

THE DEMENTIA INDIA REPORT 2010

Prevalence, impact, costs and services for dementia

EXECUTIVE SUMMARY



- In 2010, there are 3.7 million Indians with dementia and the total societal costs is about 14,700 crore
- While the numbers are expected to double by 2030, costs would increase three times
- Families are the main carers and they need support

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A report prepared for the
Alzheimer's and Related Disorders Society of India



Published by Alzheimer's and Related Disorders Society of India, New Delhi

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Citation: Alzheimer's & Related Disorders Society of India (2010). The Dementia India Report: prevalence, impact, costs and services for Dementia: Executive Summary. (Eds) Shaji KS, Jotheeswaran AT, Girish N, Srikala Bharath, Amit Dias, Meera Pattabiraman and Mathew Varghese. ARDSI, New Delhi. ISBN:

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None of the funders / funding agencies had any role in preparing the report or directly or indirectly influenced the content of the report.

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The authors would like to thank the participants who took part in the meetings across the country for their inputs and suggestions.

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Special thanks to:

Dr Neela Patel, Dr A.B. Dey and Dr E S Krishnamurthy

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The report and related initiative was possible because of the generous funding support from Dr Raghunandan Gaiind

In memory of Bau Jee, his father, an ardent educationalist and champion of equal rights for women. He would welcome this report and initiative by ARDSI in India.

ARDSI acknowledges the financial assistance and support of:

- NISD, Ministry of Social Justice and Empowerment
- Ministry of Health and Family Welfare, Government of India
- World Health Organisation
- Alzheimer's Disease International
- HelpAge India
- Eisai India Ltd

PREFACE

Meeting the challenge of dementia in India –

It is estimated that over 3.7 million people are affected by dementia in our country. This is expected to double by 2030. It is estimated that the cost of taking care of a person with dementia is about ₹43,000 annually; much of which is met by the families. The financial burden will only increase in the coming years. The challenge posed by dementia as a health and social issue is of a scale we can no longer ignore. Despite the magnitude, there is gross ignorance, neglect and scarce services for people with dementia and their families. We know that dementia is not part of aging and is caused by a variety of diseases. We now have a range of options to treat the symptoms of dementia and offer practical help to those affected.

Alzheimer's and Related Disorders Society of India (ARDSI) the national voluntary organization dedicated to the care, support and research of dementia has been in the forefront to improve the situation since 1992. ARDSI is committed to developing a society which is dementia friendly and literate. This could only happen if we have the political commitment at all levels to provide a range of solutions that deliver a life with dignity and honour for people with dementia.

The 'Dementia India Report' is an ambitious visionary document calling for government and policy makers to recognize dementia as a health and social welfare priority by developing a National Dementia Strategy. The report has been put together after a series of consultations across the country from January 2009 to March 2010. The editors have used these consultations and the data available from the findings of the 10/66 Dementia Research Group worldwide, the ADI's World Alzheimer Report 2009 and from other research in India.

This is a significant step forward in dementia care movement in our country. Many countries like Australia, England, France, Norway, Netherlands, and South Korea have already recognised the problem and have devised national dementia strategies and have made dementia a national health priority. It is coincidental the Ministry of Health is about to launch the National Health care programme for the elderly. The Ministry of Social Justice and Empowerment has undertaken the revision of the national policy for older persons. This could be used as an advantage for promoting better dementia care in the country. It is our fervent hope that this report will prompt the government for setting up memory clinics and other care services at the district levels and a National Alzheimer's Centre at the capital. We sincerely hope that the government will consider the recommendations seriously and include dementia care in the primary healthcare system.

I would like to congratulate the editorial and scientific team for producing this brilliant report, which is the first of its kind from a developing country. We hope that this will stimulate the government, policy makers, health care professionals, family members and other associations to action and collaboration. With a new case of dementia in the world every seven seconds THERE IS NO TIME TO LOSE.

Dr. K. Jacob Roy
National Chairman.
Alzheimer's and Related Disorders Society of India (ARDSI)

**Alzheimer's and Related Disorders Society of India (ARDSI)
Dementia INDIA REPORT 2010
EXECUTIVE SUMMARY**

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Introduction: The Challenge of Dementia in India

Demographic aging is a global phenomenon. It has picked up momentum in low income countries of Asia, Latin America and Africa. India's population is undergoing a rapid demographic transition now. Soon, there will be a sharp increase in the number of older people in our population. It is important to note that this rapid demographic change is happening along with fast paced social restructuring that accompanies the economic development. This makes the task of meeting the needs for the older people a more challenging and urgent one.

India is home to more than 70 million people older than 60 years as per the 2001 Census. This age group, only 7.5% of the population in 2001, is expected to grow dramatically in the coming decades. With demographic ageing comes the problem of dementia. The numbers of persons with dementia double every 5 years of age and so India will have one of the largest numbers of elders with this problem.

There is a growing realization that the care of older people with disabilities makes enormous demands on their carers. The Alzheimer's and Related Disorders Society of India (ARDSI) initiated awareness programmes in 1993 to address this growing problem in India. In affiliation with the Alzheimer's Disease International (ADI), an international umbrella organisation for all national dementia organisations, ARDSI has been working to increase the awareness of dementia and advocate care and rights of persons with dementia (PWD) and their families. Terms like dementia and Alzheimer's disease are now better understood. Still, dementia remains a largely hidden problem in India, especially in those disadvantaged parts of India where poverty and illiteracy levels are high.

Understanding dementia and its management

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

The relationship between brain pathology and dementia syndrome

The Dementia syndrome is linked to a very large number of underlying causes and diseases in the brain. The common causes accounting for 90% of all cases are Alzheimer's disease, Vascular dementia, dementia with Lewy bodies and Frontotemporal dementia. These are degenerative brain diseases and altering the progressive course of the disorder is not possible. However, symptomatic treatments

may delay the relentless course of the disease, ameliorate the troublesome behavioural symptoms and timely support can help people with dementia and carers. Some less common causes of dementia (like chronic infections, brain tumours, hypothyroidism, subdural haemorrhage, normal pressure hydrocephalus, metabolic conditions, and toxins or deficiencies of vitamin B12 and folic acid) are particularly important to detect since some of these conditions may be treated partially by timely medical or surgical intervention. The characteristic symptoms and neuropathological findings are summarised below:

Table 1: Common subtypes of irreversible dementia

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

Clinical features – the importance of behavioural and psychological symptoms of dementia (BPSD):

When making a diagnosis, clinicians focus their assessments on impairment in memory and other cognitive functions and loss of independent living skills. The focus is on the ABC symptoms of dementia i.e., the Activities of Daily living (ADL), the Behavioural and Psychological Symptoms of Dementia (BPSD), and the

Cognitive and memory symptoms. For carers, and arguably, for people with dementia, it is the behavioural and psychological symptoms linked to dementia and the deficits in the ADL that are most relevant and impact most on the burden and the quality of life. Problem behaviours include agitation, aggression, sleep disturbance, wandering, apathy, anxiety, depression, delusions and hallucinations. Most studies indicate that BPSD are an important cause of carer strain. BPSD occur most commonly in the middle stage of dementia and are mistaken by carers as deliberate behaviours.

The Course and Outcome of Dementia

Dementia affects every person in a different way. Its impact can depend on what the person was like before the disease; his/her personality, lifestyle, significant relationships and physical health. The problems linked to dementia can be best understood in three stages. The duration of each stage is given as a guideline; sometimes people can deteriorate quicker, and at other times more slowly.

Early Stage: first year or two

The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as normal part of 'old age'. As the onset of the disease is gradual, it is difficult to be sure exactly when it began. The person may have problems talking properly (language problems), become lost in familiar places, have difficulty in making decisions, show mood changes, depression or anxiety and show a loss of interest in hobbies and activities.

Middle stage: second to fourth or fifth years

As the disease progresses, limitations become pronounced and more restricting. The PwD has difficulty with day-to-day living and, may become extremely dependent on their family and carers and need help with personal hygiene like toileting, washing and dressing.

Late Stage: fifth year and after

This stage is one of near total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may have difficulty eating or difficulty walking, have bladder and bowel incontinence or be confined to a wheel chair or bed.

The Management of Dementia: The standard treatment goals are

- Early diagnosis
- Optimization of physical health, cognition, activity and well being
- Detection and treatment of BPSD
- Educating carer and providing long term support to carer

Current evidence-based treatments

Partially effective treatments are available for most core symptoms of dementia. These treatments are all symptomatic, that is, they can ameliorate a particular symptom, but do not alter the progressive course of the disease. Treatment basically is directed towards the management of the cognitive, behavioural and the ADL symptoms of dementia. The two broad interventions for management are:

a) Pharmacological Interventions

There are a number of drugs available for the management of dementia like Donepezil, Rivastigmine, Galantamine and Memantine. All these drugs are available in India at a reduced cost varying from Rs 300 a month to about Rs 1500 a month. As these drugs are less expensive, there must be an attempt to make these drugs free through the public health system as with other psychotropic drugs.

b) Psychological Interventions

Research has shown that cognitive stimulation and psychological interventions can provide benefits in the early stages of the disease. In the later stages, they are not of much use for the cognitive symptoms. Caregiver interventions can be provided at low cost and have shown an effect on decreasing caregiver strain. A large literature attests to the wide-ranging potential benefits of carer interventions in dementia.

Aetiology: Understanding Risk Factors

It is very important to understand the risk factors of dementia to plan preventive interventions. Risk factors can be divided as modifiable and non modifiable factors. In addition, various protective mechanisms are being researched. Understanding the modifiable risk factors would help in selecting the intervention strategies. Understanding the non modifiable risk factors would help in selecting the high risk groups and planning targeted preventive interventions, when universal intervention is not feasible.

Non modifiable factors	Modifiable factors
<ul style="list-style-type: none"> • Age • Family history + • ApoE4 allele • Female sex • Depression • Head trauma • Mutation on 1,14,21 chromosome • Down's syndrome 	<ul style="list-style-type: none"> • Vascular Disease • Hypertension • Diabetes • Dyslipidaemia • Nutritional deficiency (B vits) • Smoking • Alcohol • Obesity • Diet

From a primary prevention stand point, advancing age with memory problems should alert the physician to screen for dementia. Elderly individuals with genetic vulnerability and family history of dementia in first degree relatives (especially of the early onset type) are high risk groups for dementia. In addition, people who have had, vascular disease, diabetes, chronic depression and head injuries are known to be at higher risk and so should be followed up for memory problems in later life.

More research needed

The disappointing results from preventive intervention trials to date indicate that, despite much research, there is very little understanding of the environmental and lifestyle factors linked to AD and other dementias. Prevalence and incidence of AD seems to be much lower in some developing regions like India. This may be because some environmental risk factors are much less prevalent in these settings. Conversely, some risk factors may only be apparent in low and middle income countries, as they are too infrequent in the developed economies for their effects to be detected. For example, dietary deficiencies, particularly of micronutrients, are widespread and strongly linked to poverty. Deficiencies of folate and vitamin B₁₂ are of particular interest given their consequences; anaemia, raised homocysteine levels, increased risk of stroke and ischaemic heart disease.

A Public Health Model Intervention for Prevention of Dementia

There is a need to recognize the importance of prevention and early intervention and use a public health model to prevent dementia. There is some evidence from studies with other chronic diseases like hypertension and diabetes mellitus that prevention programs for vascular disorders and risk factors would possibly help in dementia prevention too. Greater integration of care and increased use of chronic disease prevention and management is recommended. A better understanding of the risk factors and identification of factors which would protect or may reduce the risk for dementia is essential for controlling this 'silent epidemic'. It is necessary to build research capacity in India in order to generate an evidence base relevant to our population.

Awareness about dementia:

AD and other dementias have been reliably identified in all countries, cultures and races in which systematic research has been carried out. However, levels of awareness vary enormously across countries and even within countries. The public awareness about dementia in India is low. In most settings, there is no awareness of dementia as an organic brain syndrome or as any kind of medical condition. Primary care doctors do not encounter many cases in their practice and there is no special emphasis on dementia diagnosis and management in the training of healthcare professionals. Media interest in dementia and related healthcare issues remain low. This general lack of awareness has serious consequences as families do not seek help and health services do not recognise the problem.

Actions to improve awareness

In developed countries, dementia awareness is growing rapidly, with the media playing an important part. Recent evidence-based reports from the UK and the Australian Alzheimer associations garnered considerable media attention and were instrumental in making dementia a national priority in both countries. Public awareness in low and middle income countries is lacking, with few media outlets carrying stories about dementia and ageing. While the media in India is now more receptive to these stories as part of their role in informing the public and stimulating debate, efforts are required to alert them of the importance of ageing and dementia, and to build their capacity to report, research and understand its local relevance. Health care professionals should have necessary skills to manage common health problems affecting older people. Medical training needs to reorient itself to meet the healthcare needs of an aging society.

Methodology used in this report

The Alzheimer's and Related Society of India (ARDSI) held a series of regional consultative meetings in 2009/10 with health care professionals, policy makers, organizations engaged in dementia care as well as carers to develop a scientific status report on dementia. The first meeting was held in January 2009 in New Delhi followed by meetings in Mumbai, Coimbatore, Bangalore, Kolkata and concluded with the final meeting in Trivandrum in March 2010. There was another national consultative meeting at New Delhi together with many NGO's, professionals, carers and members of the dementia strategy groups from the USA, UK and France and the Ministry of Social Justice and Empowerment. The deliberations at these regional and national meetings were collated and a group of experts were assigned to write out the report for India in April 2010. This report was then sent to different experts and stakeholders all over the country and also to experts from other Associations aboard.

This report describes the problem of dementia as a disease and the current evidence for medical and psychosocial management of the disease. The public health aspects of creating awareness and possible ways of prevention of the disease in India are discussed. The report makes an estimate of the number of people with dementia in different regions of India and also projections on numbers of people with dementia in the future. This report also estimates the wider impact of this devastating illness on the affected people, their families, the society and the nation at large. It also focuses on issues concerning the carers and the need to address the same. Finally, it describes the current state of dementia care and services in India. Resource limitations and feasibility concerns are taken into consideration.

The report proposes possible steps to address the public health challenges posed by dementia. The importance of prevention, early identification and need for simple effective interventions are highlighted. The report identifies strategies and

action plans which can be scaled up easily and have the potential for wider implementation across the country. A call for action based on scientific analysis of the current evidence base and the available national resources is made. It is hoped that this call for action will set the stage for the development of a National Dementia Strategy for India.

Number of Persons with dementia: prevalence

In the last 10 years, the evidence on dementia prevalence in India has expanded considerably. More than 42,000 older people have been studied in eight centres across India, and wide variations in estimates exist. Prevalence of dementia using survey diagnosis or clinical diagnosis of DSMIV or ICD 10 reported from Indian studies range from 0.6 % to 3.5% in rural areas and 0.9% to 4.8 % in urban areas. The difference in reported prevalence could be explained by lack of sensitive and specific local measures of assessment, methodological differences in the studies and a host of genetic, sociocultural and environmental factors.

Why do we need estimates for India?

Studies on dementia prevalence are scattered around India, 6 studies in south region and single studies from the west, east, and northern regions. Data were lacking in many regions of the country and the reported few studies have widely varying estimates of prevalence. Although the coverage of evidence is good in south India, wide variability compared to studies from north pose difficulties to provide a consistent overview for the whole country. Therefore, it is important to synthesise the evidence on the prevalence of dementia by generating quantitative meta-analyses with available evidence.

Methodology for estimation of numbers

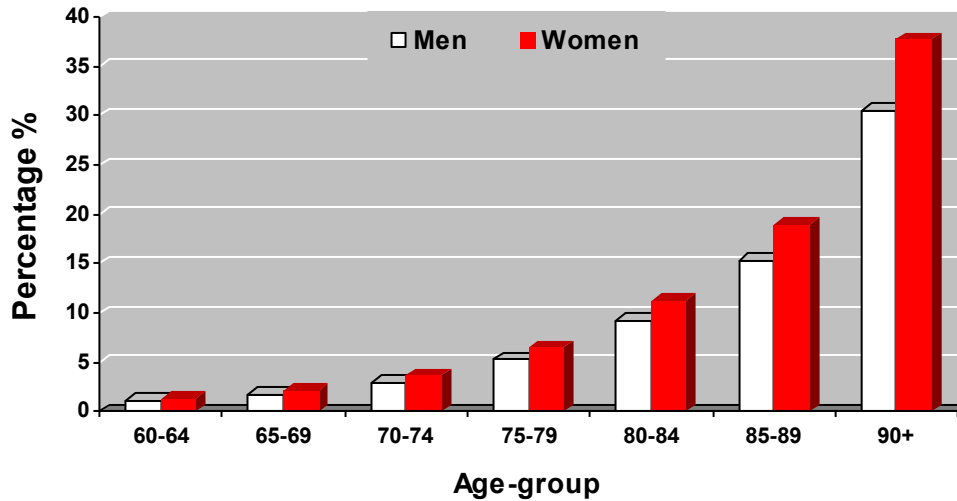
A detail literature review was conducted using search term Dementia AND Prevalence OR Epidemiology AND India in EMBASE, Medline and PsycINFO, which yielded 86 publications from India. All eligible studies were systematically coded for their study design and quality according to the decided criteria. Prevalence data was extracted from the studies. The detailed methodology is mentioned in the full report. As per the criteria, six publications were taken for further review and included in the meta-analysis.

Current Estimation and Future Projection

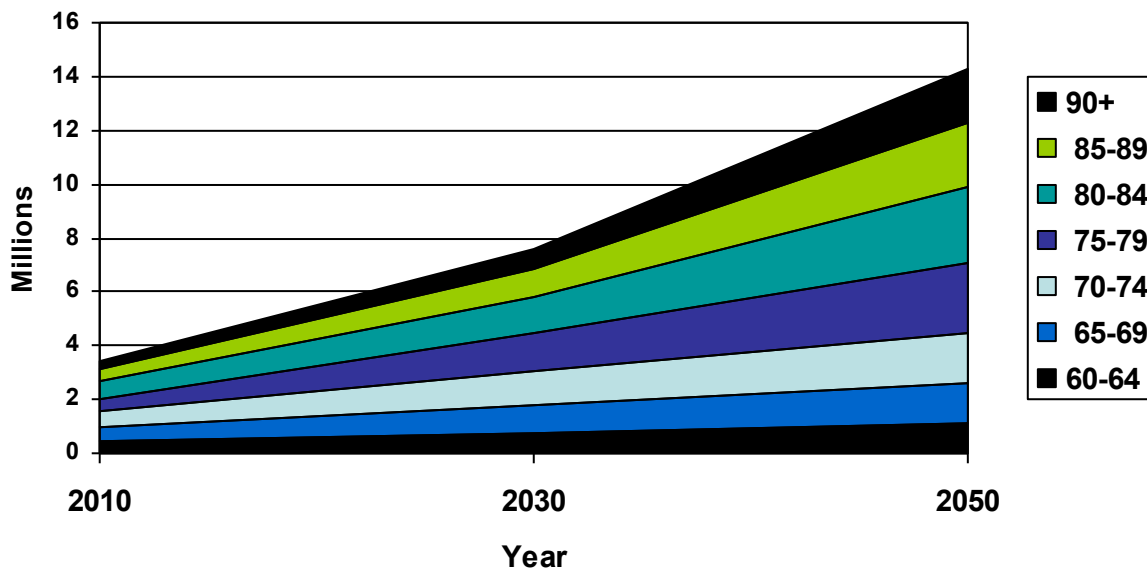
Presently, an estimated 3.7 million Indian people aged over 60 have dementia (2.1 million women and 1.5 million men). The prevalence of dementia increases steadily with age and higher prevalence is seen among older women than men. The larger proportion of older women than men who have dementia can be explained by the fact that women live longer in India. In general, studies of age-specific incidence of dementia among older people show no significant difference for women and men. It may therefore, appear that gender is not a risk factor for AD or other dementias among older people. The PwD in younger age groups of 60-75years are expected to

increase steadily over time. On the other hand, the steep increment over the 75 age group can be predictable after 2030.

Prevalence of dementia by age and gender



Numbers of people with dementia by age, 2010-2050

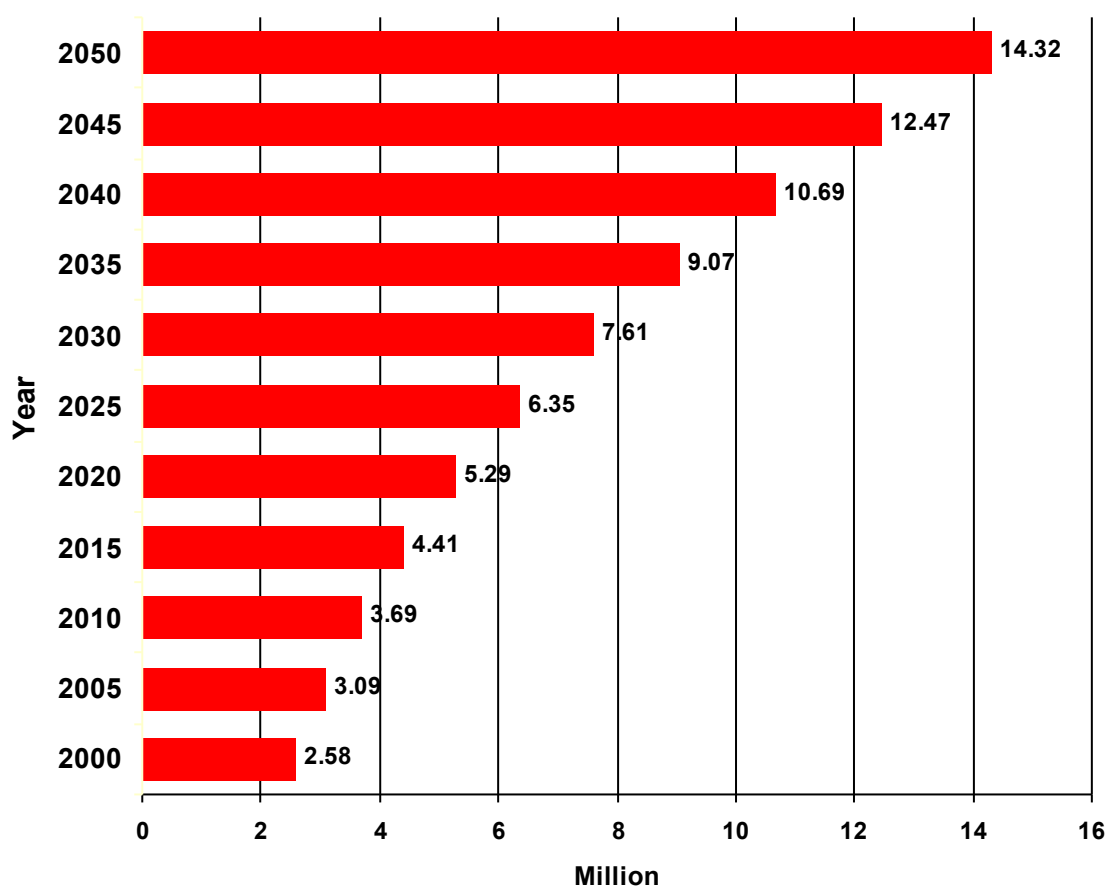


Future Projections

The future projections are estimated based on the assumption that prevalence of dementia is stable over time; however, this may not be true. If the incidence of dementia or number of older people with increases escalating life expectancy,

eventually the prevalence of dementia will eventually 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 resulting in an estimated increase of twofold by 2030 and threefold by 2050.

Estimation of number of people with dementia over 60 years in India between 2000 and 2050

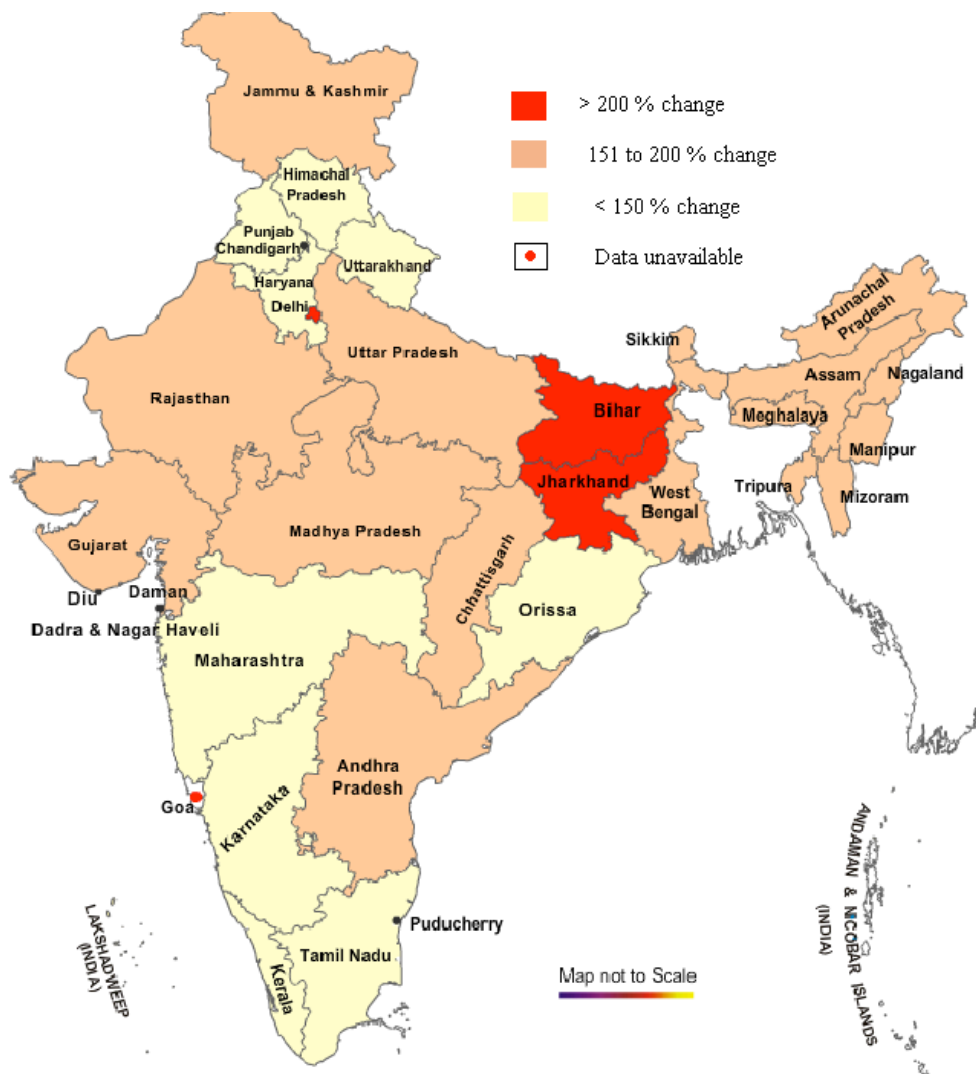


Estimates for the Numbers of People with Dementia State-wise in India

The projected number of people aged 65 and older with dementia for years 2011, 2016 and 2026 varies by state and region in India. Projections were made using meta-analyzed prevalence estimation for India and the 2001 Census data for future projection. Not only is there substantial variability by state in the projected numbers of people with dementia, but also between regions of the country. 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 the 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 estimated to experience 100% (or more) change in number of older people with dementia.

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 Southern region are not nearly as marked as those in other regions of India, it should be noted that this section of the country is the residence of a large proportion of people aged 65 and above.



Projected changes from 2006 and 2026 in number of people with dementia by State

The data on prevalence clearly identifies the importance of dementia in India, and the growing number of older PwD in upcoming years. More epidemiological studies are needed to close the gap between regions uncovered, where a large number older people are residing. Studies should also explore regional, cultural, ethnic, religious, socioeconomic diversities and co morbid chronic diseases like diabetes and vascular disease and disability, needs for care, care arrangements, health service utilization of PwD and their families.

The Impact of Dementia

The estimated number of people living with dementia in India is an important indicator of the impact of the disease; however numbers alone cannot convey the effects on the quality of the individual experience, or the wider consequences.

The impact of dementia can be understood from three inter-related levels:

1. The individual: The PwD experiences ill health, disability, impaired quality of life and reduced life expectancy.
2. The family: Dementia in a family member has an overall impact on the entire family and the kinship of the affected person. The family faces significant burden and the illness affects their quality of life. The family forms the cornerstone of care and support of the PwD.
3. The society: The cost of providing care and support is met by the society, either directly through government expenditure and monetary costs or by indirect ways. The cost of lost productivity will also have to be accounted for. Other social impacts may be harder to quantify, but are no less real.

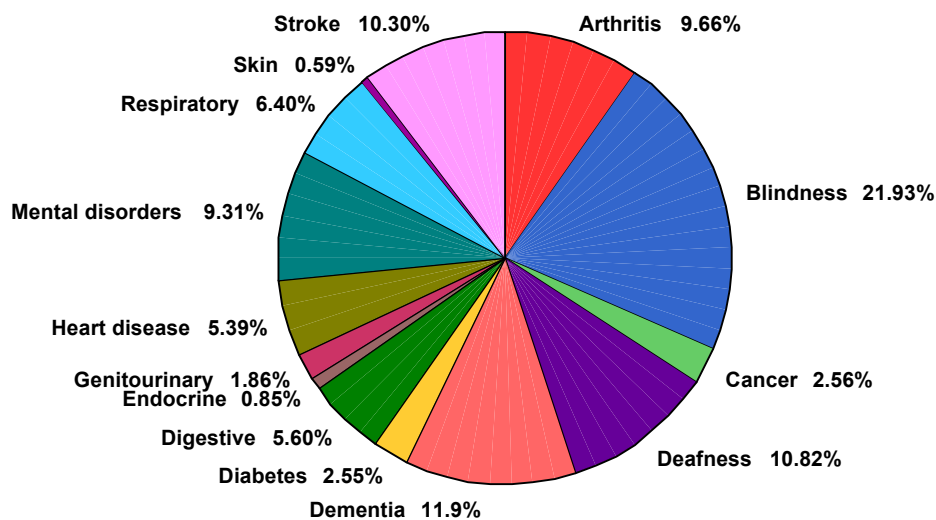
The report provides information about the impact of dementia with respect to disability, mortality and dependency and at the societal level, to economic costs in India. The extent and nature of the care provided for PwD in India, and the impact of dementia care on the carers themselves is also described.

Disability, Dependency and Mortality:

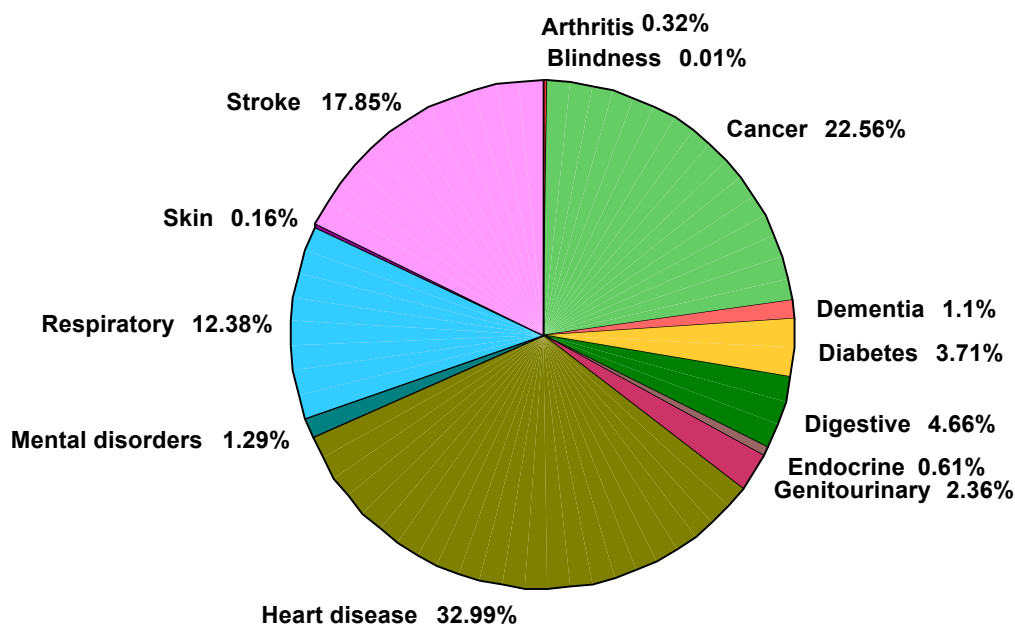
The WHO's Global Burden of Disease Report, first published in 1996 and updated in 2004, provides the key indicators as Disability Adjusted Life Years (DALYs), a composite measure of disease burden calculated as the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). The global age standardised death rate for AD and other dementias is 6.7 per 100,000 for males and 7.7 per 100,000 females. For India and WHO SEARO D sub region, the dementia mortality rate is 13.5 per 100,000 males and 11.1 per 100,000 females. Compared to other chronic medical conditions (heart diseases, cancer and stroke), AD is the fourth leading cause of death in the Asia Pacific region.

Studies from developing countries have found increased mortality risk for older PwD. In two studies from Brazilian and Nigerian on over 6000 individuals aged 65 years and over, a 51.3% death rate for the dementia group compared to non dementia group was found. Persons with dementia from Nigeria died within five years of the diagnosis. The only study from India, conducted in Chennai, investigated predictors of mortality among older people living in the community. The study reported a higher risk of mortality (2.3 times) for older people who received a diagnosis of dementia at the baseline survey and risk of mortality was linearly associated with the severity of cognitive impairment.

A key finding from the Global Burden of Disease report is that chronic non-communicable diseases are rapidly becoming the dominant causes of ill-health in all developing regions except Sub-Saharan Africa. It is important therefore, to understand the contribution of dementia, relative to that of other chronic diseases. The figure below indicates the proportionate contribution of different chronic diseases to the total chronic disease burden among people aged 60 years and over, expressed in terms of both YLD and YLL.



Contribution of chronic diseases to years lived with disability



Contribution of chronic diseases to years of life lost

The GBD report indicates that dementia is one of the main causes of disability in later life. Older people are particularly likely to have multiple health conditions. Chronic physical diseases affecting different organ systems can coexist with mental and cognitive disorders. These multiple pathologies will interact in complex ways to create difficulties in performing important tasks and activities (disability), and in determining needs for care (dependence). It is often said that dementia has a disproportionate impact on capacity for independent living.

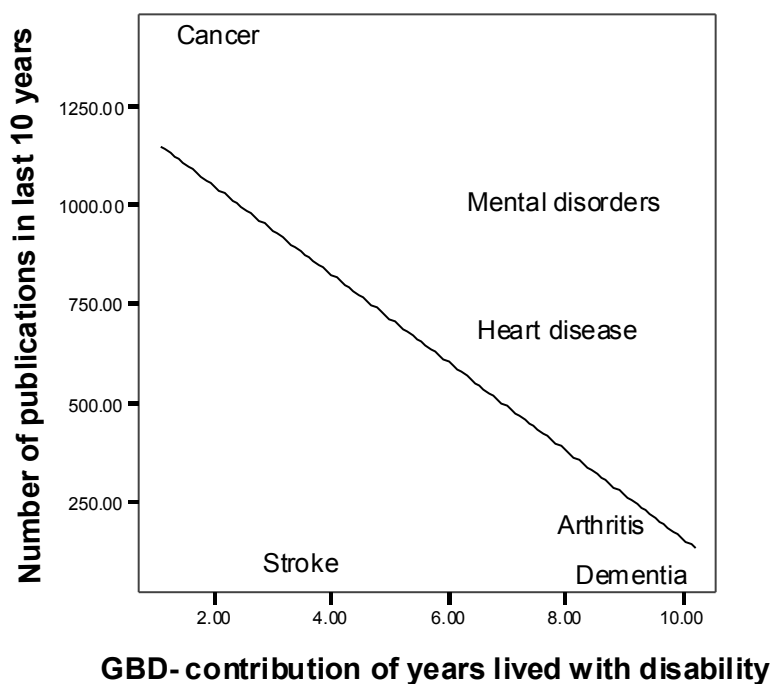
The World Alzheimer's Report (2009) highlights the importance of co-morbidity in the causation of disability and dependence. PwD often have serious co-morbid physical health problems and both contribute to disability and need for care. In three recent publications (from urban and rural sites in Cuba, Dominican Republic, Venezuela, Peru, Mexico, China and India), the 10/66 Dementia Research Group has assessed the impact of dementia, depression and physical impairment on dependence. Those with needs for care were characterised by co-morbidity between dementia (cognitive impairment) and physical and mental disorders. Dementia emerged as the leading independent cause of both disability and dependency, followed by limb weakness, stroke, depression, eyesight problems and arthritis. Neither ischaemic heart disease nor hypertension, or even chronic obstructive pulmonary disease was associated with disability or dependency.

Adding life to later years: Can we reduce functional impairment in older people?

The impact of dementia is felt much more on the quality of life of the older person. It results in significant disability, leading to impairments in activities of daily

living. This means many years lived with disability. Interventions might prevent or delay disability, thereby adding 'life to years'. Though this is important and feasible, disability reduction never gets due attention, both by policy makers and health care practitioners. Much more is spent on healthcare for cardiovascular diseases and cancer, than on healthcare for dementia. Dementia affects many more lives apart from the lives of people who have dementia. It is time that political parties, policy makers and administrators in India recognize the importance of preventing disabling conditions like dementia and providing interventions to reduce the suffering of those who live with this disability in late life.

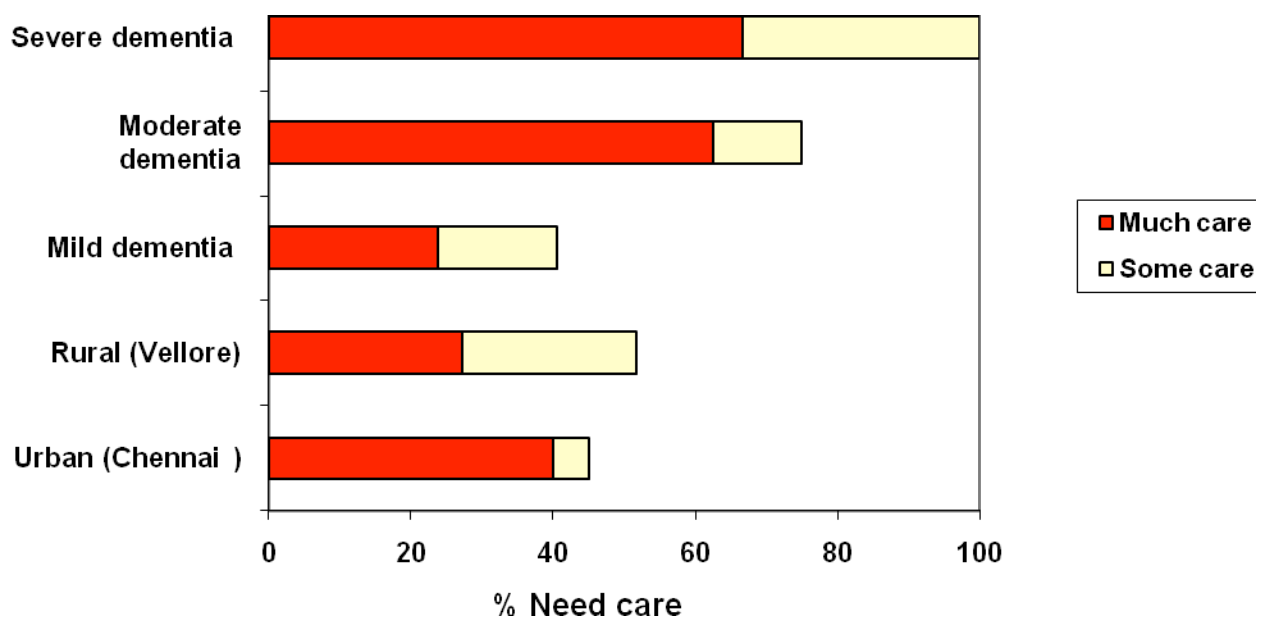
Analysing the research effort from India by a search on Pub Med/ Medline for the last 10 years revealed 1426 publications related to cancer, 604 related to heart disease, 917 related to mental disorders, 94 related to stroke, 119 related to arthritis and 76 related to dementia. The correlation between research effort (number of publications), mortality (years of life lost) and disability (years lived with disability) is presented. Clearly, the research effort on dementia is the least and there is an inverse correlation between the contribution of these chronic diseases associated with disability and research effort. The more disabling the disease, the less has it been researched. Conversely, there is a strong positive correlation between years of life lost and research effort. Only good quality research can provide proper guidance to service development with a need to develop inexpensive, effective interventions with a potential to scale up in the community. Dementia needs to be recognized by research funding agencies like the ICMR, the DST and the DBT as a priority health condition for future research.



Care of Persons with Dementia: Who needs care?

According to most diagnostic definitions, all PwD experience at least some degree of functional disability. This does not imply that they should all be regarded as needing care. Needs for care were assessed in the 10/66 Dementia Research Group's population-based studies in Latin America, India and China. The needs for care among those with dementia (CDR 1 or above) from the Indian centres are summarized in figure below. In most sites, between 50 and 70% of those with dementia were rated as needing care, and most of those needing care needed 'much care'. Needs for care varied by level of dementia, with 30% of those with mild dementia, 69% of those with moderate dementia, and 88% of those with severe dementia needing much care. In the urban Indian centre of this study, 78.5% of those with dementia needed much care. In the case of the rural Vellore, the proportion needing much care was 33.3 %.

**Needs for care among people with dementia in India
(10/66 Dementia Research Group population-based studies)**



Dementia: Who cares?

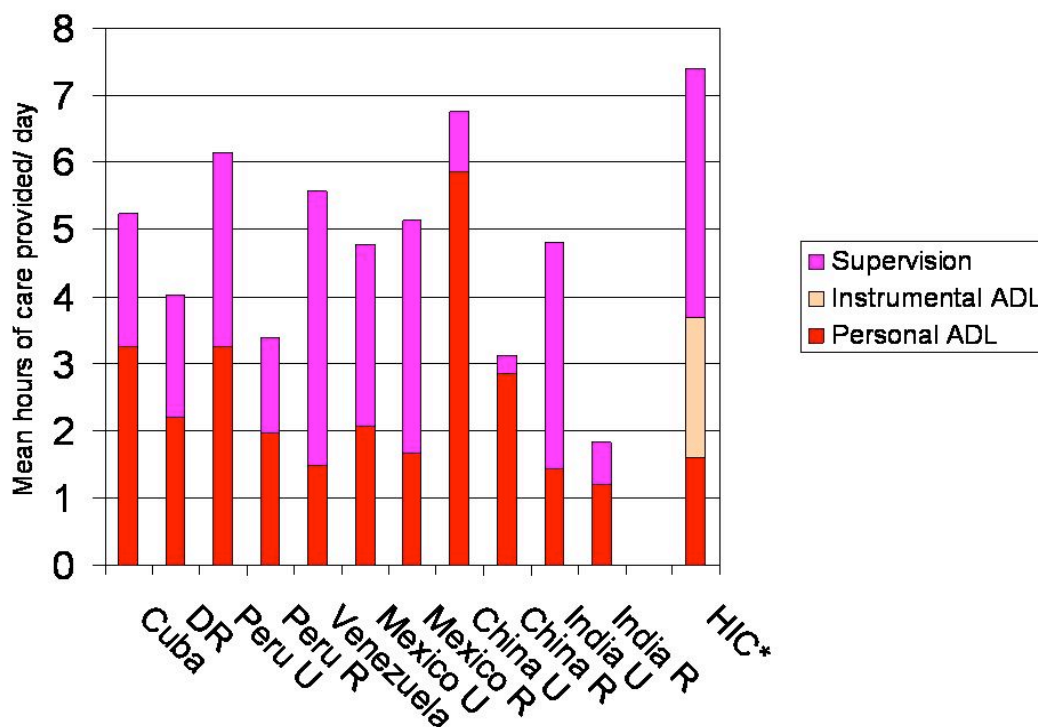
In India, PwD continue to live with their families. Dementia care is usually a joint effort by the adult members of the family who stay in the same household. The 10/66 Dementia Research Group's multicentre pilot study (10/66 Dementia Research Group, 2004) included 179 carers from six different locations in India (Bangalore, Chennai, Goa, Hyderabad, Thrissur and Vellore). Most of the primary carers were women (75%) and majority of them were co-residents (98%). Most PwD lived in large households, with extended families; one quarter to one half of households comprised three generations, including children under the age of 16 years. None of

the carers received any carer benefits. It is important to recognise that other family members and friends are often routinely involved in providing care. Paid caregivers were not involved in dementia care from the Indian centres. There is increasing demand for paid carers, more so in urban India. Though there are no formal training programmes, there are agencies that help families to hire workers. Formal short training programmes for these workers are very much needed. The placement agencies need to be registered and regulated.

Dementia: Nature of Care

The care provided for PwD can be classified into support with personal activities of daily living (PADL – including washing, dressing, grooming, toileting, eating), instrumental activities of daily living (IADL – cooking, shopping, laundry, household finances), and general supervision. A recent review of the literature found that carers of PwD spent an average of 1.6 hours daily assisting with core PADL. Including the time spent assisting with IADL increased this figure to 3.7 hours, and when general supervision was also taken into account the average care input was 7.4 hours per day. The mean daily hours of PADL care and supervision provided by carers of PwD in the 10/66 population based survey are summarised below in figure.

Mean daily hours of personal ADL care, and supervision provided by carers of PwD in high income and low and middle income countries (10/66 Dementia Research Group population-based studies)



These estimates from 10/66 Dementia Research Group centres in low and middle income countries were certainly no lower, and if anything a little higher, for

personal care, than those suggested by the earlier review of high income country studies. The severity of dementia is the strongest predictor of hours of PADL support, which increased from an average of 2.3 hours for mild dementia to 7.1 hours for severe dementia.

Impact of Dementia care- Psychological and physical health of caregivers:

The negative consequences of care giving have been widely studied. It is important to remember that most family and friends involved in providing informal care take pride in their role, and perceive many positives. The levels of carer strain in low and middle income countries were found to be as high as those seen in the European EURO CARE project. Home-based care received no formal support from existing services. Carers generally do not have access to information or advice about dementia care. Even literate caregivers tend to misinterpret symptoms of dementia as deliberate misbehaviour. Current support systems are grossly inadequate and need reinforcement. All the six 10/66 pilot study sites reported high levels of psychological morbidity, which ranged from 40 % to 72%. On an average, 60% of the 179 carers had evidence for adverse mental health impact indicated by the high scores on GHQ.

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

Dementia makes the largest independent contribution of any chronic disease to dependence (needs for care). There is also evidence to suggest that, among older people needing care, caring for a PwD compared to caring for older people with physical health conditions, places greater demands on the carer, and leads to more strain. The World Alzheimer's Report 2009 examined this issue further, using data from the 10/66 Dementia Research Group population based studies, to assess the independent effect of dementia, depression, stroke and physical impairment upon carer/co-resident psychological morbidity. In almost all sites, after adjusting for the effects of stroke, depression and physical impairment, there was a strong and statistically significant association between the presence of dementia in the older person and risk for psychological co-morbidity in the carer/co-resident. The pooled estimate across sites suggested that the carer/co-resident was twice as likely to have significant psychological morbidity in the presence of dementia.

The Costs of Dementia

Increasing costs of health care particularly large Out-Of-Pocket (OOP) expense for procuring services coupled with rapid increase in the number of people suffering from dementia indeed result in greater costs of dementia both to the family and society. Monetising or attributing money value to one or more components of management and care permits comparison either with other diseases or for the same disease over a period of time. The present estimate undertakes a family perspective of cost possibly incurred within a framework suitable and appropriate for management of dementia in the Indian context.

Cost estimates are from cost of illness studies of cost-benefit and cost-effectiveness analyses that are carried out to evaluate interventions. Cost of illness studies classifies costs into direct costs, indirect costs and intangible costs. Direct costs (medical and non medical) are those incurred directly for treatment and care for dementia within or outside the formal health care system. This includes cost of providing institutionalised care, paying care providers including physicians, long-term care/nursing homes and hospitals, medication, community-based care, over-the-counter medications and other out-of-pocket expenses. Indirect costs are those that are related to the consequence of dementia like reduction in workforce productivity, absenteeism or loss of productivity due to informal care (lost wages, lost profits, 'resources lost', etc).

The cost of dementia: global evidence

Worldwide annual cost of dementia has been estimated to be US\$ 604 billion for the year 2010 (1.01% of world GDP), an increase by 43% of the 2009 estimate (US\$ 421.6 billion) and almost double (92%) of 2005 estimate (US\$ 315.4 billion). Much of the costs have been due to informal care (US\$ 252 billion, 41.7%) or direct social cost (US\$ 256 billion, 42.3%). Worldwide the number of PwD is expected to double over the next twenty years (35.6 million in 2010 to 65.7 million by 2030); just this increase would push the cost by 85% in 2030. Low income countries with 14% of PwD contributed to less than 1% of the total cost while high income countries with 46% of PwD contributed to 89% of the costs. North America has highest cost per person (US\$48,605) and South Asia region has the lowest (US\$903): a difference of nearly 53 times. Reflective of the need for continued and long term care, direct social costs is 120 times more in higher income countries. However, two thirds of the costs in low income and lower middle income countries (58% and 65% respectively) is due to informal care as against 40% in high income countries. This is indicative of the critical and relatively dominant role of family care in resource-poor situations.

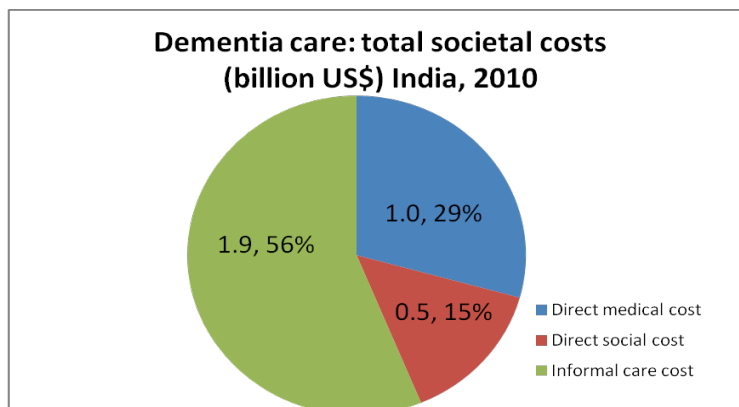
Costs of Dementia in South East Asia:

There are nearly 25 lakh PwD in the South East Asian region; this is 7% of the total global prevalence of dementia. The total cost of dementia (US\$ 3.97 billion) is about 0.3% of the GDP and contributes to less than 1% of the total global cost. The cost per person with dementia is US\$1601 and the predominant cost is due to informal care (44%). Direct medical care costs are more than two-thirds (37%) of the total costs while the remaining is direct social costs.

The cost of dementia: Indian scenario

With an estimated 3.7 million PwD in 2010, the calculated total societal cost of dementia for India was estimated to be US\$ 3.415 billion (INR 147 billion). While informal care is more than half the total cost (56%, INR 88.9 billion), nearly two-thirds (29%) of the total cost is direct medical cost (INR 46.8 billion). The total cost per person with dementia is US\$ 925 (INR 43,285). Interestingly, the informal care cost

per person in urban area (US\$ 257) was two and half times more than those in the rural area (US\$ 97).



Updating costs of dementia for 2009 from 2005, it was estimated the total societal costs of dementia for India to range between US\$ 9.4 (INR 451) billion to US\$ 13.7 (INR 657) billion, depending on the quantum of informal care (1.6 hours per day or 3.7 hours per day respectively). Direct costs were estimated to be US\$ 6.1 (INR 292) billion. With increase in quantum of informal care, the costs increased from 34% to 56%. The observed costs per PwD for the year 2005 was INR 96,850 (USD 2,229), INR 141386 (USD 3,254) and INR 263,350 (USD 5,061) with informal care of 1.6 hours per day, 3.7 hours per day and 7.4 hours per day respectively. The increased quantum of informal care indicates the increasing severity of dementia. These estimates included a direct cost of INR 198,197 (USD 4,561.5) per person per year.

The 10/66 Dementia Research Group, in their enquiry into care arrangement for PwD in developing countries observed the median per month health care cost for India to be less than INR 30 (US\$ 0.6) with an interquartile range of INR 0 to INR 171 (US\$ 0 to 3.6). While one third had reported no costs, 40% reported the costs to be range between INR 17.5 per month and INR 175 per month and the remaining (24%) reported the costs to be greater than INR 175 per month. This study did not primarily intend to capture economic data and was a pilot study undertaken on a small sample of 179 PwD in 2 centres.

Cost of Caring for the Person with Dementia:

Like several low and middle income countries, economic analysis of a disease/health situation is quite limited in the Indian subcontinent. With a lower priority for research, it is not surprising that ongoing and available research contributes little to economic analyses. To supplement available information, experience from two day care centers (Trivandrum and Bangalore), two residential centres (Trivandrum and Guruvayoor) and a hospital running an old age clinic (NIMHANS, Bangalore) were reviewed. It could be reasonably inferred that an

individual caring for a PwD in an urban area needs approximately INR 10,000 to 14,000 per month (Box).

Box

Mr. PQR provided some details of expenses incurred by 3 different persons

- | | |
|---|-----|
| 1. A person taken care by professional carers round the clock at home in a city | Rs. |
| 14,000 p.m. | |
| 2. A person staying in a small town and taken care of by semi-trained carers | Rs. |
| 8,000 p.m. | |
| 3. A person with AD who is staying in an old age home in Chennai | Rs. |
| 9,000 p.m. | |

.....the break-up of costs for the 3 stages of illness

I stage - 7,000 p.m. II stage - 10,000 p.m. III stage - 14,000 p.m.

The expenses were mounting because of doctor's home visits and frequent testing all done at home as the disease progressed.

(Source: personal communication)

In addition, to look at the household costs for dementia care, a desk work analysis was undertaken. The different components a household would incur either as specific expenditure or as foregone income was delineated and discussed with respect to a person with mild, moderate or severe form of dementia (Table 2). Further, several assumptions were made to develop a model for dementia care in India (details available on request). Accordingly, assuming that <1% of mild cases, 5 to 10% of moderate cases and 1 to 2% of severe cases of dementia currently seek treatment, the average minimum amount needed to manage one PwD would be INR 42,585 per year. Much (56.5%) of the cost would be due to informal care (primarily as money not gained by the family care giver who could have been otherwise employed and or money paid for outside help), while nearly one third (31.1%) would be due to direct social cost (transportation costs, day care costs, residential care costs), about 12.3% would be direct medical costs (cost of medication, consultation, investigation, hospitalisation). With the recognition that as the disease progresses, the costs also increase, estimates indicate that, during the average 7 years of life for a PwD, living in an urban area, the total cost of care would be about INR 9.6 lakh.

Considering the minimum amount suggested by this model and the recent estimates by ADI, India is currently spending INR 15 to 16,000 crore per year for care of PwD. It is predicted that the number of PwD would double by 2030 (3.69 million to 7.61 million), the immediate consequence would be that the cost of care would also double. Assuming a nominal 5% annual inflation, the actual cost of care would almost treble by 2030. Obviously, two-thirds or more of this huge burden is being met by individual households. It is worthwhile to note that, the above costs are not just nominal but also do not include the huge infrastructure costs needed to set up services for dementia care. Given the current levels of awareness regarding dementia care amongst the health service providers, the costs of appropriately training the health human resources itself is much larger.

Impact of costs on household economy

Care-giving in India like elsewhere in the developing world is associated with substantial economic disadvantage. The economic vulnerability of families who care for people with dementia in India is indeed overwhelming, particularly for the families who live below the poverty line. Studies from India indicate that 23% of caregivers (17% primary caregivers and additional 6% of other caregivers) cut back on work and nearly a quarter of all caregivers suffer economic losses as they are unable to fulfil their work responsibilities. The 10/66 study observed that families from the poorest sections of the society were likely to use expensive private medical services, and spend more than 10% of the per capita Gross Domestic Product on health care further pushing them into impoverishment. Unfortunately in India, currently, the provisions for financial support as a welfare measure or benefit for caregivers in taxation is meagre. While formal health insurance is a predominantly an urban phenomenon, only few older people in India receive government or occupational pension and the income security for those with dementia is marginal.

The current work indicates the enormity of the economic burden of dementia in India both in 2010 and in future. Reduced family incomes and increased out of pocket payment for care provision takes a huge toll, enhancing the economic vulnerability and making the poor poorer. Time is not far off before the service providers and policy makers would be forced to take note of this 'black hole' of 'economic drain and demand'. This is the challenge which we need to face as our population ages rapidly and we have more and more people with dementia in our midst. The Dementia India Report with this cost analysis foresees a 'wake-up call' in terms of planning and providing services, infrastructure, capacity building and training at every level.

Services for People with Dementia: Dementia Care Services In India

The Alzheimer's and Related Disorders Society of India (ARDSI), established in 1992, is a Non Government Organisation which has spearheaded the dementia movement in India. It is the first Afro-Asian organization to get officially affiliated with Alzheimer's disease International, UK which is the umbrella organization for all organizations working for the welfare of people with Alzheimer's and related diseases around the globe. ARDSI presently has 14 chapters all across India. In addition a few other organizations like Helpage India, Dignity Foundation, Nightingales Medical Trust, the Dementia Society of Goa, Sangath, Voluntary Health Services and Silver Innings Foundation are also providing such care services either in association with ARDSI or by themselves. A majority of them are in the South Indian States.

As there are limited records of dementia services in the country, ARDSI made an effort to map the services available in India by sending mails to all chapters and other partners in the country. The number of services available in the country that cater exclusively to people with dementia are given below. The available services

are grossly inadequate to meet the needs of the over 3.7 million people with dementia in India.

Services exclusively for people with dementia in India

Type of service		Approximate number of facilities in India
Day Care centers	Dementia Day Care facilities are designed for PwD who have a need for medical attention or supervised daytime care, but who do not require institutionalization in a nursing home.	10
Residential care facilities	This facility is to manage the basic day-to-day activities of the PwD. This may be long term care in a nursing home or short respite care.	6
Domiciliary care services	Provided to the PwD at the residence. Services could range from caregiver training to formal nursing care. Could be provided by geriatric home nurses or other trained personnel	6
Support groups	Support groups for caregivers of PwD. Members share experiences and get support and coping strategies.	Exact data not available
Memory clinics	Specialized clinics that offer clinical assessment, support, information and advice to persons with memory problems	100
Dementia Help Lines	Dedicated phone lines to address queries on dementia 24/7. Handled by trained personnel.	10

Residential care services:

All these services are run by registered non-profit organizations. They are funded primarily by donations and public contributions apart from the charges collected from those who utilize the services. The number of clients in these centers

range from 5 to 20. The ratio of staff to patients in most of the centres is 1:3. Professional care is provided to the patients by trained carers round the clock. The staff provide various therapies to the residents such as reminiscence therapy, music therapy, art therapy, pet therapy, yoga, light exercises, cognitive stimulation and reality orientation. These facilities also help in creating awareness in the society on a regular basis and on the occasion of World Alzheimer's Day.

Day care services:

There are around 10 day care services which are exclusively for people with dementia. There are a few general day care services for the elderly where people with dementia are also looked after. ARDSI has been successfully running the first day care centre set up in the country for the past 14 years at Cochin. Other chapters and organizations such as the Dignity foundation (Mumbai) and the Nightingales Trust (Bangalore) are also running day care services for persons with dementia.

Domiciliary care or Outreach services: Six centres provide home based care for people with dementia. Under this scheme, the part time staff, social workers or volunteers visit families of people with dementia and provide assistance in the form of counselling, guidance and sometimes physical help like bathing.

Support Groups:

While there is no definite data about the number of support groups that are helping the families of people with dementia, they are functioning in an informal basis all over the country. They provide solace and support to the care givers and family members.

Memory Clinics:

It is estimated that in the last 5-8 years there are nearly 100 memory clinics functioning all over India. Many specialty hospitals run by the public and private agencies (with neurology and psychiatry departments) run memory clinics or specialty geriatric clinics also for PwD.

Help lines:

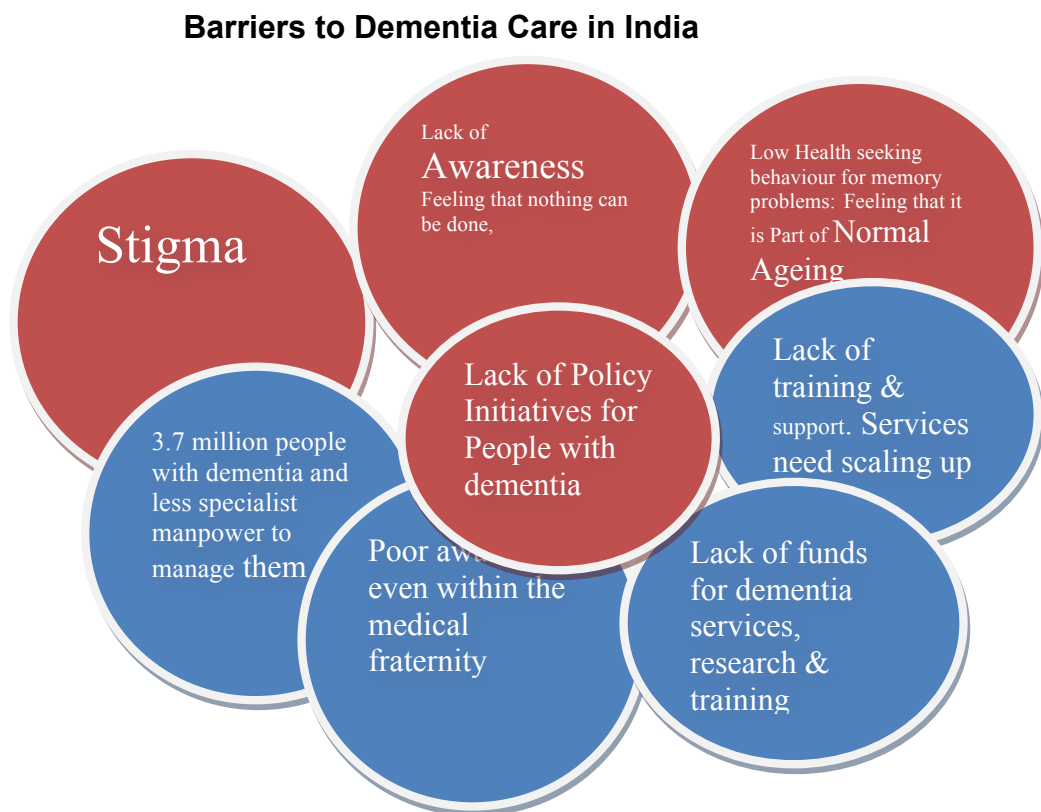
There are about 10 help lines mainly run by the national office of ARDSI and the various chapters which cater to the persons in the respective localities. Help lines are available in Cochin, Kolkata, Mumbai, Bangalore, New Delhi and Hyderabad. This shows that almost the entire country has no recourse to local help lines and support.

The help seeking behaviour of persons with dementia in India

In order to develop services for PwD, it is important to understand the health seeking behaviour of people with this disease. Several studies have looked at the use of health services by PwD. The 10/66 Dementia Research Group compared the health seeking behaviour of families in four developing countries, three months

before the interview((Prince *et al*, 2004). A majority of people required help but quite clearly, a majority of PwD in India and South Asia would avail the services of private doctors. No services were available in 33% of cases in Asia.

A study conducted in Goa and Chennai, compared the health seeking behaviours of PwD with that of people with depression and normal controls. In Goa, 76% of the PwD reported to have visited a private doctor compared to 43% in those with depression and 24% in the controls. Similarly in Chennai, 47% visited a private doctor compared to 23% each in those with depression and controls. A more recent study conducted in Chennai (Urban) and Vellore (Rural) echoed a similar trend. In the rural center at Vellore, 45% of the 106 people with dementia, availed the services of a private doctor. However, 28% had visited a PHC facility. In the urban area in Chennai, 6.7% visited a PHC while 33.3% visited a private doctor.



Proposed model for delivering services for persons with dementia in India

The immediate challenge for India is to develop culturally appropriate services which can be delivered within existing resources. We also need to consider the fact that community care has better results than institutional treatment on the outcomes and quality of life of people with chronic mental illness. In view of the above, seven core strategies were developed in consultation with experts and the evidence available in literature from the developed and developing countries. The strategies are summarized below. At present, such care services are in the infant stage in this country and the gap between the need for care services and the actual available

services is very huge. The government needs to help in setting up and promoting the establishment of care services for dementia.

Proposed model for delivering dementia care services: Seven Core Strategies

Area of Focus: What to deliver	How to deliver	Who could deliver	Where to deliver
Create Awareness & demand for services	Effective use of media, films, provide disability benefits, stigma campaigns, improve quality, accessibility of services	Government, NGOs, health professionals, media	Community, primary care, memory clinics,
Capacity building of health care teams	Training health personnel in dementia care, train health care workers in long term care	Doctors, nurses, multi- purpose health workers, ASHA ⁽²⁾ and other community outreach workers	Hospitals including primary health care centres
Provide affordable treatment (Drugs, psychological, carer training)	Use cheaper generic versions of anti dementia drugs Use existing resources for care. Integrate long term care and support programs for all dependent elderly	PwD on anti dementia drugs can review with the primary care physicians after being seen by a specialist. Community health workers could be trained in long term care	Community Primary health care level
Effective long term care through community based programmes	Train carers to establish support groups, domiciliary visits to families of PwD	Community health workers or staff specially appointed for community elder care	Primary Care, Community
Residential, respite and day care facilities	Specialized facilities with trained personnel. For severe cases of dementia or respite care	NGOs, Government	Community
Develop Legal services	Provide the much needed legal support	NGO, Government, law enforcing agencies	Community
Develop Training services	Institutes for training geriatric home nurses, Training workshops for medical fraternity could be established	Government, NGOs	Throughout the country

Training and Developing Manpower for Dementia Care

One of the most important components of developing dementia services in the country is training of manpower. Over the past few decades, the government has

responded by creating care programs and delivery services aimed at meeting the needs of older persons by the National Policy for Older Persons, the National Council for Older Persons and the National Initiative for Caring for Elderly (NICE). These initiatives have not produced the expected results. The reasons behind this are many but lack of training and initiation of programs are the critical ones. Older people have specific needs, and the health personnel need specific knowledge and training. Personnel are also needed to train older people themselves on how to maintain their well-being and independence through self-care, health promotion and disease prevention. Despite the need for and proven efficacy of geriatric care, there remains a critical shortage of specialised health care professionals in geriatrics.

Training of personnel should be considered as a prime pillar to dementia care. As Geriatric training itself is lacking in India, the dementia care training should be a part of geriatric care training. The pyramid of training should include carers and community health workers as the large base of the pyramid and professionals like nurses, dieticians, social workers, occupational, speech and physical therapists and doctors on the top. The focus for training should be both short term as well as long term.

Short term focus:

- Training existing personnel to improve care of elders with dementia.
- Train the Trainers of programs for carers and community health workers.
- In-service training for professionals
- Identifying agencies already training personnel and delegating responsibility to them in a structured manner.
- Using web based training on a regular basis to save on resources for the short term.
- Build on existing programs – NISD training of caregivers, Helpage India and ARDSI, CMAI, RCI programs.

Long term focus:

- Change existing training curricula for professionals. Change in medical education, nursing education etc, with emphasis on both theoretical knowledge and practical experiences in caring for elders.
- Using professionals from both India and abroad who have expertise in this area to develop training curricula and schedules to train at all levels.
- To coordinate the efforts of the various government and non governmental agencies which are working towards the same goals of caring for elders with dementia.

Development of a national dementia training program:

- Assist in identifying national personnel shortages and training needs specific to dementia care.
- Facilitate a coordinated national effort to promote personnel training to address the shortage of highly qualified personnel at all levels in the community
- Facilitate summer institutes and the development of online and distance education training opportunities
- Collaborate with personnel preparation programs in dementia care that currently exist in the country to make resources available that augment training activities.

India as a country should focus on implementing the recommendations from the International Plan of Action on Ageing 1982:

- Those who work with the elderly, at home or in institutions, should receive basic training for their tasks.
- Training in all aspects of gerontology and geriatrics should be encouraged and given prominence at all levels in all educational programmes.
- Intergovernmental and non-governmental organizations should take steps to have trained personnel in the field of ageing and should strengthen their efforts to disseminate information on ageing, particularly to the aged themselves.
- A national programme for training should be created to complement national and regional training programmes that are relevant to the particular conditions in those states and regions. (On lines of training conducted by NIPPCD for child services)

Training Programmes:

ARDSI has taken the initiative to conduct several training programmes with special emphasis on dementia like the 6 month certificate course in Training and Capacity Building program on old age care, one year P.G Diploma in Integrated Geriatric Care, one month certificate course on Training of NGO Functionaries and a 5 day training program on Geriatric Counselling with special reference to dementia care. ARDSI has been running a school of Geriatric Care in Cochin, Kerala since 1993.

Developing Geriatric Services in India

While we consider the need to develop specific services for PwD, we also need to consider developing geriatric services as a whole. The experts attending the consultative meetings organized by ARDSI strongly felt the need for a National Institute for Ageing in the country. Achieving these objectives is dependent on creating effective coalitions among professionals and professional organizations, state and central agencies, and other interested parties such as the ARDSI, Helpage India, NISD, Indian Academy of Geriatrics, Geriatric Society of India, Gerontological Society of India and other voluntary organizations working for geriatric care. Public–

Private participation model may be used to start many more geriatric clinics and centres in the country.

Role of the State and Central government

A start can be made to identify the current position of geriatric professionals, the kind of training available and the numbers needed to meet the needs of the elderly on a state wise and national basis. Funding for research should be available to compare the benefits of patients cared for by geriatric specialists with those cared for by generalists. It should also include research on organizations and systems and why they choose to employ workers with certain kinds of training and experience. Similarly, there is a need for more health services research to assess the effectiveness of different models of training, staffing, and organization of care and their relationship to health benefits and quality of care.

Recommendations: A call for action

The *Dementia India report 2010* identifies:

1. The number of Persons with dementia and families affected by dementia is set to increase rapidly.
2. The impact of dementia on the individual, the family and society will increase exponentially in terms of the burden, disablement, and costs of care.
3. Persons with dementia do not access and use health and social care services.
4. Dementia care is characterised by a significant lack of service delivery and evidence on outcomes with interventions.
5. A small portion of persons with dementia and families access private health services due to absence or unsatisfactory public services.
6. There will be an increase in demand for support services.
7. Increased demand for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a preponderance of the oldest people, who tend to be frailer and to have more limited informal support networks.
8. Lack of awareness among professionals, the family and community, policy makers and agencies to the needs of persons with dementia has led to dementia care being absent or delivered piecemeal and in an inefficient fashion in India.
9. More investment and careful planning will be needed to maximise the quality of life of persons with dementia and their families, and to accomplish that in an efficient manner with the available resources.
10. There are hardly any standard practice guidelines and treatment centres in India and the current health and social care system is characterized

by a widespread failure to support Persons with dementia and their families.

These findings are evident from this report and the review of the services and the impact. This failure to develop services which meets the needs of PwD is perplexing given that dementia is a significant driver of demand for health and social care. The recommendations that follow therefore contain both a series of proposals for policy development and proposals for improving the evidence base.

Recommendations:

- 1 Make dementia a national priority**
- 2 Increase funding for dementia research**
- 3 Increase awareness about dementia**
- 4 Improve dementia identification and care skills**
- 5 Develop community support**
- 6 Guarantee carer support packages**
- 7 Develop comprehensive dementia care models**
- 8 Develop new National Policies and Legislation for PwD**

Recommendation 1: Make dementia a national priority

Dementia must be made a publicly stated national public health and social care priority. This must be reflected in plans for service development, research and public spending.

Recommendation 2: Increase funding for dementia research

As a matter of urgency there must be a review of Indian medical and social research funding to establish a more ambitious funding program into the causes, prevention, cure and care of dementia.

Recommendation 3: Increase awareness about dementia

Dementia is mistaken for normal ageing and not seen as a disease. Education of the general public as well as health providers and social services is required for early identification of the disease.

Recommendation 4: Improve early identification and treatment:

Early identification of persons with dementia and care training should be made a core and substantial part of the training curriculum for physicians, nurses, other

medical specialists and social care staff. Minimum Standards must be developed to include dementia specific requirements on dementia identification, treatment and care training.

Recommendation 5: Develop home care and community support

People with dementia need improved home care support, including low-level support to retain their independence and dignity.

Recommendation 6: Guarantee carer support packages

Family carers must have guaranteed access to carer support. These include

- psychological therapies including carer training and support groups
- quality respite care for persons with dementia and carers
- provision to compensate carers with benefits (carer pension, medical insurance)

Recommendation 7: Develop comprehensive dementia care models

Develop an integrated, comprehensive range of care models for persons with dementia to bridge the gap between care at home and care in a care home.

Recommendation 8: Develop new National Policies and Legislation for PwD

There is a need to develop new policies and laws for elders and PwD.

The National Policy for Older Persons may be amended to include PwD.

Develop a separate department or division under the Ministries of Health, Social Justice & Empowerment (like an Ageing welfare department)

Amendments to the Mental Health Act and the Persons with Disabilities Act should take into consideration the rights and benefits for PwD.

More information:

For more information contact the Alzheimer's and Related Disorders Society of India:

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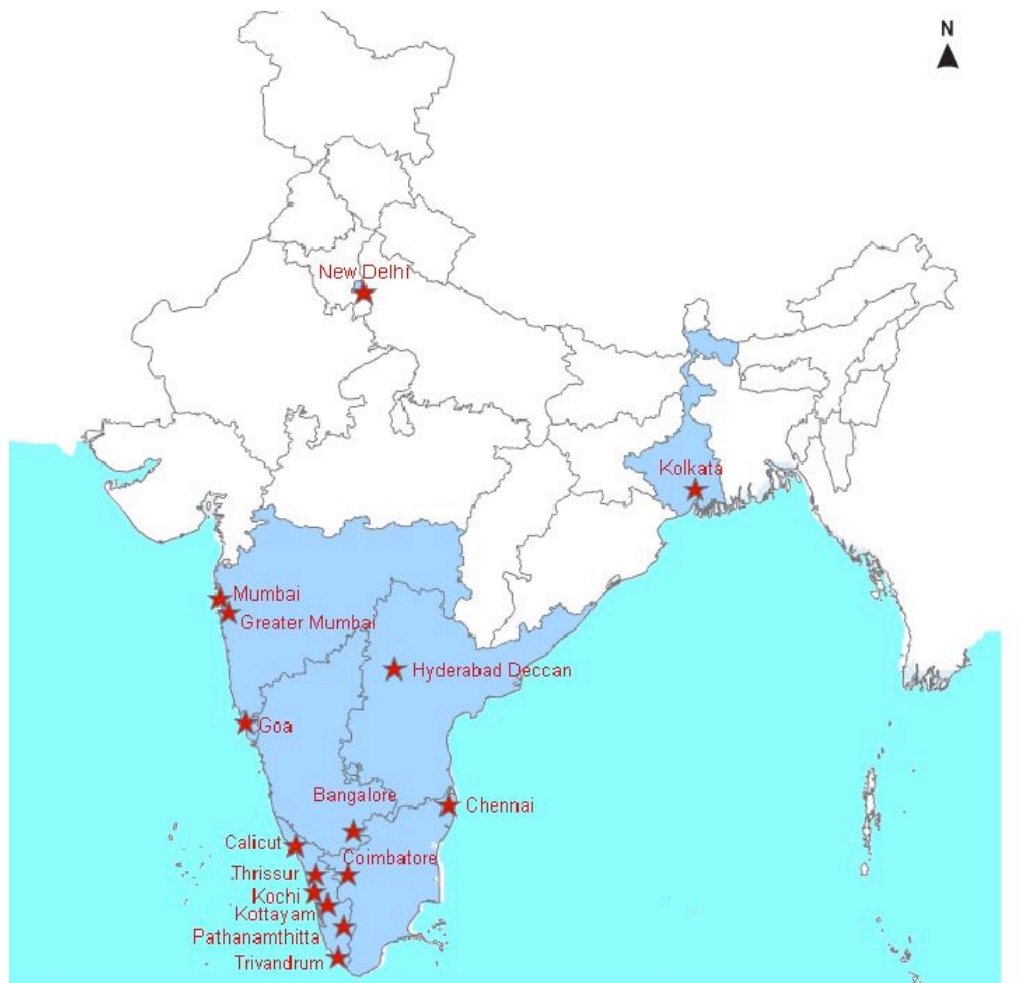
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The Alzheimer's and Related Disorders Society of India (ARDSI), is a registered secular, non-profit voluntary organisation in India. Spearheading the dementia movement in India, it is dedicated to care, support and research of Dementia. It is the first Afro Asian organization to get officially affiliated with Alzheimer's Disease International, UK. ARDSI presently has 14 chapters across India.



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Alzheimer's Disease International's Global Alzheimer's Disease Charter

We are facing a public health and social care emergency and immediate action is needed!

Six principles to make Alzheimer's disease and other dementias a global priority

- 1. Promote awareness and understanding of the disease.**
- 2. Respect the human rights of people with the disease.**
- 3. Recognize the key role of families and carers.**
- 4. Provide access to health and social care.**
- 5. Stress the importance of optimal treatment after diagnosis.**
- 6. Take action to prevent the disease, through improvements in public health.**

September 2008

(<http://www.globalcharter.org/charter.php>)