, usually chronic, characterised by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement. It mainly affects older people, but, according to different estimates, between 2% and 10% of all cases start before the age of 65 years. After this the prevalence doubles with every five year increment in age. Dementia is one of the major causes of disability in late-life.

The relationship between brain pathology and dementia syndrome

Dementia syndrome is linked to a very large number of underlying brain pathologies. Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia are the commonest. The characteristic symptoms and neuropatholgical findings are summarised in Table 1. Some rare underlying causes of dementia (subdural haematoma, normal pressure hydrocephalus, hypercalcaemia, and deficiencies of thyroid hormone, vitamin B12 and folic acid) are particularly important to detect since they may be treated effectively by timely medical or surgical intervention. Otherwise, altering the progressive course of the disorder is not possible. Nevertheless, symptomatic treatments and support can help people with dementia and carers alike.

The relative frequencies of the different subtypes of dementia are open to debate. Some of the rarer subtypes tend to be over-represented in case series from specialist clinical centres, as the unusual nature of the presentation predisposes both to help-seeking and referral. A more fundamental problem is that the borders between these different subtypes are by no means distinct. Clinico-pathological correlation studies examine the agreement between the diagnosis made in life, and the pathology evident in the brain post-mortem. These have tended to indicate that mixed pathologies are much more common than 'pure' – this is particularly true for Alzheimer's disease and vascular dementia, and Alzheimer's disease and dementia with Lewy bodies [1]. In one large case series of over 1000 post-mortems [2], while 86% of all those with dementia had Alzheimer's disease related pathology, only 43% had pure Alzheimer's disease. 26% had mixed Alzheimer's disease and cerebrovascular pathology and 10% had Alzheimer's disease with cortical Lewy bodies. Findings were similar among those who had been given a clinical diagnosis of Alzheimer's disease. 'Pure' vascular dementia was comparatively rare (7.3%). Uncommon

Table 1
Characteristics of dementia subtypes

Dementia subtype	Early, characteristic symptoms	Neuropathology	Proportion of dementia cases
Alzheimer's disease (AD) *	Impaired memory, apathy and depression Gradual onset	Cortical amyloid plaques and neurofibrillary tangles	50-75%
Vascular dementia (VaD) *	Similar to AD, but memory less affected, and mood fluctuations more prominent Physical frailty Stepwise onset	Cerebrovascular disease Single infarcts in critical regions, or more diffuse multi-infarct disease	20-30%
Dementia with Lewy Bodies (DLB)	Marked fluctuation in cognitive ability Visual hallucinations Parkinsonism (tremor and rigidity)	Cortical Lewy bodies (alpha-synuclein)	<5%
Frontotemporal dementia (FTD)	Personality changes Mood changes Disinhibition Language difficulties	No single pathology – damage limited to frontal and temporal lobes	5-10%

* Post mortem studies suggest that many people with dementia have mixed Alzheimer's disease and vascular dementia pathology, and that this 'mixed dementia' is underdiagnosed

subtypes of dementia; frontotemporal dementia, Creutzfeld Jakob and Huntington's disease tended to have been misdiagnosed in life as Alzheimer's disease. Population-based studies have suggested that frontotemporal dementia and vascular dementia are relatively common diagnoses in men with an early onset of dementia. Alzheimer's disease tends to predominate over vascular dementia among older people with dementia, particularly among women[3].

Another complicating factor is that many people with Alzheimer's disease pathology in the brain do not show signs of dementia. In part, this is because the brain changes underlying Alzheimer's disease probably develop over a period of at least 20-30 years before symptoms become noticeable. Autopsies conducted on people who have died at various ages suggest that the earliest signs are noted around the base of the brain in the fifth decade of life, plaques and tangles later spreading up to the cortical regions[4]. Dementia is conventionally diagnosed when cognitive decline affects a person's ability to carry out important routine activities. Criteria for prodromal syndromes, for example 'mild cognitive impairment (MCI)', have been proposed with a view to exploring interventions to delay or prevent dementia in those at high risk of progression. Also, findings from the Nun Study in the USA suggest that vascular damage may act as a cofactor, accelerating the onset of clinically significant symptoms in people with underlying Alzheimer's disease pathology, which would otherwise be asymptomatic[5].

Clinical features – the importance of behavioural and psychological symptoms of dementia

When making a diagnosis, clinicians focus their assessments on impairment in memory and other cognitive functions, and loss of independent living skills. For carers, it is the behavioural and psychological symptoms (BPSD) linked to dementia that are most relevant and impact most on quality of life. Problem behaviours include agitation, aggression, calling out, sleep disturbance, wandering and apathy. Common psychological symptoms include anxiety, depression, delusions and hallucinations. Most studies indicate that BPSD are an important cause of carer strain[6], and a common reason for institutionalisation as the family's coping reserves become exhausted[7]. BPSD occur most commonly in the middle stage of dementia (see also Course and Outcome). In the population-based Cache County study in the USA, 61% of people with dementia had exhibited one or more behavioural or psychological disturbances in the past month. Apathy (27%), depression (24%), and agitation/aggression (24%) were the most common symptoms, and these were around four times more common in those with dementia than in those without it[8]. Participants with Alzheimer's disease were more likely to have delusions and less likely to have depression. Agitation and aggression were more common in participants with advanced dementia. In the 10/66 Dementia Research Group pilot studies[6], behavioural and psychological symptoms seemed to be just as common in low and middle income countries. In a sample of 555 carers from 21 centres in Latin America, India, China and SE Asia and Nigeria, 71% reported at least one problem behaviour. The people with dementia were also assessed, and significant psychological symptoms were detected in half; 44% were diagnosed with depression, 14% with anxiety disorder, and 11% with psychotic symptoms (delusions or hallucinations). In some respects the developing country carers were more disadvantaged. Given the generally low levels of awareness about dementia as an organic brain disease (see below), they often could not understand their relative's condition, and tended to misinterpret BPSD as deliberate misbehaviour on the part of the person with dementia[9]. Others tended to blame the carers for the distress and disturbed behaviour of the person for whom they were caring[10].

Awareness

Dementia, and Alzheimer's disease have been reliably identified in all countries, cultures and races in which systematic research has been carried out. However, levels of awareness vary enormously. Alzheimer's Disease International has identified raising awareness of dementia among the general population and among health workers as a global priority [11].

Low and middle income countries

Three studies from India (with a mixture of focus group discussion and open-ended interviews) illustrate the pervasive problem in low and middle income countries [9;12;13]. The typical features of dementia are widely recognized, and indeed named 'Chinnan' (literally childishness) in Kerala [9], 'nerva frakese' (tired brain) in Goa [13], and 'weak brain' in Banares [12]. However, in none of these settings was there any awareness of dementia as an organic brain syndrome, or indeed as any kind of medical condition. Rather, it was perceived as a normal, anticipated part of ageing. This general lack of awareness has important consequences:

1 Help from formal medical care services is not sought [13].

2 There is no structured training on the recognition and management of dementia at any level of the health service.

3 There is no constituency to place pressure on the government or policy makers to start to provide more responsive dementia care services [9].

4 While families are the main caregivers, they must do so with little support or understanding from other individuals or agencies.

In the absence of understanding regarding its origins, dementia is stigmatized. In Goa, the likely causes were cited as 'neglect by family members, abuse, tension and lack of love' [13]. In Kerala, it was reported that most carers tended to misinterpret symptoms of the disease and to designate these as deliberate misbehaviour by the person with dementia [9]. Sufferers are specifically excluded from residential care, and often denied admission to hospital facilities [13]. Disturbed behaviour, common among people with dementia, is particularly poorly understood leading to stigma, blame, and distress for carers [14].

High income countries

The problem of low awareness is certainly not limited to low and middle income countries. For example, the National Dementia Strategy for the UK highlights stigma (preventing discussion of the problem) and two false beliefs (that dementia is a normal part of ageing, and that nothing can be done) as the main factors linked to inactivity in seeking or offering help [15]. In the UK, people typically wait three years before reporting symptoms of dementia to their doctor, 70% of carers report being unaware of the symptoms of dementia before diagnosis, and 58% of carers believe the symptoms to be just a normal part of ageing [16]. Only 31% of primary care doctors believe that they have received sufficient training to diagnose and manage dementia [17].

Actions to improve awareness

In developed countries dementia awareness is growing rapidly, with the news media playing an important part; coverage over 18 months in the UK *Daily Telegraph* has increased from 57 articles in 1998/9 [18] to 112 when re-examined in 2006/7 [19]. Recent evidence-based reports from the UK and the Australian Alzheimer associations garnered considerable media attention and were instrumental in making dementia a national priority in both countries (see Chapter 3). In France, the new president launched a national plan in 2008.

Public awareness in low and middle income countries is less developed, with few media outlets carrying stories about dementia and ageing – a search in 1999 of *The Times of India* identified no articles [18]. 10/66 Dementia Research Group teams in Argentina, Venezuela, Peru, Dominican Republic and India have succeeded in getting the message out in newspapers, TV and radio (http://www.alz.co.uk/1066/1066_in_the_news.php). *The Times of India* published 15 articles in the last 18 months alone. Our experience is that while media in low and middle income countries are receptive to these stories as part of their role in informing the public and stimulating debate, efforts are required to alert them to the importance of ageing and dementia, and to build their capacity to report research and understand its local relevance.

Aetiology (risk factors)

Established risk factors

The main risk factor for most forms of dementia is advanced age, with prevalence roughly doubling every five years over the age of 65. Onset before this age is very unusual and, in the case of Alzheimer's disease, often suggests a genetic cause. Single gene mutations at one of three loci (Beta amyloid precursor protein, presenilin1 and presenilin2) account for most of these cases. For late-onset Alzheimer's disease both environmental (lifestyle) and genetic factors are important. A common genetic polymorphism, the apolipoprotein E (apoE) gene e4 allele, greatly increases risk of going on to suffer from dementia; up to 25% of the population has one or two copies [20;21]. However, it is not uncommon for one identical twin to suffer from dementia, and the other not. This implies a strong influence of the environment [22]. Evidence from cross-sectional and case-control studies suggest associations between Alzheimer's disease and limited education [23], and head injury [24;25], which, however, are only partly supported by longitudinal (follow-up) studies [26]. Depression is a risk factor in short term longitudinal studies, but this may be because depression is an early presenting symptom, rather than a cause of dementia [27].

Modifiable risk factors – cardiovascular risk factors and cardiovascular disease

Despite occasional negative findings from large prospective studies [28;29], the accumulated evidence for a causal role for cardiovascular risk factors (CVRF) and cardiovascular disease (CVD) in the aetiology of dementia and Alzheimer's disease is very strong. In short [30-32] and longer latency [33;34] incidence studies, smoking increases the risk for Alzheimer's disease. Diabetes is also a risk factor [35], and in longer term cohort studies, midlife hypertension [36;37] and hypercholesterolaemia [37] are associated with Alzheimer's disease onset in later life. Those with high cardiovascular risk scores (incorporating hypertension, diabetes, hypercholesterolaemia and smoking) have an increased risk for dementia incidence whether exposure is measured in midlife [34] or a few years before dementia onset [32]. Recent studies report associations between metabolic syndrome and incident cognitive decline [38], and insulin resistance and impaired executive function [39]. These findings have led to the hypothesis that atherosclerosis and Alzheimer's disease are linked disease processes [40], with several common underlying factors (the apoE e4 gene, hypertension, increased fat intake and obesity, raised cholesterol, diabetes, the metabolic syndrome, smoking and systemic inflammation).

Attempts at primary prevention

A main aim of epidemiological research is to identify modifiable risk factors. Removing these risk factors through preventive interventions can then reduce the incidence of the disease. Epidemiological cohort studies indicated protective effects of non-steroidal anti-inflammatory drugs (NSAIDs), hormone replacement therapy (HRT) and cholesterol lowering therapies (statins). However, a randomised controlled trial of HRT as a preventive therapy in post-menopausal women indicated, against expectation, that it raised rather than lowered the incidence of dementia [41]. The two trials of statins have showed no preventive benefit [42]. The ADAPT trial of NSAIDs had to be stopped because of warnings of cardiovascular adverse effects in another trial of NSAIDs [43]. Antihypertensive treatment also seems to be ineffective as a preventive strategy [44].

More research needed

The disappointing results from preventive intervention trials to date indicate that, despite much research, we still understand far too little about the environmental and lifestyle factors linked to dementia and Alzheimer's disease. It may be that our focus upon research in the developed West has limited possibilities to identify risk factors. Prevalence and incidence of Alzheimer's disease seems to be much lower in some developing regions. This may be because some environmental risk factors are much less prevalent in these settings – for example, African men tend to have good cardiovascular health with low cholesterol, low blood pressure and low incidence of heart disease and stroke. Conversely some risk factors may only be apparent in low and middle income countries, as they are too infrequent in the developed economies for their effects to be detected. For example, in low and middle income countries dietary deficiencies, particularly of micronutrients, are widespread and strongly linked to poverty. Deficiencies of folate and vitamin B12 are of particular interest given their consequences: anaemia, raised homocysteine levels [45], increased risk of stroke and ischaemic heart disease [46]. Vitamin B12 deficiency is very common (> 40%) across Latin America [47-49]. Folate deficiency is endemic in those living in poverty [48], and after economic crisis [49]. Micronutrient deficiency is probably even more common in older people but there are few data on this age group [47]. Research on micronutrients and dementia in developed countries has focussed upon antioxidants [50] with less attention towards deficiencies in vitamin B12 and folate [51-54]. Available studies were small in size and provide inconsistent findings – two out of three studies testing for an effect of folate deficiency on dementia risk were positive [51;52], B12 was associated in only one out of four studies [52]. Anaemia, strongly linked to undernutrition, has been identified as a risk factor for dementia in India [6], and needs to be explored elsewhere.

The course and outcome of dementia

Dementia affects every person in a different way. Its impact can depend on what the person was like before the disease; their personality, their lifestyle, their significant relationships and their physical health.

The problems linked to dementia can be best understood in three stages:

1 Early stage – first year or two

2 Middle stage – second to fourth or fifth years

3 Late stage – fifth year and after

These times are given as guidelines only – sometimes people can deteriorate more quickly, sometimes more slowly.

Dementia reduces the lifespan of affected people. In the developed West a person with dementia can expect to live for roughly 5-7 years after onset/diagnosis [56;57]. In low and middle income countries, diagnosis is often much delayed, and survival may be much shorter [58]. Again, of course, there is much individual variation – some may live for longer, and some may live for shorter times because of intercurrent health conditions.

Not all people with dementia will display all the symptoms described below. Nevertheless, a summary of this kind can help carers to be aware of potential problems and to allow them to think about future care needs.

Early stage

The early stage of dementia is often overlooked. Relatives and friends (and sometimes professionals as well) see it as 'old age'; just a normal part of the ageing process. Because the onset of dementia is gradual, it is often difficult to be sure exactly when it begins. The person may:

- Have problems talking properly (language problems)
- Have significant memory loss – particularly for things that have just happened
- Not know the time of day or the day of the week
- Become lost in familiar places
- Have difficulty in making decisions
- Become inactive and unmotivated
- Show mood changes, depression or anxiety
- React unusually angrily or aggressively on occasion
- Show a loss of interest in hobbies and activities

Middle stage

As the disease progresses, limitations become clearer and more restricting. The person with dementia has difficulty with day-to-day living and:

- May become very forgetful – especially of recent events and people's names
- Can no longer manage to live alone without problems
- Is unable to cook, clean or shop
- May become extremely dependent on their family and caregivers
- Needs help with personal hygiene, i.e. toilet, washing and dressing
- Has increased difficulty with speech
- Shows problems with wandering and other behaviour problems such as repeated questioning and calling out, clinging and disturbed sleeping
- Becomes lost at home as well as outside
- May have hallucinations (seeing or hearing things which aren't really there)

Late stage

This stage is one of near total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may:

- Have difficulty eating
- Be incapable of communicating
- Not recognise relatives, friends and familiar objects
- Have difficulty understanding what is going on around them
- Be unable to find their way around in the home
- Have difficulty walking
- Have bladder and bowel incontinence
- Display inappropriate behaviour in public
- Be confined to a wheel chair or bed

The management of dementia

Guiding principles

The principal goals of dementia management and care:

- Early diagnosis
- Optimising physical health, cognition, activity and well-being
- Detecting and treating behavioural and psychological symptoms
- Providing information and long-term support to carers

The person with dementia needs to be treated at all times with patience and respect for their dignity and personhood. The carer needs unconditional support and understanding – their needs should also be determined and attended to. Carers can be educated about dementia, countering lack of understanding and awareness about the nature of the problems faced. They can also be trained to better manage most of the common behavioural symptoms, in such a way that their frequency and/or the strain experienced by the carer is reduced. Above all, the person with dementia and the family carers need to be supported over the longer term.

The hope for a cure

Currently, there are no treatments available that cure or even alter the progressive course of dementia, although numerous new therapies are being investigated in various stages of clinical trials. This is a very active and promising field for drug development [59]. Given that any new disease-modifying agent would be likely to be very expensive, thought should be given now to the huge ethical and practical challenges involved in making such a treatment widely and equitably available, particularly to the two-thirds of people with dementia living in low and middle income countries. This problem is being addressed with respect to antiretroviral drugs for HIV/AIDS through an unprecedented global alliance, led by the Global Fund and US Presidential PEPFAR initiatives.

Current evidence-based treatments

Partially effective treatments are available for most core symptoms of dementia. These treatments are all symptomatic, that is they can ameliorate a particular symptom, but do not alter the progressive course of the disease. Importantly, psychological and psychosocial interventions (sometimes referred to as 'non-pharmacological' interventions) may be as effective as drugs in many areas, but have been less extensively researched, and much less effectively promoted. The evidence base for dementia care comes, overwhelmingly, from high income countries.

TREATMENTS FOR COGNITIVE IMPAIRMENT

Cholinesterase Inhibitors (ChEIs) [60-62] and NDMA receptor antagonists [63] can lead to useful improvements in cognitive function. Cost-effectiveness is by no means established [64], and recommendations regarding their use will depend upon affordability and availability of specialist support. Costs of ChEIs are reimbursed in some countries and regions but not all. Cheaper 'generic' ChEIs are available in India. Patent law is side-stepped by Huperzine A, a cheap plant extract with similar properties used in China [58]. The evidence-base from low and middle income countries is limited to one small RCT of donepezil in Brazil [65] and open-label trials of galantamine in Brazil [66] and China [67]. More development and research is needed to see if reminiscence therapy [68], cognitive stimulation [69;70] and rehabilitation [71] could be feasible and effective community interventions.

TREATMENTS FOR BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD)

For BPSD, antipsychotic drugs are minimally efficacious overall, although they may be very helpful for some patients [72-75], particularly those for whom aggression is a problem. There are serious concerns about their safety with an increased risk of death [76] and cerebrovascular adverse events [74]. Too little research has been carried out to be clear about the potential benefits of SSRI antidepressants [77-79] and carbamezepine [80;81]. For these reasons, drug treatment cannot be recommended as first-line management, other than with specialist input, for severe and distressing behaviour disturbance where there is clear and imminent risk of harm. Physical health assessment, carer training and support are all indicated. More research is needed into the potential benefits of simple low-cost strategies, easily applied by carers at home; for example massage [82;83] and aroma therapy [84].

The importance of carer interventions

A large literature attests to the wide-ranging potential benefits of carer interventions in dementia [85]. Carer interventions include:

- Psychoeducational interventions, many of which include an element of carer training

- Psychological therapies, e.g. cognitive behavioural therapy (CBT), and counselling
- Carer support
- Respite care

Many interventions combine several of these elements. There are several systematic reviews and meta-analyses [86-90]. Outcomes studied include carer strain, depression and subjective well-being; behaviour disturbance and mood in the care recipient; and institutionalisation.

Most carer interventions seemed to benefit carer strain and depression, CBT having the largest impact on depression. Psychoeducational interventions required the active participation of the carer (for example in role-playing activities) to be effective [86]. Carer support interventions seemed only to be efficacious in increasing carer well-being [86]. For respite care, non-randomised interventions suggest significant reductions in carer strain and psychological morbidity [86]. While nearly all of the carer intervention trials to date were conducted in high income countries, two low and middle income trials of a brief carer education and training intervention – the ADI/1066 'Helping Carers to Care' intervention – were published recently, one from India [91] and one from Russia [92]. Although small in size, both indicated much larger treatment effects than are typically seen in trials of such interventions in high income countries, on carer psychological morbidity [91] and strain [92].

Finally, there is clear evidence from the pooled results of ten randomised controlled trials [90] that carer interventions delay institutionalisation in high income countries. People with dementia whose carer received the intervention were 40% less likely to be institutionalised over the follow-up period (OR=0.60, 95% CI=0.43-0.85). The effective interventions were structured, intensive and multicomponent, offering a choice of services and supports to carers [86;90]. Prevention or delay of institutionalisation confers a substantial societal benefit given the very high costs in high income countries (see Chapter 2).

Structure of the report

Chapter 1: The global prevalence of dementia describes the systematic review of the world literature on the prevalence of dementia, the approach used to generate new prevalence estimates for the 21 Global Burden of Disease regions, and the estimated numbers of people with dementia in each region with projections from 2010 to 2050.

Chapter 2: The impact of dementia provides information regarding the impact of dementia, at the level of the individual, the family and wider society; the evidence on the contribution of dementia, compared with other chronic diseases, to disability, mortality and dependence is summarised; the care arrangements for people with dementia in many world regions, and the strain experienced by their carers are described; finally the impact of dementia and other chronic diseases in terms of the societal economic cost is summarised.

Chapter 3: From recognition to action sets out the challenges to be faced by governments and health systems worldwide to meet the needs of the growing numbers of people living with dementia, their families and carers.

Chapter 4: Recommendations offers recommendations built on the evidence base set out in earlier chapters.

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World Alzheimer Report
Chapter 1

The global prevalence of dementia

Good care in a group setting involves individualized care. The staff at the Day Care Center in Cochin, India, understand the need to find activities that are meaningful to the participants given both their backgrounds and their present capabilities. This woman, a former mathematics teacher, likes to write numbers on paper or on the blackboard. They purchased the blackboard to help her feel connected to her past, experiencing old pleasures.

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Background

The wider context – ageing in a developing world

Older people, their health and social welfare, have for too long been under-prioritised in global public health policy. This is now changing with increasing recognition, over the past twenty years, of their growing importance in all parts of the world, including low and middle income countries [1]. Demographic ageing (the 'greying' of the population) is proceeding more rapidly than first anticipated in all world regions, particularly China, India and Latin America [2]. The proportion of older people increases as mortality falls and life expectancy increases. Population growth slows as fertility declines to replacement levels. In the 30 years up to 2020 the oldest sector of the population will have increased by 200% in low and middle income countries as compared to 68% in the developed world [3]. By 2020, two-thirds of all those over 60 will be living in developing countries [4]. In the accompanying health transition chronic non-communicable diseases assume a progressively greater significance in low and middle income countries. Chronic diseases are already the leading cause of death in all world regions apart from Sub-Saharan Africa [5]. This is partly because most of the world's older people live in these regions. However, changing lifestyles and patterns of risk exposure also contribute.

The prevalence of dementia

In 2004, Alzheimer's Disease International convened a panel of international experts to review the global evidence on the prevalence of dementia, and to estimate the prevalence of dementia in each world region, the current numbers of people affected, and the projected increases over time. The results were published in the medical journal *The Lancet* in 2005. In 2001, 24.2 million people lived with dementia worldwide, with 4.6 million new cases annually [6] (similar to the global incidence of non-fatal stroke [7]). Two-thirds of all people with dementia lived in low or middle income countries. Numbers were predicted to double every twenty years to over 80 million by 2040, with much sharper increases in low and middle income countries compared with high income countries. These projected increases were accounted for solely by the different patterns of demographic ageing (the increase in the absolute and relative numbers of older people), since the age-specific prevalence of dementia was assumed to remain constant over time.

A tendency had been noted for prevalence to be somewhat lower in developing countries than in the developed North [8], strikingly so in some studies [9;10]. This trend was supported by the consensus judgment of the ADI expert panel, reviewing all evidence available at that time [6]. Differences in survival could only be part of the explanation, as estimates of incidence in some studies [11;12] were also much lower than those reported in the west. It may be that mild dementia is underdetected in developing countries because of difficulties in establishing the criterion of social and occupational impairment [9;13]. Differences in levels of exposure to environmental risk factors might also have contributed [14]. The strikingly different patterns of mortality in early life might also be implicated; older people in very poor countries are exceptional survivors – this characteristic may also confer protection against dementia and Alzheimer's disease.

Long-term studies from Sweden and the US suggest that the age-specific prevalence of dementia has changed little over the last 30 or 40 years in high income countries [15;16]. Trends in low and middle income countries have not been assessed in such a rigorous way, although there is some evidence for a recent increase in the prevalence of dementia in China [17]. Whatever the explanation for the current discrepancy between the prevalence of dementia in high income and low income countries, it seems probable that as patterns of morbidity and mortality converge with those of the developed West, then dementia prevalence levels will do likewise [6]. This would result in an even greater increase in the burden of dementia in poorer countries, on top of that which is anticipated as a result of demographic ageing.

Studies in developed countries have consistently reported Alzheimer's disease to be more prevalent than vascular dementia [18]. Early surveys from South-East and East Asian countries provided an exception with an equal distribution of Alzheimer's disease and vascular dementia [18]. More recent research suggests this situation has now reversed [17;19]. This may be due to increasing longevity and better physical health: Alzheimer's disease, whose onset is in general later than vascular dementia, increases as the number of very old people increases, while better physical health reduces the number of stroke sufferers and thus the number with vascular dementia [19]. This change also affects the gender balance among dementia sufferers, increasing the number of females and reducing the number of males.

Why do we need new estimates?

1 The *Lancet*/ADI baseline estimates were for the year 2001, with projections to 2020 and 2040. The inexorable, rapid growth in the world's older population means that this number will, by now, have increased considerably. The latest figures generated by the ADI office for 2009 (based upon the *Lancet*/ADI prevalence estimates) are 31.0 million, however, the baseline figures for 2001 (24.2 million) continue to be widely cited.

2 The *Lancet*/ADI estimates were described as 'provisional', given that prevalence data were lacking in many world regions, and inconsistent in others, with few studies and widely varying estimates [6]. Coverage was good in Europe, North America, and in developed Asia–Pacific countries: South Korea, Japan, Chinese Taipei and Australia. Several studies have been published from India and China, but estimates were too few and/or too variable to provide a consistent overview for these huge countries. There was a particular dearth of published epidemiological studies in Latin America [20-22], Africa [10], Russia, the Middle East and Indonesia. We therefore, of necessity, relied heavily upon the consensus judgment of our international panel of experts.

3 Since the *Lancet*/ADI estimates were published, the global evidence-base has expanded considerably. There have been new studies from Spain [23;24], Italy [25] and the USA [26]. An exciting development has been an explosion of studies from low and middle income countries, and other regions and groups previously under-represented in the literature. These include ADI's 10/66 Dementia Research Group studies in Brazil, Cuba, Dominican Republic, Peru, Mexico, Venezuela, India and China [13;27], and further new prevalence studies from Brazil [28], Peru [29], Cuba [30], Venezuela [31], China [32], Korea [33], India [34], Thailand [35], Australia (indigenous people) [36], Guam [37], Poland [38] and Turkey [39].

4 The leaders of the *Lancet*/ADI review, Martin Prince and Cleusa Ferri, were commissioned in 2008 to assist the World Health Organization (WHO) in updating the Global Burden of Disease (GBD) estimates, by conducting fully systematic reviews of the prevalence and incidence of dementia, and associated mortality, in 21 GBD world regions. This provided an ideal opportunity to revisit the literature and to assess the extent to which it was possible, in some or all regions, to summarise the evidence on the prevalence of dementia by carrying out quantitative meta-analyses of the available data, rather than relying on expert consensus. The differences in approach between the earlier *Lancet*/ADI estimates and the new estimates derived for this report are summarised in Table 1.1.

Table 1.1
Main differences in approach between *Lancet*/ADI estimates and current World Alzheimer Report estimates

	***Lancet*/ADI**	**Current review**
Search strategy	Limited time and resources did not permit fully systematic review	Fully systematic review, with inclusion/exclusion criteria, specified search terms, multiple databases
Regional subdivisions	Estimates provided for 14 WHO world regions	Estimates provided for 21 WHO Global Burden of Disease world regions
Method for generating regional estimates	Regional estimates generated from expert Delphi consensus guided by all the available evidence	Regional estimates generated, where possible, from quantitative meta-analysis
Stratification for prevalence estimates	Age-specific prevalence in five year age bands to 85 and over	Age- and gender-specific prevalence in five year age bands to 90 and over
Base year	2001	2010
Future projections	2020/2040	2020/2030/2040/2050

Methods

We conducted a systematic review of the world literature on the prevalence of dementia. We used the following search terms, using Pubmed/Medline – ("Dementia"[Mesh] AND (("Prevalence"[Mesh]) OR "Epidemiology"[Mesh])).

Inclusion criteria

Population-based studies of the prevalence of dementia among people aged 60 years and over (according to DSM-IV or ICD-10 criteria, or similar clinical criteria), for which the field work started on or after 1 January 1980.

Exclusion criteria

BASE POPULATION

- Studies of prevalence from the follow-up phase (rather than the inception phase) of a population cohort
- Studies sampling from an out-of-date population register (prepared more than three years prior to the survey)
- Studies of nursing home or residential care populations
- Studies of primary care attendees or other unrepresentative service-user populations

ASCERTAINMENT/OUTCOME DEFINITION

- Studies in which the ascertainment of dementia depended upon help-seeking and/or receipt of dementia care services
- Studies in which 'dementia' was diagnosed purely on the basis of cognitive impairment, for example according to a cutpoint on the Mini Mental State Examination (MMSE)
- Two phase studies, in which screening procedures were clearly inadequate and two phase methodology was not properly applied (see below); this applied to all large scale screening studies of people of all ages for all neurological disorders, using WHO methodology
- Studies of the prevalence of Alzheimer's disease or other subtypes of dementia
- Studies restricted to young onset dementia

Procedures

In the first stage of the search, Martin Prince and Cleusa Ferri read the abstracts of all publications identified on the electronic databases, excluding only those that clearly did not meet the above criteria. In the next stage, we obtained printed copies of the remaining publications. These were then read by either Martin Prince, Cleusa Ferri, Renata Sousa, Wagner Ribeiro or Emiliano Albanese, and a consensus was made on those that met all criteria. We were able to read studies published in English, French, Spanish, Portuguese and German and recruited outside assistance for studies published in Japanese and Polish. Unfortunately, we were not able to obtain and/or read many of the studies published originally in Chinese within the time frame for this review. This work will be completed later, but for the time being, we relied on a recently published systematic review and meta-analysis that included both English language and Chinese publications from 1980-2004 [17], which we supplemented with four other, mainly more recent, studies from China published in English and not included in that meta-analysis [13;32;40].

All eligible studies were systematically coded for their study design and quality according to the following criteria:

1 Country

2 WHO / Global Burden of Disease world region (see Appendix 1 for list of countries and regions)

3 Inclusion of residents of long term care institutions

4 Start and finish dates for fieldwork, and census dates if provided

5 Lower and upper age limits

6 Sampling (simple random / stratified random / whole population / other)

7 Design (one phase / two phase / three phase)

8 Overall sample size (first phase)

9 Numbers interviewed (first phase) and proportion responding

10 For two phase surveys only:
   - a Numbers selected for the second phase (for two phase surveys)
   - b Numbers interviewed (second phase) and proportion responding
   - c Screen negatives sampled for the second phase (yes/no)
   - d Screen negatives given same assessment as screen positives (yes/no)
   - e Weighting back carried out (no weighting back / appropriate weighting back / no weighting back, but no false positives)
   - f Time interval between first and second phase
   - g Screening instrument/s

11 Diagnostic criteria (not specified/ICD/DSM/GMS/AGECAT/CAMDEX/other clinical criteria)

12 Use of multidomain cognitive assessment, informant interview, disability assessment, neuroimaging

An overall quality score was derived by summing scores for the following elements:

Sample size

<500	0.5 points
500-1499	1 point
1500-2999	1.5 points
>=3000	2 points

Design

Two phase study with no sampling of screen negatives	0 points
Two phase study with sampling of screen negatives but no weighting back	1 point
One phase study or two phase study with appropriate sampling and weighting	2 points

Response proportion

<60%	1 point
60-79%	2 points
>=80%	3 points

Diagnostic assessment

Inclusion of multidomain cognitive test battery, formal disability assessment, informant interview and clinical interview	1 point each

Data extraction

Prevalence data was extracted from the studies as follows.

For *unweighted prevalence*, we extracted (according to the data presentation in the paper) either numerator and denominator, or prevalence and denominator, or prevalence and standard error, or prevalence and 95% confidence intervals. Numerator and denominator could then be calculated from any of these combinations.

For *weighted prevalence* we extracted (according to the data presentation in the paper) either weighted prevalence and weighted standard error, or weighted prevalence and weighted 95% confidence intervals. Effective numerators and denominators (taking account of the design effect) could then be calculated from either of these combinations.

Prevalence estimates were stratified differently in different publications. To maximise the precision of our meta-analysed estimates (see below) we required estimates of prevalence in five year age bands, separately for men and women (age- and gender-specific prevalence). In practice:

a) some studies simply gave an overall prevalence for the whole sample, stratified neither by age nor gender

b) others provided gender-specific estimates, not stratified by age

c) others provided age-specific estimates, not stratified by gender.

In each of the scenarios a) – c) above, we wrote to the authors to request age- and gender-specific prevalence data. Prevalence data in formats a) and b) could not be used in our meta-analyses, since the main aim was to model the effect of age on dementia prevalence. Therefore, such studies had to be excluded. Age-specific prevalence data (as c) above) could be used, and these data were generally available or could be calculated from age- and gender-specific estimates. Therefore we could model the effect of age on dementia prevalence for all included studies, and the effects of age and gender for the subset of studies that had provided age- and gender-specific estimates.

Meta-analytical methods for estimating dementia prevalence within regions

Within each GBD region, where there were sufficient data to conduct a meta-analysis, we used a random effect exponential (Poisson) model to assess the effect of age, and age and gender on the prevalence of dementia. Random effects are assumed to have a gamma distribution – the alpha coefficient is an estimate of overdispersion and an index of between study heterogeneity. Age was coded as the mean for each age group reported. For high income countries, this was calculated from the US Census, while for low and middle income countries we estimated this as the mean observed in the relevant 10/66 Dementia Research Group population-based studies [13]. In practice these sets of means differed only slightly, although those for India were lower. For each region we ran two models, one for the effect of age, and one for the main effects of age and gender, and an interaction between age and gender. We then applied the relevant mean ages and gender codings to the coefficients estimated from the models, to estimate prevalence in five year age-bands from 60-89 years, and for those aged 90 and over, for both genders combined (from the age only model), and for men and women separately (from the age and gender model).

Results

The extent of the evidence-base

The initial search of PubMed database yielded abstracts for 2017 publications. After reading the abstracts, 1764 publications were excluded as clearly ineligible, leaving 253 publications for further review. Where possible, we obtained copies of the full published version of each paper, which were then carefully assessed against inclusion/exclusion criteria. A further 98 publications were excluded at this stage, leaving 155 publications (describing 167 studies) that were provisionally eligible for inclusion in the review. For 20 of these publications, we were either unable to confirm eligibility with the information available, or could not use the data in the form in which it was provided in the publication. These publications were coded 'pending' awaiting clarification from authors.

A full list of excluded and pending publications is provided in Appendix 5 online at www.alz.co.uk/worldreport. Finally, 135 publications (describing 147 studies) were fully eligible for inclusion in the review. We assessed the adequacy of the search by sending the results to the 94 members of ADI's Medical and Scientific Advisory Panel, asking if there were any studies that they knew of, which we had missed. None were identified.

The coverage of the evidence-base

The number of studies identified in each GBD world region and the number of older participants studied are listed in Table 1.2.

Table 1.2
Coverage, by region, with respect to size of elderly population

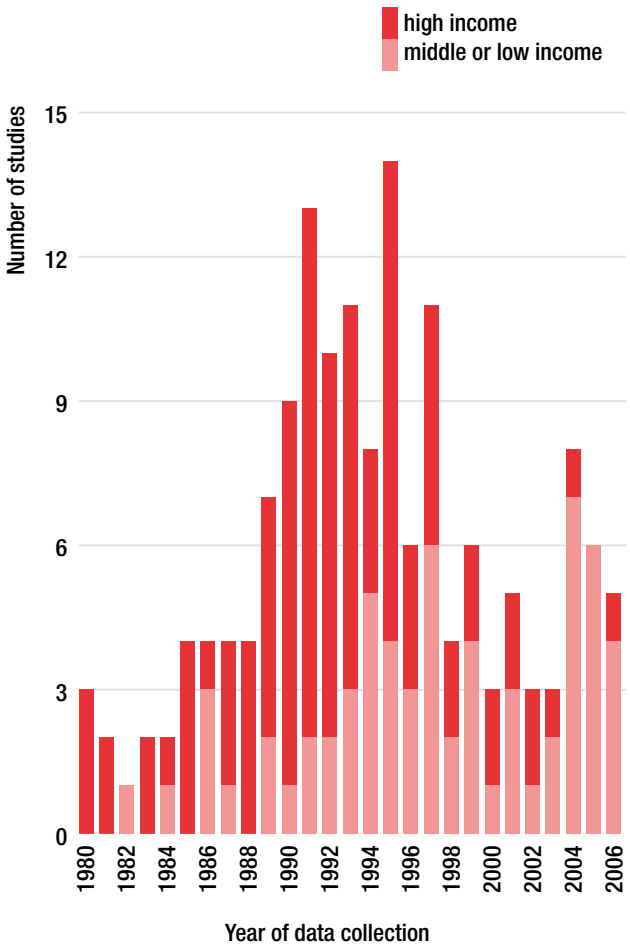
Region	Over 60 year old population (millions)	Number of eligible dementia prevalence studies	Number of studies/ 10 million population	Total population studied	Total population studied/ million population
ASIA	**406.6**	**73**	**1.7**	**193924**	**477**
Australasia	4.8	4	8.3	2223	462
Asia Pacific, High Income	46.6	22	4.7	31201	669
Asia, Central	7.2	0	0.0	0	0
Asia, East	171.6	34	2.0	142402	830
Asia, South	124.6	7	0.6	11905	96
Asia, Southeast	51.2	5	1.0	4164	81
Oceania	0.5	1	20.3	2029	4116
EUROPE	**160.2**	**61**	**3.8**	**80882**	**504**
Europe, Western	97.3	56	5.8	79043	813
Europe, Central	23.6	4	0.8	1839	78
Europe, Eastern	39.3	1	0.3	Not known	-
THE AMERICAS	**120.7**	**28**	**2.3**	**85053**	**705**
North America	63.7	13	2.0	38205	600
Caribbean	5.1	4	7.9	24425	4831
Latin America, Andean	4.5	3	6.7	3465	769
Latin America, Central	19.5	4	2.0	6344	325
Latin America, Southern	8.7	1	1.1	4689	537
Latin America, Tropical	19.2	3	1.6	5925	308
AFRICA	**71.2**	**5**	**0.7**	**6593**	**93**
North Africa / Middle East	31.1	2	0.6	3019	97
Sub-Saharan Africa, Central	3.9	0	0.0	0	0
Sub-Saharan Africa, East	16.0	0	0.0	0	0
Sub-Saharan Africa, Southern	4.7	1	2.1	150	32
Sub-Saharan Africa, West	15.3	2	1.3	3424	223

Good to reasonable coverage was identified for 11 of the 21 GBD regions. Two regions, Western Europe (61 studies) and East Asia (34 studies) accounted for the majority of the world's studies. The next best represented region was Asia Pacific High Income (22 studies), followed by North America (13 studies), and Latin America, if considered as a single region (11 studies). Other regions with reasonable coverage were South Asia (7 studies), South East Asia (5 studies) and Australasia (4 studies). Sparse coverage only was achieved in five regions; the Caribbean (4 studies), Central Europe (4 studies), North Africa / Middle East (2 studies), Eastern Europe (1 study) and West Sub-Saharan Africa (2 studies) and Southern Sub-Saharan Africa (1 study). No eligible studies were identified for the remaining three GBD world regions; Central and Eastern Sub-Saharan Africa, and Central Asia. The rationale for calculating studies and participants/ million older population (Table 1.2) was to provide an index of the research effort relative to the size and probable diversity of the countries and regions concerned. According to these criteria, broadly similar coverage was achieved in the Asia Pacific, East Asia, Western Europe, North America, Latin America and Caribbean regions. There was a higher density of studies in Western Europe, but these tended to be smaller in size than those in North America and East Asia. Apart from those regions with no studies, South Asia, Eastern Europe and North Africa / Middle East stand out as regions with sizeable populations of older people and little research relative to the size of that population.

Adequate coverage of large and populous countries such as the USA or China would require a large number of studies in different regions encompassing the racial, cultural, economic and social diversity of the nation as a whole. The most informative approach would be a study of a nationally representative sample, but to our knowledge such studies have only been carried out in the USA (but on a very small sample [26]) and in Canada [41]. The MRC CFA study in the UK [42] provides good coverage of different regions and urban and rural populations, but is not nationally representative. By the same token, studies carried out in just one or two countries, may not safely be generalised to a large number of other countries in the same GBD region. For example, in the Caribbean, the evidence base derives from three studies in Cuba and one in the Dominican Republic, with no studies from the other 25 countries. These include some of the poorest (Haiti) and richest (The Bahamas) countries in the world, and those colonised by the British, Dutch, French and Americans, as well as other Hispanic cultures. Limits to generalisability are particularly marked when the few or only available studies are small, conducted some time ago, and/or of poor methodological quality. All of these strictures apply, for example, to the one study identified in Southern Sub-Saharan Africa [43].

When it was founded, in 1998, the title of the 10/66 Dementia Research Group referred to the 10% of population-based research that had been conducted in low and middle income countries (LAMIC), relative to the two-thirds of people with dementia living in those regions. By 2009, the situation is transformed with 65 out of 167 (39%) of dementia prevalence studies having been conducted in LAMIC. Figure 1.1 indicates the large, sustained increase in studies conducted in LAMIC since the mid 1990s. Of more concern is the finding that studies in high income countries peaked in the early 1990s and declined sharply thereafter; 26.9% of high income country studies (chiefly Europe and North America) were conducted in the 1980s, 63.4% in the 1990s and just 9.7% in the 2000s.

Figure 1.1
Numbers of prevalence studies, by year of data collection and income level of the country where the research was carried out



The quality of the research

The principal characteristics of the included studies are described in Table 1.3, by world region.

STUDY DESIGN

The major quality control issue concerns the use of surveys with two or more phases. Multiphase survey designs are popular in dementia research because of perceived efficiencies in interviewer time and cost. Overall, 70% of dementia prevalence studies used this design. All participants are assessed in the first phase, with a brief dementia screening assessment (often the Mini-Mental State Examination). Those scoring below a pre-defined cutpoint ('screen positives') are more likely to have dementia, and all of them enter a second phase of the survey in which they undergo a comprehensive dementia diagnostic assessment. A fundamental error is to fail also to submit a random sample of those scoring above the pre-defined cutpoint ('screen-negatives') to the same diagnostic assessment. No screening assessment is perfectly sensitive, and it is therefore likely that some dementia cases will have been missed. The correct procedure is to estimate the false positive rate among the screen negatives, and then to 'weight back', calculating an overall prevalence taking account of the different sampling proportions of screen positives and screen negatives. Put simply, if all screen positives and one in ten screen negatives are assessed in the second phase, then in calculating the overall prevalence from the results of the second phase diagnostic assessment, each screen positive counts as one, but each screen negative counts as ten. Unfortunately, most investigators using a multiphase design did not sample screen negatives, and those that did often did not weight back appropriately. For fully 79% of multiphase studies (accounting for 49% of all studies) the design was not correctly applied and/or analysed appropriately. Misapplication of multiphase methods will always tend towards an under-estimation of true dementia prevalence and an over-estimation of precision. Even when applied correctly, all multiphase studies are complicated by the often quite high levels of loss to follow-up that occur between the screening and definitive diagnostic assessment [8]; this is again likely to lead to bias, which could be over- or under-estimation of true prevalence [44].

SCOPE OF DEFINITIVE DIAGNOSTIC ASSESSMENT

Dementia diagnosis requires the demonstration of cognitive impairment (and decline from a previous level of functioning) in memory and other domains of intellectual function, and demonstration of consequent social or occupational impairment. Other causes of cognitive and functional impairment, including functional psychosis, depression and delirium should be excluded. A diagnostic assessment should therefore include multidomain cognitive testing, disability assessment, clinical interview and informant interview. Overall, less than half (43%) of all studies met this requirement. Informant interviews were the element most likely to be missed out. The effect of applying more limited ascertainment procedures on dementia prevalence is uncertain. In principle it could lead either to under- or over-estimation of true prevalence.

SAMPLE SIZE

Worldwide, just over a half of all studies had sample sizes smaller than 1500. Nearly a third of Western European studies had sample sizes smaller than 500. East Asia (China and Chinese Taipei) contributed a relatively high proportion of large studies. In general, sample sizes tended to be larger in LAMIC. In principle, sample size, in and of itself, should not have any effect on prevalence, other than that it will be estimated with less precision by smaller studies. A study of 500 participants could estimate a true prevalence of 6% for all those aged 65 and over with a precision of +/- 2.1%. Precision increases to +/- 1.2% for a sample size of 1500 and to +/- 0.8% for a sample size of 3000.

RESPONSE PROPORTION

One cannot assume that those who do not agree to participate in surveys, or who cannot be contacted or interviewed (non-responders), have the same characteristics as those who do participate. Those with dementia may be under-represented in the interviewed sample as they may find it difficult to answer questions, or their relatives may be reluctant for them to participate. Alternatively, they may be over-represented as they may be more likely to be at home when interviewers call. The direction of the bias arising from non-response is therefore hard to predict. However, studies with higher proportions of participants responding should provide more accurate prevalence estimates. Participation in studies of dementia prevalence was generally adequate to good; only six studies (4%) reported fewer than 60% of eligible participants responding, while more than half reported 80% or more responding. However, 15% of studies provided no information on the proportion responding.

OVERALL QUALITY

Mean scores for our ad hoc quality index varied significantly between regions. Overall study

Table 1.3
Study characteristics, by region (for those regions within which meta-analyses were conducted), and by country income level
HIC = high income countries LAMIC = low and middle income countries

	Europe	North America	Latin America and Caribbean	Asia Pacific High Income	Austral-asia	Asia, East	Asia, South	Asia, South East	HIC	LAMIC	All regions
Number of studies [1]	51	13	15	20	4	34	7	5	93	64	157
Year of research											
1980-1989	13 (26%)	3 (23%)	0	7 (35%)	2 (50%)	5 (15%)	0	1 (20%)	25 (27%)	8 (13%)	33 (21%)
1990-1999	34 (67%)	9 (69%)	3 (20%)	10 (50%)	1 (25%)	25 (74%)	4 (57%)	2 (40%	59 (63%)	32 (50%)	91 (58%)
After 2000	4 (8%)	1 (8%)	12 (80%)	3 (15%)	1 (25%)	4 (12%)	3 (43%)	2 (40%)	9 (10%)	24 (38%)	33 (21%)
Sample size											
<500	16 (31%)	0	0	3 (16%)	2 (50%)	0	1 (14%)	1 (20%)	21 (23%)	3 (5%)	24 (16%)
500-1499	19 (37%)	4 (31%)	5 (36%)	7 (37%)	2 (50%)	10 (29%)	3 (43%)	4 (80%)	34 (37%)	24 (38%)	58 (37%)
1500-2999	9 (18%)	5 (39%)	8 (57%)	5 (26%)	0	10 (29%)	2 (29%)	0	21 (23%)	22 (34%)	43 (28%)
>=3000	7 (14%)	4 (31%)	1 (7%)	4 (21%)	0	14 (41%)	1 (14%)	0	16 (17%)	15 (23%)	31 (20%)
Outcome (Dementia criterion)											
ICD-10	1 (2%)	0 (0%)	0	1 (5%)	0	1 (7%)	1 (14%)	0	3 (3%)	2 (5%)	5 (4%)
DSM-IV/IIIR	37 (73%)	9 (69%)	8 (53%)	17 (85%)	2 (67%)	10 (71%)	4 (57%)	4 (80%)	69 (75%)	25 (60%)	94 (70%)
GMS/AGECAT	2 (4%)	1 (8%)	0	0 (0%)	0	0	0 (0%)	1 (20%)	3 (3%)	1 (2%)	4 (3%)
CAMDEX	6 (12%)	0 (0%)	0	0 (0%)	0	0	0	0	6 (7%)	1 (2%)	7 (5%)
Other	5 (10%)	3 (23%)	7 (47%)	2 (10%)	1 (33%)	3 (21%)	2 (29%)	0	11 (12%)	13 (31%)	24 (18%)
Design											
One phase	16 (31%)	2 (15%)	10 (67%)	3 (15%)	3 (75%)	3 (21%)	3 (43%)	0	25 (27%)	16 (36%)	41 (30%)
Two or more phases	36 (69%)	11 (85%)	5 (33%)	17 (85%)	1 (25%)	11 (89%)	4 (57.%)	5 (100%)	69 (73.%)	20 (46%)	97 (70%)
Multiphase design applied and analysed correctly [2]	22%	55%	20%	12%	100%	9%	0%	0%	25%	11%	21%
Response proportion											
<60%	5 (10%)	0	0	0	0	0	0	0	5 (5.3%)	1 (2%)	6 (4%)
60-79%	16 (31%)	6 (46%)	2								
(13%)	3 (15%)	2									
(50%)	4 (29%)	1 (14%)	1 (20%)	29 (31%)	8 (18%)	37 (27%)					
80-100%	28 (54%)	5 (39%)	10 (67%)	10 (50%)	2 (50%)	10 (71%)	5 (71%)	1 (20%)	48 (51%)	26 (59%)	74 (54%)
Not specified	3 (6%)	2 (15%)	3 (20%)	7 (35%)	0	0	1 (14%)	3 (60%)	12 (13%)	9 (21%)	21 (15%)
Assessment quality											
Comprehensive diagnostic assessment [3]	28 (55%)	5 (39%)	11 (73%)	2 (10%)	0	4 (31%)	3 (43%)	1 (20%)	36 (39%)	21 (51%)	57 (43%)
Overall quality score [4]											
Mean (SD)	8.2 (1.8)	8.2 (1.7)	9.7 (2.0)	6.6 (1.6)	8.3 (0.9)	8.0 (1.9)	8.4 (2.2)	5.5 (0.7)	7.8 (1.8)	8.3 (2.5)	7.9 (2.0)

1 These numbers differ from the totals listed in Table 1.2 as we were not able to ascertain some or all study characteristics for some of the 'pending' studies, about which we were seeking further information from authors. Also full details on methodology were not available from several of the Chinese language publications, summarised in a previous published meta-analysis [17].

2 As a proportion of all studies using a multiphase design (i.e. with two or more phases, with screening performed on all in the first phase, and definitive diagnostic assessment on a sub-sample based on screening score).

3 Defined as a multidomain cognitive battery, an informant interview, a formal assessment of disability, and a clinical interview.

4 Derived from sample size, design, response proportion and assessment quality (see text for details).

quality was high for the Latin American region, and particularly poor for Asia Pacific High Income (mainly attributable to the Japanese studies) and South East Asia studies. Study quality did not differ significantly between high income and low/middle income countries. There was a pronounced tendency for study quality to have improved over time – from a mean of 7.3 for studies conducted in the 1980s, to 7.8 for the 1990s, to 9.0 for studies conducted this century.

Meta-analysis of dementia prevalence within GBD regions

We considered that the evidence-base was sufficient in terms of number and quality of studies, and coverage, to conduct meta-analyses for 11 of the 21 GBD regions; Western Europe, North America, Latin America (combining the Latin American Andean, Central, Southern and Tropical regions), Asia Pacific High Income, Australasia, East Asia, Southeast Asia and South Asia. The countries included in each region, those among them in which prevalence studies had been conducted, and the approach used to generate regional prevalence and numbers is summarised in Appendix 1. Given that the North American region included just two countries, Canada and the USA, and that Canada was represented by a large and well-conducted survey on a nationally representative sample [41], we used a slightly different approach for this region, applying the Canadian Study of Health and Aging (CSHA) prevalence figures to Canada, and meta-analysing the USA studies to generate estimates for that country.

THE EFFECTS OF AGE AND GENDER

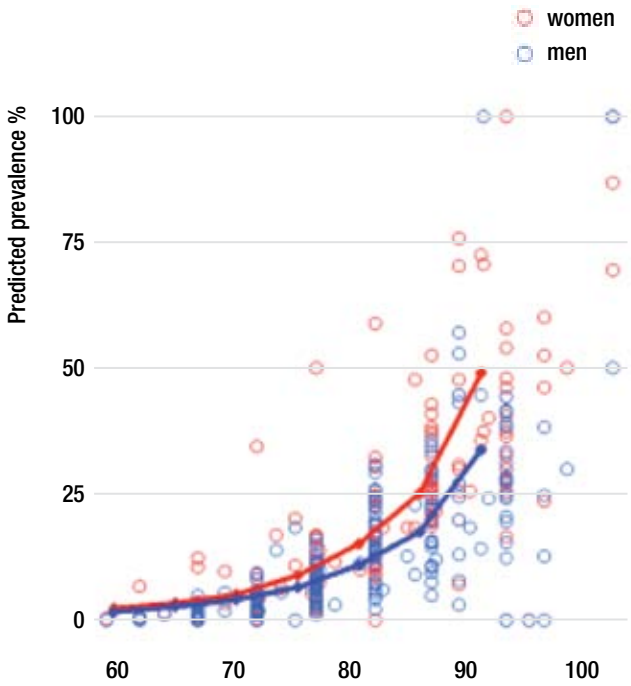
In fitting the models, we noted a strong effect of age in each region. The prevalence of dementia increased exponentially with age, doubling with every 5.5 year increment in age in North America, Latin America and Asia Pacific, with every 5.6 year increment in East Asia, every 6.3 years in West Europe and South Asia, and every 6.7 years in South East Asia and Australasia.

We also noted an independent effect of gender in all regions other than North America and Asia Pacific, the predicted prevalence for men being between 19 and 29% lower than that for women. An interaction was noted between age and dementia, with a tendency in all regions for the divergence in prevalence between men and women to increase with increasing age; however, this was statistically significant only for the Asia Pacific region.

HETEROGENEITY OF PREVALENCE WITHIN REGIONS

There was statistically significant overdispersion in all of the models other than that for SE Asia, indicating significant heterogeneity in age-specific or age- and gender-specific prevalence between studies, within regions. Heterogeneity was most marked for South Asia (alpha=0.39), Western Europe (alpha=0.19) and Asia Pacific (alpha=0.18). The extent of this heterogeneity is best illustrated in a scatter plot (Figure 1.2). The dots on the plot shows the individual age- and gender-specific prevalence estimates from the 46 Western Europe studies (red for men and blue for women) and the continuous lines represent the age- and gender-specific prevalence predicted from the Poisson model. The scatter of the individual study estimates around the lines provides an index of heterogeneity. It should be noted that the plot does not give any information about the size of the studies – the larger studies are given more weight in the predictive model. Some of the individual study estimates for prevalence among those over 90 are based on fewer than five participants, hence accounting for the otherwise surprisingly low prevalence recorded in these age groups in some studies.

Figure 1.2
Heterogeneity in dementia prevalence estimates in Western Europe (46 studies), and goodness of fit of the predictive model



An advantage of modelling prevalence with Poisson random effects exponential regression is that it allows us to explore possible sources of heterogeneity between study estimates, by extending the model to include study characteristics. We have demonstrated such an analysis using data for the Western Europe region, since this was the GBD region represented by the largest number of studies. The results of this modelling exercise are summarised in Table 1.4. The base model (not shown) included the effects of age, gender and an interaction between age and gender, with an alpha of 0.19. Excluding the two studies from Israel, one of which reported an unusually high prevalence [45], reduced alpha to 0.16. Adding methodological factors and year of study (Model 1) reduced alpha to 0.10. Adding country further reduced alpha to 0.07. Thus, much of the variation in prevalence between Western European studies could be explained by the study design (a higher prevalence in two phase studies, particularly when incorrectly applied), year of study (a non-linear effect, with a higher prevalence from studies carried out in the 1990s compared with those carried out before or after that decade) and method of dementia ascertainment (a higher prevalence in studies that included informant interview). The country in which the survey was carried out accounted for a smaller degree of heterogeneity, with the highest prevalence seen in France, followed by Belgium, Norway, Denmark, Italy, Spain, Germany, UK, San Marino, Switzerland, Netherlands, Sweden and Finland.

Table 1.4

Modelling the effects of study characteristics upon observed prevalence in Western Europe (46 studies)

Study characteristic	Model 1	Model 2
Design		
Two phase survey incorrectly applied	1 (ref)	
Two phase survey correctly applied	0.81 (0.61-1.09)	0.98 (0.70-1.36)
One phase survey	0.68 (0.53-0.85)	0.91 (0.65-1.27)
Year		
1980 – 1989	1 (ref)	
1990 – 1999	1.36 (1.06-1.75)	1.15 (0.83-1.59)
2000 –	0.74 (0.48-1.13)	0.69 (0.43-1.10)
Dementia ascertainment		
Informant interview included	1.13 (0.91-1.41)	1.27 (0.98-1.65)
Country		
Italy		1 (ref)
France		1.77 (1.00-3.14)
Netherlands		0.65 (0.42-1.01)
Sweden		0.64 (0.40-1.03)
Germany		0.83 (0.52-1.34)
Finland		0.67 (0.34-1.29)
Denmark		1.16 (0.65-2.06)
Spain		0.99 (0.71-1.38)
Belgium		1.32 (0.74-2.36)
Norway		1.22 (0.64-2.32)
San Marino		0.73 (0.35-1.50)
UK		0.80 (0.52-1.24)
Switzerland		0.70 (0.35-1.43)
Heterogeneity		
Alpha	0.10 (0.60-0.16)	0.07 (0.04-0.11)

Generating prevalence estimates

As described earlier, we generated both age-specific and age- and gender-specific meta-analysed dementia prevalence estimates. These are described for each region in Table 1.5. We decided to prioritise the age- and gender-specific estimates since they should, in principle, provide the most precise overall prediction of regional prevalence. However, we could not calculate age- and gender-specific prevalence for Australasia, since no studies reported prevalence in this way, and in South East Asia only two of five studies could be used for this purpose. Therefore, for these two regions, we have prioritised age-specific prevalence instead. To facilitate comparison between regions and with previous estimates for the same regions, we have also calculated overall age- and age- and gender-standardised prevalence for all those aged 60 and over, using Western Europe as the standard population.

The highest standardised prevalence was observed in Latin America (8.50%), and the lowest in East Asia (4.98%). The other regions occupied a fairly narrow band of prevalence, ranging between 5.65% and 7.29%. When compared with our earlier *Lancet*/ADI consensus estimates (again standardised to the same Western European population) some were higher; 7.29% for West Europe (compared with 5.92% for the equivalent *Lancet*/ADI EURO A region), 5.65% for South Asia (compared with 3.40% for the equivalent SEARO D region) and 8.50% for Latin America

Table 1.5
Meta-analysed estimates of dementia prevalence, generated from Poisson random effects models, by GBD region

Global Burden of Disease region	Number of studies		Gender	Age group							Standardised prevalence[1], for those aged 60 and over
	Potentially eligible studies	Used in meta-analysis (age-specific, age- and gender specific)		60-64	65-69	70-74	75-79	80-84	85-89	90+	
ASIA											
Australasia	4	3, 0	All	1.8	2.8	4.5	7.5	12.5	20.3	38.3	6.91*
Asia Pacific, High Income	22	14, 10	M	1.4	2.3	3.8	6.4	10.9	18	34.9	6.30*
			F	0.9	1.7	3.1	6.0	11.7	21.7	49.2	
			All	1.0	1.7	2.9	5.5	10.3	18.5	40.1	5.57
Asia, East	34	34, 31	M	0.8	1.3	2.2	4.0	7.3	16.7	26.4	4.98*
			F	0.9	1.6	2.9	5.3	10.0	17.9	38.7	
			All	0.7	1.2	3.1	4.0	7.4	13.3	28.7	4.19
Asia, South	8	7, 6	M	1.0	1.7	2.9	5.3	9.4	16.4	33.7	5.65*
			F	1.5	2.3	3.8	6.5	11	18.1	35.1	
			All	1.3	2.1	3.5	6.1	10.6	17.8	35.4	5.78
Asia, Southeast	6	5, 2	M	1.7	2.6	4.0	6.2	9.8	15	26.4	7.63
			F	1.8	3.0	5.1	9.0	15.9	27.2	54.9	
			All	1.6	2.6	4.2	6.9	11.6	18.7	35.4	6.38*
EUROPE											
Europe, Western	56	52, 46	M	1.4	2.3	3.7	6.3	10.6	17.4	33.4	7.29*
			F	1.9	3.0	5.0	8.6	14.8	24.7	48.3	
			All	1.6	2.6	4.3	7.4	12.9	21.7	43.1	6.92
THE AMERICAS											
North America (USA only)	11	8, 6	M	1.3	2.1	3.7	6.8	12.3	21.6	45.2	6.77*
			F	1.0	1.8	3.3	6.4	12.5	23.2	52.7	
			All	1.1	1.9	3.4	6.3	11.9	21.7	47.5	6.46
Latin America	11	11, 10	M	1.0	1.9	3.7	7.0	13.0	24.3	55.0	8.50*
			F	1.0	2.0	4.2	8.4	16.4	32.5	79.5	
			All	1.3	2.4	4.5	8.4	15.4	28.6	63.9	8.48

(compared with 7.25% for the equivalent AMRO B region). Others were lower, particularly 4.98% for East Asia, (compared with 6.46% for the equivalent WPRO B region). The estimate for North America (6.77%) was effectively identical to the AMRO A estimate (6.54%).

Generation of prevalence estimates for other GBD regions where it was not possible to conduct a meta-analysis

Where it was not possible to conduct a meta-analysis, due to lack of available data, our default option was to apply the relevant estimates from the *Lancet*/ADI Delphi consensus from 2005, representing the best available estimates of likely dementia prevalence in those regions [6]. This was complicated somewhat by the mismatch between the 14 WHO world regions (based on geography and patterns of mortality) and the 21 new WHO GBD regions (based on geography alone). Therefore, we applied the relevant *Lancet*/ADI regional age-specific estimates to each country in the GBD region, and then aggregated prevalence as a weighted average across the region. For some countries, we felt that recent good quality studies arguably provided better estimates, for that country (and in some instances for some of its neighbours), than the *Lancet*/ADI regional estimate. This applied to the following GBD regions and countries (study references provided in brackets):

Caribbean – Cuba [46] and Dominican Republic [13].

North Africa / Middle East – Egypt [47] (applied to Egypt and three other EMRO D countries – Iraq, Morocco and Yemen). The estimates from the one eligible study for Turkey [39] were not applied to this country owing to the unusually high observed prevalence (11.4% for all those aged 60 and over, when standardised to the Western Europe population).

West Sub Saharan Africa – Nigeria [10], applied also to all other countries in this region.

The age-specific aggregated dementia prevalence estimates for each region are provided in Table 1.6. To facilitate comparison between regions, we have again calculated overall age- and age- and gender-standardised prevalence for all those aged 60 and over, using Western Europe as the standard population.

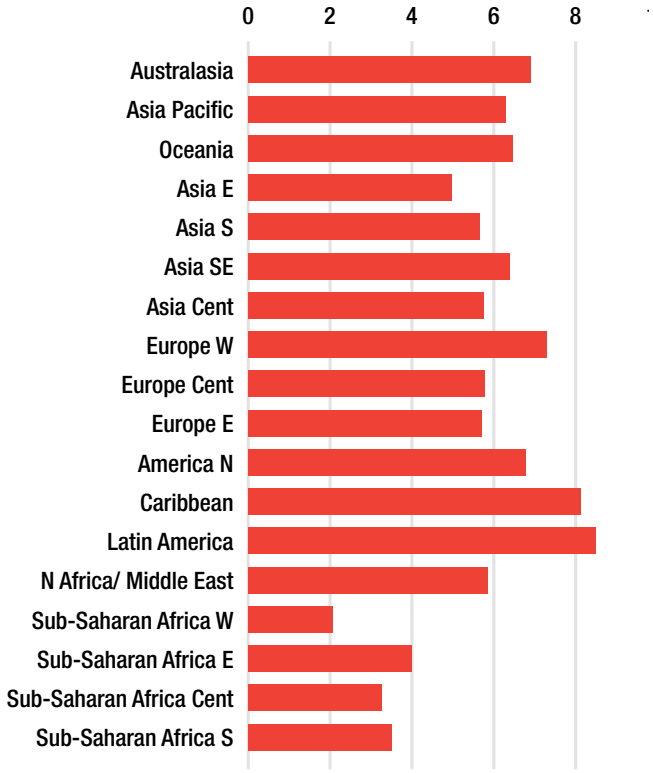
Table 1.6
Estimates of dementia prevalence (%) for GBD regions where it was not possible to carry out a quantitative meta-analysis

	Sources of prevalence data used to calculate regional weighted average	60-64	65-69	70-74	75-79	80-84	85+	Age-standardised prevalence for all those aged 60 years and over
ASIA								
Asia, Central	EURO B, EURO C	0.9	1.3	3.2	5.8	12.1	24.7	5.75
Oceania	WPRO B	0.6	1.8	3.7	7.0	14.4	26.2	6.46
EUROPE								
Europe, Central	EURO A, EURO B	0.9	1.3	3.3	5.8	12.2	24.7	5.78
Europe, Eastern	EURO C	0.9	1.3	3.2	5.8	11.8	24.5	5.70
THE AMERICAS								
Caribbean	AMRO B, AMRO D, Cuba [13;46], Dominican Republic [13]	1.3	2.6	4.9	8.5	16.0	33.2	8.12
AFRICA								
North Africa / Middle East	EMRO B, AFRO D, Egypt [47]	1.0	1.6	3.5	6.0	12.9	23.0	5.85
Sub-Saharan Africa, Central	AFRO D, AFRO E	0.5	0.9	1.8	3.5	6.4	13.8	3.25
Sub-Saharan Africa, East	AFRO E, AFRO D, EMRO D	0.6	1.2	2.3	4.3	8.2	16.3	4.00
Sub-Saharan Africa, Southern		0.5	1.0	1.9	3.8	7.0	14.9	3.51
Sub-Saharan Africa, West	Nigeria [10]	0.3	0.86		2.72		9.59	2.07

Final summary of estimated prevalence

Estimated prevalence for all those aged 60 years and over, standardised to the Western European population structure, can be compared directly between the 21 GBD regions (Figure 1.3). There is a four-fold variation in prevalence overall, from 2.07% (Sub-Saharan Africa, West) to 8.50% (Latin America). However, most of the estimated prevalence figures lie in a band between 5% and 7%. The major source of variation is clearly the very low estimated prevalence for the four Sub-Saharan African regions.

Figure 1.3
Estimated prevalence of dementia for those aged 60 and over, standardised to Western Europe population, by GBD region (%)



Estimation of numbers of people with dementia

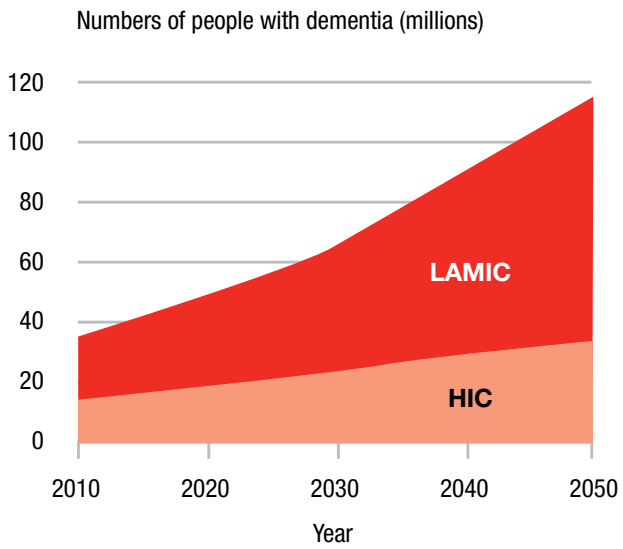
Having applied the age-specific, or age- and gender-specific prevalence estimates to the UN population projections (see method section for details), we estimate that 35.6 million people worldwide will be living with dementia in 2010 (Table 1.7 and Figure 1.4). This number will almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Much of the increase is clearly attributable to increases in the numbers of people with dementia in low and middle income countries (LAMIC) (Figure 1.4) – in 2010, 57.7% of all people with dementia live in LAMIC, rising to 63.4% in 2030 and 70.5% in 2050.

Our new estimates for 2020 (48.1 million) and 2040 (90.3 million) can be compared directly with those from the earlier *Lancet*/ADI consensus (42.7 million for 2020 and 82.0 million for 2040). The new estimates are approximately 10% higher.

Western Europe is the GBD region with the highest number of people with dementia (7.0 million), closely followed by East Asia with 5.5 million, South Asia with 4.5 million and North America with 4.4 million.

Our earlier projections for growth in the number of people with dementia indicated that world regions fell into three broad groups. Developed regions started from a high base, but would experience only a moderate proportionate increase. Latin America and Africa started from a low base but would experience a particularly rapid increase in numbers. India, China, and their south Asian and western-pacific neighbours started from a high base and would also experience a relatively rapid growth. A similar pattern is observed in our latest projections, these changes being driven mainly by population growth and demographic ageing (Table 1.7). Over the next twenty years 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

Figure 1.4
The growth in numbers of people with dementia in high income countries (HIC) and low and middle income countries (LAMIC)



rest of Latin America, and 125% in North Africa and the Middle East. Predictions of growth for Sub-Saharan Africa are now more modest, consistent with projections for demographic ageing in the light of persistent high child mortality and the effects of the HIV epidemic.

Table 1.7
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**

Conclusions and recommendations

Validity

With a large increase in the numbers of prevalence studies, particularly from low and middle income countries, it is now possible to rely less on expert opinion guided by scant research, and more on the direct evidence of the accumulated prevalence data. Having reviewed systematically the research evidence from community surveys, and applied strict inclusion and exclusion criteria, we were able to identify sufficient studies to carry out quantitative regional meta-analyses in 11 out of 21 WHO Global Burden of Disease regions. We were also able to supplement the previous *Lancet*/ADI estimates with data from well-conducted studies, which could be applied to the country concerned, and, where appropriate, to some of its regional neighbours.

Our new estimates suggest that the number of people with dementia worldwide was previously underestimated by around 10% (48.1 million for 2020 versus 42.7 million for the same year from the earlier *Lancet*/ADI estimates). The differences between the two sets of estimates are accounted for principally by:

- A sizeable increase (5.65% vs. 3.40%) in the estimated prevalence for South Asia, a region that includes the vast populations of India, Pakistan and Bangladesh and an estimated 125 million older people in 2010
- An important increase (7.29% vs. 5.92%) in the estimated prevalence for Western Europe, which with 97 million older residents in 2010 is the 2nd largest GBD region in terms of older population
- A modest increase (8.50% vs. 7.25%) in the estimated prevalence for the Latin American regions, with 52 million older inhabitants

These increases were partly offset by the reduction (4.98% vs. 6.46%) in the estimated prevalence for East Asia, which includes China, the world's most populous country, and 172 million older people.

We believe that these new estimates for these regions are likely to represent an improvement upon those provided earlier. We were able to include seven studies from South Asia, 52 from Western Europe, 34 from East Asia and 11 from Latin America in the regional meta-analyses. At the time of the *Lancet*/ADI estimates there was just one prevalence study available from Latin America [20]. The evidence base from China has been considerably extended by a recent systematic review that included data from a large number of publications previously only available in Chinese journals [17]. The *Lancet*/ADI estimates for South Asia were heavily, perhaps disproportionately, influenced by one large study, from rural Ballabgarh, Northern India, in which the prevalence was strikingly low [9]. The *Lancet*/ADI European estimates were strongly influenced by the results of two previous EURODEM reviews and their pooled analyses covering the periods 1980-1990 [48] and 1990-2000 [49]. Our current systematic review is much more comprehensive. Furthermore, our estimates for Europe also coincide with those derived from a recent systematic review of the European literature, limited to studies published since 1990, carried out by the European Collaboration on Dementia group (EuroCoDe) for Alzheimer Europe; the age- and gender-standardised prevalence for EuroCoDe was 7.1%, effectively identical to the 7.3% that we have estimated using a different methodology. EuroCoDe estimates 7.3 million people with dementia in the 25 European Union states.

Limitations

The main limitations of this exercise are:

- The poor coverage of the evidence-base in many world regions
- The poor relatively quality of many of the studies that were included in the review
- The heterogeneity (variability) of prevalence estimates between studies within regions

These are considered in detail below. It should also be noted that our projections for future growth in the numbers of people with dementia should be interpreted with particular caution. First, these relied on demographic statistics, which might not be accurate for many parts of the world, especially for older age groups. Second, we assumed that age-specific prevalence in each region would remain constant over time. Changes in risk exposure might increase or decrease incidence. Conversely, specific therapies and better social and medical care might reduce case mortality and increase prevalence. Disease modifying therapies that delay onset even to a modest extent would have considerable potential for reducing age-specific prevalence.

Coverage

The recent expansion of population-based research into dementia in China, Latin America and the Caribbean means that the coverage of the evidence-base for these regions is now as good as for Western Europe and North America. However, our systematic review has highlighted continued deficiencies in research evidence for several other regions. The

low estimated prevalence in Sub-Saharan Africa is influenced to a large extent by the evidence from the one good quality study to have been published from that continent [10]. The North Africa and Middle Eastern region includes as many older people as the whole of Sub-Saharan Africa combined, and with a much steeper projected increase in numbers; as yet, only one study from Egypt [47] and one from Turkey [39] were eligible for inclusion in the review. Eastern Europe (including Russia) and Central Asia remain essentially uncovered by research, and again, our estimates remain highly tentative. South East Asia is represented by 5 studies, but none from Indonesia whose 21 million older people account for two-fifths of the total for the whole region.

A key finding from this review has been that descriptive population-based research into dementia in high income countries peaked in the 1990s, and dropped off sharply since then. This is most regrettable, and very short-sighted. Prevalence can change over time, either because of changes in disease incidence (for example, because of improvements in cardiovascular health) or disease duration (reductions in dementia mortality associated with improved long-term care). Future policymaking and planning requires accurate up-to-date figures, and these are no longer available for most high income countries. Apart from tracking changes in disease prevalence and incidence, descriptive surveys can be used to estimate access to care, and the cost of health and social services provided for people with dementia. Again, these parameters will change over time, with increasing demand and supply. It may be that biomedical research funding agencies view such research as unoriginal, and hence uncompetitive when compared with population research orientated to elucidation of risk factors. Arguably, the responsibility for commissioning and funding such research should, increasingly, be devolved to government whose ministries and agencies will be the main clients for the data generated. Nationally representative surveys provide the best information for policymaking and planning; however, as yet only two countries, Canada [41] and the USA [26] benefit from such information. As with the USA ADAMS survey, dementia can usefully and efficiently be studied in a detailed add-on sub-study to an ongoing nationally representative survey of ageing and health (the Health and Retirement Survey).

Quality

The quality of prevalence studies, as assessed in this review, is a cause for concern, most particularly since the problems identified can all lead to biased, inaccurate estimates of prevalence and numbers. There are two main issues. The first relates to the procedures for making a diagnosis of dementia. This requires, as a minimum, a multidomain cognitive test battery, an informant interview, a structured disability assessment (which could form part of the informant interview) and a clinical interview to exclude other causes of cognitive impairment. Less than half of all studies met these standards, with the informant interview being most frequently omitted. Evidence from Europe, presented in the review, suggests that this omission might lead to an underestimate of dementia prevalence. Misapplication of study designs involving two or more phases was even more widespread. The correct procedures for designing, conducting and analysing such studies are very well established [50]. However, awareness among dementia researchers is low. Many among them, presumably, simply replicate the erroneous procedures adopted in other previous studies. This must change. Research funders have a duty not to fund research proposals, and ethics committees not to approve study designs, that are faulty in this respect. Journal editors should not accept for publication studies that were properly conducted until or unless weighting back has been applied in the analysis. Completed studies with faulty designs should still be published, but it should be clarified in the title, abstract, methods and discussion that the study is a study of the minimum prevalence of dementia. In fact, our analysis of European studies indicates that two phase designs tend if anything to overestimate the prevalence of dementia with respect to one phase designs. This tendency, which has also been noted in a previous analysis of methodological effects on prevalence [51], is likely explained by a generic problem with two phase studies: attrition between the first (screening) and second (diagnostic) phases. It seems likely that those with dementia may be selectively more likely to participate, hence producing a biased overestimate of prevalence. This effect can be minimised by keeping the delay between the two phases to a minimum. It may also be possible to examine the likely size and direction of the effect of non-response.

Heterogeneity

A fundamental assumption, implicit in the modelling approach in this review, was that the prevalence of dementia was uniform within GBD regions. This could then be estimated from the available evidence and applied to all countries in that region. In fact, and contrary to some previous suggestions [52], we observed statistically significant heterogeneity of

age- and gender-specific prevalence in almost all regions. In many ways, this is not surprising given the varied languages, cultures, levels of development, and demographic compositions of the national and sub-national units that make up a GBD world region. Indeed, despite the statistical significance of the heterogeneity, arguably one should be more impressed by the similarity rather than the differences in prevalence between studies. Furthermore, our analysis of Western European studies indicated, that, for that region at least, methodological factors, that is differences in the way that studies were designed and conducted, might have accounted for more of the observed variability than country or region effects. Methodological variability can be reduced through standardisation of study procedures. Common sense indicates that the way in which the diagnosis of dementia is defined and applied may be among the most important sources of variability. DSM-IV criteria, the most widely applied dementia diagnosis, is not, in fact, fully operationalised, although it is possible to do this [53]. It would be desirable to reach an international consensus regarding what constitutes cognitive impairment, what constitutes social and occupational impairment, and how these should be measured. Of course, due allowance would have to be made for necessary cultural adaptations. Clinicians, understandably, resist the degree of straitjacketing that full operationalisation imposes. A parallel set of more specific research diagnostic criteria would therefore be helpful.

Implications for future public health and social policy

We believe that the detailed estimates contained in this paper constitute the best currently available basis for policymaking, planning and allocation of health and welfare resources.

In high income countries, numbers of people with dementia will continue to grow, particularly among the oldest old. As we shall see in the later sections of this report, the provision and financing of measures to meet their long term care needs, including support for their family carers, is becoming an increasingly urgent political priority. The health and social care needs of the large and rapidly growing numbers of frail dependent older people should also be a matter of great concern for policymakers in low and middle income countries. If government policies are well formulated and planned with the projections described in this paper in mind, the inevitable shift of resource expenditure towards older people can be predicted and its consequences mitigated [1]. If, as seems likely, early and late life patterns of morbidity and mortality converge with those of the developed west, then dementia prevalence levels will do likewise. The implication is that our projections of rates of growth in the numbers of people with dementia in developing regions (based on an assumption of constant prevalence) may turn out to be conservative.

Efforts to improve the quality and availability of care, and to seek a cure, should be coupled with urgent investment in primary disease prevention measures. More research is required to identify modifiable risk factors. In the meantime, primary prevention should focus upon targets suggested by current evidence: risk factors for vascular disease, including hypertension, smoking, type II diabetes and hyperlipidaemia. In comparison with the situation in most high income countries, efforts to prevent and control the coming epidemic of cardiovascular and other chronic diseases in low and middle income countries are in their infancy [54]. Advocated measures include the implementation of tobacco-free policies, taxation of tobacco products, comprehensive bans on advertising of tobacco products, salt reduction through voluntary agreements with the food industry, and combination drug therapy for those at high risk of cardiovascular disease [54]. The detection and control of hypertension, hyperlipidaemia, diabetes and metabolic syndrome is poorly implemented by overstretched primary care services that struggle to cope with the double burden of historic priorities (maternal, child and communicable diseases) and the rising tide of chronic disease in adults. Health systems are not trained, equipped or structured to deal with the latter. Given the strong evidence for cardiovascular disease and cardiovascular risk factors as risk factors for dementia, the success or otherwise of these initiatives should in principle have an important impact on the future prevalence and incidence of dementia worldwide [6].

Future directions

Efforts need to be made in all regions to monitor secular trends in incidence and prevalence of dementia associated with the epidemiological transition, and with changes in medical and social care. The estimates contained in this report will now be updated regularly in future World Alzheimer Reports. The current evidence base provides a strong baseline, which will yet be improved as more evidence accumulates from currently underrepresented regions. Most importantly, using the methods illustrated in this chapter, we will be able to monitor the progress of the dementia epidemic in all world regions. For Western

Europe, we did not find evidence for a consistent progressive trend in prevalence over time. There is a suggestion from China that prevalence in that country may be increasing in recent years [17], and we will seek to confirm this in future reports, having accessed the original data from all published studies.

In the interests of transparency, and international scientific collaboration, all of the documentation for this review is made available at www.alz.co.uk/worldreport, including the data file with extracted study characteristics and prevalence data. We would be grateful for information regarding any omissions or errors.

Recommendations

- **More studies are required of the prevalence and incidence of dementia, to chart the course of the epidemic in high income and in low and middle income countries, and to allow policymakers to plan the need for services.**
- **Governments should play an increasing role in commissioning prevalence studies, to be repeated at regular intervals to monitor trends.**
- **Such studies would monitor the effectiveness of specific prevention measures and the likely impact of changes in health behaviours.**
- **The quality of prevalence and incidence studies needs to be improved. Researchers, research funders, and scientific journal editors all have a role to play.**
- **The large and rapidly growing numbers of people with dementia predicted for all world regions signifies the enormity of the challenge for global public health.**

Urgent action is required, to identify opportunities for effective disease prevention, and to ensure that all those with the condition have the opportunity to access affordable, effective care.

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World Alzheimer Report
Chapter 2

The impact of dementia

Len and Bette have been married for 63 years. He cared for her at home in Ohio, USA, for the first years of her cognitive difficulties, until her wandering and other problems led both the doctor and their children to urge an institutional placement. Len is consumed by her losses and his losses. 'I've left everything in the house the way it used to be as if she might come home. But in the long run I know it's not true. I've lost her. She's here but I've lost her. I'd give you my bronze star if you could bring her back.'

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The impact of dementia

The number of people worldwide living with dementia (Chapter 1) is an important indicator of the impact of the disease. However, numbers alone cannot convey a proper sense either of the quality of the individual experience or the wider consequences. The impact of dementia can be understood at three inter-related levels:

1 The person with dementia who experiences ill health, disability, impaired quality of life and reduced life expectancy

2 The family and friends of the person with dementia who, in all world regions, are the cornerstone of the system of care and support

3 Wider society, which, either directly through government expenditure, or in other ways, incurs the cost of providing health and social care and the opportunity cost of lost productivity. Other social impacts may be harder to quantify, but no less real.

The purpose of this section of the report is to provide information about the contribution of dementia to disability, mortality and dependency, and, at the societal level, to economic costs. The extent and nature of the care provided for people with dementia and the impact of providing care upon their carers are also assessed. Two themes run throughout this section. First, the effects of dementia are compared with those of other important chronic diseases, taking account, where possible, of the frequent comorbidity between physical, mental and cognitive disorders. Second, given that most of the detailed information regarding the impact of dementia has come from research carried out in high income countries, newly available data from the 10/66 Dementia Research Group's population-based studies in Latin America, India and China [(1)] is now presented alongside.

The 10/66 Dementia Research Group's population-based studies

Alzheimer's Disease International's 10/66 Dementia Research Group has conducted population-based surveys (2003-2007) of dementia prevalence and impact in 14 catchment areas in 10 low and middle income countries (India, China, Nigeria, Cuba, Dominican Republic, Brazil, Venezuela, Mexico, Peru and Argentina) [(1)]. New studies are also underway in Puerto Rico and South Africa. China, India, Peru, Mexico and Argentina recruited from separate urban and rural catchment areas; the other centres included urban catchment areas only. Cross-sectional, comprehensive, one phase surveys have been conducted of all residents aged 65 and over of geographically defined catchment areas in each centre with a sample size of between 1000 and 3000 (generally 2000) in each of the ten countries. Each of the studies uses the same core minimum data set with cross-culturally validated assessments (dementia diagnosis and subtypes, mental disorders, physical health, anthropometry, demographics, extensive non communicable disease risk factor questionnaires, disability/functioning, health service utilisation, care arrangements and carer strain). The net result is a unique resource of directly comparable data, comprising 19,000 older adults from three continents. A publicly accessible data archive has been established as a resource for the academic and policy community. Nested within the population-based studies is a randomised controlled trial of a carer intervention for people with dementia and their families – 'Helping Carers to Care'. The group is now engaged in an incidence phase with a 2.5 to 3 year follow-up of baseline participants in seven of the 10 countries (2007-2010).

DISABILITY, DEPENDENCY AND MORTALITY

1 The Global Burden of Disease report

Background

The World Health Organization's Global Burden of Disease (GBD) report, first published in 1996 and currently updated to 2004, provides important evidence on the relative impact of health conditions worldwide [2;3], influencing prioritisation for policymaking and planning nationally, regionally and internationally. The key indicator is the Disability Adjusted Life Year (DALY), a composite measure of disease burden calculated as the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). Thus, the DALY summarises the effects of disease, both on the quantity (premature mortality) and quality of life (disability). These effects are summed across estimated numbers of affected individuals to express the regional and global impact of disease.

Mortality, and dementia in the GBD

Dying one year before an optimal developed country life span entails the loss of one DALY. For the GBD report, the impact of individual conditions upon mortality is assessed through estimates of increased mortality risk. For dementia, those from the EURODEM incidence studies were used, which reported a constant relative risk of 2.38 up to age 89, declining to 1.80 in females and 1.60 in males over the age of 90. However, a systematic review of the literature on cognitive impairment, dementia and mortality has reported a slightly higher relative risk of 2.63 (95% CI 2.17-3.21) for the effect of dementia, and a dose response relationship between level of cognitive impairment and increasing mortality [4]. In the two studies of dementia and mortality carried out in LAMIC, the relative risks were somewhat larger; 5.16 in Brazil [5] and 2.83 in Nigeria [6]. In the UK, it has been estimated that the proportion of deaths attributable to dementia increases steadily from 2% at age 65 to a peak of 18% at age 85-89 in men, and from 1% at age 65 to a peak of 23% at age 85-89 in women [7]. Overall, 10% of deaths in men over 65 years and 15% of deaths in women were attributable to dementia. 59,685 deaths annually among the over 65s could have been averted if dementia were removed from the population.

Disability and dementia in the GBD

The effect of living for one year with disability depends upon the disability weight attached to the health condition concerned. In a wide consensus consultation for the Global Burden of Disease report, disability from dementia was accorded a higher disability weight (0.67) than that for almost any other condition, with the exception of severe developmental disorders [8]. This weight signifies that each year lived with dementia entails the loss of two-thirds of one DALY.

The global impact of dementia, according to the GBD

According to the latest available GBD figures, for 2004, dementia contributes 0.8% of all DALYs worldwide, 1.6% of Years Lived with Disability and just 0.2% of Years of Life Lost. Since dementia is mainly a disease of older people, the proportionate contribution is much greater among those aged 60 and over; 4.1% of DALYs, 11.3% of Years Lived with Disability and 0.9% of Years of Life Lost. A key finding from the Global Burden of Disease report is that chronic non-communicable diseases are rapidly becoming the dominant causes of ill-health in all developing regions except Sub-Saharan Africa [9]. It is important therefore to understand the contribution of dementia relative to that of other chronic diseases. Table 2.1 (overleaf) indicates the proportionate contribution of different chronic diseases to the total chronic disease burden among people aged 60 years and over, expressed in terms both of YLD and YLL. The same data is provided graphically in Figures 2.1 and 2.2.

The first thing to note is that the total YLL from chronic diseases (131.7 million years) is more than double the YLD (61.8 million years). Therefore, the way that the DALY is calculated (as the sum of YLDs and YLLs) implicitly gives a greater overall weighting to the burden arising from premature mortality, compared with the burden arising from living with chronic disability. Second, the relative contributions of the chronic diseases to disability and mortality are quite different. The three leading contributors to Years Lived with Disability among older people are blindness (21.5%), dementia (11.9%) and deafness (10.6%) – however, these are 12th, 8th and 13th respectively in the order of conditions contributing to Years of Life Lost. The three main contributors to Years of Life Lost are heart disease (32.9%), cancer (22.5%) and stroke (17.8%) – however, these are 8th, 9th and 4th respectively in the rank of disabling conditions.

Table 2.1
Relative contribution of different chronic diseases and conditions to the total global burden from chronic diseases, for those aged 60 years and over, expressed as years lived with disability and years of life lost

Chronic disease/ condition	Years lived with disability (YLD, millions) and % contribution to total chronic disease YLDs	Rank order (YLD)	Years of Life Lost (YLL, millions) and % contribution to total chronic disease YLLs	Rank order (YLL)
Blindness	13.3 (21.5%)	1	0.0 (0.0)	12
Dementia	7.4 (11.9%)	2	1.4 (1.1%)	8
Deafness	6.5 (10.6%)	3	0.0 (0.0%)	13
Stroke	6.2 (10.1%)	4	23.4 (17.8%)	3
Arthritis	5.8 (9.5%)	5	0.4 (0.3%)	10
Mental disorders	5.6 (9.1%)	6	1.7 (1.3%)	7
Digestive	3.4 (5.5%)	7	6.1 (4.6%)	4
Heart disease	3.3 (5.3%)	8	43.3 (32.9%)	1
Cancer	1.5 (2.5%)	9	29.6 (22.5%)	2
Diabetes	1.5 (2.5%)	10	4.9 (3.7%)	5
Genitourinary	1.1 (1.8%)	11	3.1 (2.4%)	6
Endocrine	0.5 (0.8%)	12	0.8 (0.6%)	9
Skin	0.4 (0.6%)	13	0.2 (0.2%)	11
Total chronic disease burden	61.8 (100%)		131.7 (100%)	

Figure 2.1
Contribution of chronic diseases to years lived with disability

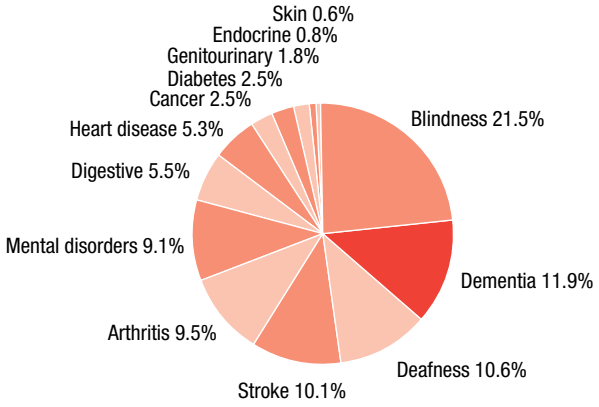
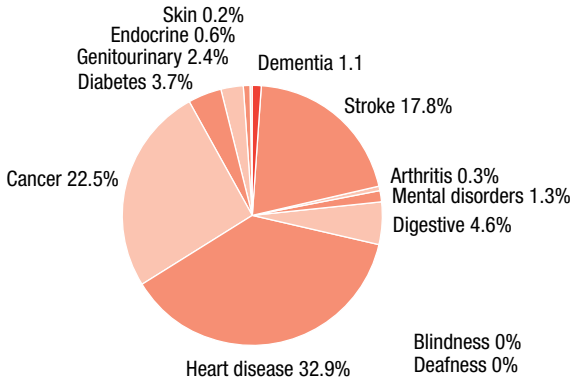


Figure 2.2
Contribution of chronic diseases to years of life lost



DISABILITY, DEPENDENCY AND MORTALITY

2 Other studies of disability and dependence

The GBD report indicates that dementia is one of the main causes of disability in later life. Of course, older people are particularly likely to have multiple health conditions – chronic physical diseases affecting different organ systems, coexisting with mental and cognitive disorders. These multiple pathologies will interact in complex ways to create difficulties in performing important tasks and activities (disability), and in determining needs for care (dependence). It is often said that dementia has a disproportionate impact on capacity for independent living. In developed countries, where institutionalised long-term care is widely available, the onset of cognitive decline is often the precipitant for institutional placement, whereas people with quite severe disabilities arising from physical impairment continue to be supported at home by community services. As many as three-quarters or more of nursing home residents have dementia [7], and estimates of the proportion of all people with dementia that live in residential care homes vary between one-third [7] and one half [10;11]. Given that people with dementia often have serious comorbid physical health problems, what is the independent contribution of dementia to disability and needs for care, relative to that of other conditions? This issue is not addressed by the Global Burden of Disease methodology, which assumes that the impact of different conditions can be estimated quite separately from each other, ignoring comorbidity.

The contribution of dementia compared with that of other chronic diseases to dependency and disability

HIGH INCOME COUNTRIES

There is an extensive literature from developed countries on the factors associated with institutionalisation among older people. In a comprehensive meta-analysis of 77 longitudinal community-based studies from the USA [12], cognitive impairment was by far the strongest health condition predictor of institutionalisation, increasing the risk two and a half fold (RR 2.54, 95% CI 1.43 to 4.51). In comparison, the increased risks associated with cancer (RR 1.15), hypertension (RR 1.04) and diabetes (RR 1.35) were modest, while there were no associations observed with cardiovascular disease, arthritis, or lung disease. There have been fewer good quality studies of the contribution of dementia and other conditions to disability. However, in the Canadian Study of Health and Aging, there was a clear and substantial excess disability attributable to dementia, having accounted for the effects of the major physical, mental and substance use disorders [13].

LOW AND MIDDLE INCOME COUNTRIES

In low and middle income countries, residential care is generally unavailable, and care is typically provided by family members, at home. In three recent publications, the 10/66 Dementia Research Group has assessed the impact of dementia, depression and physical impairment on dependence in Cuba [14], the Dominican Republic [15], and Nigeria [16]. Those with needs for care were characterised by comorbidity between dementia/cognitive impairment and physical and mental disorders [15;16]. The independent contributions of individual chronic diseases were assessed in multivariate Poisson regression models, calculating the population attributable prevalence fractions (PAPF), representing the proportion of dependence that could theoretically be avoided if the health condition could be removed from the population, taking into account its effect on both the incidence and duration of dependence, and assuming a causal relationship. In Cuba, dementia was by far the strongest correlate of dependence; those with dementia were 17.8 times more likely to be dependent on others; 65% of dependence in the population was attributable to dementia, compared with 23% attributable to physical impairment, and 2% attributable to depression [14]. In the Dominican Republic these proportions were for dementia 44%, for physical impairment 43% and for depression 16% [15]. In Nigeria, the effect of cognitive impairment was somewhat less (10%), and the effect of depression somewhat greater (29%), with respect to physical impairment (17%).

In the light of these findings, the 10/66 Dementia Research Group has carried out a more extensive analysis across all 10/66 study sites (urban sites in Cuba, Dominican Republic and Venezuela, and both rural and urban sites in Peru, Mexico, China and India), using a more detailed breakdown of chronic diseases, similar to that used in the GBD report. These included six diagnoses: dementia, depression, stroke, ischaemic heart disease, hypertension, and Chronic Obstructive Pulmonary Disease (COPD), and six self-reported physical impairments: weakness or loss of a limb, eyesight problems, stomach or intestine problems, arthritis or rheumatism, hearing difficulties or deafness, and skin disorders. The sample comprised nearly 15,000 participants, with representative samples of 1,000 to 3,000 people aged 65 years and over in each site. Poisson

regression working models were used to estimate the independent associations of each health condition with a) dependency and b) severe disability (15 or more disability days in the last month) in each study site, controlling for age, gender, education and all other health conditions. The population attributable prevalence fraction (PAPF) for each health condition was calculated, using the Stata aflogit command. A fixed-effects meta-analysis was used to summarise the associations across the sites by combining the site adjusted prevalence ratios, and by taking the means of the PAPFs. A formal test for between studies heterogeneity was performed. A summary of the results is provided in Table 2.2.

Dementia emerged as the leading independent cause of both disability and dependency, followed by limb weakness, stroke, depression, eyesight problems and arthritis. Neither ischaemic heart disease nor hypertension nor chronic obstructive pulmonary disease was associated with disability or dependency. Dementia was the only health condition to be consistently strongly associated with dependency in all sites, although the size of the association varied significantly from a prevalence ratio of 2.87 (1.83-4.51) in rural India to 9.46 (7.01-12.76) in Cuba. The rank orderings of the contributions of the different chronic diseases to dependence and severe disability observed in the 10/66 population-based surveys differ from those reported in the GBD (see Table 2.1). Dementia is relatively more important, and blindness and deafness less so. According to these findings, stroke and arthritis also would seem to merit a higher ranking, particularly since some of the impact of 'limb weakness' impairment almost certainly arises from these two diagnoses, which may have been under-reported.

Table 2.2
Associations between chronic diseases/impairments and dependence and disability, meta-analysed across 11 10/66 Dementia Research Group population-based study sites – Prevalence ratios (PR) and population attributable prevalence fractions (PAPF)

Chronic disease / impairment	Meta-analysed association with dependence, PR (95% CI)	Mean PAPF (SD)	Mean population attributable fraction (SD)	Mean population attributable fraction (SD)
Dementia	4.5 (4.0-5.1)	36.0% (11.0)	1.9 (1.8-2.0)	15.8% (11.7)
Limb paralysis/weakness	2.8 (2.4-3.2)	11.9% (13.2)	1.7 (1.6-1.9)	11.0% (10.5)
Stroke	1.8 (1.6-2.1)	8.7% (4.1)	1.4 (1.3-1.5)	5.8% (5.3)
Hypertension	0.9 (0.8-1.0)	6.6% (9.2)	1.1 (0.9-1.1)	9.2% (9.9)
Depression	1.7 (1.5-2.0)	6.5% (5.0)	1.4 (1.3-1.5)	3.9% (3.2)
Eye problems	1.2 (1.1-1.3)	5.4% (5.0)	1.1 (1.1-1.2)	6.6% (6.1)
Gastrointestinal problems	1.1 (1.0-1.3)	3.3% (5.3)	1.2 (1.1-1.2)	3.7% (4.6)
Arthritis	1.1 (1.0-1.3)	2.6% (2.5)	1.3 (1.3-1.4)	5% (7.9)
Hearing problems	1.1 (0.9-1.2)	1.4% (1.7)	1.1 (1.1-1.2)	0.9% (1.8)
Chronic Obstructive Pulmonary disease	1.1 (0.9-1.3)	0.8% (1.6)	1.0 (0.9-1.1)	2.5% (3.4)
Ischaemic heart disease	1.0 (0.9-1.2)	0.5% (1.0)	1.1 (0.9-1.2)	0.1% (0.3)
Skin diseases	1.1 (0.9-1.3)	0.4% (1.2)	1.2 (1.1-1.3)	0.5% (1.0)

Chronic diseases indicated in *italics* are those for which there was no statistically significant association with either/both dependence and disability. The population attributable fractions for these conditions should probably be ignored.

DISABILITY, DEPENDENCY AND MORTALITY

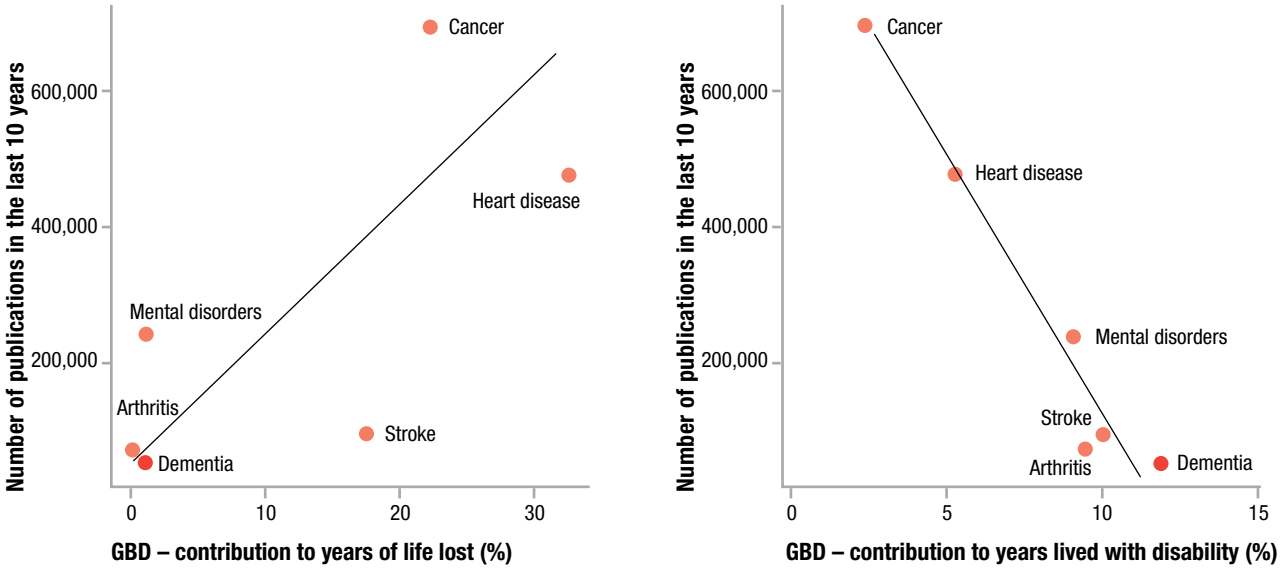
3 Adding years to life and life to years

As we have seen, different chronic diseases appear to have starkly different impacts on disability and mortality. Cardiovascular disease and cancer contribute much more to mortality than to disability. Successful interventions can add years to life. The impact of dementia is felt much more through years lived with disability. Interventions might prevent or delay disability, adding 'life to years'. In practice, how do policymakers and practitioners balance these priorities?

In the UK, much more is spent on healthcare for cardiovascular disease and cancer than on healthcare for dementia. The annual cost to the UK National Health Service (NHS) of treating coronary heart disease and hypertension has been estimated at £4.3bn. A further £2.3bn is spent treating stroke (Institute of Actuaries). The cost of cancer care in the UK has been estimated at £2.1bn [17], but this figure is low compared to international norms; 10% of all healthcare spend in the UK compared with an estimated 40% in the USA [17]. In the recent Dementia UK report the cost to the NHS of treating dementia was estimated to be just £1.4bn [7].

Another index of the priority accorded to different chronic diseases is the research effort that is contributed to each. In the USA, the National Institutes of Health report research expenditure in 2008 of $5.6bn on cancer, $2.0bn on cardiovascular disease, $0.3bn on stroke, and $0.4bn on dementia Internationally, research effort can be readily assessed through Index Medicus listed research publications. A search of PubMed/Medline for the last 10 years identified 701,876 publications related to cancer, 476,487 related to heart disease, 233,872 related to mental disorders, 87,973 related to stroke, 64,080 related to arthritis and just 44,168 related to dementia. The correlation between research effort (number of publications), mortality (years of life lost) and disability (years lived with disability) is presented in Figure 2.3. Clearly, there is an inverse correlation between the contribution of these chronic diseases to Years Lived with Disability and research effort. The more disabling the disease, the less it has been researched. Conversely, there is a strong positive correlation between years of life lost and research effort; the greater the disease contribution to mortality, the more it has been researched.

Figure 2.3
Correlation of research effort (publications in last 10 years) with contribution to mortality (years of life lost) and disability (years lived with disability), for six major chronic diseases



The family and other informal carers

All over the world, the family remains the cornerstone of care for older people who have lost the capacity for independent living. In developed countries with their comprehensive health and social care systems, the vital caring role of families, and their need for support, is often overlooked. In developing countries, the reliability and universality of the family care system is often overestimated [18;19].

Schulz [20] has defined caregiving as:

'…the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.'

Most research into caregiving in dementia is cross-sectional, capturing snap-shots in time. However, for carers and care recipients it is a long-term, evolving process with key transition phases, sometimes referred to as the caregiving 'career'. The onset of caring is often hard to define; it tends to emerge naturally from the customary family transactions, involving support given and received, that existed before the onset of dementia. The need for care may precede or post-date a formal diagnosis of dementia. Needs for care tend to escalate over time, from increased support for household, financial and social activities, to personal care, to what for some is almost constant supervision and surveillance. Important transitions include the involvement of professional carers, institutionalisation and bereavement.

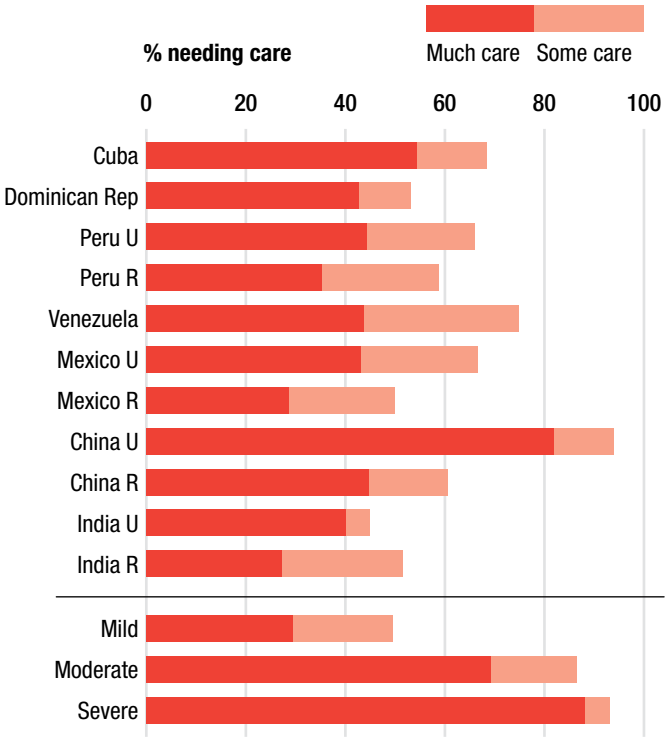
Who needs care?

According to most diagnostic definitions, all people with dementia experience at least some degree of functional disability. This does not imply that they should all be regarded as needing care. Needs for care were assessed by the interviewer for all participants in the 10/66 Dementia Research Group's population-based studies in Latin America, India and China; needs for care among those with dementia (CDR 1 or above) are summarized in Figure 2.4. In most sites, between 50 and 70% of those with dementia were rated as needing care, and most of those needing care needed 'much care'. Needs for care varied by level of dementia, with 30% of those with mild dementia, 69% of those with moderate dementia, and 88% of those with severe dementia needing much care.

Who are the carers?

The 10/66 Dementia Research Group's multicentre pilot study included 706 carers of people with dementia in Latin America, India and China [21]. The EUROCARE study included 280 spouse carers from 14 European countries [22]. In both studies, and across nearly all settings, most carers were women. In Europe, 85% or more of couples (one having dementia, the other being their carer) lived on their own, other than in southern European countries; Greece (60% of couples living on their own), Italy (40%) and Spain (69%). In contrast, people with dementia in the 10/66 pilot studies typically lived in large households, with extended families; one quarter to one half of households comprised three generations [21], including children under the age of 16 years. Both studies recruited convenience samples of people with dementia and their carers, which may not have been truly representative of the situation in the population as a whole. Living arrangements for people with dementia and the characteristics of their carers were also assessed in the 10/66 Dementia Research Group's population-based studies, where 1345 people with dementia were studied in 11 sites in Latin America, China and India. These data are summarised

Figure 2.4
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)
U = Urban R = Rural



in Table 2.3. Living alone, or with a spouse only was very uncommon – the norm was to be living with adult children and/or children-in-law, often also with children under the age of 16. However, in urban China over a third of people with dementia lived with their spouse only. In all sites other than rural China, the overwhelming majority of carers were women, usually daughters or daughters-in-law caring for a parent. Only in China was the spouse quite commonly identified as the main carer.

In many developing countries traditional family and kinship structures are widely perceived as under threat from the social and economic changes that accompany economic development and globalisation [18]. Several trends are in operation:

1 The education of women and their increasing participation in the workforce (generally seen as key positive development indicators), tending to reduce their availability for caregiving and their willingness to take on this additional role.

2 Migration; populations are increasingly mobile as education, cheap travel and flexible labour markets induce children to migrate to cities and abroad to seek work. In India, Venkoba Rao has coined an acronym to describe this growing social phenomenon – PICA, Parents in India, Children Abroad.

3 Declining fertility in final stage of the demographic transition. Its effects are perhaps most evident in China where the one-child family law leaves increasing numbers of older people, particularly those with a daughter, bereft of family support.

4 In Sub-Saharan Africa, the HIV/AIDS epidemic has 'orphaned' parents as well as children.

It is important to recognise that, as well as the main carer, other family members and friends are often routinely involved in providing dementia care. Thus, in the 10/66 Dementia Research Group population-based studies (Table 2.4), one fifth to one third of main carers acknowledged receiving substantial additional help from other unpaid carers. In several sites, paid carers also played an important role. This was particularly the case in urban Peru and urban China, where it seemed that rather than giving up or cutting back on work to provide hands-on care, the main family carer took a more organisational role and hired a paid carer to provide cover.

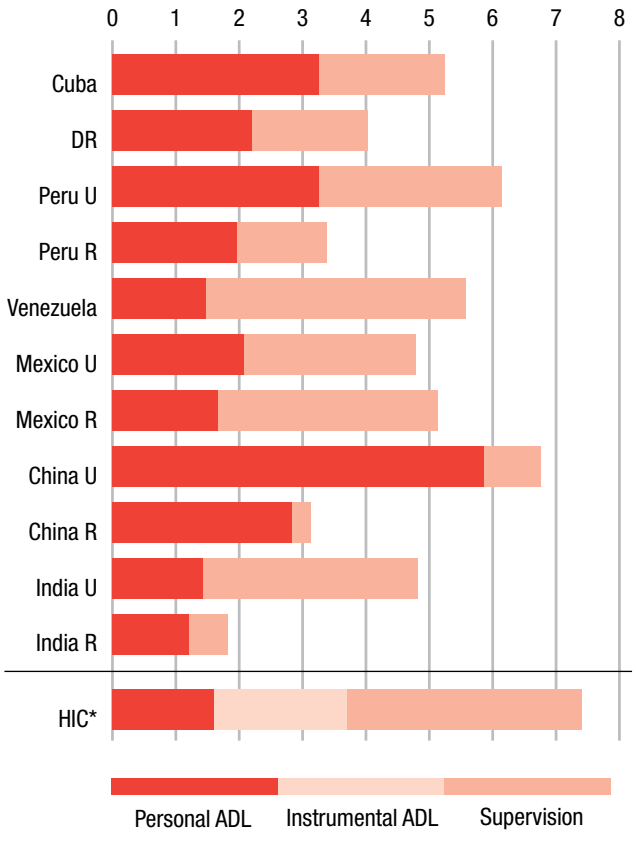
Table 2.3
Household living arrangements, and characteristics of the main carer for people with dementia in 11 sites in Latin America, China and India. (10/66 Dementia Research Group population-based studies – data release 2.2)

10/66 DRG study site	n	Household living arrangements				Characteristics of the main carer			
		Alone	Spouse only	Adult children	One or more children under the age of 16	Spouse	Child or child-in-law	Non-relative	Female carer
Cuba	316	6.3%	10.2%	54.7%	33.7%	17.3%	67.7%	5.8%	80.0%
Dominican Republic	235	8.5%	10.2%	48.5%	39.9%	21.4%	44.6%	11.6%	81.3%
Venezuela	140	5.7%	4.9%	68.1%	53.8%	13.7%	68.4%	2.8%	80.7%
Peru (urban)	129	1.6%	9.4%	54.3%	27.1%	13.0%	41.6%	30.1%	83.7%
Peru (rural)	36	13.9%	8.3%	63.9%	38.9%	16.7%	58.4%	2.8%	86.1%
Mexico (urban)	86	14.0%	9.3%	55.8%	38.4%	5.8%	79.1%	3.5%	83.7%
Mexico (rural)	85	16.5%	11.1%	55.3%	31.8%	12.9%	68.2%	2.4%	76.5%
China (urban)	81	2.5%	34.5%	38.3%	7.4%	36.1%	47.3%	13.9%	66.7%
China (rural)	56	3.6%	8.9%	75.0%	60.7%	42.9%	57.1%	0%	35.7%
India (urban)	75	4.0%	13.3%	72.0%	49.2%	26.7%	40.0%	0%	69.3%
India (rural)	106	15.1%	5.7%	67.0%	52.8%	23.3%	70.0%	0%	80.2%

Table 2.4
Additional care inputs reported by carers of people with dementia in 11 sites in Latin America, China and India (10/66 Dementia Research Group population-based studies – data release 2.2)

Site	n	Main carer cut back on paid work to care	Additional unpaid care	Paid day-time care	Paid night-time care
Cuba	316	19.2%	27.5%	7.9%	1.9%
Dominican Republic	235	14.1%	20.0%	9.9%	7.7%
Venezuela	140	14.2%	36.9%	8.4%	2.1%
Peru (urban)	129	6.2%	27.1%	22.5%	15.6%
Peru (rural)	36	11.1%	19.4%	2.8%	2.8%
Mexico (urban)	86	12.8%	33.7%	2.4%	1.2%
Mexico (rural)	85	11.8%	21.2%	1.2%	0%
China (urban)	81	6.1%	7.4%	46.9%	45.7%
China (rural)	56	30.4%	14.3%	0%	0%
India (urban)	75	14.7%	6.7%	0%	0%
India (rural)	106	10.3%	19.8%	0%	0%

Figure 2.5 **Mean daily hours of personal ADL care and supervision provided by carers of people with dementia in high income and low and middle income countries (10/66 Dementia Research Group population-based studies, data release 2.2)** U = Urban R = Rural



* Estimates from Wimo et al (23) systematic review, almost entirely from high income country (HIC) studies

What care is provided?

The nature of the care provided for people with dementia can be classified into support with personal activities of daily living (PADL – including washing, dressing, grooming, toileting, eating), instrumental activities of daily living (IADL – cooking, shopping, laundry, household finances), and general supervision. A recent review of the literature [23] identified 27 studies, overwhelmingly from high income countries, that provided information on time spent caring. Carers of people with dementia spent an average of 1.6 hours daily assisting with core PADL. Including time spent assisting with IADL increased this figure to 3.7 hours, and when general supervision was also taken into account the average care input was 7.4 hours per day.

The mean daily hours of PADL care and supervision provided by carers of people with dementia in the 10/66 population-based survey are summarised in Figure 2.5.

These estimates from 10/66 Dementia Research Group low and middle income countries were certainly no lower, and if anything a little higher, for personal care than those suggested by the earlier review of high income country studies [23]. The average figures encompass a good deal of intra-individual variation. Further analysis indicates that the severity of dementia is the strongest predictor of hours of PADL support, which increased from an average of 2.3 hours for mild dementia to 7.1 hours for severe dementia.

What are the consequences of caregiving?

The negative consequences of caregiving have been widely studied. It is important to remember that most family and friends involved in providing informal care take pride in their role, and perceive many positives. In Canada, 80% of a nationally representative sample of carers of people with dementia were able to identify positive aspects when asked to do so [24]. These included companionship (23%), fulfillment (13%), enjoyment (13%), providing quality of life (6%) and meaningfulness (6%). Nevertheless, carers of people with dementia also experience high levels of strain, psychological morbidity and, possibly, impaired physical health.

Carer strain

Carer perceptions of strain are often assessed using the Zarit Burden Interview (ZBI) [25-27] with 22 items that assess the carer's appraisal of the impact their involvement has had on their lives, including questions such as; 'Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?' and 'Do you feel strained when you are around your relative?'. In the USA, more than 40% of family and other unpaid carers of people with dementia rate the emotional stress of caregiving as high or very high. Interestingly, in low and middle income countries [28], while being part of a large household attenuated slightly the strain experienced by the main carer, traditional extended family care networks provided little protection; levels of carer strain were, in general, still as high as those seen in the European EUROCARE project [22].

The main factors consistently found to be associated with carer strain are highlighted in Table 2.5.

PSYCHOLOGICAL MORBIDITY

Many studies have reported very high levels of psychological morbidity among carers of people with dementia, 40% to 75% in EUROCARE [22], with the same range of prevalence observed in 21 of the 24 10/66 pilot centres [28]. A recent systematic review identified 10 studies that assessed the prevalence of major depressive disorder among carers of people with dementia using structured clinical interviews, which varied between 15 and 32% [29]. In six of these studies the prevalence of major depression was compared with that in a control sample, with the

Table 2.5
Factors found to be associated with carer strain, among carers of people with dementia

The carer	
Demographic factors	Female carers Spousal carers, particularly those of younger people with dementia Carers living with the care recipient Carers with low incomes or financial strain
Personality	High level of neuroticism High expressed emotion
Perception and experience of caregiving role	A low sense of confidence by the carer in their role High 'role captivity' – carers feeling trapped in their role
Coping strategies	Emotion-based or confrontative coping strategies
The person with dementia	
Dementia type	Frontotemporal dementia (FTD)
Severity	Behavioural and psychological symptoms of dementia – particularly apathy, irritability, anxiety, depression, delusional beliefs Cognitive impairment is not usually associated with carer strain
Relationship factors	
Intimacy	Poorer relationship quality Low levels of past and current intimacy

prevalence in carers being 2.8 to 38.7 times higher. The many studies comparing depression symptoms between carers and non-carers have also been meta-analysed, and show a fairly consistent and significant tendency towards higher symptom levels among carers [30]. The difference is larger for studies of dementia carers compared with studies of mixed groups or people caring for those with physical disorders.

PHYSICAL HEALTH

It has also been suggested that the prolonged stress and physical demands of caregiving, coupled with the biological vulnerabilities of older carers may increase their risk for physical health problems [20]. There is some evidence for small decrements in subjective and objective physical health [30] and impaired immunity [31]. One study shows an increased risk of mortality confined to carers who experience strain [32].

Independent effects of dementia, compared with other chronic diseases, on carer strain

The main weakness of the carer research literature is the widespread use of unrepresentative convenience samples, accounting for the overwhelming majority of studies to date. Carers selected for such studies, often through carer associations and service contacts, may well have experienced atypically high levels of strain. There is evidence that the extent of the excess depression seen in carers may have been overestimated in convenience, as compared with representative samples. In the 10/66 Dementia Research Group sites, where representative samples were studied, the prevalence of psychological morbidity was consistently higher among carers of people with dementia than among co-residents of older people (Table 2.6). In most sites, one fifth to one third of carers had significant psychological morbidity. The prevalence of psychological morbidity was much lower in China; however, it is well recognised from general population surveys that Chinese participants tend to have low levels of reported psychological symptoms, using western assessments.

As reported earlier in this report, dementia makes the largest independent contribution of any chronic disease to dependence (needs for care). There is also evidence to suggest that, among older people needing care, caring for a person with dementia compared with caring for older people with physical health conditions places greater demands on the carer and leads to more strain. Thus, in the 10/66 Dementia Research Group studies in the Dominican Republic and Nigeria, those with cognitive impairment or dementia [15] had greater overall needs for care, particularly core ADL support, and their carers were

Table 2.6
The prevalence of psychological morbidity among co-residents of older people with and without dementia, and among carers of older people with dementia who needed care. (10/66 Dementia Research Group population-based studies data release 2.2)

10/66 DRG study site	The prevalence of psychological morbidity (an SRQ score of 8 or more) among carers/co-residents of:					
	all older people free of dementia		all older people with dementia		older people with dementia needing care	
	n		n		n	
Cuba	2615	8.6%	316	22.5%	175	24.9%
Dominican Republic	1776	17.0%	235	28.5%	106	30.1%
Venezuela	1824	6.9%	140	19.1%	92	19.8%
Peru (urban)	1250	15.4%	129	47.3%	77	53.2%
Peru (rural)	516	10.9%	36	58.3%	12	75.0%
Mexico (urban)	917	11.3%	86	23.3%	48	22.9%
Mexico (rural)	915	9.1%	85	16.5%	27	33.3%
China (urban)	1079	1.3%	81	2.5%	72	2.8%
China (rural)	946	0.2%	56	1.8%	28	3.6%
India (urban)	930	2.2%	75	8.0%	15	20.0%
India (rural)	893	9.2%	106	9.4%	30	16.7%

more likely to report strain. Similar findings were reported from the National Caregivers Survey in the USA [33], where, additionally, carers of people with dementia were also more likely to report giving up their vacations or hobbies, having less time for their family, having more family conflicts and work-related difficulties. In the meta-analysis of the effects of caregiving on depression in the carer, differences in depression symptom levels between carers and controls were larger for those studies in which the carers all cared for a person with dementia compared with those where the carer group was mixed or consisted only of people caring for those with physical disorders [30].

This issue is further examined here using data from the 10/66 Dementia Research Group population-based studies to assess the independent effect of dementia, depression, stroke and physical impairment upon carer/co-resident psychological morbidity. The same analytical approach (multivariate Poisson working models and meta-analysis across sites) as previously described was used to assess and compare the independent effects of different chronic diseases on disability and dependency (see page 52 for details). Results of these analyses are summarized in Table 2.7.

In almost all sites, after adjusting for the effects of stroke, depression and physical impairment, there was a strong and statistically significant association between the presence of dementia in the older person and risk for psychological comorbidity in the carer/co-resident. The pooled estimate across sites suggested that the carer/co-resident was twice as likely to have significant psychological morbidity in the presence of dementia. The effect of dementia on the carer's mental state was partly but not entirely explained by the older person's needs for care – after adjusting for either disability or dependence the pooled effect was reduced to 1.5 (95% confidence intervals 1.3-1.8). Physical impairments, stroke and depression were also each independently associated with carer/co-resident psychological morbidity. In fact, physical impairments made the largest contribution (mean population attributable prevalence fraction 18%) followed by dementia (10%), depression (8%) and stroke (3%). Taken together, the chronic disease health state of the older person accounted for a remarkable 30% of the prevalence of psychological morbidity in their carers/co-residents.

Table 2.7
The independent effect of dementia upon carer/co-resident psychological morbidity meta-analysed across 11 10/66 Dementia Research Group population-based study sites – Prevalence ratios (PR) and population attributable prevalence fractions (PAPF) (data release 2.2)

10/66 Dementia Research Group population-based study sites	Adjusted* prevalence ratio for the association between dementia in the older person and psychological morbidity in the carer/co-resident		Population attributable prevalence fraction (95% confidence intervals)	
Cuba	2.1	(1.6-2.8)	13%	(8-17%)
Dominican Republic	1.1	(0.8-1.5)	1%	(0-6%)
Peru (urban)	2.3	(1.7-3.1)	14%	(11-17%)
Peru (rural)	4.2	(2.7-6.4)	22%	(16-27%)
Venezuela	1.9	(1.2-3.1)	6%	(1-11%)
Mexico (urban)	1.9	(1.1-3.1)	9%	(3-15%)
Mexico (rural)	2.0	(0.9-4.3)	8%	(0-16%)
China (urban)	1.2	(0.2-6.8)	1%	(0-19%)
India (urban)	2.6	(0.9-7.3)	14%	(0-31%)
India (rural)	1.6	(0.8-3.2)	5%	(0-10%)
Pooled meta-analysis				
Meta-analysed estimate	2.0	(1.7-2.3)	10	(mean)

* Adjusted for stroke, depression, physical impairment in the older participant, and for participant's and co-resident's age, gender, education, marital status and household assets

The cost of dementia

The economic costs of dementia are enormous. These can include the costs of:

a) 'formal care' – health care, social/community care, respite and long-term residential or nursing home care

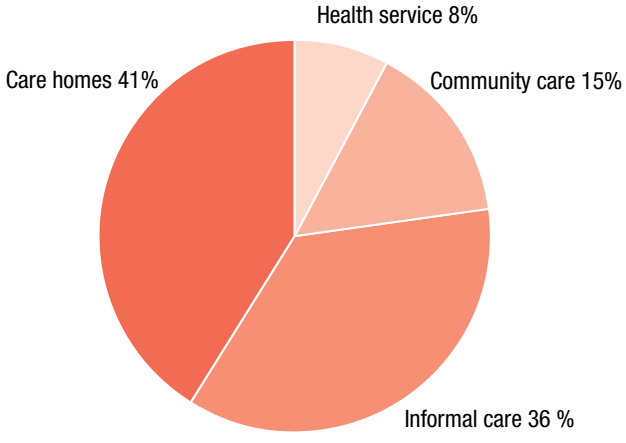
b) 'informal care' – unpaid care by family members or others including their lost opportunity to earn income

The cost of dementia in high income countries

There have been many studies of the cost of dementia in high income countries. For example, 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. The breakdown of this total cost is illustrated in Figure 2.6 below.

Informal care accounts for just more than one third of the total. The single largest cost driver is 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 account 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 carers and specialist medical care arises, then so the direct social and healthcare costs will increase. Thus, in the United Kingdom the average annual cost per person with dementia was estimated as £25,472. This varied from £14,540 for a person with mild dementia living in the community (where informal care makes the largest contribution) to £20,355 for a person with moderate dementia living in the community, to £31,263 for a person with dementia living in a care home.

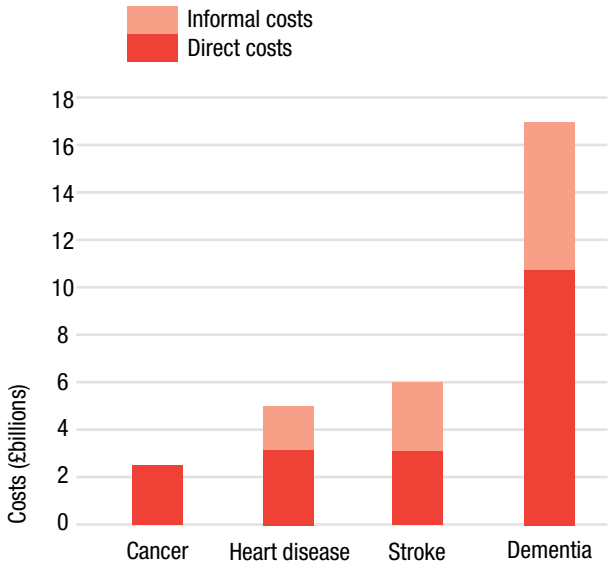
Figure 2.6
The breakdown of the total annual cost of dementia (£17 billion) in the United Kingdom [7]



The cost of dementia relative to that of other chronic diseases

How does the cost of dementia compare with the cost of other chronic health conditions? Lowin et al estimated the societal costs of dementia (£7.1-14.9 billion), stroke (£3.2 billion), heart disease (£4.1 billlion) and cancer (£1.6 billion) in the United Kingdom for 1998-1999 [34]. We have updated these estimates by using the latest Dementia UK estimates for the cost of dementia [7], more recent data for the direct (healthcare costs) arising from cancer [17], and for the direct and indirect costs of ischaemic heart disease and stroke [35]. The results are summarised in Figure 2.7 below. Note that the cost of informal care for people with cancer is not available; however, it is anticipated that this would be relatively modest. Also, the costs of lost productivity arising from disability and mortality from heart disease and stroke have not been included as no such calculations had been carried out for dementia. If lost productivity were included, this would have added another £3.9 billion to the annual cost of heart disease and another £2.2 billion to the annual cost of stroke. Regardless, it is clear that the annual societal cost of dementia in the UK (£17.0 billion) far exceeds the societal costs of

Figure 2.7
The comparative societal costs of cancer, ischaemic heart disease, stroke and dementia in the United Kingdom



cancer, heart disease or stroke. Indeed, the cost of dementia exceeds the combined cost of cancer, heart disease and stroke (£13.8 billion) and almost equals the total cost for these three conditions when lost productivity is included (£19.9 billion).

The cost of dementia in low and middle income countries

Very little 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 [36]. 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 people with dementia [37]. In Turkey, only 1% of older people live in residential care, therefore families provide most of the care. The average annual cost of care (excluding hospitalisation) was US$1766 for mild dementia and US$4930 for severe dementia. While most costs increased with the severity of the disease, out-patient costs declined. In Argentina [38], the annual direct costs of the disease increased with disease severity, from US$3420 in mild to US$9658 in severe Alzheimer's disease, and with institutionalisation (US$3189 for community dwelling and US$14,448 for institutionalised). Most direct costs were paid for by the family. The 10/66 Dementia Research Group has also examined the economic impact of dementia in its pilot study of 706 people with dementia, and their carers, living in Latin America, India, China and Nigeria [21]. One of the key findings from this study, from the development perspective, was that caregiving in the developing world was associated with substantial economic disadvantage. As shown in the 10/66 population-based studies (Table 2.4, page 56), a high proportion of carers had to cut back on their paid work to care, and paid carers were also relatively common. People with dementia were heavy users of health services, and associated direct costs were high [21]. Compensatory financial support was negligible; few older people in developing countries receive government or occupational pensions, and virtually none of the people with dementia in the 10/66 study received disability pensions [21]. Very similar findings, with further evidence of economic vulnerability, have now been reported with new and representative data from the 11 sites in the 10/66 Dementia Research Group population-based studies [39] (Table 2.8). Alarmingly high rates of food insecurity (people with dementia going hungry through lack of resources to purchase food) were seen in the Dominican Republic, rural Peru and rural Mexico and in both Indian sites. These sites were all characterised by low pension coverage and high reliance on family transfers.

Table 2.8
Income security for older people with dementia in the 10/66 Dementia Research Group population-based studies (data release 2.0) [39]

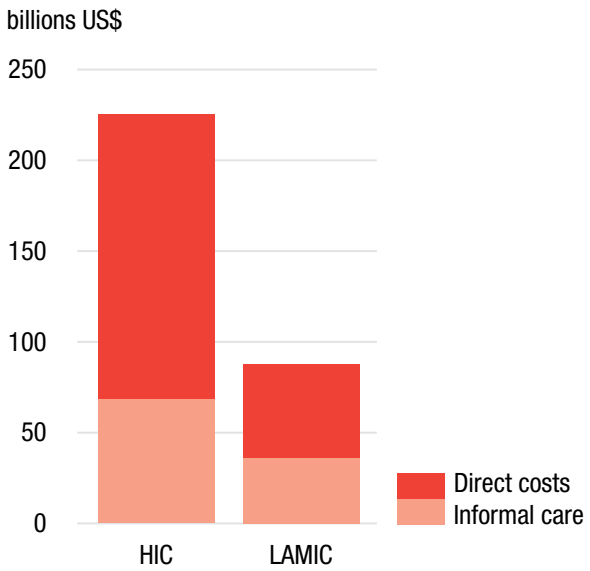
Population-based centre catchment area	n	Income security			
		Receiving a government or occupational pension	Receiving income from family transfers	Receiving a disability pension	Experiencing food insecurity
Cuba	323	81.4%	7.4%	0.9%	5.6%
Dominican Republic	242	27.3%	23.6%	0.8%	13.7%
Venezuela	146	41.1%	2.7%	4.1%	2.7%
Peru (Urban)	130	58.5%	5.4%	1.1%	1.6%
Peru (Rural)	36	66.7%	0.0%	0.0%	8.6%
Mexico (Urban)	93	78.5%	7.5%	1.1%	3.2%
Mexico (Rural)	87	34.5%	17.2%	2.3%	12.6%
China (Urban)	84	84.5%	11.9%	0.0%	0.0%
China (Rural)	56	10.7%	23.2%	0.0%	3.6%
India (Urban)	75	13.3%	28.0%	2.7%	28.0%
India (Rural)	108	26.9%	44.4%	0.0%	17.6%

The combination of reduced family incomes and increased family expenditure on care is obviously particularly stressful in lower income countries where so many households exist at or near to subsistence level. Families from the poorest countries were particularly likely to have used expensive private medical services, and to be spending more than 10% of the per capita Gross Domestic Product on healthcare [21].

The global cost of dementia

A research group from Sweden's Karolinska Institute has attempted to estimate the worldwide cost of dementia [23;40;41]. This amounts to US$315 billion per year, of which US$227 billion (72% of the worldwide total) is contributed by high income countries (World Economic Outlook (WEO) advanced economies) and US$88 billion (28% of the total) by low and middle income countries (WEO emerging market and developing countries). The estimated breakdown of these costs is illustrated in Figure 2.8. It can be seen that informal (family) care is relatively more important in resource-poor countries, where there a few formal health or social care services available [42]. Indeed, when broken down further, informal care accounts for 56% of costs in low income countries, 42% in middle income countries, and just 31% in high income countries [41]. Costs per person with dementia ranged from US$1,521 for low income countries, to US$4,588 in middle income countries, and US$17,964 in high income countries.

Figure 2.8
The global societal cost of dementia in 2005, attributable to direct and indirect costs, in high income countries (HIC) and low and middle income countries (LAMIC), as estimated by Wimo et al [23]



Costs are rising fast in low and middle income countries [23], attributable to:

1 Rapid increases in numbers of people with dementia in those regions (Chapter 1)

2 Substantial increases in average wages, used to calculate the opportunity cost or replacement cost of informal care, and

3 Very high out of pocket healthcare costs reported from some middle income countries [38].

The Karolinska group have provided the best current estimates of worldwide cost, but based upon limited available data. The biggest limitation is the absence of information on direct costs in low and middle income countries. These therefore had to be estimated, by assuming a relationship between direct costs per person with dementia (which information is available from many high income countries) and per capita GDP (based on Purchase Power Parities (PPP)). As such, no distinction could be made between different elements of direct cost, particularly health versus social care costs. Furthermore, their review of the literature available at that time revealed very limited data on informal care inputs from low and middle income countries. These deficits will be remedied, to a large extent, by the inclusion of new data from the 10/66 Dementia Research Group's population-based studies, comprising use of a wide range of healthcare services with associated out of pocket costs, informal care from the main carer and additional carers, loss of work, and expenses on paid care [1]. Next year's World Alzheimer Report will feature revised, updated and much more detailed estimates of the cost of dementia worldwide and in different world regions, prepared in collaboration with Prof Wimo and his group from the Karolinska Institute.

Summary and conclusion

The Global Burden of Disease (GBD) report indicates that dementia is a leading cause of disability among older people, second only to blindness. However, dementia makes a smaller contribution to years of life lost, relative to cardiovascular disease and cancer. Overall, among people aged 60 years and over, dementia accounts for 4.1% of all Disability Adjusted Life Years (DALYs), 11.3% of Years Lived with Disability (YLDs) and 0.9% of Years of Life Lost (YLLs). In the Global Burden of Disease report the contribution of different diseases to disability is estimated using disability weights. In this year's World Alzheimer Report, we have reviewed findings from other studies that have assessed disability directly, and also presented results of new analyses from the 10/66 Dementia Research Group studies. These provide consistent evidence that dementia is, in fact, the single leading contributor to disability and dependency among older people.

The Global Burden of Disease estimates are currently undergoing a comprehensive review, the first since 1996. This process is likely to have important consequences for the absolute and relative burden of dementia. We will include a detailed analysis of the revised GBD estimates in a future World Alzheimer Report, as soon as these become available. The important changes are as follows:

1 The revised estimates will be founded on new systematic reviews of dementia prevalence, incidence and associated mortality. As described in Chapter 1, our review of prevalence indicates that prevalence and numbers of people with dementia may previously have been underestimated in several world regions. The reviews of incidence and mortality will be described in next year's World Alzheimer Report.

2 New disability weights will be calculated for all important health conditions, based on a much broader consensus including the general public and those affected by disease across many countries and cultures. Separate weights will be calculated for mild, moderate and severe dementia. The impact of these revised weights on Years Lived with Disability and Disability Adjusted Life Years is difficult to predict.

3 Age-weighting, by which years lived in old age (and childhood) were accorded a lower value than those lived in 'productive' adulthood, has proved controversial and is likely to be abandoned in the revised GBD. This would result in an increase in the contribution of dementia to GBD (and a decrease in some chronic midlife conditions, e.g. mental disorder).

Our report has 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. 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. Our 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, 14 times more dollars are spent on research into cancer, and 5 times more is spent on research into heart disease, than is spent on research into dementia. Worldwide, in the last 10 years, there were 16 times as many research publications on cancer, and 11 times as many on heart disease as there were on dementia. Healthcare expenditure is also skewed towards cancer and heart disease.

Does this make sense? Data presented in this report show that the total societal costs of dementia already far exceed those of cancer, heart disease or stroke. While the health care costs for dementia are 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 developed countries, institutional care homes. Clearly, the costs of chronic diseases to society are driven mainly by long-term disability and dependency. While governments may tend to regard family care as a 'free good', they do so at their peril. Families need and deserve support, and for this the state is the ultimate guarantor. In at least three domains, 'indirect' costs are likely to translate into increased 'direct' costs.

1 First, healthcare expenditure is lower than it should be; evidence-based interventions, including carer support and training, and respite care should be being routinely provided, but are not, even in high income countries.

2 Second, evidence suggests, in all parts of the world, that caring for a person with dementia is associated with substantial economic disadvantage and strain. When carers give up work to care, this means lost national productivity, and, for the family, a shrinking household budget. These families deserve to be compensated. Where disability pensions are provided, people with dementia should be eligible. Carer benefits, even when relatively modest, confer status on the carer and recognition for the valuable role that they perform.

3 Third, even when carers are properly supported, it seems likely that the need for high quality, cost-intensive community and institutional care will

continue to grow, and with it the direct costs of dementia care. This has certainly been the case in high income countries such as the United Kingdom and the USA, which were among the first to be hit by the coming epidemic of dementia. 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 [43]. 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 legislation states,

'old age has become a major social challenge and there is need to give more attention to care and protection of older persons. Many older persons . . . are now forced to spend their twilight years all alone and are exposed to emotional neglect and lack of physical and financial support'.

The Social Justice Minister, Meira Kumar said,

'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 for 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 carers. 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 1 April 2000, to implement a long-term care insurance plan entitling those eligible to services worth 365,400 yen a month (US$3,840), with the obligation of a 10% co-payment [44]. Despite initial public misgivings regarding its cultural appropriateness [44], the new system has proved popular with families and care-providing entrepreneurs alike [45].

Ultimately the major driver of the need for formal community and institutional care 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 Hong Kong and Macau); and from 9% to over 12% in India [46]. Under the most pessimistic scenario, by 2050 the dependency ratio will have reached 20% in China [46].

An adequate response to these challenges will require:

- Policies to prevent disability through the prevention and control of chronic diseases including dementia
- Policies to limit disability through more active community-based rehabilitation
- Policies to mitigate the effects of disability upon participation
- Policies to manage disability through universal access to long-term care

Such measures are already strongly advocated through international agreements. The Madrid International Plan for Action on Ageing (paragraph 90) calls for the maintenance of maximum function, and the fullest possible societal participation of older people with disabilities. The UN Convention on the Rights of People with Disabilities enshrines participation, income and access to healthcare as basic rights for all disabled people. 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 carers, and the eligibility for and the financing of this long-term care [47]. In practice, governments have not heeded this call, and relatively few, particularly low and middle income countries, have comprehensive policies and plans [48].

We hope that the information provided in this and future World Alzheimer Reports will help to promote understanding of the societal costs of dementia, in absolute terms and relative to the contributions of different chronic diseases. This should inform prioritisation – and, it is hoped, lead to a shift towards both primary prevention and universal access to good quality long-term care.

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World Alzheimer Report
Chapter 3

From recognition to action

Laughter and good moments are important for everyone, but are sometimes lacking for people with dementia This carer in an Alzheimer's unit in Kyoto knew how to bring good humour, laughter, and an elevation of mood to the people he worked with.

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From recognition to action

The demographic and economic analyses in chapters 1 and 2 demonstrate that dementia is an immense challenge for governments throughout the world. For high income countries there is a need to provide accessible, affordable and good quality services that meet the needs and expectations of people with dementia and their families. In addition, for low and middle income countries there is the opportunity not to repeat the mistakes of high income countries that have become over dependent on institutional care.

Described here are the practical steps that governments can take in response to the growing numbers of people with dementia worldwide [1]. The challenges facing all governments are substantial. However, for low income countries and their governments the challenges are much greater. We therefore propose a graduated or stepped approach to policy and service development in accordance with the principles of the Global Alzheimer's Disease Charter which was adopted by Alzheimer's Disease International in 2008.

The following assumptions have been made:

- The number of people with dementia will grow substantially in line with the increases in life expectancy throughout the world for the foreseeable future (see Chapter 1)
- Only a small proportion of people with dementia receive a diagnosis [2]
- Support and services for people with dementia and their family carers should be provided equitably
- Few governments are fully prepared to face the economic and social consequences (see Chapter 2) of the number of people with dementia [3]
- Recognition by WHO and national governments that the growing number of people with dementia is an extremely serious problem will be the vital first step to taking global action

Global Alzheimer's Disease Charter

The following six principles should be adopted to make Alzheimer's disease and other dementias a global priority:

1 **Promote awareness and understanding of the disease**

2 **Respect the human rights of people with dementia**

3 **Recognise the key role of families and carers**

4 **Provide access to health and social care**

5 **Stress the importance of optimal treatment after diagnosis**

6 **Take action to prevent the disease through improvements in public health**

Alzheimer's Disease International

Context

Perceptions of the diseases and illnesses with the greatest mortality, premature death, morbidity and disability are changing. While a recent analysis of WHO's budget [4] found that 'allocations were heavily skewed toward infectious diseases' in 2006-07, other studies show that the impact of chronic, non-communicable disease is becoming recognised. For example, in China the declining death rates for infectious diseases, pneumonia and perinatel disorders have been compared with the rising rates for lung cancer, cerebrovascular illnesses, coronary heart disease and diabetes [5]. This is acknowledged in WHO's 2008-2013 Action Plan for the global strategy for the prevention and control of noncommunicable diseases [6].

This has to be considered against a background of many countries allocating a relatively small proportion of their GNP for healthcare expenditure and of health inequalities within countries. Table 3.1 shows not only the disparities in health expenditure but also that, in low income countries, a very high proportion is met by individuals rather than government.

The lack of social protection in many low and middle income countries means that out of pocket payments are the main way in which healthcare is purchased and provided [7]. For long term diseases such as dementia, the impact of these costs on the families of people with dementia can be 'catastrophic' [8]. Even when health insurance schemes are introduced, out of pocket payments may not be reduced [9]. Although there are higher levels of expenditure on social protection in Organisation for Economic Co-operation and Development (OECD) countries, there is evidence that levels of benefit were less at the beginning of the 21st century than they had been in the mid-1980s [10].

Table 3.2 shows how levels of health expenditure translate into the numbers of doctors and nurses. Again the disparities are striking. This means that, although it is clearly desirable to encourage low expenditure countries to spend more on healthcare, in the short term it will be essential to identify low cost interventions that can be equitably delivered across urban and rural populations. For many countries this will be in the context of developing basic primary health services.

Opportunities for improving dementia care, especially in low and middle income countries, will be enhanced where there are cross-benefits with other health development priorities including:

Table 3.1
A comparison of health expenditure in selected countries (The World Health Report 2006)

	Per capita total expenditure on health at average exchange rate (US$), 2003	Per capita government expenditure on health at average exchange rate (US$), 2003
Argentina	305	148
Australia	2519	1699
China	61	22
Democratic People's Republic of Korea	<1	<1
Dominican Republic	132	44
Egypt	55	24
Finland	2307	1766
France	2902	2213
Germany	3204	2506
India	27	7
Iran, Islamic Republic of	131	62
Malawi	13	5
Romania	159	100
Russian Federation	167	98
Singapore	964	348
Sri Lanka	31	14
United Kingdom	2428	2081
USA	5711	2548

- Improving daily living conditions as recommended by the 2008 WHO Commission on Social Determinants of Health [11]
- Improvements in social protection for older people
- Proposals for active ageing, especially those that make a contribution to risk reduction
- Improving access to health care facilities for older people [12,13]
- Scaling up mental health services [13]
- Integrating mental health in primary care [14]

This report shows that improvements in dementia care are not only necessary for the growing numbers of people with dementia, but that they are capable of being achieved given the commitment and determination of national governments and their healthcare systems.

Table 3.2
A comparison of the numbers of physicians and nurses in selected countries (The World Health Report 2006)

	Physicians per 1,000 population	Nurses per 1,000 population
Argentina	3.01	0.08
Australia	2.47	9.71
China	1.06	1.05
Democratic People's Republic of Korea	3.29	3.85
Dominican Republic	1.88	1.84
Egypt	0.54	2.00
Finland	3.16	14.33
France	3.37	7.24
Germany	3.37	9.72
India	0.60	0.80
Iran, Islamic Republic of	0.45	1.31
Malawi	0.02	0.59
Romania	1.90	3.89
Russian Federation	4.25	8.05
Singapore	1.40	4.24
Sri Lanka	0.55	1.58
United Kingdom	2.30	12.12
USA	2.56	9.37

Dementia and services

The introductory explanation of dementia described the course of dementia and how it can be managed by health and care services supporting families. Chapter 2 showed the impact of dementia, not only on people with dementia but also their family carers.

The concerns of family carers include:

- How to deal with the new situation
- Where to get help
- Who can take care of the person with dementia
- How to manage the economic impact [15]

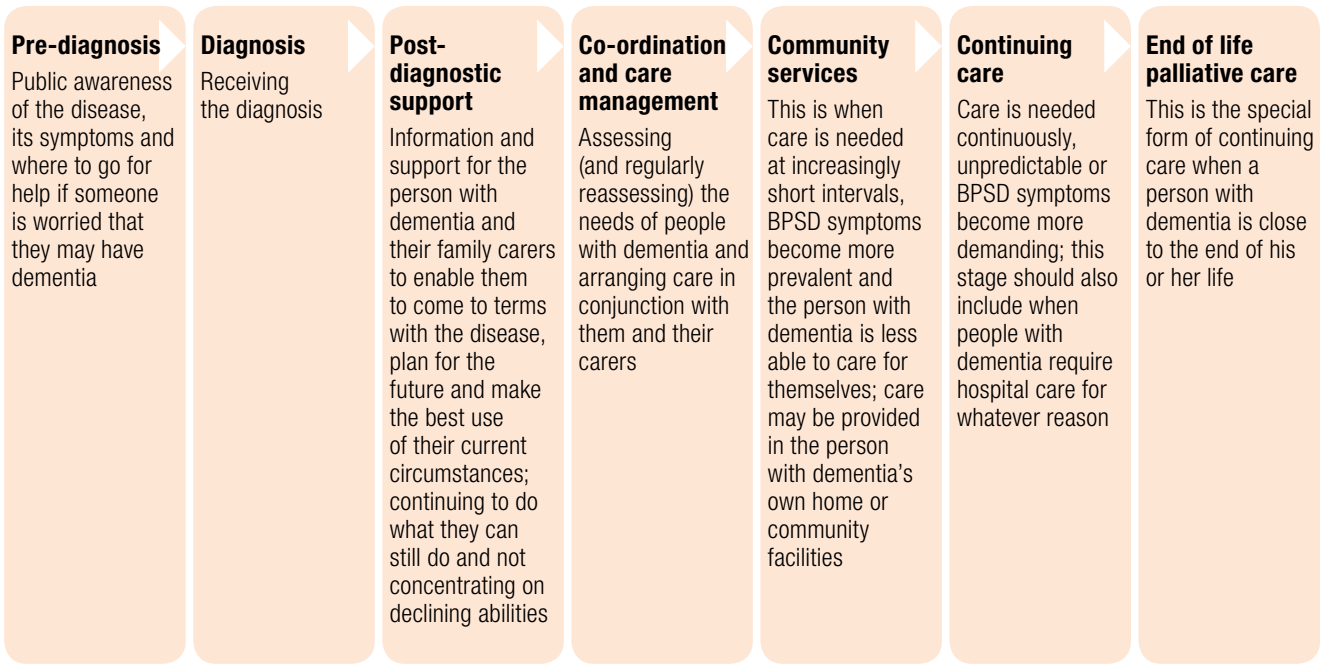
Policy and service responses to dementia need to take into account the increasing dependency of people with dementia and the consequent need for help from others. Dementia can become particularly difficult to manage when the person with dementia has profound behavioural and psychological symptoms [16]. The impact on family carers of looking after people with dementia is substantial. Even in economically developed countries most care is provided by families. People with dementia who live alone and some distance from their families require support and services earlier than other people with dementia, especially when they have low personal incomes. This poses serious challenges for the provision of services.

Figure 3.1 is a comprehensive framework for the development of dementia services. Its first purpose is to point healthcare planners towards the need for a range of services which reflect the progressive nature of dementia and also for planning collaboratively with community based social care and support services.

The second purpose of this figure is to illustrate the stages that some people with dementia will go through as they become more dependent – the journey of dementia care. Some people with dementia may live for 10-15 years from diagnosis to end of life palliative care. Other people with dementia may only need to access services part way through the journey of dementia care or may die before they need end of life care services.

Figure 3.1 represents the goal of comprehensive dementia services that relatively high income countries should aspire to achieve. Governments in Australia, France and the United Kingdom are already working along these lines. The South Korean government has declared 'War on Dementia' [17]. The Netherlands government, in conjunction with the national Alzheimer association, has issued a Guideline for Integrated Dementia Care [18].

Figure 3.1
Seven stage model for planning dementia services
The co-ordination and care management stage should apply throughout the journey of dementia care from diagnosis to palliative care. (BPSD = Behavioural and Psychological Symptoms of Dementia)



A graduated approach for low and middle income countries is illustrated in Figure 3.2. It focuses initial attention on awareness and understanding and, from this, moves on to risk reduction and the underlying issues of capacity building and resource development. Service development starts in primary care before secondary care can be considered because it will be more equitable, benefiting more people with dementia and their families. It has the potential to prevent or at least delay the need for expensive institutional services that only few families can afford. In countries where funding for healthcare is severely restricted, it is essential to start with initiatives which have the maximum impact for as many people as possible.

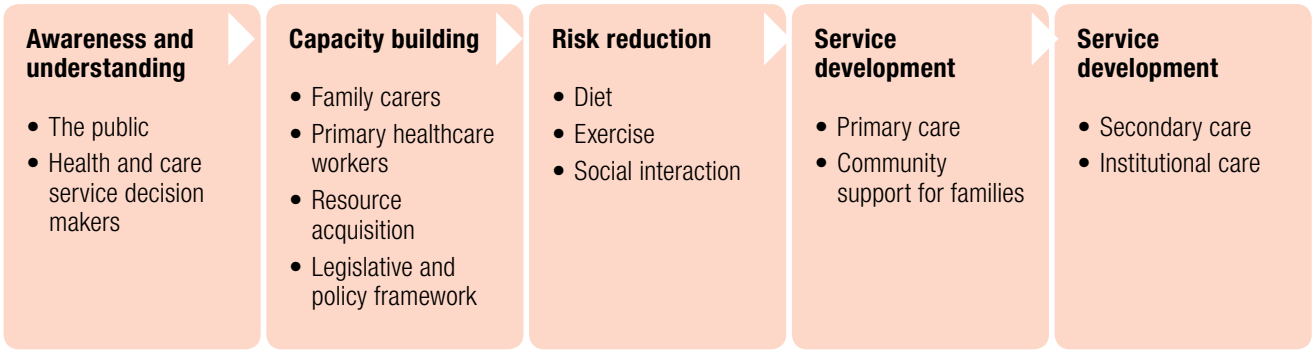
Although awareness raising may appear to stand alone, in practice it should be considered in parallel to capacity building because when awareness is raised, expectations will also be raised that health and care services will be able to respond in some way. In enhancing the capacity of primary healthcare workers, the first step is being taken to develop dementia services.

Awareness raising and information

The heart of awareness raising and information is to explain that dementia is an illness/disease, that it is not an inevitable consequence of ageing and that it is worth assisting family carers who care for people with dementia and helping people with dementia live as normal a life as possible for as long as possible. Awareness raising and increasing understanding are important to counter the fatalism and stigma that are often associated with dementia. Awareness raising is also the first step in enhancing the capacity of family carers to look after their relative with dementia.

Awareness raising and increasing understanding is also essential for all those involved in decision making about dementia services. Without a basic understanding of the nature of the illness, its social and economic consequences and the practical steps which can be taken, it is unlikely that either existing services will be redesigned or enhanced or that new services will be considered.

Figure 3.2
A graduated approach to dementia service development



Capacity building

Capacity building applies to family carers, healthcare workers and the healthcare systems in which dementia care is provided.

Family carers can provide better care if they are trained in the skills of how to cope with the difficulties they face when the person with dementia for whom they care has behavioural and psychological symptoms (see Chapter 2). Ideally, this should be supported by local community services such as day centres. In the absence of such services, support from friends and neighbours can make a real difference but is often not forthcoming because of fear and stigma.

If healthcare systems are only able to do one thing for people with dementia and their families, it should be to provide the information, advice and training that will enable them to enhance their skills to care and thus minimise the pressures on themselves. There is evidence that support of family carers is effective [19]. It is therefore necessary to find ways of training local healthcare workers to be able to deliver this training.

The highest level of capacity building are the national plans for dementia (see appendices 3 and 4) which are emerging, the most recent is for England [2] (see Figure 3.3). The English strategy is underpinned with a number of capacity building initiatives including developing work force competencies, training, commissioning strategy, performance monitoring and evaluation, and research.

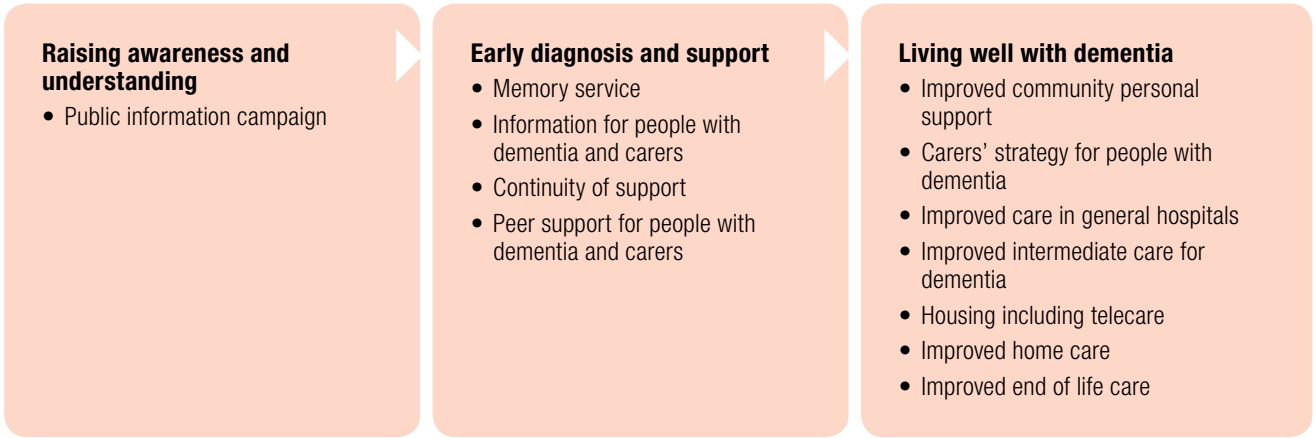
Plans need resources in order to be implemented. The National Framework for Action on Dementia 2006-2010 is the current action plan in Australia [20]. It is a joint policy between National, State and Territory levels of government. The priority areas for action are:

- Care and support
- Access and equity
- Information and education
- Research
- Workforce and training

Priority for dementia was introduced in the 2005 budget when the Australian Government allocated A$320 million additional funding over five years to the 'Dementia: a national health priority' initiative which included:

- Programmes, services and resources that will be of direct assistance to people with dementia with high level needs and their families and carers (A$220 million)
- Training programmes and resources for care workers and health professionals working with people with dementia (A$25 million)
- Dementia related research, including three new Dementia Collaborative Research Centres (A$28 million)
- Delivery of the National Dementia Support Programme through Alzheimer's Australia to promote prevention and screening, early diagnosis and early intervention for people at risk of, or in early stages of dementia (A$18 million)

Figure 3.3
The English National Dementia Strategy and care pathway to enable people with dementia to live well [2]



Quality

It is not what you do but the way that you do it

Quality in health and social care is complex because how a service is provided may affect people differently. The US Institute of Health has identified six dimensions [21] which attempt to capture the complexity of the elements that contribute to quality:

- Safety
- Effectiveness
- Patient-centredness
- Timeliness
- Efficiency
- Equity

The patient-centredness dimension is about ensuring that good quality care addresses how each person with dementia perceives his or her needs as well as directly treating the symptoms of dementia. The Australian Alzheimer's association says that the quality of dementia care is likely to be high if it is driven by:

- A philosophical approach that emphasises person-centred care
- A partnership approach between care workers, providers, the person with dementia and his or her family
- A professionally based care environment characterised by strong leadership
- Adoption of best care practices that reflect the integration of a clear philosophy, current knowledge and applied skills

To achieve good quality service provision, governments will need to invest in the capacity of their health and social care workforce. It will not be enough to just invest in service provision.

Risk reduction

Although the research evidence is not strong enough to show how dementia might be prevented in individuals [22], it is increasingly clear that, when applied to populations of people at risk of dementia, there are a number of activities and lifestyle choices which have an impact on the risk of dementia. For example, the EuroCoDe Report contains a section [23] on risk factors and prevention with recommendations about what to do and what to avoid (see boxes below).

These findings do not stand in isolation but are in line with recommendations for active ageing and modifying the risks for cardiovascular diseases, cancers, chronic respiratory diseases and diabetes [6]. This has been demonstrated by the National Healthy Lifestyle Campaign [24] which the Singapore Government has promoted since 1992 with its emphasis on encouraging:

- Physical activity, proper nutrition and smoking reduction
- Cognitive stimulation – for example, language classes, bridge and sudoku
- Prevention and control of diabetes, hypertension and hyperlipidaemia

Protective factors

- Good social ties
- Many diverse leisure activities
- Physical activity at least three times a week
- Mediterranean diet
- Eat fruit and vegetables regularly
- Eat fatty fish at least once per week
- Challenging work and cognitive activity

Actions for reducing risk

- Avoid heavy drinking
- Avoid being overweight
- Avoid central obesity
- Avoid high levels of cholesterol
- Reduce saturated fat intake
- Reduce meat intake
- Avoid type 2 diabetes
- Avoid high blood pressure
- Avoid smoking
- Prevent depression
- Avoid working with pesticides
- Avoid head trauma

Service development

Primary care

An essential stage in dementia care is identifying people with dementia and giving them a diagnosis. In low income countries this might be carried out by healthcare workers [25] supervised by nurses or doctors. In more advanced healthcare systems diagnosis tends to be the responsibility of doctors, especially when there is funding available for drug treatment.

However, diagnosis without follow-up support will not help people with dementia and their families to plan and prepare to face the disease. Information, training and helping people with dementia to come to terms with their diagnosis are all vital if families are to maximise the quality of life of the person with dementia. This may be provided by nurses, healthcare workers [26] or trained and supervised volunteers mobilised by non-governmental organisations.

The training programme for certified carers promoted by the Fundacion Alzheimer de Venezuela and the Instituto de Formacion de Recursos Humanos para Personas con Discapacidad demonstrates how a new generation of paid carers, many of whom were previously unemployed, can be trained to provide support to families that is more affordable than home nursing provided by professional nurses [15]. In South Korea, ordinary citizens are being trained to be dementia supporters who will be able to assist people with dementia and their family carers. The aim is to recruit 120,000 supporters by 2012 [17].

A crucial feature of primary care is to ensure that where possible other illnesses are also treated and that as much assistance as possible is available to support family carers. Community services for people with dementia should be designed around their personal needs. This could include home support services, day opportunities and day centres.

Secondary care

As dementia progresses the person with dementia becomes increasingly dependent on help from others. In low income countries this will almost entirely be provided by families but in higher income countries there is considerable use of care and nursing homes where staff are employed to look after people with dementia when families are unable to do so for themselves. The development of institutional care requires considerable investment in premises and the capability of staff in order to provide good quality care.

This is also the stage of dementia when the behaviour of people with dementia can be particularly difficult for both families and care staff. Good quality behavioural and psychiatric assessment by experienced dementia care specialists can make a valuable contribution to the design of individual care plans that maximise the contributions of medical and care services.

Our vision for the future

In an ideal world, our vision for low, middle and high income countries would be identical. To be practical we have to recognise that some countries will start from a low level of recognition of dementia and that dementia will be competing with other priorities for healthcare expenditure.

We recommend that such countries start by enhancing their primary healthcare services. From this beginning, something can be done now for people with dementia and their families and over time service development can begin to include some of the features of services in high income countries. However, service development should not emulate services in high income countries automatically. To do so risks repeating the mistake of becoming over dependent on expensive institutional care. Low and middle income countries have the opportunity to fashion dementia services in a way that develops and sustains informal caring and community support and that responds more specifically to the need of the individual with dementia.

	Low and middle income countries	High income countries
Awareness and understanding	• Public education – dementia as an illness, not an inevitable part of old age; where to go for help and information • Risk reduction as part of general health promotion • Campaigns against stigma and discrimination	• Public education – dementia as an illness, not an inevitable part of old age; where to go for help and information • Risk reduction as part of general health promotion • Campaigns for early help-seeking and recognition of dementia • Campaigns against stigma and discrimination
Capacity building	• Integrate dementia awareness and understanding into primary health care planning • Education/training for health care professionals, auxiliary health workers and care workers • Information and training for family carers • Integrate dementia into curricula for healthcare professionals	• National plans for dementia services, from diagnosis to palliative care • Budgets specifically for dementia • Education/training for health care professionals, auxiliary health workers and care workers • Information and training for family carers • Integrate dementia into curricula for healthcare professionals
Services	• Detection and diagnosis in primary health care • Information, advice and support for family carers through auxiliary health workers • Treatment of cognitive impairment with cholinesterase inhibitors where affordable • Care workers employed by families of people with dementia • Advice and support from primary care if behavioural and psychological symptoms of dementia (BPSD) become problematic.	• Detection and diagnosis shared between primary and secondary health care • Treatment of cognitive impairment with cholinesterase inhibitors • Post-diagnosis support for people with dementia • Information, advice and support for family carers through self-help groups and specialist dementia workers • Community based services for people with dementia to provide stimulation and help maintain skills whilst providing respite for family carers • Extra support for people with dementia experiencing BPSD including secondary medical care • Continuing care in the person with dementia's own home for as long as possible • High quality care homes for people with dementia no longer able to care for themselves in their own homes • End of life palliative care

Act now

The demographic changes facing most countries and the growing economic impact of dementia make it imperative that governments take urgent action to improve dementia services in their countries. Irrespective of the levels of funding available, it is possible to improve services starting with low cost initiatives focused on awareness raising and capacity building. High income countries need to take up the dementia challenge by creating national action plans and resource allocation programmes.

Governments will have willing partners in national Alzheimer associations. They will be able to provide advice and information based on the experience of their members and the worldwide knowledge of dementia that can be shared by being part of Alzheimer's Disease International.

The most important stage is to start and begin a cycle of planning, action and evaluation (see Figure 3.4). Learning from experience [27] will ensure that dementia services are developed which are relevant to local needs, recognising the views and experiences of people with dementia and their families and local cultural traditions and thereby maximise success.

Figure 3.4
The plan-do-study-act cycle [28,29]

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World Alzheimer Report
Chapter 4

Recommendations

This photograph was taken on Mrs. Hagamima's 88th birthday. Her Alzheimer's disease did not prevent her from responding with great emotion to the singing of 'Happy Birthday'.

Recommendations

This report ends with eight recommendations. It is the shortest chapter of the report but the most important. We have shown that the number of people with dementia is rising substantially worldwide and that the impact of dementia on families, governments and national healthcare systems will be immense. We have also shown that it is possible for governments to respond constructively to the challenge of dementia. These recommendations provide a global framework for action on dementia.

1 **The World Health Organization (WHO) should declare dementia a world health priority.**

2 **National governments should declare dementia a health priority and develop national strategies to provide services and support for people with dementia and their families.**

3 **Low and medium income countries should create dementia strategies based first on enhancing primary healthcare and other community services.**

4 **High income countries should develop national dementia action plans with designated resource allocations.**

5 **Develop services that reflect the progressive nature of dementia.**

6 **Distribute services with the core principle of maximising coverage and ensuring equity of access, to benefit people with dementia regardless of age, gender, wealth, disability, and rural or urban residence.**

7 **Create collaboration between governments, people with dementia, their carers and their Alzheimer associations, and other relevant Non-Governmental Organisations and professional healthcare bodies.**

8 **More research needs to be funded and conducted into the causes of Alzheimer's disease and other dementias, pharmacological and psychosocial treatments, the prevalence and impact of dementia, and the prevention of dementia.**

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Appendices

Hilda came to Silverado with her piano and plays every day. She has a repertoire of 200-300 songs that she plays by heart and sings all the words.

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APPENDIX 1

Global Burden of Disease (GBD) regions

GBD Region	Countries (those with one or more studies underlined)	Relationship to WHO regions used for *Lancet*/ADI estimates	Approach used to generate regional prevalence and numbers
ASIA			
Australasia	Australia, New Zealand	WPRO A	Apply estimates from meta-analysis.
Asia Pacific, High Income	Brunei, Japan, Republic of Korea, Singapore	WPRO A except for Korea (WPRO B)	Apply estimates from meta-analysis.
Asia, East	China, Democratic People's Republic of Korea, Hong Kong, Taiwan ROC	WPRO B except for Democratic People's Republic of Korea (SEARO D)	Apply estimates from meta-analysis.
Asia, South	Afghanistan, Bangladesh Bhutan, India, Nepal, Pakistan	SEARO D except for Afghanistan and Pakistan (EMRO D)	Apply estimates from meta-analysis.
Asia, Southeast	Cambodia, Indonesia, Laos, Malaysia, Maldives, Mauritius, Mayotte, Myanmar, Philippines, Seychelles, Sri Lanka, Thailand, Timore Leste, Viet Nam	Mainly SEARO B and WPRO B.	Apply estimates from meta-analysis.
EUROPE			
Europe, Western	Andorra, Austria, Belgium, Channel Islands, Cyprus, Denmark, Faeroe Islands, Finland, France, Germany, Gibraltar, Greece, Greenland, Holy See, Iceland, Ireland, Isle of Man, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, Saint Pierre et Miquelon, San Marino, Spain, Sweden, Switzerland, United Kingdom	EURO A	Apply estimates from meta-analysis.
THE AMERICAS			
North America	Canada, United States of America	AMRO A	Conduct meta-analysis for USA. Apply CSHA data for Canada, then aggregate
Latin America, Andean	Bolivia, Ecuador, Peru	AMRO D	Apply estimates from meta-analysis conducted across all four regions
Latin America, Central	Colombia, Costa Rica, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Venezuela	AMRO B except for Guatemala and Nicaragua (AMRO D)	
Latin America, Southern	Argentina, Chile, Falkland Islands (Malvinas), Uruguay	AMRO B	
Latin America, Tropical	Brazil, Paraguay	AMRO B	

Region	Countries (those with one or more studies underlined)	Relationship to WHO regions used in *Lancet*/ ADI estimates	Approach
ASIA			
Asia, Central	Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, Mongolia, Tajikistan, Turkmenistan, Uzbekistan	EURO B, except for Kazakhstan (EURO C)	Apply relevant *Lancet*/ ADI estimates to each country and aggregate
Oceania	American Samoa, Cook Islands, Fiji, French Polynesia, Guam, Kiribati, Marshall Islands, Micronesia (Federated States of), Nauru, New Caledonia, Niue, Northern Mariana Islands, Palau, Papua New Guinea, Pitcairn, Samoa, Solomon Islands, Tokelau, Tonga, Tuvalu, Vanuatu, Wallis and Futuna Islands	WPRO B	Data from one study in Guam only (indigenous Chamorros islanders. Therefore use *Lancet*/ ADI WPRO B for all countries
EUROPE			
Europe, Central	Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Hungary, Poland, Romania, Serbia and Montenegro, Slovakia, Slovenia, The Former Yugoslav Republic of Macedonia	EURO B, except for Croatia, Czech Republic and Slovenia (EURO A)	Apply relevant *Lancet*/ ADI estimates to each country and aggregate
Europe, Eastern	Belarus, Estonia, Latvia, Lithuania, Republic of Moldova, Russian Federation, Ukraine	EURO C	Apply *Lancet*/ADI EURO C estimates
THE AMERICAS			
Caribbean	Anguilla, Antigua and Barbuda, Aruba, Bahamas, Barbados, Belize, Bermuda, British Virgin Islands, Cayman Islands, Cuba, Dominica, Dominican Republic, French Guiana, Grenada, Guadaloupe, Guyana, Haiti, Jamaica, Martinique, Montserrat, Netherlands Antilles, Saint Kitts and Nevis, St. Lucia, St. Vincent, Suriname, Trinidad and Tobago, Turks and Caicos Islands	AMRO B, other than Haiti (AMRO D) and Cuba (AMRO A)	Use 10/66 Cuba and Dominican Republic prevalence for those countries. Apply relevant *Lancet*/ADI estimates to other countries and aggregate
AFRICA			
North Africa / Middle East	Algeria, Bahrain, Egypt, Iran (Islamic Republic of), Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Occupied Palestinian Territory, Oman, Qatar, Saudi Arabia, Syrian Arab Republic, Tunisia, Turkey, United Arab Emirates, Western Sahara, Yemen	EMRO B, except for Egypt, Iraq, Morocco and Yemen (EMRO D), Algeria (AFRO D) and Turkey (EURO B)	Apply Egypt study estimates to Egypt and other EMRO D countries. Apply relevant *Lancet*/ ADI estimates to other countries and aggregate
Sub-Saharan Africa, Central	Angola, Central African Republic, Congo, Democratic Republic of the Congo, Equatorial Guinea, Gabon	A mixture of AFRO D and AFRO E	Apply relevant *Lancet*/ ADI estimates to each country and aggregate
Sub-Saharan Africa, East	Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mozambique, Rwanda, Somalia, Sudan, Uganda, United Republic of Tanzania, Zambia	AFRO E except for Comoros (AFRO D) and Somalia and Sudan (EMRO D)	Apply relevant *Lancet*/ ADI estimates to each country and aggregate
Sub-Saharan Africa, Southern	Botswana, Lesotho, Namibia, South Africa, Swaziland, Zimbabwe	AFRO E	Apply *Lancet*/ADI AFRO E estimates
Sub-Saharan Africa, West	Benin, Burkina Faso, Cameroon, Cape Verde, Chad, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Saint Helena, Sao Tome and Principe, Senegal, Sierra Leone, Togo	AFRO D	Apply Nigeria (Hendrie) prevalence estimates to all countries in this region

APPENDIX 2

Alzheimer associations' annual research expenditure budgets

Association	Budget	Budget in US$
Australia	AU$400,000	329,500
Canada	CAD 2,192,000	1,980,000
France	€ 1,010,862	1,424,834
Germany	€ 105,000	148,000
Ireland	€ 50,000	70,476
Japan	JPY 3,600,000	360,000
Netherlands	€ 849,000	1,197,000
Scotland	GB£ 100,000	165,000
Switzerland	CHF 379,000	351,000
Sweden	SEK 10,000,000	1,412,000
UK	GB£ 2,093,000	3,445,000
USA	$ 32,335,000	32,335,000
Total		**43,217,810**

Data collected from ADI member associations. Figures are for most recent year available (2007/2008)

APPENDIX 3

Comparison of the English and French dementia plans

National Dementia Strategy – Living well with dementia	The French Alzheimer plan – L'engagement de tous
Five year plan	**Five year plan**
£150million extra funding (for years 1 and 2)	200 million Euros – research 200 million Euros – medical care 1.2 billion Euros – medico-social support
Four key themes • Improving awareness • Early and better diagnosis • Improved quality of care • Delivering the strategy/making the change	**Three main themes** • Developing our understanding of the disease / knowledge for action • Improving the quality of life for patients and carers • Mobilising society for the fight against dementia by developing a voluntary approach and synergisms
Raising awareness and understanding • Public information campaign	**Knowledge for action** • Making unprecedented efforts in research • Strengthening clinical and research capacity • Epidemiological surveillance and follow up
Early diagnosis and support • Memory services • Information for people with dementia and carers • Continuity of support for people with dementia and their carers • Peer support for people with dementia and carers	**Improving the quality of life for patients and carers** • Increasing support for carers • Strengthening coordination between all involved in dementia care • Enabling patients and their families to choose support at home • Improving access to diagnosis and care pathways • Recognising skills and developing training for health professionals
Living well with dementia • Improved community personal support • Implementing carers' strategy for people with dementia • Improved care in general hospitals • Improved intermediate care for dementia • Housing including telecare • Improved care home care • Improved end of life care	**Mobilising around a social issue** • Providing information for general public awareness • Promoting ethical considerations and an ethical approach • Making Alzheimer's disease a European priority
Delivering the strategy • Workforce competencies, development and training • Joint local commissioning strategy and world class commissioning • Performance monitoring and evaluation including inspection • Research • Effective national and regional support for implementation of the strategy	**Delivering the strategy** • Direct reporting to the President of the French Republic every six months
Other important features • 18 demonstration sites for peer support and learning networks • 22 demonstration sites for dementia advisors • Early intervention for dementia is clinically and cost effective – 'spend to save' • Getting rid of the stigma attached to dementia • Dementia Research Summit to establish a clearer picture of research needs	**Other important features** • Foundation for scientific cooperation to stimulate and coordinate scientific research • Experimenting innovative respite solutions • Two days training a year for carers • 1,000 coordinators (case managers) • Creating a national reference centre for young patients • Creating a national centre for ethics on dementia
Sources • Presentation by Sube Banerjee, Professor of Mental Health and Ageing, the Institute of Psychiatry, King's College, London to Alzheimer's Disease International Conference, Singapore, 2009 • Living well with dementia: a national dementia strategy, Department of Health, 2009	**Sources** • Presentation by Florence Lustman, Inspector General des Finances, Steering Committee for the Alzheimer Plan, to Alzheimer's Disease International Conference, Singapore, 2009 • Alzheimer Plan 2008-2012: L'engagement de tous; www.plan-alzheimer.gouv.fr

APPENDIX 4

Comparison of dementia plans in Australia and South Korea

Australia: National framework for action on dementia	South Korea's war on dementia
Key priority areas • Care and support • Access and support • Information and education • Research • Workforce and training	**Aim** • Raise the quality of life of people with dementia and maintain their dignity
Timescale • 2006 – 2010 • Government has confirmed that the framework will continue beyond 2009	**Timescale** • 2008 – 2012
Additional funding • A$220 million for programmes, services and resources that will be of direct assistance to people with dementia with high level needs and their families • A$25 million for training programmes and resources for care workers and health care professionals working with people with dementia • A$28 million for dementia related research, including three new dementia Research Collaborative Centres • A$18 million for the delivery of the National Dementia Support Programme through Alzheimer's Australia to promote prevention and screening, early diagnosis and early intervention for people at risk of or in the early stages of dementia	**Objectives** • Increase diagnosis from 3.7% in 2007 to 60% in 2012 • Increase coverage of public health centres from 50% to 100% • Establish a national dementia centre and four outposts in regional hospitals • 6,000 healthcare professionals specialising in dementia care • 120,000 dementia supporters (ordinary citizens such as students and apartment porters, to be given a basic understanding of how to help people with dementia), to serve as 'guardians' of their communities by 2012 • Increase eligibility for long term care insurance, +20,000 per year • To provide 'dementia vouchers' for free early diagnosis for those on low incomes (Cost KRW130billion over three years from 2009)

Glossary

Aetiology
Aetiology refers to the causes of disease. These may be genetic factors, such as Apolipoprotein E, or environmental and lifestyle factors, many of which (diet, exercise, cardiovascular disease, education) have been implicated in dementia. In research, analytical studies are used to help identify genetic and environmental risk factors for dementia.

Analytical studies
The basic strategy is to compare the distribution of disease between groups or between populations, looking for associations between risk factors (genes, behaviours, lifestyles, environmental exposures) and health states. The starting point is a hypothesis that risk factor A causes disease B. Two types of studies are generally carried out, case control studies and cohort studies.

Cohort studies give more reliable information about likely risk factors because of their prospective nature. This means that they are less prone to bias, and that the direction of causality can be clarified (that it is the risk factor [e.g. poor diet] that is causing dementia and not dementia that is causing the risk factor). However, case control studies are easier, cheaper and quicker to carry out.

Associations
An association refers to a statistical link between a risk factor and a disease. It may, or may not, be the case that the risk factor is a cause of the disease. Other possible explanations include chance, bias, confounding and reverse causality.

Bias
Bias is a special kind of error that can arise in the way that studies are designed and/or implemented, in such a way as to distort the findings. This bias could result in a lower, or higher prevalence of dementia, or an over- or underestimation of an association with dementia. Bias comes mainly from the way that participants are selected into studies (selection bias) and the way that information is gathered about exposure to risk factors and disease outcomes (information bias).

Catchment area
A catchment area is a defined district (for example, a small part of a city) that is mapped out, and all the households contacted for the purposes of a door to door cross-sectional survey. Findings from a survey conducted in a single catchment area (for example on the prevalence of dementia) will apply to that defined area, but not necessarily to other districts of the same city, or other parts of the country. To measure prevalence in a larger population (for example the whole country) it is necessary first to take a random sample of the whole older population, perhaps by using population registers.

Confidence intervals
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. Thus, 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.

Confounding
A confounder is a 3rd variable that is associated both with the risk factor and the disease, in such a way as to confound (muddle up) the association under study. Smoking may be associated with dementia simply because older people are more likely to have smoked and because older people are more likely to have dementia. So, it would be important to control for age when examining the association between smoking and dementia.

Cross-sectional survey
The cross-sectional survey is the basic epidemiological descriptive study. All members of a population, or a representative sample of the population are surveyed simultaneously for evidence of the disease under study (the outcome) and for exposure to potential risk factors.

Cross-sectional surveys can be used to measure the prevalence of a disorder within a population. This may be useful for:
- Planning services – identifying need, both met and unmet
- Drawing public and political attention to the extent of a problem within a community
- Making comparisons with other populations or regions (in a series of comparable surveys conducted in different populations)
- Charting trends over time (in a series of comparable surveys of the same population repeated over time)

Epidemiology
Epidemiology is defined as 'The study of the distribution and determinants of health-related states

or events in specified populations, and the application of this study to the control of health problems' (Last, 1995).

Epidemiology is concerned with the health of populations, communities and groups. The health state of individuals is the concern of clinical medicine. Epidemiology may simply describe the distribution of health states (extent, type, severity, impact) within a population. This is descriptive epidemiology. Epidemiological studies are also used to identify causes of disease. This is analytical epidemiology.

Exposure
See *Risk factors*.

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 (heterogeneity), this may be explained by a real difference in what one is measuring, or by the different research methods used in different studies.

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. ADI applied incidence rates to the global population to calculate that one new case of dementia occurs every 7 seconds.

Meta-analysis
Meta-analysis is a statistical procedure allowing findings from several different studies to be combined. Meta-analytical techniques can be applied to descriptive research (for example studies of the prevalence of dementia), analytical research (for example studies of risk factors for dementia) and experimental research (for example randomised controlled trials of a new drug treatment for dementia). The general aims are the same:

- To include the totality of the available research evidence
- To arrive at a more precise estimate of what is being measured
- To understand the extent to which findings from similar studies are similar or different (see also heterogeneity)

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.

Poisson regression working models
Poisson regression is one of several statistical methods available to estimate the independent effect of one exposure while adjusting for the possible effects of others (see also confounding). Poisson regression has been widely used in this report, because it generates prevalence ratios as the measure of association.

Population attributable prevalence fractions (PAPF)
The PAPF provides a way of estimating the importance of an association (measured using a prevalence ratio) at the whole population level. Thus the prevalence ratio of 4.5 for the association between dementia and dependency translates into a PAPF of 35.0%. Therefore, put simply, just over one-third of dependency (needs for care) may be attributed to dementia and could be avoided if dementia could be prevented or cured.

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. The prevalence of dementia (and of the common sub-type, Alzheimer's disease) increases exponentially with increasing age, and is therefore generally reported as age-specific prevalence in five year age bands. This simple proportion is sometimes referred to as crude prevalence, to distinguish it from standardised prevalence.

Prevalence ratio (PR)
A measure of the strength of an association from a cross-sectional study. The prevalence ratio is the ratio of the proportion of one subgroup that have the outcome under study to that of the proportion in the other subgroup. For example the PR of 4.5 for the association between dementia and dependency implies that dependency (needs for care) are four and a half times as common in people with dementia compared with others.

Prospective studies
In a prospective study (sometimes called a cohort study), people are followed up over time. Such studies can be used to:

- Estimate the incidence of dementia, by following up those free of dementia at the outset (sometimes referred to as the baseline phase) and observing the rate at which they develop dementia up to the time of follow-up (sometimes referred to as the incidence phase)
- Estimate the course of dementia (changing clinical severity, disability, dependency and needs for care, caregiver strain, mortality) by following up those with dementia at the outset
- Investigate the aetiology of dementia, by following up those who are exposed and not exposed to a possible risk factor and are free of dementia at the outset, and observing and comparing the rate at which people in the two groups develop dementia (incidence rate)

Relative risk
The relative risk is a measure of the strength of association between a possible risk factor and a disease outcome in a cohort study. It is calculated as the incidence rate in the exposed (e.g smokers), divided by the incidence rate in the unexposed (non-smokers). A relative risk (RR) of 2.0 would imply that smokers were twice as likely to develop dementia over the follow up period as non-smokers.

Response proportion
Sometimes referred to as response rate. This is the proportion of eligible people who are approached to participate in a study, who agree to do so, and are successfully interviewed. Non-response (the inverse of the response proportion) can be an important cause of bias.

Risk factors
Risk factors (sometimes referred to as 'exposures') are factors hypothesized or found to be associated with a disease outcome (for example, dementia).

Standard deviation (SD)
In a sample of people of different ages, the mean is the average age. The standard deviation is the average extent to which any one person's age differs from the mean. Therefore, it is a measure of the amount of variability in age in the sample.

Standardised prevalence
Since the prevalence of dementia is heavily influenced by age, when comparing prevalence between two or more populations or samples it is important to adjust for the possible different age distributions. If people are, on average, older in country A than country B, then one would expect a higher overall proportion of people with dementia. Direct standardisation involves applying the age-specific prevalences from two or more samples (to be compared) to the age-distribution of a third 'standard population'. This allows like to be compared with like. Sometimes standardisation is carried out for several characteristics simultaneously, for example age and gender.

Alzheimer's Disease International

Alzheimer's Disease International
25 YEARS 1984-2009

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 71 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 organisations 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 organisation 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 organisation 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

Alzheimer's Disease International:
The International Federation
of Alzheimer's Disease and
Related Disorders Societies, Inc.
is incorporated in Illinois, USA,
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