

DEMENTIA

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Background

Dementia is characterized by loss of or decline in memory and other cognitive abilities and reduces the lifespan of affected people^{1,2}. In 2005, it was estimated that 24.3 million worldwide and 1.8 million people in India are affected with dementia¹. In India the number of people with Alzheimer's Disease and other dementias is increasing every year because of the steady growth in the older population and stable increment in life expectancy and it is expected to increase two-fold by 2030 and three-fold by 2050.² Dementia is often associated with physical, mental and financial burden and evidence suggests that elderly people with dementia in developing countries do not often utilise health care services, and when they do, the health care system is often ill prepared to provide quality services for dementia^{3,4}. Around 10-37% of the elderly population with dementia in developing countries are classified as having potentially vulnerable living circumstances with requiring long-term and specialised care⁵.

This chapter will provide a description of dementia, its measurement and present the prevalence and incidence of dementia in India. The burden of dementia in India will be explored. Risk factors for dementia, co-morbid conditions, best management practice and treatment of dementia will be also included. Current dementia policy, research programs in dementia in India, and gaps of research will also be reviewed.

Morbidity and Mortality associated with Dementia

Global Morbidity and Mortality

- In 2000 , age-standardized dementia mortality rate was 6.7 and 7.7 for 100,000 male and female respectively.¹
- 24.3 million have dementia²
- 4.6 million new cases per year²
- World wide dementia contributes 4.1% of all disability-adjusted life years (DALYs) and 11.3% of years lived with disability and 0.9% of years of life lost⁶.

India Morbidity and Mortality

- age standardized death rate of 12.1 per 100,000 reference number?⁶
- 1.8 million have dementia in India and South Asia in people >60 years of age.²
- 400,000 new cases per year for India + South Asia.²
- 1,034 per 100,000 DALYs.⁶

What is dementia?

Dementia is characterized by loss of or decline in memory and other cognitive abilities. It is caused by various diseases and conditions that result in damaged brain cells⁷. To diagnosis someone with dementia, the following criteria is widely used:⁷

A) A decline in memory and in at least one of the following cognitive abilities:

1. Ability to generate coherent speech or understand spoken or written language;
2. Ability to recognize or identify objects, assuming intact sensory function;
3. Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and
4. Ability to think abstractly, make sound judgments and plan and carry out complex tasks.

B) The decline in cognitive abilities must be severe enough to interfere with daily life.

Alzheimer's disease (AD) is the most common sub-type of dementia with, approximately two-third of dementia cases in over 65 years being diagnosed as AD⁸. The other subtype of dementia includes vascular dementia or multi-infarct dementia (MID), Lewy bodies, Parkinson's disease, Frontotemporal dementia, Creutzfeldt-Jakob disease (table 1).

Course and outcome of dementia

Dementia reduces the lifespan of affected people.⁹ In the developed world, a person with dementia can expect to live for roughly 5-7 years after onset of diagnosis.^{10;11} In low and middle income countries, diagnosis is often much delayed, and survival may be much shorter.¹² The symptoms and problems linked to dementia can be best understood in three stages⁶:

1-Early stage (developed in 1-2 years):

The early stage of dementia is often overlooked because the onset of dementia is gradual, it is often difficult to be sure exactly when it begins.⁶ The person may for example:

- 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.

Table 1: Types of Dementia and their Clinical Characteristics⁷

Types of Dementia	Characteristics
AD	<ul style="list-style-type: none"> • Most common type of dementia; accounts for 60 to 80 percent of cases. <ul style="list-style-type: none"> ▪ Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. ▪ Later symptoms include impaired judgment, disorientation, confusion, behaviour changes, and trouble in speaking, swallowing and walking. ▪ Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).
Vascular dementia (also known as multi-infarct dementia or vascular cognitive impairment)	<ul style="list-style-type: none"> ▪ Considered the second most common type of dementia. ▪ Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. ▪ Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed type	<ul style="list-style-type: none"> ▪ Characterized by the presence of the hallmark abnormalities of Alzheimer's and another type of dementia, most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.
Dementia with Lewy bodies	<ul style="list-style-type: none"> ▪ Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment and behaviour changes. ▪ Alertness and severity of cognitive symptoms may fluctuate daily. ▪ Visual hallucinations, muscle rigidity and tremors are common. ▪ Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain. ▪
Parkinson's disease	<ul style="list-style-type: none"> ▪ Many people who have Parkinson's disease develop dementia in the later stages of the disease. ▪ The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.
Front temporal dementia	<ul style="list-style-type: none"> ▪ Involves damage to brain cells, especially in the front and side regions of the brain. ▪ Typical symptoms include changes in personality and behaviour and difficulty with language. ▪ No distinguishing microscopic abnormality is linked to all cases. ▪ Pick's disease, characterized by Pick's bodies, is one type of front temporal dementia. ▪
Creutzfeldt-Jakob disease	<ul style="list-style-type: none"> ▪ Rapidly fatal disorder that impairs memory and coordination and causes behaviour changes. ▪ Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease. Caused by the misfolding of prion protein throughout the brain.

2-Middle stage (developed in second to fifth year):

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.

3-Late stage (developed in fifth year or after):

This stage is one of near total dependence and inactivity. Memory disturbances are 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.
- Display inappropriate behaviour in public.
- Be confined to a wheel chair or bed.

Types of criteria used for diagnosis of dementia in India studies

Two main types of criteria used for diagnosing dementia are explored below:

The DSM IV criteria (The Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition)¹³; recommends that factors A-D must all be satisfied to make a diagnosis for dementia

- A. The development of multiple cognitive deficits manifested by both
1. memory impairment (impaired ability to learn new information or to recall previously learned information)
 2. one (or more) of the following cognitive disturbances:
 - a. aphasia (language disturbance)
 - b. apraxia (impaired ability to carry out motor activities despite intact motor function)
 - c. agnosia (failure to recognize or identify objects despite intact sensory function)
 - d. disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)
- B. The cognitive deficits in Criteria A1 and A2 each
1. cause significant impairment in social or occupational functioning, and

2. represent a significant decline from a previous level of functioning.

C. The deficits do not occur exclusively during the course of a delirium.

D. The disturbance is not better accounted for by another axis I disorder (for example, major depressive disorder, and schizophrenia)

The DSM IV criterion was developed by American Psychiatry Association¹³ and has been widely used in both clinical and epidemiological research in India.¹⁴ There is strong face validity and it defines a progressive and relatively pervasive disorder by seeking to distinguish between dementia on the one hand, and potentially remediable cognitive impairment arising from delirium or mental disorder on the other. Its elements are, for the most part, objectively verifiable. The main weakness is the lack of operational definition; e.g. what constitutes memory impairment, or cognitive disturbance? In most part, the usual practice is to rely on clinical judgment (in research often by a consensus panel of expert diagnosticians). However, even when structured assessments have been used, the lack of clarity in these areas introduces much scope for unreliability¹⁵.

The 10/66 dementia diagnosis: This criterion relies on an algorithm which was validated in an extensive pilot study conducted in 25 centres in India, China and southeast Asia, Latin America, the Caribbean, and Africa.¹⁶ It has an overall sensitivity of 94% and a specificity of 97% for those with higher, and 94% for those with lower levels of education. In a further criterion validation nested in the prevalence study in Cuba, 10/66 dementia criteria corresponded more closely to a 'Cuban clinical interviewer dementia diagnoses' compared to the DSM-IV dementia criteria, which selectively missed mild and moderate cases.¹⁷ The 10/66 dementia diagnosis algorithm requires:

- (i) A structured clinical mental state interview, the Geriatric Mental State, which applies a computer algorithm (AGECAT) to identify organicity (probable dementia), depression, anxiety and psychosis and;
- (ii) A cognitive test battery comprising a) the Community Screening Instrument for Dementia (CSID') COGSCORE (incorporating the CERAD animal naming verbal fluency task), and b) the modified CERAD 10 word list learning task with delayed recall and;
- (iii) An informant interview the CSID' RELSCORE , for evidence of cognitive and functional decline;
- (iv) an extended informant interview, the History and Aetiology Schedule – Dementia Diagnosis and Subtype (HAS-DDS), which is a modification of the earlier HAS, providing more detailed information on onset and course of a possible dementia syndrome;

- v) The NEUROEX, a brief fully structured neurological assessment with objectified quantifiable measures of lateralising signs, parkinsonism, ataxia, apraxia and primitive 'release' reflexes.
- (vi) Behavioural and Psychological symptoms of dementia (BPSD); assessed using an informant questionnaire, the Neuropsychiatric Inventory (NPI-Q).

Final dementia diagnoses is made in two ways. The main dementia outcome is defined as those scoring above a cut-point of predicted probability of DSM IV Dementia syndrome from the logistic regression equation developed in the 10/66 international pilot study, using coefficients from the GMS, CSI-D and 10 word list learning tasks. The second approach involves the direct application of research diagnostic criteria for DSM IV and for the following dementia subtype diagnoses; NINCDS-ADRDA Alzheimer's disease criteria, NINDS-AIREN vascular dementia criteria, and Lewy Body Dementia.^{15,18}

Methodological constraints in dementia studies

One of the main methodological problem is with the assessment of dementia. For example, the disparity in prevalence reported using DSM IV and 10/66 dementia diagnosis is explained by the observation that informant/caregivers in India are less likely to report cognitive decline and social impairment (an essential criterion for DSM IV dementia diagnosis) even in the presence of objective memory impairment⁵. Conceivably using DSM IV dementia criteria in population survey may underestimate true prevalence, particularly in India where low level of awareness about dementia is reported^{18, 19;20}.

The majority tend to use two and three phase study design and DSM-IV criteria for dementia diagnosis,⁵ whilst the 10/66 studies conducted in Chennai and Vellore used a simpler one phase dementia diagnosis.²¹ Multi-stage sampling permits prevalence estimates to be generated for much larger base populations but sample weights need to be used to calculate prevalence and confidence intervals, and it is not clear whether it was done⁵. One phase diagnosis offers several advantages over two or more phases; e.g. study of a wider range of outcomes, no attrition between phases and increased efficiency when the sum of the sensitivity and specificity of the screening instrument is < 1.6. A bigger concern is that for several of the two or three phase studies in India, the methods used seemed not to have been applied in the recommended manner.⁵ Either screen negatives were not selected for the second phase or weighting back was not carried out properly or not carried out at all.^{5,22} The end result is either under or over-estimation of true prevalence.

Mortality of dementia

The global age standardised death rate for AD and other dementias is 6.7 per 100,000 for males and 7.7 per 100,000 females⁸. According to the World Health Organisation, the **South-East Asia Region** (WHO SEAR), the dementia mortality rate for India is 13.5 per 100,000 males and 11.1 for 100,000 females.²³ Compared to other chronic medical conditions (heart diseases, cancer and stroke) AD is in fourth position for the leading cause of death in the Asia Pacific region²⁴. A 15 year community-based follow-up study in the United States of 1,670 adults aged over 65 years reported a 40% mortality risk for AD and predicted AD as being a leading cause of death and shortened survival time of older people¹⁰. A systematic review, reported a positive dose response relationship between the level of cognitive impairment and increasing risk of mortality.²⁵ A review further found increased risk of mortality for moderate levels of cognitive impairment and a two-fold mortality risk for severe cognitive impairment²⁶.

Most of the evidence on these associations between dementia and mortality are from studies undertaken in developed countries. However, studies from developing countries have also found increased mortality risk for older people with dementia, for example: a Brazilian observational study conducted with 1,656 individuals aged 65 and over reported a 51.3% death rate for the dementia group compared to non dementia group and concluded that dementia was the most significant predictor of mortality among Brazilian older people.²⁷ A larger population study from Nigeria with 4,699 similarly reported an increased risk of mortality for an elderly population with dementia: the association of dementia and mortality persisted with 70% of people over the age of 75 with dementia dying within five years of diagnosis.²⁸

Prevalence of dementia in India

Epidemiological studies in dementia: According to the Delphi census, 93.1 million older people over 60 years of age, globally were estimated to be living with dementia; an overall prevalence of 1.6 %.² The Delphi census estimated that in India, 3.7 million people aged over 60 have dementia.² Evidence based on more than 42,000 older people studied in eight centres (5 urban and 4 rural areas) across India, suggests that Ballabgarh and Vellor have the lowest

estimated prevalence rates whilst Tiruvandrum and Thiropour have the highest rates.²¹⁻²⁶ (Table 2)

Table 2: Prevalence rates for dementia in India

Setting	Location	Prevalence %
Urban	Chennai ²⁹	0.9 % for age > 65
	Kochi ³⁰	3.3 % for age >65
	Kolkata ³¹	1 % for age >60
	Mumbai ²¹	2.3 % for age >65
	Tiruvandrum ³²	4.8% for age >65
Rural	Ballabgarh (Delhi) ²⁰	0.6% for age ≥55 1.1% for age > 65
	Ernakalum (Kerala) ³³	3.1% for age >60
	Thiropour-semi rural (Tamil Nadu) ³⁴	3.5 % for age >60
	Vellore (Tamil Nadu) ²⁹	0.8 % for age >65

The prevalence of dementia in India compared to the European prevalence is much lower.³⁵ (Figure 1: for Chennai and Vellore, two diagnostic criteria were applied -DSMIV and 10/66 dementia diagnosis.) Various reasons have been proposed for the low prevalence of dementia in India; they include lack of sensitive and specific local measures of assessment, diet rich in antioxidants, predominantly rural residence, differing lifestyles when compared to the developed world, protective family structure.^{19,30;33;36-44}

Prevalence of Dementia by Age and Gender

Of the 3.7 million Indian people aged over 60, 2.1 million are women 1.5 million men.⁴⁵ The prevalence of dementia increases steadily with age and higher prevalence is seen among older women compared with men (figure 2). It is argued that this cannot be explained by the fact that women live longer in India,⁴⁶ because, studies of age-specific incidence of dementia among older people show no significant differences between women and men.⁴⁷ It may, therefore, appear that gender is not a risk factor for AD or other dementia among older people.

Figure 1: Prevalence of dementia in India compared with Europe (and 95% confidence intervals) ³⁵

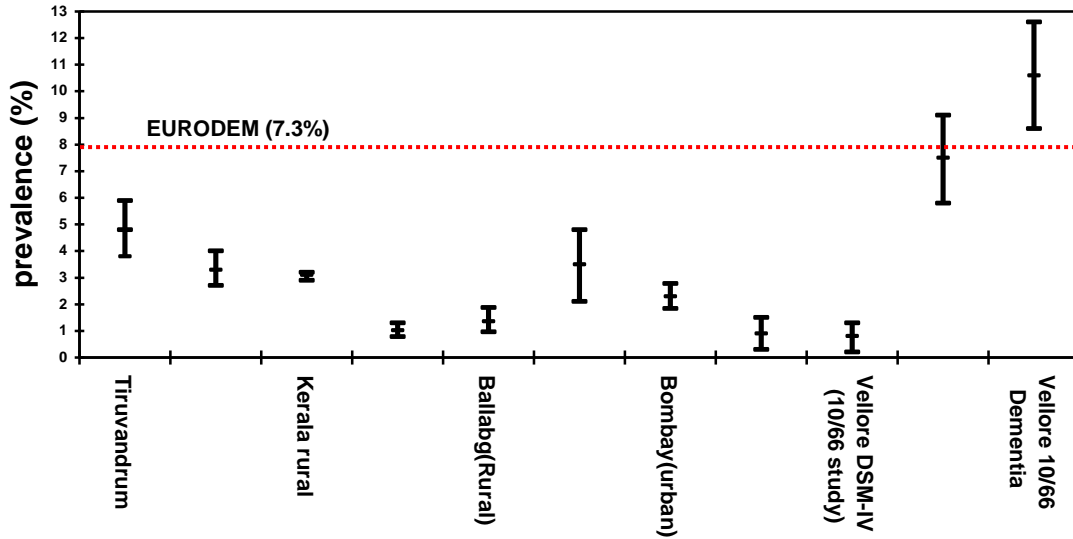
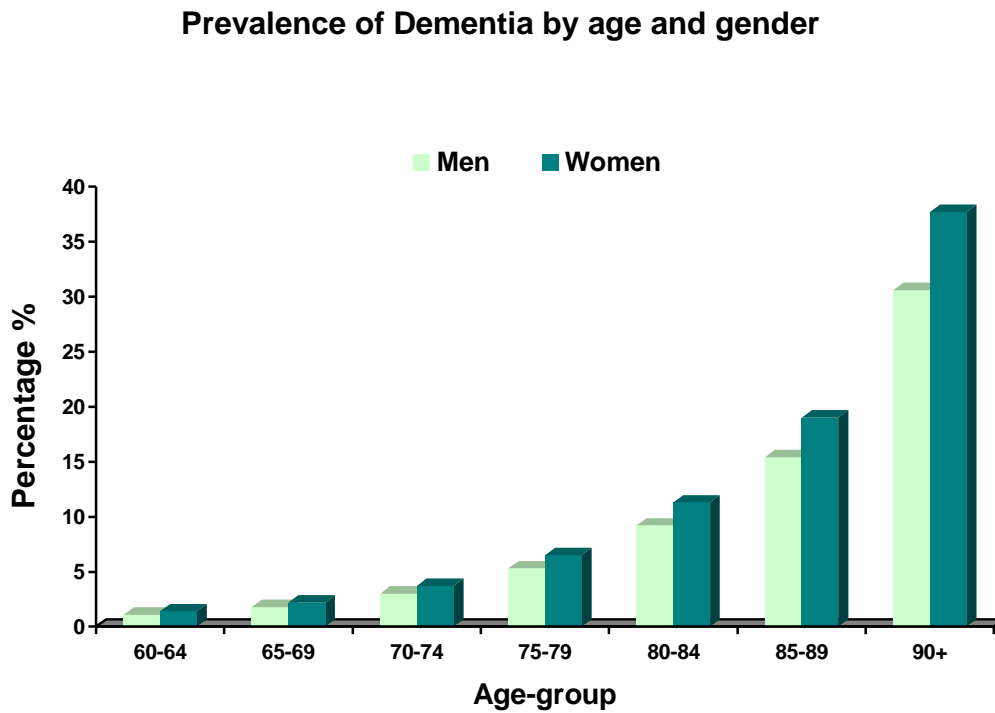


Figure 2: Prevalence of Dementia for India by Age and Gender, 2010 ⁴⁸



Incidence of Dementia:

The Delphi consensus study² estimated that on a global basis, there are 4.6 million new cases of dementia every year (about one new case every 7 second) and that the number of people living with dementia is projected to double every 20 years. Incidence data on dementia from India is limited; a study conducted on rural Ballabgarh, Haryana reported a 3.24 incidence rate per 100,000 (95% confidence intervals [CI] 1.48–6.14) for people over 65 years of age. The overall (using age-standardized against the age distribution of the 1990 US population) incidence rate among those aged 65 years in Ballabgarh was 4.7 per 1000 person–years.⁴⁷

Current Estimation and Future Projection

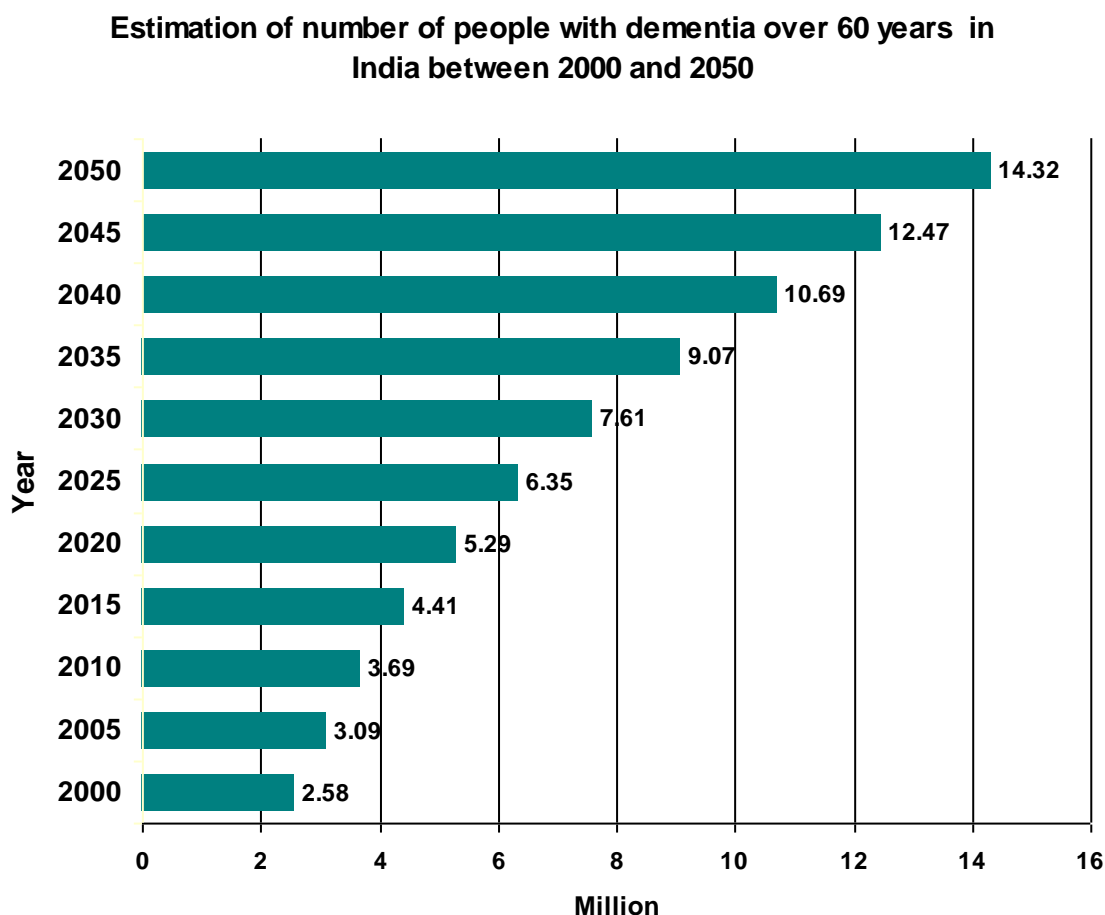
Future Projections

The future projections estimated in the World Alzheimer Report 2009⁶ are based on the assumption that prevalence of dementia is stable over time, but this may not be true. If the number of older people increases with escalating life expectancy, eventually the prevalence of dementia will increase. For example, in India the number of people with AD and other dementias is increasing every year because of the steady growth in the older population and stable increment in life expectancy (figure 3) resulting in an estimated increase of twofold by 2030 and threefold by 2050.

Estimates for the Numbers of People with Dementia, by State in India

Appendix 1 indicates the variation of projected estimates of the number of people aged over 65 of age with dementia for years 2011, 2016 and 2026 by state and region in India. It illustrates that by 2026 more than 500,000 older people with dementia are expected to be living in Uttar Pradesh and Maharashtra. In other states (Rajasthan, Gujarat, Bihar, West Bengal, Madhya Pradesh, Orissa, Andhra Pradesh, Karnataka, Kerala and Tamil Nadu) around 20,000 to 40,000 persons with dementia are expected within the next 26 years. Compared to 2006, Delhi, Bihar and Jharkhand are expected to experience 200% (or greater) increment in total number of dementia cases over 26-year period. Other states (Jammu and Kashmir, Uttar Pradesh, Rajasthan, Madhya Pradesh, West Bengal, Assam, Chhattisgarh, Gujarat, Andhra Pradesh, Haryana, Uttaranchal, Maharashtra, Karnataka and Tamil Nadu) are proposed to experience 100% (or more) change in number of people older people with dementia.

Figure 3: Estimation of number of people with dementia over 60 years in India between 2000 and 2050 ⁴⁸



The increased numbers of people with dementia will have a marked impact on states’ infrastructures and healthcare systems, which are ill prepared in many regions and also on families and caregivers. Although the projected increases in the South region are not nearly as marked as those in other regions of the Indian population, it should be noted that this section of the country is the residence of a large proportion of people aged 65 ⁴⁹.

Impact of Dementia

Burden of dementia: According to the World Health Organisation (WHO) Global Burden of Disease report 2006, dementia is the third leading cause contributors to years if life lost due to disability (YLD) in the elderly in low-income and middle-income countries⁵⁰. The WHO Report estimated that dementia is the a second highest source of disease burden after tropical diseases⁵⁰.

In terms of YLD, dementia contributes 11.2% of YLD in people aged 60 and over, which is more than stroke at 9.5%, musculoskeletal disorders at 8.9%, cardiovascular disease at 5.0% and all forms of cancer at 2.4%⁵⁰. It is predicted that the economic burden of dementia in the Asian region will increase from 58% in 2005 to 68% in 2030, while other conditions will fall from 31% to 19% in 2030⁵¹.

Dementia is often associated with physical, mental and financial burden and Governments neither provide long-term care nor support carers⁵. The 10/66 Dementia Research Group's study in India and other low income and middle income countries examined the impact of care giving for an elderly population and found that carers of people with dementia spent significantly longer time providing care compared to carers and co-residents of depressed persons or others.³⁷ The highest proportion of time was spent communicating, supervising, and helping with eating and toileting.³⁷ The majority of carers were in paid employment, many of which were having to take time off work to provide care.³⁷ This resulted in an economic burden exacerbated with increased health care expenses over time.⁵² Moreover, carers of elderly people with dementia experienced greater psychological distress compared with carers of elderly people with other medical conditions⁵².

Evidence suggests that elderly people with dementia in developing countries do not often utilise health services, and when they do, the health care system is often ill prepared to provide quality services for dementia³⁹. In comparison with developed countries, older people in India with dementia or other disabling condition receive low pension benefits; for example: 44% and 28% of older people with dementia in rural and urban India are reliant on family income⁶. (Table 3) In addition, around one fifth of older people with dementia (10% to 37% by country) in developing countries are classified as having potentially vulnerable living circumstances⁶. (Table 3) Many need long-term care, currently provided by family carers, with primary care services not meeting their needs⁵.

Aetiology

Risk factors

Advanced age remains the main risk factor for most forms of dementia, with prevalence roughly doubling every five years over the age of 65 in India and in the neighbouring regions⁶. Onset

Table 3: Social protection for older people with dementia - 10/66 catchment area surveys in Latin America, India and China ⁵

Population-based centre catchment area	n	Income security			Secure living arrangements			Availability of family support			
		Receiving a government or occupational pension %	Receiving income from family transfers %	Receiving a disability pension %	Experiencing food insecurity %	Living alone %	Living with spouse only %	Total %	No children %	No children within 50 miles %	Total %
Cuba (urban)	323	81.4	7.4	0.9	5.6	6.3	10.2	16.5	16.5	3.0	19.5
Dominican Republic (urban)	242	27.3	23.6	0.8	13.7	8.5	10.2	18.7	12.0	13.1	25.1
Venezuela (urban)	146	41.1	2.7	4.1	2.7	5.7	4.9	10.6	7.8	5.6	13.4
Peru (urban)	130	58.5	5.4	1.1	1.6	1.6	9.4	11.0	16.4	0.0	16.4
Peru (rural)	36	66.7	0.0	0.0	8.6	13.9	8.3	22.2	19.4	5.7	25.1
Mexico (urban)	93	78.5	7.5	1.1	3.2	14.0	9.3	23.3	4.3	0.0	4.3
Mexico (rural)	87	34.5	17.2	2.3	12.6	16.5	11.1	27.6	4.6	1.2	5.8
China (urban)	84	84.5	11.9	0.0	0.0	2.5	34.5	37.0	0.0	0.0	0.0
China (rural)	56	10.7	23.2	0.0	3.6	3.6	8.9	12.5	3.6	4.2	7.8
India (urban)	75	13.3	28.0	2.7	28.0	4.0	13.3	17.3	5.3	0.0	5.3
India (rural)	108	26.9	44.4	0.0	17.6	15.1	5.7	20.8	8.3	2.6	10.9

before 65 year of age is rare and, in the case of AD, often suggests a genetic cause⁵³. Single gene mutations at one of three loci (Beta amyloid precursor protein, presenilin1 and presenilin2) account for most of these cases⁵⁴.

For late-onset of 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 has one or two copies^{53;54}. However, the frequency of the *APOE E*4* allele is reported as lower in two population based studies^{55;56}.

The evidence strongly establishes a causal role of cardiovascular risk factors and cardiovascular disease in the aetiology of dementia and AD⁵⁷. In short⁵⁸⁻⁶⁰ and longer latency^{61;62} incidence studies, smoking increases the risk for AD: odds ratio (OR) 2.40 (95% CI,1.16-5.17)⁶¹. However occasional negative finding have also been reported from large populations based prospective studies^{58;63}.

Those with high cardiovascular risk scores (incorporating hypertension, diabetes, hypercholesterolemia and smoking) have an increased risk for dementia incidence whether exposure is measured in midlife or a few years before dementia onset.²⁸⁻²⁹ Recent studies report associations between metabolic syndrome and incident cognitive decline⁶⁴, and insulin resistance and impaired executive function⁶⁵. Diabetes is also reported as a risk factor⁶⁶, and

long term cohort studies, midlife hypertension and hypercholesterolemia^{67;68} have been shown to be associated with late life onset of AD.

Evidence from cross-sectional and case-control studies suggest associations between AD disease and limited education: relative risks [RR] 3.2 (95% CI)2.2 to 4.6)⁶⁹ and head injury: RR 1.82 (95% CI 1.26–2.67)^{70 71} which, however, are only partly supported by longitudinal (follow-up) studies⁷².

Depression had been reported as a risk factor: RR 2.94; (95% CI, 1.76 to 4.91) in short term longitudinal studies, but this may be because depression is an early presenting symptom, rather than a cause of dementia⁷³.

The findings from these studies supports the hypothesis that atherosclerosis⁶⁸ and AD are linked, with several common underlying risk factors such as apoE e4 gene (0.3 ± 0.042 in AD vs 0.16 ± 0.027 in controls)⁵³, hypertension, increased fat intake and obesity; RR 1.35 (95% CI,1.14 to 1.60)⁷⁴, raised cholesterol: OR 2.2 (95% CI 1.0 to 4.7)⁶⁸, diabetes ; RR 1.9 (95% CI, 1.2 to 3.1)⁶⁶, metabolic syndrome RR; 1.66 (95% CI, 1.19 to 2.32)⁶⁴.

Management of dementia

The standard treatment goals of dementia management include⁶:

- Early diagnosis.
- Optimization of physical health, cognition, activity and well being.
- Detection and treatment of Behavioural and Psychological Symptoms of Dementia.
- Educating carer and providing long term support to carer.

Treatments for Cognitive impairment and Behavioural and Psychological Symptoms of Dementia

Cholinesterase Inhibitors (ChEIs) and N-methyl D-aspartate (NDMA)⁷⁵⁻⁷⁷ receptor antagonists have been reported to be useful in improving cognitive function of older person with dementia. Cost effectiveness of such medication hasn't been tested in India and recommendations regarding their use will depend upon affordability and availability of specialist support.⁶ Costs

of ChEIs are available at low cost in India.⁶ Although antipsychotic drugs have shown to be less effective in trials, they may provide benefits for some patients⁷⁸⁻⁸¹ particularly those for whom aggression is a problem⁸². However, there are serious concerns about their safety in terms of an increased risk of death⁸⁰ and adverse cerebrovascular events⁸¹. Insufficient research has been carried out to be clear about the potential benefits of Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants⁸³⁻⁸⁵ and carbamazepine⁸⁶.

Carer interventions: Key components of carer interventions include⁸⁷:

- Psycho educational interventions, many of which include an element of carer training.
- Psychological therapies, e.g. cognitive behavioural therapy (CBT), and counselling.
- Carer support.
- Respite care.

Systematic reviews and meta-analyses have shown the benefit of carer interventions in preventing or delaying hospitalisation, carer strain, depression and subjective well-being.⁸⁸ Many carer interventions combine several of these elements. Unfortunately, most of the carer intervention trials have been conducted only in developed countries. However, one trial from India with a small sample size showed a larger treatment effect than are typically seen in trials of such interventions in high income countries, on carer psychological morbidity and strain⁸⁹. This trial, originally developed in India, with input from the wider 10/66 group including experts from more developed countries⁹⁰ was specifically designed for diverse low and middle income country settings where services are not orientated to meet the needs of people with dementia. It focused its attention on the concept of the multi-purpose health worker with the aim to provide basic education about dementia and specific training on managing problem behaviours of dementia. In parallel with other epidemiological surveys, the 10/66 dementia research group have tested the effectiveness of training these health workers^{39, 91, 92} and initial findings has shown highly promising results⁹³.

Dementia care in India

There is limited evidence about health care utilization for dementia in India. Older people with dementia and their families are unlikely to access healthcare, despite the high levels of associated disability and caregiver strain.⁵ Lack of service development is also due to tendency to view dementia as normal part of ageing.⁴³ In the current India scenario and despite a number of government initiatives (discussed below), the current primary care system is ill prepared to

provide dementia care, therefore most dementia cases are managed in specialist or secondary care units.⁹⁴ Constructing dementia care at community level, could encourage easy help-seeking. However, efforts to increase demand for dementia community care must be accompanied by health system and health service reform, so that help-seeking is met with a supply of better-prepared, more responsive services.

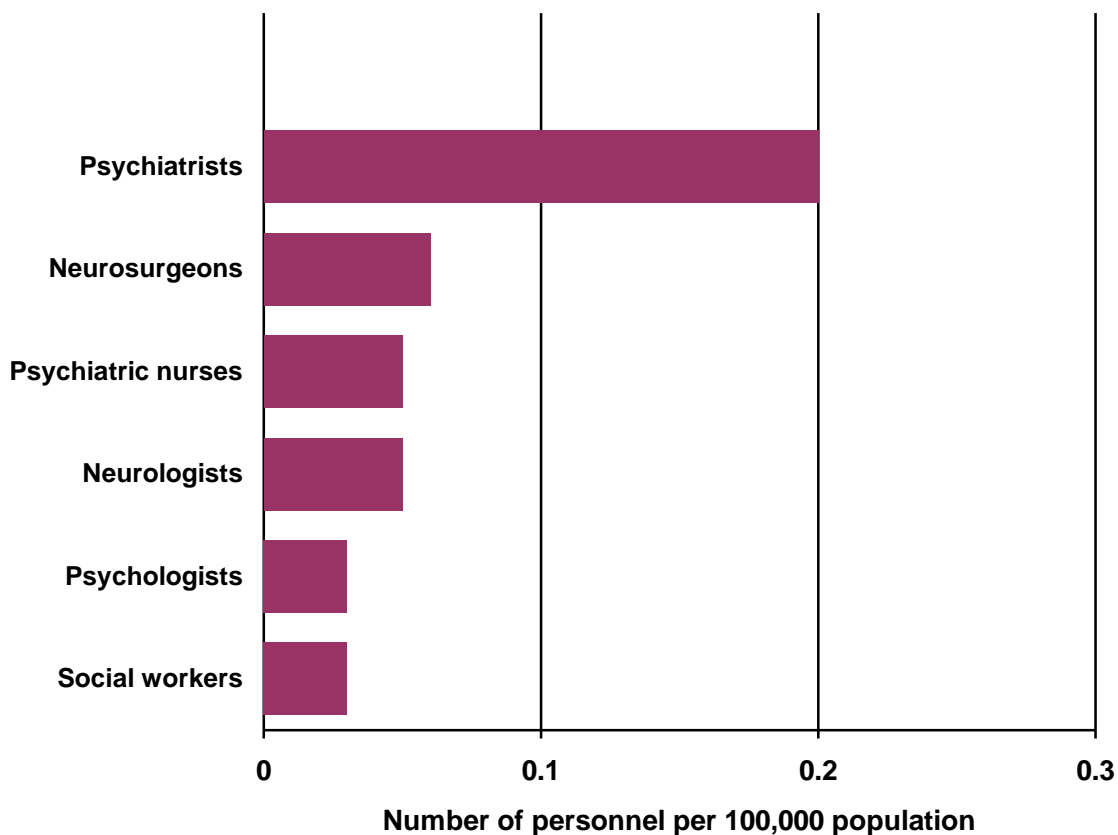
Barriers to Scale -up dementia care services in India

Awareness: In India, early memory related impairments are considered to be normal part of aging⁴³. Although typical features of dementia are widely recognised in India⁹⁵, the condition is not considered as a health problem and is not perceived as requiring medical care⁴⁰. To a large extent cognitive and functional impairment caused by AD is tolerated by family members and friends⁴³. Moreover, the Indian community and family place few expectations for elderly⁴¹. This particular cultural norm complicates assessment of functional decline in older persons with dementia which is integral part of diagnostic criteria of dementia. Thus, primary health physicians rarely see this condition in their clinical work, whereas community health workers do⁴³.

Mental Health resources: One well established barrier to scaling up dementia care service is insufficient number of people who are trained to provide care (figure 4)⁹⁶. Poor working conditions and low status of the profession means that few people enter mental health field⁹⁷. At the same time higher salaries in private practice and overseas means that mental health professionals prefer and take these options⁹⁷. According to 2001 census data, 78% of older people in India live in rural areas and migration of young adults to the urban areas isolates many older people with increasing need for care⁴⁶. The specific issue is that mental health professionals tend to work in urban areas with few incentives to live in rural areas⁹⁷ In addition, comparative to urban areas, low mental health resources are allocated to rural areas in India.⁹⁷

Lack of Policy initiative on dementia care: Unfortunately dementia is not considered as health care priority in India. Findings from 10/66 dementia research group study reports that disability and dependency is strongly linked to poverty, and imposes additional economic strain on families³⁷. In most parts of India institutionalised care is not available.⁴ Even if relevant services were available, the affordability would become a burden for many families,⁴

Figure 4: Human resource for dementia care in India, per 100,000 populations.⁹⁶



resulting in the majority of older people with dementia being cared at home by their families.¹⁹ Although dementia has been reported as a well established cause of dependency among older people, no clear system has been developed for ensuring the social protection of older people with dementia⁵.

National and international policies in dementia

National Dementia initiatives: Alzheimer’s and Related Disorders Society of India (ARDSI) with the support from The Ministries of Social Justice & Empowerment and Health & Family welfare have recently undertaken consultative meetings across India with the aim to identify the gaps in diagnosis, treatment, care, support, and research for people affected by dementia in India. As an outcome “The Dementia India Report”⁴⁵ was released at National Dementia summit, New Delhi, September, 2010.⁹⁸ It is expected to serve as a road map and a policy guide

for the Government of India in developing a National Dementia Strategy. The report will include:

- Dementia as a public health problem.
- Prevalence rates and projections for 20 years.
- Impact of Dementia – on family, society, health service system.
- Dementia co-morbidity and relation to elder disability.
- Treatments available for dementia - drugs and psycho-social interventions.
- Available services - pathways to care.
- Costs of dementia care - direct, indirect and intangible.
- Legal issues - rights, laws and associated acts.
- Preventive strategies - primary, secondary, tertiary measures.

While there is currently no direct policy for the care of people with dementia, there are a number of government and voluntary initiatives that support the health and social care needs of the elderly in India. They include some of the following:

The National Policy for Older Persons 1999 aims to promote the health and welfare of senior citizens in India and encourages individuals to make provision for their own as well as their spouse's old age. It also strives to encourage families to take care of their older family members. This policy enables and supports voluntary and non-governmental organizations to supplement the care provided by the family and provide care and protection to vulnerable elderly people. Health care, research, creation of awareness and training facilities to geriatric caregivers have also been enumerated under this policy. This policy has resulted in the launch of new schemes such as:

1. Strengthening of primary health care system to enable it to meet the health care needs of older persons.
2. Training and orientation to medical and paramedical personnel in health care of the elderly.
3. Promotion of the concept of healthy ageing.
4. Assistance to societies for production and distribution of material on geriatric care.
5. Provision of separate queues and reservation of beds for elderly patients in hospitals.
6. Extended coverage under the Antyodaya Scheme with emphasis on provision of food at subsidized rates for the benefit of older persons especially the destitute and marginalized sections.

The Integrated Programme for Older Persons (2007) is a scheme that provides financial assistance to non-governmental organizations to establish and maintain old age homes, day care centers, mobile Medicare units and that provides non-institutional services to older persons.

The National Mental Health Programme (1982) focuses on prevention and treatment of mental and neurological disorders and their associated disabilities and use of mental health technology to improve general health services. Despite there being a focus on the needs of senior citizens who are affected with AD and other dementias, Parkinson’s disease, depression and psycho-geriatric disorders, it failed to make adequate provision for specific dementia treatments and services.⁹⁹ For example, under the NMHP, essential psychiatric drugs were to be provided in all health care facilities, but the coverage for mental illnesses, especially AD remains poor. (Table 4).⁹⁹

Table 4: Actual and target coverage of medication for patients with mental disorders, India 2003^{99, 100}

Disorder	Current percentage	Target percentage
Schizophrenia	39.8	76.0
Bipolar disorder	38.3	74.5
Depression	28.3	67.0
Panic disorder	16.3	62.5
Alcohol misuse	20.3	73.0
Alcohol dependence	22.8	71.0
Alzheimer’s disease	9.0	69.0

Source: Adapted from Ferri *et al.* (2004: 225).

International initiatives¹⁰¹

WHO: The WHO have been instrumental in developing policy and practice guidelines for governments. While in no way binding, these detailed documents can be influential in steering national, regional and global health policy.

The WHO policy document *Towards an international consensus on policy for long-term care of the ageing*¹⁰² describes principles to inform policies for sustainable programmes in long-term care of the ageing population that are consistent with the priorities of countries at different levels of development. This is meant as a first step towards devising an international consensus.

In addition, the WHO Global Report on *Innovative care for chronic conditions*¹⁰³ alerts policy makers, particularly those in low and middle income countries to the implications of the decreases in communicable diseases and the rapid ageing of populations. It provides a flexible and comprehensive framework¹⁰⁴, on which to build or redesign health systems that are fit for purpose at the micro (patient and family), meso (healthcare organization and community), and macro (policy) levels.

AD International's Kyoto Declaration: At their 20th annual conference held in Kyoto, Japan, AD International (ADI) released a Kyoto Declaration, comprising minimum recommendations for dementia care, based upon overall recommendations from the 2001 WHO Health Report. The ADI Kyoto Declaration benchmarks progress in ten key areas. (Appendix 2) This framework addresses health services and system structures, treatment gaps, policies, research and training and identifies target levels of attainment, for countries with low, medium and high levels of resources. Hence, it proposes a feasible, pragmatic series of objectives and actions for health systems at all levels of development.

Dementia research initiative in India

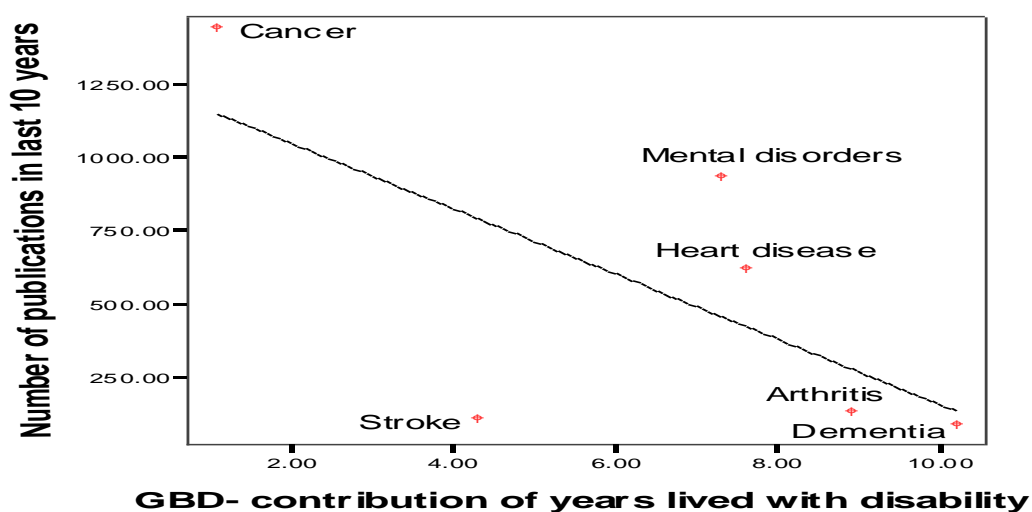
A search of PubMed/Medline for the last 10 years identified 1426 publications from India related to cancer, 604 related to heart disease, 917 related to mental disorder (excluding dementia), 94 related to stroke, 119 related to arthritis and 76 related to dementia. The correlation between research effort (number of publications in India) and disability (years lived with disability) is presented in Figure 5.¹⁰⁵ Clearly, research efforts on dementia is minimal with an inverse correlation between the contribution of these chronic diseases associated with disability, and research effort. The more disabling the disease, the less it seems to be researched in India. As such, the following research priorities are recommended:

- Better surveillance to provide timely and reliable prevalence, incidence and mortality rates.
- Community based cohort studies investigating risk factors for dementia such as early life exposure.
- Suitable and cost-effective interventions in the management and treatment of dementia. For example, more research is needed to test the effectiveness and potential benefits of simple low-cost strategies and to investigate the effectiveness of non-pharmacological

interventions such as reminiscence therapy, cognitive stimulation, massage and aroma therapy which can be easily applied by carers at home. Decentralisation of tertiary care institutions, development of community-based rehabilitation services, psychiatric care in general hospitals and mental health care in primary health care and other health care settings need to be developed and evaluated especially in the rural areas.

- Economic cost of dementia care in both rural and urban sites.

Figure 5: Correlation of research effort in India (publications in last 10 years) with disability (years lived with disability, for six major chronic diseases)¹⁰⁵



Appendix 1: Estimation for number of people living with dementia by State between 2006 and 2026 ⁴⁸

States	Year	Projected numbers (in '000s) with dementia by age group					Percentage of change in dementia's compared to 2006
		65-69	70-74	75-79	80+	Total	
Jammu& Kashmir	2006	4.0	4.9	6.4	6.9	22.2	
	2011	4.6	5.8	6.7	13.0	30.0	35
	2016	5.5	6.7	8.1	17.1	37.4	68
	2021	6.9	8.2	9.5	21.7	46.3	108
	2026	8.5	10.4	11.7	26.6	57.3	158
Himachal Pradesh	2006	3.0	3.9	5.7	9.3	21.8	
	2011	3.3	4.3	5.5	13.7	26.8	23
	2016	3.9	4.9	6.2	16.1	31.0	42
	2021	4.7	5.8	7.0	18.6	36.1	65
	2026	5.5	7.0	8.4	21.4	42.3	94
Punjab	2006	11.5	16.8	23.3	35.3	86.9	
	2011	11.9	17.1	23.7	54.8	107.6	24
	2016	14.7	17.8	24.4	67.5	124.4	43
	2021	18.8	22.1	25.7	76.6	143.1	65
	2026	23.0	28.5	32.0	83.9	167.5	93
Uttaranchal	2006	3.8	4.9	6.3	7.2	22.1	
	2011	4.2	5.5	6.7	12.8	29.1	31
	2016	4.9	6.1	7.7	17.1	35.7	61
	2021	5.8	7.2	8.7	21.0	42.7	93
	2026	6.8	8.7	10.3	25.1	50.9	130
Haryana	2006	8.5	12.4	16.8	18.6	56.4	
	2011	8.7	12.7	17.6	35.0	74.0	31
	2016	10.7	13.0	18.2	46.1	88.0	56
	2021	14.2	16.2	18.8	54.0	103.1	83
	2026	18.3	21.5	23.5	59.8	123.0	118
Delhi	2006	4.8	5.7	7.1	8.5	26.1	

	2011	6.0	7.1	8.1	15.1	36.3	39
	2016	8.2	9.0	10.2	20.7	48.1	84
	2021	11.1	12.4	13.1	27.1	63.7	144
	2026	14.9	16.9	18.1	35.3	85.1	226
Rajasthan	2006	22.7	29.3	37.1	23.5	112.6	
	2011	24.5	33.1	40.8	66.6	164.9	46
	2016	29.0	36.2	46.7	98.0	209.9	86
	2021	36.2	43.1	51.6	126.2	257.0	128
	2026	44.6	54.3	62.0	150.7	311.6	176
Uttar Pradesh	2006	68.1	85.7	106.1	50.3	310.3	
	2011	72.0	96.5	115.0	172.7	456.3	47
	2016	83.1	104.4	133.2	259.7	580.4	87
	2021	102.0	122.4	147.0	340.4	711.7	129
	2026	123.7	152.1	174.6	411.0	861.4	177
Bihar	2006	33.3	40.9	40.2	19.6	134.0	
	2011	36.2	47.5	54.8	67.3	205.7	53
	2016	42.6	52.5	65.3	116.6	277.0	106
	2021	52.6	62.6	73.3	161.9	350.3	161
	2026	63.7	78.1	88.3	201.2	431.3	221
Assam	2006	9.0	11.0	13.6	9.3	41.9	
	2011	10.0	12.5	14.3	23.4	60.3	40
	2016	12.4	14.1	16.8	33.1	76.4	78
	2021	16.0	17.9	19.5	42.9	96.2	124
	2026	20.5	23.4	25.1	52.7	121.7	183
West Bengal	2006	33.5	41.9	53.6	53.7	182.7	
	2011	38.1	47.9	56.4	102.2	244.7	33
	2016	46.9	55.2	65.7	135.4	303.2	66
	2021	59.5	68.7	76.8	169.2	374.2	104
	2026	73.9	88.0	96.8	206.0	464.6	154
Jharkhand	2006	10.2	11.6	11.0	5.5	38.3	
	2011	11.8	14.2	15.3	18.6	59.9	56
	2016	14.5	16.9	19.2	32.6	83.1	117
	2021	18.1	21.0	23.3	46.7	109.1	184

	2026	21.8	26.5	29.4	61.3	139.0	262
Orissa	2006	17.5	22.1	27.1	28.9	95.6	
	2011	18.3	24.4	28.8	51.7	123.3	28
	2016	21.0	26.2	33.0	68.7	148.9	55
	2021	26.0	30.7	36.3	85.9	178.9	87
	2026	32.0	38.5	43.4	101.8	215.8	125
Chhattisgarh	2006	9.2	11.1	12.7	7.1	40.0	
	2011	9.9	12.7	14.3	20.9	57.8	44
	2016	11.4	14.1	17.0	31.4	73.9	84
	2021	13.8	16.5	19.3	41.9	91.4	128
	2026	16.8	20.2	23.0	51.9	111.9	180
Madhya Pradesh	2006	24.8	31.3	37.8	21.4	115.3	
	2011	25.8	34.6	40.8	63.0	164.3	42
	2016	29.5	36.9	46.6	92.6	205.6	78
	2021	36.8	42.8	50.9	119.6	250.0	116
	2026	46.6	54.2	60.2	142.8	303.9	163
Gujarat	2006	21.6	26.8	32.5	42.6	123.5	
	2011	24.7	31.7	37.0	69.0	163.1	32
	2016	30.7	36.8	44.7	92.8	204.9	66
	2021	39.3	46.1	52.6	118.3	256.3	107
	2026	48.9	59.6	66.6	145.5	320.6	159
Maharashtra	2006	47.7	67.5	80.0	82.8	277.9	
	2011	47.7	68.2	89.2	155.0	360.1	29
	2016	56.4	69.1	92.2	211.8	429.5	54
	2021	71.2	82.7	95.0	252.1	501.0	80
	2026	88.8	105.4	115.3	282.3	591.7	112
Andhra Pradesh	2006	35.6	43.5	50.3	54.0	183.4	
	2011	38.7	50.6	57.6	99.0	245.9	34
	2016	46.3	55.9	68.9	136.8	307.9	68
	2021	56.7	67.9	77.5	176.4	378.5	106
	2026	68.3	84.0	95.3	213.5	461.1	151
Karnataka	2006	23.9	29.9	38.2	47.8	139.8	
	2011	26.8	34.7	41.1	80.5	183.1	31
	2016	33.3	39.4	48.4	104.6	225.8	61

	2021	41.3	49.4	55.8	130.3	276.8	98
	2026	49.4	61.8	70.5	156.7	338.4	142
Kerala	2006	18.4	24.7	33.0	58.1	134.3	
	2011	20.1	26.8	33.6	77.6	158.1	17
	2016	24.5	29.7	37.3	90.9	182.5	35
	2021	29.6	36.6	41.9	104.8	212.9	58
	2026	33.9	44.6	52.2	120.3	251.0	87
Tamil Nadu	2006	34.0	40.9	49.4	85.2	209.4	
	2011	38.2	48.3	54.3	114.6	255.4	22
	2016	45.0	55.0	65.4	140.0	305.5	45
	2021	53.4	65.8	75.9	171.9	366.9	75
	2026	61.8	78.8	92.0	207.0	439.5	110
North East States (Excluding Assam)	2006	4.1	5.1	7.1	8.5	24.8	
	2011	4.9	6.0	7.3	15.8	34.0	37
	2016	6.3	7.2	8.6	20.7	42.9	73
	2021	8.1	4.7	10.5	25.7	49.0	97
	2026	10.1	12.2	13.8	31.6	67.8	173

Appendix 2. Minimum actions required for dementia care (based on overall recommendations from the World Health Report, 2001).¹⁰¹			
	Scenario A:	Scenario B:	Scenario C:
Ten overall recommendations	Countries with a low level of resources	Countries with a medium level of resources	Countries with a high level of resources
1. Provide treatment in primary care	Recognize dementia care as a component of primary healthcare 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 5 years).	Develop locally relevant training materials Provide refresher training to primary care physicians (100% coverage in 5 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 healthcare 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 Move people with dementia out of inappropriate institutional settings	Initiate pilot projects on integration of dementia care with general healthcare 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	Develop alternative residential facilities Provide community care facilities (100% coverage) Give individualized care in the community to people with dementia

		accreditation	
4. Educate the public	Promote public campaigns against stigma and discrimination Support non-governmental 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 non-governmental 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 sub national 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 healthcare workers. Initiate higher professional training programmes for doctors and nurses in old age 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	Strengthen community programmes	Occupational health services for people with early dementia Provide special facilities in the

	activities of non-governmental organizations		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 healthcare 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

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