

CHAPTER 3

neurological disorders

a public health approach

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This chapter consists of 10 sections that focus on the public health aspects of the common neurological disorders as outlined in the box. Although notable differences exist between relevant public health issues for each neurological disorder, most sections cover the following topics: diagnosis and classification; etiology and risk factors; course and outcome; magnitude (prevalence, incidence, distribution

by age and sex, global and regional distribution); disability and mortality; burden on patients' families and communities; treatment, management and rehabilitation; delivery and cost of care; gaps in treatment and other services; policies; research; and education and training.

3.1 Dementia

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Dementia is a syndrome caused by disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Dementia mainly affects older people: only 2% of 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 later life.

There are very many underlying causes of dementia. Alzheimer's disease (AD), characterized by cortical amyloid plaques and neurofibrillary tangles is the most common, accounting for one half to three quarters of all cases. Vascular dementia (VaD) is diagnosed when the brain's supply of oxygenated blood is repeatedly disrupted by strokes or other blood vessel pathology, leading to significant accumulated damage to brain tissue and function. The distinction between AD and VaD has been called into question, given that mixed pathologies are very common. Perhaps vascular damage is no more than a cofactor accelerating the onset of clinically significant symptoms in people with AD. There are a few rare causes of dementia that may be treated effectively by timely medical or surgical intervention— these include hypercalcaemia, subdural haematoma, normal pressure hydrocephalus, and deficiencies of thyroid hormone, vitamin B12 and folic acid. For the most part, altering the progressive course of the disorder is unfortunately not possible. Symptomatic treatments and support can, however, transform the outcome for people with dementia and their caregivers.

Alzheimer and other dementias have been reliably identified in all countries, cultures and races in which systematic research has been carried out, though levels of awareness vary enormously. In India, for example, while the syndrome is widely recognized and named, it is not seen as a medical condition. Indeed, it is often regarded as part of normal ageing (7).

For the purpose of making a diagnosis, clinicians focus in their assessments upon impairment in memory and other cognitive functions, and loss of independent living skills. For carers and, arguably, for people with dementia, it is the behavioural and psychological symptoms of dementia (BPSD) that are most relevant. Nearly all studies indicate that BPSD are an important cause of caregiver strain. They are a common reason for institutionalization as the family's coping reserves become exhausted. Problem behaviours may include agitation, aggression, calling out repeatedly, sleep disturbance (day–night reversal), wandering and apathy. Common psychological symptoms include anxiety, depression, delusions and hallucinations. BPSD occur most commonly in the middle stage of dementia (see also the section on Course and outcome, below). Despite their significance, there has been relatively little research into BPSD across cultures. One might anticipate that cultural and environmental factors could have a strong influence upon both the expression

of BPSD and their perception by caregivers as problematic (2). Behavioural and psychological symptoms appear to be just as common in dementia sufferers in developing countries (3). In some respects the developing country caregivers were more disadvantaged. Given the generally low levels of awareness about dementia as an organic brain condition, family members could not understand their relative's behaviour, and others tended to blame the carers for the distress and disturbance of the person they were looking after.

ETIOLOGY AND 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 years. Onset before this age is very unusual and, in the case of AD, 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 AD 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 have one or two copies (4, 5). 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 (6). Evidence from cross-sectional and case-control studies suggests associations between AD and limited education (7) and head injury (8, 9), which, however, are only partly supported by longitudinal (follow-up) studies (10). 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 (11). Recent research suggests that vascular disease predisposes to AD as well as to VaD (12). Smoking seems to increase the risk for AD as well as VaD (13). Long-term follow-up studies show that high blood pressure (14, 15) and high cholesterol levels (15) in middle age each increase the risk of going on to develop AD in later life.

Reports from epidemiological studies of protective effects of certain prescribed medication, non-steroidal anti-inflammatory drugs, hormone replacement therapy (HRT) and cholesterol-lowering therapies are now being investigated in randomized controlled trials. The randomized controlled trial of HRT in postmenopausal women indicated, against expectation, that it increased rather than lowered the incidence of dementia.

Despite many investigations, far too little is still understood about the environmental and lifestyle factors linked to AD and other dementias. It may be that the focus on research in developed countries has limited possibilities to identify risk factors. Prevalence and incidence of AD seem to be much lower in some developing regions (see the section on Epidemiology and burden, below). This may be because some environmental risk factors are much less prevalent in these settings. For example, African men tend to be very healthy from a cardiovascular point of view with low cholesterol, low blood pressure and low incidence of heart disease and stroke. Conversely, some risk factors may only be apparent in developing countries, as they are too infrequent in the developed economies for their effects to be detected; for example, anaemia has been identified as a risk factor in India (16).

COURSE AND OUTCOME

Dementia is usually a progressive disease and can be cured only if a reversible condition is identified as a cause and treated effectively. This happens in a small number of cases in the developed world, but could be more common in developing countries, where relevant underlying physical conditions (including marked nutritional and hormonal deficiencies) are more common.

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

The problems linked to dementia can be best understood in three stages (see Box 3.1.1).

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Times are given as guidelines only — sometimes people can deteriorate more quickly and sometimes more slowly. Dementia reduces the lifespan of affected persons. In the developed, high income countries, a person with dementia can expect to live for approximately 5–7 years after diagnosis. In low and middle income countries, diagnosis is often much delayed, and survival in any case may be shorter. Again, of course, there is much individual variation — some may live for longer, and some may live for shorter times because of interacting health conditions.

Symptoms of dementia in early, middle and late stage of the disease are given in Box 3.1.1. It should be noted that not all persons with dementia will display all the symptoms. Nevertheless, a summary of this kind can help caregivers to be aware of potential problems and can allow them to think about future care needs. At the same time, one must not alarm people in the early stages of the disease by giving them too much information.

EPIDEMIOLOGY AND BURDEN

In 2005, Alzheimer’s Disease International commissioned a panel of experts to review all available epidemiological data and reach a consensus estimate of prevalence in each region and the numbers of people affected. Evidence from well-conducted, representative epidemiological surveys was lacking in many regions. The panel estimated that, globally, 24.3 million people have dementia today, with 4.6 million new cases annually. Numbers of people affected will double every 20 years to 81.1 million by 2040. Most people with dementia live in developing countries: 60% in 2001 rising to an estimated 71% by 2040. Rates of increase are not uniform; numbers in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in China, India and neighbouring countries in South-East Asia and the Western Pacific. The detailed estimates contained

Box 3.1.1 Stages and symptoms of dementia (Alzheimer’s disease)

Early stage	Middle stage	Late stage
<p>The early stage 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 the disease is gradual, it is difficult to be sure exactly when it begins. The person may:</p> <ul style="list-style-type: none"> ■ 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 	<p>As the disease progresses, limitations become clearer and more restricting. The person with dementia has difficulty with day-to-day living and:</p> <ul style="list-style-type: none"> ■ 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 family members and caregivers ■ needs help with personal hygiene, i.e. 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 that are not there) 	<p>The late stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may:</p> <ul style="list-style-type: none"> ■ have difficulty eating ■ be incapable of communicating ■ not recognize relatives, friends and familiar objects ■ have difficulty understanding what is going on around them ■ be unable to find his or her way around in the home ■ have difficulty walking ■ have difficulty swallowing ■ have bladder and bowel incontinence ■ display inappropriate behaviour in public ■ be confined to a wheelchair or bed

in this document (17) constitute the best available basis for policy-making, planning and allocation of health and welfare resources.

There is a clear and general tendency for prevalence to be somewhat lower in developing countries than in the industrialized world (18), strikingly so in some studies (19, 20). This trend was supported by the consensus judgement of the expert panel convened by Alzheimer's Disease International, reviewing all available evidence (17). It does not seem to be explained merely by differences in survival, as estimates of incidence are also much lower than those reported in developed countries (21, 22). It may be that mild dementia is underdetected in developing countries because of difficulties in establishing the criterion of social and occupational impairment. Differences in level of exposure to environmental risk factors might also have contributed. 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 AD and other dementias.

Long-term studies from Sweden and the United States of America suggest that the age-specific prevalence of dementia has not changed over the last 30 or 40 years (23). Whatever the explanation for the current discrepancy between prevalence in developed and developing countries, it seems probable that, as patterns of morbidity and mortality converge with those of the richer countries, dementia prevalence levels will do likewise, leading to an increased burden of dementia in poorer countries.

Studies in developed countries have consistently reported AD to be more prevalent than VaD. Early surveys from South-East Asia provided an exception, though more recent work suggests this situation has now reversed. This may be due to increasing longevity and better physical health: AD, whose onset is in general later than that of VaD, increases as the number of very old people increases, while better physical health reduces the number of stroke sufferers and thus the number with VaD. This change also affects the sex distribution among dementia sufferers, increasing the number of females and reducing the number of males.

Disability, burden and cost

Dementia is one of the main causes of disability in later life. In a wide consensus consultation for the Global Burden of Disease (GBD) report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. 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. Dementia, however, has a disproportionate impact on capacity for independent living, yet its global public health significance continues to be underappreciated and misunderstood. According to the GBD estimates in *The world health report 2003*, dementia contributed 11.2% of all years lived with disability among people aged 60 years and over: more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%). However, the research papers (since 2002) devoted to these chronic disorders reveal a starkly different ordering of priorities: cancer 23.5%, cardiovascular disease 17.6%, musculoskeletal disorders 6.9%, stroke 3.1% and dementia 1.4%.

The economic costs of dementia are enormous. These can include the costs of “formal care” (health care, social and community care, respite care and long-term residential or nursing-home care) and “informal care” (unpaid care by family members, including their lost opportunity to earn income).

In the United Kingdom, direct formal care costs alone have been estimated at US\$ 8 billion, or US\$ 13 000 per patient. In the United States, costs have been estimated at US\$ 100 billion per year, with patients with severe dementia costing US\$ 36 794 each (1998 prices) (23, 24). A more recent estimate is of US\$ 18 billion annually in the United States for informal costs alone. In developed

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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 medical staff involvement increases, formal care costs will increase. Institutionalization is generally the biggest single contributor to costs of care.

Very little work has been done on evaluating the economic costs of dementia in developing countries. Shah et al. (25) list five reasons for this: the absence of trained health economists, the low priority given to mental health, the poorly developed state of mental health services, the lack of justification for such services, and the absence of data sets. Given the inevitability that the needs of frail older persons will come to dominate health and social care budgets in these regions, more data are urgently needed.

Detailed studies of informal costs outside western Europe and North America are rare, but a careful study of a sample of 42 AD patients in Denizli, Turkey, provides interesting data (26). Formal care for the elderly was rare: only 1% of old people in Turkey live in residential care. Families therefore provide most of the care. The average annual cost of care (excluding hospitalization) was US\$ 4930 for severe cases and US\$ 1766 for mild ones. Most costs increased with the severity of the disease, though outpatient costs declined. Carers spent three hours a day looking after the most severely affected patients.

The 10/66 Dementia Research Group also examined the economic impact of dementia in its pilot study of 706 persons with dementia and their caregivers living in China, India, Latin America and Nigeria (27). The key findings from this study are summarized in Box 3.1.2.

TREATMENT AND CARE

Early diagnosis is helpful so that the caregiver can be better equipped to deal with the disease and to know what to expect. A diagnosis is the first step towards planning for the future. There is no simple test to make a diagnosis. The diagnosis of AD is made by taking a careful account of the person's problems from a close relative or friend, together with an examination of the person's physical and mental state. It is important to exclude other conditions or illnesses that cause memory loss, including depression, alcohol problems and some physical illnesses with organic brain effects.

Currently there are no treatments that cure dementia. There is, however, evidence that drugs (cholinesterase inhibitors), in some cases but not all, temporarily decelerate the progressive cognitive decline that occurs in AD, and maybe in other forms of neurodegenerative dementia. These drugs act on the symptoms but not on the disease itself; they make only a small contribution to maintaining function. Evidence-based drug therapies are available for psychological symptoms such as depression, anxiety, agitation, delusions and hallucinations that can occur in people with dementia. There are modestly effective drugs (neuroleptics) available for the treatment of associated behavioural problems such as agitation. All of these drugs should be used with caution (the doctrine being "start low, go slow"), particularly tricyclic antidepressants (because of anticholinergic side-effects, therefore SSRI antidepressants — selective serotonin reuptake inhibitors — should always be preferred) and neuroleptics (because of anticholinergic side-effects, sedation, and an increased risk of stroke and higher all-cause mortality).

It is important to recognize that non-drug interventions are often highly effective, and should generally be the first choice when managing behavioural problems. The first step is to try to identify and treat the cause, which could be physical, psychological or environmental. Psychosocial interventions, particularly the provision of information and support to carers, have been shown to reduce the severe psychological distress often experienced by carers. Carers are also greatly assisted by a network of community health and social services; self-help organizations, especially Alzheimer associations, can also help them to find appropriate help. 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 manage better most of the common behavioural symptoms, in such a way that the frequency of the symptoms 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. People with dementia need to be treated at all times with patience and respect for their dignity and personhood; carers need unconditional support and understanding — their needs should also be determined and attended to.

Resources and prevention

Developing-country health services are generally ill-equipped to meet the needs of older persons. Health care, even at the primary care level, is clinic-based; the older person must attend the clinic, often involving a long journey and waiting time in the clinic, to receive care. Even if they can get to the clinic the assessment and treatment that they receive are orientated towards acute rather than chronic conditions. The perception is that the former are treatable, the latter intractable and not within the realm of responsibility of health services. The 10/66 Dementia Research Group's caregiver pilot study in 2004 indicated that people with dementia were using primary and secondary care health services. Only 33% of people with dementia in India, 11% in China and South-East Asia and 18% in Latin America had used no health services at all in the previous three months. In all centres, particularly in India and Latin America, there was heavy use of private medical services. One may speculate that this reflects the caregivers' perception of the relative unresponsiveness of the cheaper government medical services.

The gross disparities in resources within and between developed and developing countries are leading to serious concerns regarding the flouting of the central ethical principle of distributive justice. New drug treatments are very expensive. Anticholinesterase therapies for AD are beyond the reach of all but the richest families in most developing countries. The same would be true for most SSRI antidepressants and "atypical" antipsychotic drugs, both of which are generally favoured in the West for use in older patients over the older and cheaper tricyclic antidepressants and "typical" antipsychotic drugs because of their better safety and side-effect profiles. The advent of a disease-modifying, as opposed to symptomatic, treatment for AD would introduce similar ethical concerns regarding accessibility to those that have arisen in relation to the management of HIV/AIDS in low income countries. Equity is also an important issue within developing countries. Access to care is often entirely dependent upon means to pay. Quite apart from economic constraints, health-care resources are grossly unevenly distributed between rural and urban districts. Most specialists, indeed most doctors, work in cities. Provision of even basic services to far-flung rural communities is an enormous challenge.

Box 3.1.2 The 10/66 Dementia Research Group: key findings

From the development perspective, one of the key findings from the study was that caregiving in the developing world is associated with substantial economic disadvantage. A high proportion of caregivers had to cut back on their paid work in order to care. Many caregivers needed and obtained additional support, and while this was often informal unpaid care from friends and other family members, paid caregivers were also relatively common.

People with dementia were heavy users of health services, and associated direct costs were high. 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.

Caregivers were commonly in paid employment, and almost none received any form of caring allowance. 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 subsistence level. While health-care services are cheaper in low income countries, in relative terms families from the poorer countries spend a greater proportion of their income on health care for the person with dementia. They also appear to be more likely to use the more expensive services of private doctors, in preference to government-funded primary care, presumably because this fails to meet their needs.

Source: (7).

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Future development of services for older people needs to be tailored to suit the health systems context. “Health systems” here can be taken to include macroeconomic factors, social structures, cultural values and norms, and existing health and welfare policy and provision.

Specialists — neurologists, psychiatrists, psychologists and geriatricians — are far too scarce a resource to take on any substantial role in the first-line care for people with dementia. The focus must be upon primary care. Many developing countries have in place comprehensive community-based primary care systems staffed by doctors, nurses and generic multipurpose health workers. The need is for:

- more training in the basic curriculum regarding diagnostic and needs-based assessments;
- a paradigm shift beyond the current preoccupation with prevention and simple curative interventions to encompass long-term support and chronic disease management;
- outreach care, assessing and managing patients in their own homes.

For many low income countries, the most cost-effective way to manage people with dementia will be through supporting, educating and advising family caregivers. This may be supplemented by home nursing or paid home-care workers; however, to date most of the growth in this area has been that of untrained paid carers operating in the private sector. The direct and indirect costs of care in this model therefore tend to fall upon the family. Some governmental input, whether in terms of allowances for people with dementia and/or caregivers or subsidized care would be desirable and equitable. The next level of care to be prioritized would be respite care, both in day centres and (for longer periods) in residential or nursing homes. Such facilities (as envisaged in Goa, for example) could act also as training resource centres for caregivers. Day care and residential respite care are more expensive than home care, but nevertheless basic to a community’s needs, particularly for people with more advanced dementia.

Residential care for older people is unlikely to be a priority for government investment, when the housing conditions of the general population remain poor, with homelessness, overcrowding and poor sanitation. Nevertheless, even in some of the poorest developing countries (e.g. China and India), nursing and residential care homes are opening up in the private sector to meet the demand from the growing affluent middle class. Good quality, well-regulated residential care has a role to play in all societies, for those with no family support or whose family support capacity is exhausted, both as temporary respite and for provision of longer-term care. Absence of regulation, staff training and quality assurance is a serious concern in developed and developing countries alike.

Similarly, low income countries lack the economic and human capital to contemplate widespread introduction of more sophisticated services; specialist multidisciplinary staff and community services backed up with memory clinics and outpatient, inpatient and day care facilities. Nevertheless, services comprising some of these elements are being established as demonstration projects. The ethics of health care require that governments take initial planning steps, now. The one certainty is that “in the absence of clear strategies and policies, the old will absorb increasing proportions of the resources devoted to health care in developing countries” (28). This shift in resource expenditure is, of course, likely to occur regardless. At least, if policies are well formulated, its consequences can be predicted and mitigated.

Prevention, where it can be achieved, is clearly the best option, with enormous potential benefits for the quality of life of the individual, the family and carers, and for society as a whole. Primary preventive interventions can be highly cost effective, given the enormous costs associated with the care and treatment of those with dementia (see the section on Disability, burden and cost, above). The primary prevention of dementia is therefore a relatively neglected area. Evidence from the developed world suggests that risk factors for vascular disease, including hypertension, smoking, type II diabetes, and hypercholesterolaemia may all be risk factors for AD as well as VaD. The epidemic of smoking in developing countries (with 13% of African teenagers currently

smoking), and the high and rising prevalence of type II diabetes in South-East Asia (a forecast 57% increase in prevalence between 2000 and 2010, compared with a 24% increase in Europe) should therefore be particular causes of concern. It is as yet unclear whether the improvements in control of hypertension, diet and exercise, and particularly the decline in smoking seen in developed Western countries that has led to rapid declines in mortality from ischaemic heart disease and stroke, will lead to a later decline in the age-specific incidence of AD and other dementias. Many of these preventive measures are also likely to improve general health (29).

Delivery of care

All over the world the family remains the cornerstone of care for older people who have lost the capacity for independent living, whether as a result of dementia or other mental disorder. However, stereotypes abound and have the potential to mislead. Thus, 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. This is true for example in the United Kingdom, where despite nuclear family structures and contrary to supposition, there is a strong tradition that persists today for local children to provide support for their infirm parents. Conversely, in developing countries the reliability and universality of the family care system is often overestimated. Older people are among the most vulnerable groups in the developing world, in part because of the continuing myths that surround their place in society (30). It is often assumed that their welfare is assured by the existence of the extended family. Arguably, the greatest obstacle to providing effective support and care for older persons is the lack of awareness of the problem among policy-makers, health-care providers and the community. Mythologizing the caring role of the family evidently carries the risk of perpetuating complacency.

The previously mentioned 10/66 Dementia Research Group's multicentre pilot study was the first systematic, comprehensive assessment of care arrangements for people with dementia in the developing world, and of the impacts upon their family caregivers (27). As in the EURO CARE study with data from 14 European countries (31), most caregivers in developing countries were older women caring for their husbands or younger women caring for a parent. Caring was associated with substantial psychological strain as evidenced by high rates of psychiatric morbidity and high levels of caregiver strain. These parameters were again very similar to those reported in the EURO CARE study. Some aspects, however, were radically different. People with dementia in developing countries typically live in large households, with extended families. Larger families were associated with lower caregiver strain; however, this effect was small and applied only where the principal caregiver was co-resident. Indeed, it seemed to operate in the opposite direction where the caregiver was non-resident, perhaps because of the increased potential for family conflict.

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 globalization (30). Some of the contributing factors include the following:

- Changing attitudes towards older people.
- The education of women and their increasing participation in the workforce (generally seen as key positive development indicators); tending to reduce both their availability for caregiving and their willingness to take on this additional role.
- Migration. Populations are increasingly mobile as education, cheap travel and flexible labour markets induce young people 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. "Push factors" are also important. In the economic catastrophe of the 1980s, two million Ghanaians left the country in search of economic betterment; 63% of older persons have lost the support of one or more of their children who have migrated to distant places in Ghana or abroad. Older people are particularly vulnerable after displacement as a result of war or natural disaster.

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- Declining fertility in the course of the final 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.
- In sub-Saharan Africa, changing patterns of morbidity and mortality are more relevant; the ravages of the HIV/AIDS epidemic have “orphaned” parents as well as children, as bereaved older persons are robbed of the expectation of economic and practical support into later life.

A PUBLIC HEALTH FRAMEWORK

At its 20th annual conference held in Kyoto, Japan, Alzheimer’s Disease International released a Kyoto Declaration, benchmarking progress in ten key areas using a public health framework developed by WHO (see Table 3.1.1). The framework addresses treatment gaps, policies, research and training and identifies three levels of attainment for countries with low, medium and high levels of resources, hence suggesting a feasible, pragmatic series of actions and objectives for health systems at all levels of development.

Table 3.1.1 Minimum actions required for dementia care^a

Ten overall recommendations	Scenario A Low level of resources	Scenario B Medium level of resources	Scenario C High level of resources
1. Provide treatment in primary care	Recognize dementia care as a component of primary health care Include the recognition and treatment of dementia in training curricula of all health personnel Provide refresher training to primary care physicians (at least 50% coverage in five years)	Develop locally relevant training materials Provide refresher training to primary care physicians (100% coverage in five years)	Improve effectiveness of management of dementia in primary health care Improve referral patterns
2. Make appropriate treatments available	Increase availability of essential drugs for the treatment of dementia and associated psychological and behavioural symptoms Develop and evaluate basic educational and training interventions for caregivers	Ensure availability of essential drugs in all health-care settings Make effective caregiver interventions generally available	Provide easier access to newer drugs (e.g. anticholinesterase agents) under public or private treatment plans
3. Give care in the community	Establish the principle that people with dementia are best assessed and treated in their own homes Develop and promote standard needs assessments for use in primary and secondary care Initiate pilot projects on development of multidisciplinary community care teams, day care and short-term respite care Move people with dementia out of inappropriate institutional settings	Initiate pilot projects on integration of dementia care with general health care Provide community care facilities (at least 50% coverage with multidisciplinary community teams, day care, respite and inpatient units for acute assessment and treatment) According to need, encourage the development of residential and nursing-home facilities, including regulatory framework and system for staff training and accreditation	Develop alternative residential facilities Provide community care facilities (100% coverage) Give individualized care in the community to people with dementia

Ten overall recommendations	Scenario A Low level of resources	Scenario B Medium level of resources	Scenario C High level of resources
4. Educate the public	Promote public campaigns against stigma and discrimination Support nongovernmental organizations in public education	Use the mass media to promote awareness of dementia, foster positive attitudes, and help prevent cognitive impairment and dementia	Launch public campaigns for early help-seeking, recognition and appropriate management of dementia
5. Involve communities, families and consumers	Support the formation of self-help groups Fund schemes for nongovernmental organizations	Ensure representation of communities, families, and consumers in policy-making, service development and implementation	Foster advocacy initiatives
6. Establish national policies, programmes and legislation	Revise legislation based on current knowledge and human rights considerations Formulate dementia care programmes and policies: – Legal framework to support and protect those with impaired mental capacity – Inclusion of people with dementia in disability benefit schemes – Inclusion of caregivers in compensatory benefit schemes Establish health and social care budgets for older persons	Implement dementia care policies at national and subnational levels Establish health and social care budgets for dementia care Increase the budget for mental health care	Ensure fairness in access to primary and secondary health care services, and to social welfare programmes and benefits
7. Develop human resources	Train primary health-care workers Initiate higher professional training programmes for doctors and nurses in geriatric psychiatry and medicine Develop training and resource centres	Create a network of national training centres for physicians, psychiatrists, nurses, psychologists and social workers	Train specialists in advanced treatment skills
8. Link with other sectors	Initiate community, school and workplace dementia awareness programmes Encourage the activities of nongovernmental organizations	Strengthen community programmes	Extend occupational health services to people with early dementia Provide special facilities in the workplace for caregivers of people with dementia Initiate evidence-based mental health promotion programmes in collaboration with other sectors
9. Monitor community health	Include dementia in basic health information systems Survey high-risk population groups	Institute surveillance for early dementia in the community	Develop advanced monitoring systems Monitor effectiveness of preventive programmes
10. Support more research	Conduct studies in primary health-care settings on the prevalence, course, outcome and impact of dementia in the community	Institute effectiveness and cost-effectiveness studies for community management of dementia	Extend research on the causes of dementia Carry out research on service delivery Investigate evidence on the prevention of dementia

^a Based on overall recommendations from *The world health report 2001* (32).

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CONCLUSIONS AND RECOMMENDATIONS	
1	Dementia is a disease and not a part of normal ageing.
2	Dementia affects some 24 million people, most of them elderly, worldwide. Up to two thirds live in low and middle income countries.
3	Awareness of dementia is very low in all world regions, a problem leading to stigmatization and inefficient help-seeking.
4	No cure is currently available for the most common causes of dementia, but much can and should be done to improve the quality of life of people with dementia and their carers.
5	Governments should be urged to take account of the needs of people with dementia, as an integral part of a comprehensive programme of health and welfare services for older people.
6	The priority should be to strengthen primary care services, through training and reorientation from clinic-based acute treatment services to provision of outreach and long-term support.
7	Governments, nongovernmental organizations working in the area of Alzheimer and other dementias, professionals and carers need to work together to raise awareness, counter stigma and improve the quality and coverage of care services.

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RECOMMENDED READING

For professionals

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- Draper B, Melding P, Brodaty H, eds. *Psychogeriatric service delivery: an international perspective*. New York, Oxford University Press, 2004.

For carers and non-medical readers

- Cayton H, Graham N, Warner J. *Dementia – Alzheimer's and other dementias*, 2nd ed. London, Class Publishing, 2003 (translated into several languages).
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Box 3.1.3 Case-study: Brazil

Brazil has among the 11 largest populations of elderly people in the world; eight of these populations are in developing countries. According to the Brazilian 2000 census, there are 10 million people aged 65 years and over, corresponding to about 6% of the whole population. It is predicted that by 2050 the elderly population will have increased by over 300%, whereas the population as a whole will have increased only by over 30%. Brazil has also one of the highest rates of urbanization in the world with almost one third of the whole population living in only three metropolitan areas (São Paulo, Rio de Janeiro and Belo Horizonte), as well as one of the highest levels of inequality between the rich and the poor with almost 50% of the national income concentrated among the richest 10% of the population. Most elderly people live in large cities in poverty.

According to a recent consensus on the global prevalence of dementia, Brazil has today 729 000 people with dementia; this number is estimated to increase to 1.4 million by 2020 and to 3.2 million by 2040. Dementia in Brazil is still a hidden problem and there is little awareness of it.

Most elderly people live with their spouses or extended family (only 15% live alone and fewer than 1% live in institutions). Families with one or more elderly members are relatively advantaged because of the means-tested non-contributory pension benefits for older Brazilians, introduced in the 1990s. However, the informal support that family caregivers can offer to their relations in more need is still difficult because of impoverishment.

The majority of Brazilians (75%) are cared for by the federal programme SUS (Unified Health System) while the remainder are in the hands of a private system. Primary care is provided primarily by the Family Health Programme, in which health professionals go to the patient's home for periodic health evaluation and management; however, this programme covers only 40% of the population. Specialists (geriatricians, psychiatrists and neurologists) see referred patients as outpatients and inpatients. Long-term care is scarce and is mostly provided by religious organizations for those with severe disability and limited family support. Community care is generally available in metropolitan areas, but only from private providers for those who can afford the charges. Home care provided by SUS is being introduced but still covers only a small proportion of the elderly population.

While the current health system does not meet the needs of older people, there are encouraging developments. The Brazilian Psychiatric Association has a Geriatric Psychiatry section promoting training in dementia assessment and care; the geriatricians and neurologists have similar initiatives. Four universities have research programmes in dementia. Several regional nongovernmental organizations work to support people with dementia and their caregivers; these are united in a federation — Federação Brasileira de Associações de Alzheimer (FEBRAZ) — which is a member of Alzheimer's Disease International.

Box 3.1.4 Case-study: India

In India, life expectancy has gone up from 20 years at the beginning of the 20th century to 62 years at present. Better medical care and low fertility have made the elderly population the fastest growing section of society. India has over one billion people, 16% of the world's population: it is estimated that the growth in the elderly population is 5–8% higher than growth in the total population. The consequence is that, while in 2001 there were 70 million people aged over 60 years, by 2025 there will be an estimated 177 million.

According to a recent consensus, the prevalence of dementia in India is 1.9% over the age of 60 years. In the context of the large population and demographic transition, the total numbers are estimated to more than treble in the next 35 years, reaching over six million by 2040. The public health and socioeconomic implications are enormous.

The joint family system — the traditional support system for frail elderly people — is crumbling because of the migration of the younger generation to the cities in search of better prospects. The women who traditionally took on the role of caregivers are also working and cannot spend as much time caring for the elderly. Dementia is considered as a normal part of ageing and is not perceived as requiring medical care. Thus primary health-care physicians rarely see this condition in their clinical work. Private medical care

(which includes home visits) is preferred and this leads to a higher out-of-pocket cost for dementia care. Carers experience significant burdens and health strain. More than 80% of carers are female and around 50% are spouses who are themselves quite old. People with dementia are often neglected, ridiculed and abused. Old-age homes do not admit people with dementia.

These research findings led to the implementation of the Dementia Home Care Project which was supported by WHO. In this project, a flexible, stepped-care intervention was adopted to empower the carers with knowledge and skills to manage the person with dementia at home. The intervention was implemented by locally trained home care advisers under supervision. This not only helped in decreasing the stress of looking after a person with dementia, but also helped the caregivers to manage behavioural problems and thus reduced the number of deaths in the intervention group.

Evidence from research has helped the advocacy campaign in India. There is a need to make dementia a public health priority and create a network of home care advisers to provide supportive and educational interventions for the family caregivers through the primary health-care system in India.

Box 3.1.5 Case-study: Nigeria

Nigeria is the most populous African country, with about 130 million inhabitants. According to United Nations estimates, it is likely that the figure of 0.5 million (4.7% of the whole population) people over 60 years of age in 2000 will have more than trebled by 2040 (1.8 million people, i.e. 7.5% of the population). Old people have traditionally been cared for within the extended family. Social and economic changes have disrupted this system, however, especially by young people moving into the towns and leaving the old people to cope on their own. No effective alternatives have been provided for their care.

Specialist health services are in short supply. In 2005 there were only about 77 psychiatrists and three occupational therapists in the country. Industrial therapy was not offered anywhere. Specialist social workers are few and work under severe limitations. There are no specialist services for the elderly (geriatric or psychogeriatric services, meals on wheels, respite care or drop-in centres) and few nursing homes. There is no insurance cover for medical services for elderly people.

Usually record-keeping, accountability and political will are poor, so that many elderly people who retire do not receive their benefits. Recently the Federal Government has introduced a contributory pension scheme, but in the past elderly people found it difficult to learn about and access their entitlements. Elderly Nigerians are among the poorest groups in the country.

A national policy on elderly care was published in 2003, and a National Implementation Plan is now under way, but is being piloted only among certain Federal civil servants.

Assessing the extent of dementia among this huge, varied and shifting population is not easy, but what little research has been done suggests prevalence rates for dementia may be low. Interest in the mental health of elderly Nigerians is only just beginning: for example in the past three years, old-age mental health clinics have been established at two universities. There is no formal training for geriatric medicine and psychiatry. Anti-dementia drugs are rarely available.