

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!

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

September 2008 (<http://www.globalcharter.org/charter.php>)

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DEMENTIA INDIA REPORT 2010

Prevalence, Impact, Costs & Services for Dementia



In 2010, there are 3.7 million Indians with
dementia and the total societal cost
is about ₹ 14,700 crores

While the numbers are expected to
double by 2030 cost would increase three times

Families are main carers and
they need support

THE DEMENTIA INDIA REPORT 2010

Prevalence, impact, costs and services for dementia

A report prepared for the

Alzheimer's and Related Disorders Society of India



By

Shaji KS
Jotheeswaran AT,
Girish N,
Srikala Bharath,
Amit Dias,
Meera Pattabiraman
Mathew Varghese

Editorial and Scientific support:

Prof Martin Prince

&

Dr Cleusa Ferri,

Institute of Psychiatry, London

&

Alzheimer's Disease International's 10/66 Dementia Research Group

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Contributors:

- Dr Shaji KS, Professor of Psychiatry, Medical College, Thrissur (Chapters 1 and 3)
- Jotheeswaran AT, PhD Research Fellow, Public Health Foundation of India, New Delhi, India (Chapter 2)
- Dr Girish N, Associate Professor of Epidemiology, NIMHANS, Bangalore (Chapter 3: Costs of dementia and Assistant Editor)
- Dr Srikala Bharath, Professor of Psychiatry, NIMHANS, Bangalore (Chapter 3: Costs of dementia)
- Dr Amit Dias, Coordinator, Medical and Scientific Advisory Panel, ARDSI and Lecturer in Preventive & Social Medicine, Goa Medical College, Goa (Chapter 4)
- Meera Pattabiraman, Secretary General, ARDSI (Chapter 4)
- Dr Mathew Varghese, Professor of Psychiatry, NIMHANS, Bangalore (Chapters 1 and 5 and Executive Summary)

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

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Dr. Cathy Greenblat

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FOREWORD

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. 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 it 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. It is estimated that the cost of taking care of a person with dementia is about ₹43000 annually; most 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.

India as a nation is making rapid progress as an economic power in the world. But, do we as a nation, value the contribution made by our senior citizens in the twilight of their lives? Don't we have the responsibility to respond to the needs of people with dementia and their families?

Alzheimer's and Related Disorders Society of India (ARDSI) is a national voluntary organization dedicated to the care, support and research of dementia. Since 1992, it has been in the forefront to improve the welfare of persons with dementia and their families. ARDSI is committed to developing a society which is dementia friendly and literate. However, this can be achieved only with the same kind of political and social commitment at all levels. It is our duty to make it possible for a person with dementia to live a life with dignity and honour.

The '**Dementia India Report**' is an ambitious, visionary document calling for the government and policy makers to recognize dementia as a health and social welfare priority by developing a National Dementia Strategy.

I would like to congratulate the research team led by Prof. Mathew Varghese, Dr. Amit Dias, Dr. K.S. Shaji, Mr. Jotheeswaran, Dr. Srikala Bharath, Dr. Girish Rao and Mrs. Meera Pattabiraman for producing this excellent report, which is the first of its kind from a developing country. I would like to thank Prof. Martin Prince for his valuable support. I would also like to place on record the role played by Mr. Marc Wortmann, Executive Director, Alzheimer's Disease International and Mr. Andrew Ketteringham, Director external affairs, Alzheimer's Society, UK. We are indeed grateful to Dr. Raghu Gaiind, Senior Consultant Psychiatrist UK, for his generous funding to produce this report.

This is a significant step forward in the dementia care movement in the country. It is coincidental that the Ministry of Health is about to launch the National Health care programme for the elderly. Also, the Ministry of Social Justice and Empowerment has undertaken the revision of the national policy for older persons. So, this is the right opportunity for promoting better dementia care in the country. It is our fervent hope that this report will prompt the government to set up memory clinics and other care services at the district levels and a National Alzheimer's Centre in the capital. We sincerely hope that the government will consider the recommendations made in this report seriously and include dementia care in the primary healthcare system.

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



Chapter-1
Understanding Dementia
and Its Management

**THE DEMENTIA INDIA
REPORT**

The report for improving dementia care in India

Understanding dementia and its management

1.1 INTRODUCTION

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. 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 accompanied by economic development. Regions with more favourable health indicators seem to be ageing faster.

India was home to more than 75 million people older than sixty years in 2001. This age group, which was 7.5% of the population, is expected to grow dramatically in the coming decades. Analysis of the census data shows marked variations in the rate of demographic aging within India ranging from 10.5% in Kerala to 4% in Dadra and Nagar Haveli. Other regions with elderly population above 8% include Himachal Pradesh (9%), Punjab (9%), Maharashtra (8.7%), Tamil Nadu (8.8%), Orissa (8.3%), Goa (8.3%), and Pondicherry (8.3%). The demand for services will soon be evident in such places and will make the task of meeting the needs for the older people more challenging and urgent.

There is a growing realization that the care of older people with disabilities makes enormous demands on their carers. Terms like dementia and Alzheimer's disease are now better understood. However, this was not the case when the Alzheimer's and Related Disorders Society of India (ARDSI) initiated awareness programmes in 1992. Dementia remains a largely hidden problem in India, especially in those parts of India where poverty and illiteracy levels are high.

1.2 CONSENSUS REGIONAL MEETINGS OF EXPERTS, CARER AND SOCIETY - 2009-2010

The Alzheimer's and Related Society of India (ARDSI) held a series of regional consultative meetings in 2009 and 2010 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 held in January 2009 in New Delhi was followed by meetings in Mumbai, Coimbatore, Bangalore and Kolkata and concluded with the final meeting in Trivandrum in March 2010. There was another national consultative meeting in 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, Government of India.

The deliberations at these regional and national meetings were collated and a group of experts were assigned to write the report for India in April 2010. This report was sent to different experts and stakeholders all over the country and also to experts abroad.

The Dementia India report at first describes the problem of dementia, as a disease and the current evidence for medical and psychosocial management of the disease. It focuses on issues concerning the carers and the need to address the same. Further, the public health aspects of creating awareness and possible ways of prevention of the disease in India are discussed. In subsequent chapters, the report makes an accurate 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. The report estimates the wider impact of the devastating illness process on the affected people, their families, the society and the nation at large. It describes the current state of dementia care and services in India. The evidence base for management of dementia was evaluated from a public health perspective along with a review of the international experience in dementia care. Resource limitations and feasibility concerns were taken into consideration.

The report proposes possible steps to address the public health challenges posed by dementia; the importance of 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.

1.3 WHAT IS DEMENTIA?

The definition of dementia

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; about 2% of cases start before the age of 65 years. After this, the prevalence doubles every five years. 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. The characteristic symptoms and neuropathological findings are summarised in Table 1. 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. Otherwise, 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 (PWD) and carers alike.

Table 1.1: Common subtypes of irreversible dementia

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

A fundamental problem is that the borders between these different subtypes are by no means distinct. Clinico-pathological correlation studies examine the agreement between the diagnosis made in life, and the pathology evident in the brain post-mortem. These have tended to indicate that mixed pathologies are much more common than 'pure' – this is particularly true for Alzheimer's disease (AD) and vascular dementia, and AD and dementia with Lewy bodies (DLB). In one large study of over 1000 post-mortems, while 86% of all those with dementia had AD related pathology, only 43% had pure AD. 26% had mixed AD and cerebrovascular pathology and 10% had AD with cortical Lewy bodies.

Findings were similar among those who had been given a clinical diagnosis of AD. 'Pure' vascular dementia was comparatively rare (7.3%). Uncommon subtypes of dementia: frontotemporal dementia, Creutzfeldt Jakob and Huntington's disease tended to have been misdiagnosed in life as AD. Population-based studies have suggested that FTD and vascular dementia were relatively common diagnoses in men with an early onset of dementia. AD tended to predominate over VaD among older PWD, particularly among women.

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

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 referred to as **ABC symptoms of dementia: Activities of Daily living (ADL), the Behavioural and Psychological symptoms, and the Cognitive and memory symptoms**. For carers, and, arguably, for PwD, it is the behavioural and psychological symptoms (BPSD) 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, calling out, sleep disturbance, wandering and apathy. Common psychological symptoms include anxiety, depression, delusions and hallucinations. BPSD occur most commonly in the middle stage of dementia (see also Course and Outcome). Most studies indicate that BPSD are an important cause of carer strain. In the 10/66 Dementia Research Group pilot studies, BPSD seemed to be just as common in low and middle income countries as in the developed ones. Many studies from India which looked at BPSD found these symptoms to be common both in the community and in clinical settings. They are considered as most distressing by carers. Given the generally low levels of awareness about dementia as an organic brain disease, carers or their families, often could not understand their relative's condition, and tended to misinterpret BPSD as deliberate misbehaviour on the part of the PwD. (Pinto and Seetalakshmi, 2006; Shaji et al 2009)

The course and outcome of dementia

Dementia affects every person in different ways. 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 (Box 1): early stage – first year or two, middle stage – second to fourth or fifth year and late stage – fifth year and after.

These are guidelines only - some people deteriorate faster, and others more slowly. Dementia reduces the lifespan of affected persons. In the developed west, a person with dementia can expect to live for roughly 5-7 years after onset / diagnosis (Ganguli et al 2005;

Fitzpatrick et al 2005). In low and middle income countries, diagnosis is often much delayed, and survival may be much shorter. The mortality rates could be higher in the absence of interventions (Dias et al, 2008) and the severity at the time of identification could also predict mortality. Patients with moderate to severe illness have a higher mortality than cognitively unimpaired elderly. Again, there is much individual variation because of intercurrent health conditions and co-morbidity is very common in this age group.

Not all PwD will display all the symptoms which have been described. Knowing them makes carers to be aware of potential problems and helps to plan the future care needs.

BOX 1.1

Early Stage

The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as 'old age', just a normal part of the ageing process. The onset of the disease is gradual and difficult to recognise.

- Have problems talking properly (language problems)
- Have some memory loss, particularly of recent events
- Have difficulty in making decisions
- Become inactive and unmotivated, show mood changes, depression or anxiety and may react angrily or aggressively
- Show a loss of interest in hobbies and activities

Middle Stage

As the disease progresses, limitations become pronounced and more restricting. The PwD have difficulty with day-to-day living.

- May become very forgetful - especially of recent events and people's names
- May become extremely dependent on their family and carers; unable to cook, clean or shop; needs help with personal hygiene
- Has wandering and other behaviour problems such as repeated questioning and calling out, clinging and disturbed sleep
- Unable to recognise familiar and unfamiliar places at home or outside
- May have hallucinations (seeing or hearing things which are not really there)

Late Stage

This stage is one of near total dependence (confined to a wheel chair or bed). Memory disturbances are very serious with more physical complications. The person may:

- Have difficulty eating, walking and be incapable of communicating
- Not recognise relatives, friends and familiar objects
- Have bladder and bowel incontinence, breathing difficulties and respiratory infections

1.4 MANAGEMENT OF DEMENTIA

Guiding principles

The standard treatment goals of dementia management include:

- 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

The evidence base for dementia care comes, overwhelmingly, from high income countries. The PwD need to be treated at all times with patience and should be respected for their dignity and personhood. The carers need unconditional support and understanding – their needs should also be determined and attended to. Carers need to be educated about the course and symptoms of dementia, and about the nature of the problems. They can also be trained to appropriately manage most of the common behavioural symptoms in such a way that the frequency of symptoms and/or the strain experienced by the carer are reduced. The PwD and the family carers need to be supported over the prolonged period of care.

Current evidence-based treatments

Partially effective treatments are available for most core symptoms of dementia. These treatments are all symptomatic, that is, they reduce a particular symptom, but do not alter the progressive course of the disease. Importantly, psychological and psychosocial interventions (sometimes referred to as ‘non-pharmacological’ interventions) may be as effective as drugs, but have been less extensively researched, and much less effectively promoted.

Cognitive impairment

Cholinesterase Inhibitors (ChEIs), namely donepezil, rivastigmine and galantamine have been shown to improve the cognitive, behavioural and ADL symptoms in both Alzheimer’s and Vascular dementia especially in the early and moderate stages (Birks and Harvey, 2006; Loy and Schneider 2006; Birks et al, 2009). The NMDA receptor antagonists (memantine) can lead to useful improvements in cognitive, behavioural symptoms and daily functioning and are indicated in moderate to severe stages of AD and VaD (McShane et al, 2006). As their cost-effectiveness has not yet been established (NICE, 2007) they are not freely available or prescribed in many countries. Recommendations regarding their use will depend upon affordability and availability of specialist support. The costs of these drugs in India are much less than the international prices. Despite this, poorer sections in India may not be able to buy them. Hence, there must be an attempt to make these drugs available through the health system as with other psychotropic drugs. The evidence-base from low and middle income countries is limited to one RCT of donepezil in Brazil (Moraes et al, 2008) and open-label trials of galantamine in Brazil (Caramelli et al, 2004) and China (Chu et al, 2007). A clinical audit from a geriatric clinic in Bangalore (Prasad K et al, 2009) found donepezil to be the commonly prescribed drug.

More development and research is needed to see if reminiscence therapy (Woods et al, 2005), cognitive stimulation (Bottino et al, 2005; Spector et al, 2003) and rehabilitation (Clare et al, 2003) could be feasible and effective community interventions. We do not have any studies in India which have looked at the efficacy of these non-pharmacological interventions.

Behavioural and Psychological Symptoms of Dementia (BPSD)

For BPSD, antipsychotic drugs, namely the atypicals, are effective minimally for the BPSD, although they may be very helpful for some patients (Lonergan et al, 2002; Ballard and Waite, 2006; Schneider et al 2006), particularly amongst those with aggression as the main problem. There are serious concerns about their safety with an increased risk of death and cerebrovascular adverse events (Schneider et al, 2005; Ballard and Howard, 2006). Too little research has been carried out to be clear about the potential benefits of the SSRI antidepressants (Pollock et al, 2002; Torres et al, 2004; Finkel et al 2004) or carbamazepine (Tariot et al, 1998; Olin et al, 2001). For these reasons, a brief duration of anti-psychotic or SSRI drugs may be recommended with specialist input, particularly when severe and distressing behaviour is troublesome and there is an imminent risk of harm.

Physical health assessment, carer training and support are all indicated. More research is needed into the potential benefits of simple low-cost strategies to manage BPSD, easily applied by carers at home; for example, massage, music (Viggo et al, 2006; Remington et al, 2002) and aroma therapy (Ballard et al, 2002).

The importance of carer interventions

- A) large literature is available regarding the wide-ranging potential benefits of carer interventions in dementia (Sorensen et al, 2006). These include
- a) Psycho-educational interventions, many of which include an element of carer training,
 - b) psychological therapies e.g. cognitive behavioural therapy (CBT), and counselling,
 - c) carer support and respite care.

Many interventions have one or more of these elements. There are several systematic reviews and meta-analyses (Brodaty et al 2003; Lee and Cameron, 2004; Smits et al 2007), which have shown the benefit of carer interventions in preventing or delaying hospitalisation or institutionalization. Most carer interventions seem to benefit carer strain and depression with CBT having the largest impact on depression. Psycho-educational interventions require the active participation of the carer (for example in role-playing activities) to be effective. Carer support interventions are effective in enhancing carer well-being (Pinquart and Sorensen, 2006). For respite care, non-randomised interventions suggest significant reductions in carer strain and psychological morbidity. While nearly all of the carer intervention trials to date have been conducted in high income countries, two trials of a brief carer education and training intervention are from low and middle income countries. The ADI/1066 ‘Helping Carers to Care’

intervention have been published recently, one from India (Dias et al, 2008) and one from Russia (Gavrilova et al, 2008). Although small in size, both indicated much larger treatment effects (carer psychological morbidity and strain) than are typically seen in trials of such interventions in high income countries.

Finally, there is clear evidence from the pooled results of ten randomised controlled trials (Spijker et al, 2008), that carer interventions delay institutionalisation in high income countries. PwD whose carers received the intervention were 40% less likely to be institutionalised over the follow-up period (OR=0.60, 95% CI=0.43-0.85). The effective interventions were structured, intensive and multi component, offering a choice of services and supports to carers. Preventing or delaying institutionalisation reduces costs and thus contributes to a substantial societal benefit given the very high costs in high income countries.

The hope for a cure

Currently, there are no treatments available that cure or even alter the progressive course of dementia. Numerous new therapies being investigated are in various stages of clinical trials and this is a very active and promising field for drug development (Rafii and Aisen, 2009). Any new disease-modifying agent would be very expensive and would pose an ethical and practical challenge in making such a treatment widely and equitably available, particularly to the two-thirds of PwD living in low and middle income countries. It is necessary to formulate ways and means by which new cost-effective treatments can be made affordable to most people who will need it as with antiretroviral drugs for HIV/AIDS.

1.5 ETIOLOGY (RISK FACTORS)

Understanding Risk factors:

It is very important to understand the risk factors for dementia before planning interventions. Risk factors (Box 1.2) can be divided as potentially modifiable and non modifiable risk factors. In addition, there are various protective mechanisms that have come to light. Understanding the potentially modifiable risk factors would help in selecting the management strategies. Understanding the non modifiable risk factors would help in identifying high risk groups and planning targeted interventions.

Non modifiable risk factors:

The main risk factor for most forms of dementia is advancing age, with prevalence roughly doubling every five years over the age of 65yrs. Onset before this age is very unusual and, in the case of AD often suggests a genetic cause. Single gene mutations at one of three loci (Beta amyloid precursor protein, presenilin1 and presenilin2) account for most of these cases. For late-onset AD both environmental (lifestyle) and genetic factors are

Box 1.2

Non modifiable factors

- Age
- Family history +
- ApoE4 allele
- Female sex
- Depression
- Head trauma
- Mutation on 1,14,21 chromosome
- Down's syndrome

Potentially Modifiable factors

- Vascular Disease
- Hypertension
- Diabetes
- Dyslipidaemia
- Nutritional deficiency (Vit B)
- Smoking
- Alcohol
- Obesity
- Diet

important. A common genetic polymorphism, the apolipoprotein E (apoE) gene e4 allele greatly increases risk of developing dementia; up to 25% of the population has one or two copies (Saunders et al, 1993; Nalbantoglu et al, 1994). However, it is not uncommon for one identical twin to suffer from dementia, and the other not. This implies a strong influence of the environment. Evidence from cross-sectional and case-control studies suggest associations between AD and limited education, and head injury (Mortimer et al, 1991; Mayeux et al, 1995), which, however, are only partly supported by longitudinal (follow-up) studies. Depression identified as a risk factor in short term longitudinal studies, may be an early presenting symptom, rather than a cause of 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 chronic depression in their earlier life and head injuries are known to be at higher risk and so should be watched for memory problems in later life.

Potentially modifiable risk factors - vascular risk factors and cardiovascular disease

Despite occasional negative findings from large prospective studies (Yip et al, 2006; Bursi et al, 2006), the accumulated evidence for a causal role for cardiovascular risk factors (CVRF) and cardiovascular disease (CVD) in the aetiology of dementia and AD is very strong. Short (Ott et al, 1998; Juan et al, 2004; Luchsinger et al, 2005) and long duration (Tyas et al, 2003; Whitmer et al, 2005) incidence studies suggest that smoking increases the risk of AD. Long term cohort studies indicate midlife hypertension and hypercholesterolemia are associated with AD onset in later life. 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. While, diabetes is a recognised risk factor recent studies report associations between metabolic syndrome and incident cognitive decline, and insulin resistance and impaired executive function. All these findings have led to the hypothesis that atherosclerosis and AD are linked disease processes,

with several common underlying factors (the APOE e4 gene, hypertension, increased fat intake and obesity, raised cholesterol, diabetes, the metabolic syndrome, smoking and systemic inflammation). The potential risks posed by diabetes, metabolic syndrome, hypertension and smoking have special relevance for India and other developing regions.

1.6 AWARENESS

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. Three studies which adopted a mix of focus group discussion and open-ended interviews illustrate the pervasive problem of dementia awareness in LAMIC. The typical features of dementia are widely recognized, and indeed named “Chinnan” (literally childishness) in Kerala, “nerva frakese” (tired brain) in Goa, and “weak brain” in Banares. However, in none of these settings was there any awareness of dementia as an organic brain syndrome, or indeed, as any kind of medical condition. Rather, it was perceived as a normal, anticipated part of ageing. 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.

1. Most PwD and their families do not understand dementia as a health problem. Hence, dementia does not get recognized early and the diagnosis is often delayed.
2. There is little help sought from formal medical care services.
3. There is no structured training on the recognition and management of dementia at any level of health service.
4. Health care services remain insensitive to and do not provide the much needed information and support for carers and family members.
5. While family members are the main carers, they must do so with little support or understanding from other individuals or agencies.
6. There is no constituency to place pressure on the government or policy makers to provide more responsive dementia care services.

PwD are stigmatized because the underlying cause is not understood. In Goa, the likely causes were cited as “neglect by family members, abuse, tension and lack of love”. PwD were specifically excluded from residential care, and often denied admission to hospital facilities. In Kerala, it was reported that most carers tended to misinterpret symptoms of the disease and to designate these as deliberate misbehaviour by the PwD. Disturbed behaviour, common among PwD, is particularly poorly understood leading to stigma, blame, and distress for carers. Low awareness and the resultant low demand for services perpetuates the silent suffering of the affected people and their families. It is essential to change this state of affairs by the concerted effort of all stakeholders with an important role for the government.

Actions to improve awareness

- a) Public awareness: In developed countries, dementia awareness is growing rapidly, with the media playing an important part. Coverage over 18 months in the UK Daily Telegraph has increased from 57 articles in 1998/9 to 112 when re-examined in 2006/7. Recent evidence-based reports from the UK and the Australian Alzheimer's associations garnered considerable media attention and were instrumental in making dementia a national priority.

Public awareness in low and middle income countries is lacking, few media carry stories about dementia and ageing. The 10/66 Dementia Research Group teams have succeeded in getting the message out in newspapers, TV and radio (http://www.alz.co.uk/1066/1066_in_the_news.php). While a search in 1999 retrieved no articles, the same paper (The Times of India) published 15 articles in 18 months in the recent past. Media in India are now more receptive to inform the public and stimulate debate about ageing and dementia. Systematic efforts are required to build their capacity to report, research and understand its local relevance.

- b) Creating awareness in health professionals: The unprecedented pace of demographic aging of our population demands an urgent need to train our health professionals to look after older sections of the society. Health professionals trained in this country should receive basic training to identify conditions like dementia and depression, two common health problems which occur in late life. Health care professionals should have necessary skills to manage common health problems affecting older people. Immediate and decisive action is required to meet this challenge.

From awareness to understanding

Ideally, we need to aim at improving the understanding about dementia. It is easy to give a name to the condition, whether AD or other dementias and do nothing. This can happen if we fail to acquire a scientific understanding of the condition. Naming is important and necessary for identification, but understanding is the key to management and improving care. Carers, the families and the civil society need to know more about dementia. We should at least know that there are many things which we can do for PwD. Initiatives from the Alzheimer's Society in UK highlight the need for better understanding of the condition. Their recent publications “Dementia: Out of the shadows” and “My name is not Dementia” exemplifies the efforts to move forward from the general awareness level to that of a better understanding about the meaning of having dementia and its implications. A lot can be done to improve the quality of life of the person with dementia, his or her life and the lives of people who provide home based care.

1.7 A PUBLIC HEALTH MODEL INTERVENTION FOR PREVENTION OF DEMENTIA

There is a need to recognize the importance of early intervention strategy and use a public health model for dementia care. There is some evidence from studies with other chronic diseases, like hypertension and diabetes mellitus that intervention 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 approach is desirable.

Table 1.2: Population and individual level prevention strategies in Dementia care

	PRIMARY LEVEL (Identification and treatment of risk factors)	SECONDARY LEVEL (early detection of dementia)	TERTIARY LEVEL (rehabilitation)
POPULATION	Public awareness education. Education of physicians, health workers	Identifying high risk elderly.	Educational and behaviour therapies for carers
INDIVIDUAL	Early detection and treatment of modifiable factors (e.g. vascular)	Specialists & Care facilities- hospitals, Treatment of dementia and behavioural problems, non pharmacological management day care, respite care	Drug treatment for reducing ABC of moderate- severe dementia. Non pharmacological management strategies Long term care.

More research needed in Prevention

Epidemiological research identifies modifiable risk factors and preventive interventions than reduce the incidence of the disease. Epidemiological cohort studies indicated protective effects of non-steroidal anti-inflammatory drugs, hormone replacement therapy (HRT) and cholesterol lowering therapies (statins). However, a randomised controlled trial of HRT as a preventive therapy in post-menopausal women indicated, against expectation, that it raised rather than lowered the incidence of dementia . The two trials of statins have showed no preventive benefit. The ADAPT trial of NSAIDs had to be stopped because of warnings of cardiovascular adverse effects in another trial of NSAIDs (ADATP research Group, 2006). Antihypertensive treatment also seemed to be not so effective as a preventive strategy (McGuinness et al, 2006).

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. This may be because some environmental risk factors are much less prevalent in these settings – for example, African men tend to have good cardiovascular health with low cholesterol, low blood pressure and low incidence of heart disease and stroke.

Conversely some risk factors may only be apparent in low and middle income countries, as they are too infrequent in the developed economies for effects to be detected. In low and middle income countries, dietary deficiencies, particularly of micronutrients, are widespread and strongly linked to poverty. Deficiencies of folate and vitamin B12 are of particular interest given their consequences; anaemia, raised homocysteine levels, increased risk of stroke and ischaemic heart disease. Vitamin B12 deficiency is very common (> 40%) across Latin America. Folate deficiency is endemic in those living in poverty, and after economic crisis .

Micronutrient deficiency is common in older people but there is limited data . Research on micronutrients and dementia in developed countries focussed on antioxidants with less attention towards deficiencies in vitamin B12 and folate . Available studies were small in size and provide inconsistent findings - two out of three studies testing for an effect of folate deficiency on dementia risk were positive , B12 was associated in only one out of four studies . Anaemia, strongly linked to under nutrition, has been identified as a risk factor for dementia in India , and needs to be explored.

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.



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Chapter-2
Number of Persons with
Dementia in India

**THE DEMENTIA INDIA
REPORT**

The report for improving dementia care in India

Number of Persons with Dementia in India

2.1 BACKGROUND

Why do we need estimates for India?

In the last 10 years, the evidence on dementia prevalence in India has increased considerably. More than 42,000 older people have been studied by eight centres in 5 urban and 4 rural sites across the country, and there are wide variations in estimates. Prevalence of dementia using survey diagnosis or clinical diagnosis of DSM IV or ICD 10 reported from Indian studies amongst the elderly range from 0.6% to 10.6% in rural areas and 0.9% to 7.5% in urban areas (Table 2.1). The heterogeneity in reported prevalence could be due to lack of sensitive and specific local measures of assessment, being predominantly rural, important protective family structures (extended families being the norm), differing lifestyles and diets rich in antioxidants. Methodological problems in the studies may also account for regional differences .

Studies on dementia prevalence have not been uniform across the country: six studies in Southern region and single studies each from West, East, and Northern regions. Although the coverage of evidence is good in south India, the wide variation in estimates in studies from other regions makes it difficult to provide a consistent overview for the entire country. Therefore, it is important to synthesize the evidence on the prevalence of dementia by generating quantitative meta-analyses with available information.

2.2 METHODS

Detailed review of literature and meta-analysis was carried out by using search terms Dementia AND Prevalence OR Epidemiology AND India in EMBASE, Medline and PsycINFO. This yielded 86 publications. Eligible studies were analysed based on the following criteria:

Inclusion criteria

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

Exclusion criteria

- a) Studies in clinical setting or of populations in residential care
- b) Studies in which 'dementia' was diagnosed purely on the basis of cognitive impairment, for example according to a cut point on the Mini Mental State Examination (MMSE) or other cognitive screening tool

- c) Two phase studies, in which screening procedures were clearly inadequate and two phase studies, where methodology was not properly applied. For example, large scale screening studies of people of all ages for multiple neurological disorders.

Procedures

In the first stage of the search, the abstracts of all publications identified were read on the electronic databases, excluding only those that clearly did not meet the above criteria. In the next stage, printed copies of the remaining publications were obtained. These were then carefully read and consensus was arrived at regarding studies meeting the criteria.

All eligible studies were systematically coded for their study design and quality using the following:

1. Start and finish dates for fieldwork, and census dates if provided
2. Lower and upper age limits
3. Sampling (simple random/stratified random/whole population/other)
4. Design (one phase/two phase/three phase)
5. Overall sample size (first phase)
6. Numbers interviewed (first phase) and proportion responding
7. For two phase surveys only:
 - a) Numbers selected for the second phase
 - b) Numbers interviewed during second phase and proportion responding
 - c) Screen negatives sampled for the second phase (yes/no)
 - d) Screen negatives given same assessment as screen positives (yes/no)
 - e) Weighting back carried out (no weighting back / appropriate weighting back / no weighting back, but no false positives)
 - f) Time interval between first and second phase
 - g) Screening instrument/s
8. Diagnostic criteria (not specified / ICD / DSM / GMS / AGE CAT / CAMDEX / other clinical criteria)
9. Use of multi-domain cognitive assessment, informant interview, disability assessment, neuro-imaging

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

1. Sample size

- | | |
|----------------|------------|
| a. <500 | 0.5 points |
| b. 500-1499 | 1 point |
| c. 1500-2999 | 1.5 points |
| d. ≥ 3000 | 2 points |

2. Design

- | | |
|---|----------|
| a. Two phase study with no sampling of screen negatives - | 0 points |
| b. Two phase study with sampling of screen negatives but no weighting back - | 1 point |
| c. One phase study or two phase study with appropriate sampling and weighting - | 2 points |

3. Response proportion

- | | |
|----------------|----------|
| a. <60% | 1 point |
| b. 60-79% | 2 points |
| c. $\geq 80\%$ | 3 points |

4. Diagnostic assessment

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

Data extraction

Prevalence data was extracted from the studies as follows:

- For unweighted prevalence (according to the data presentation in the paper), either numerator and denominator, or prevalence and denominator, or prevalence and standard error, or prevalence and 95% confidence intervals were extracted with an aim to arrive at the numerator and denominator
- For weighted prevalence (according to the data presentation in the paper), either weighted prevalence and weighted standard error, or weighted prevalence and weighted 95% confidence intervals were extracted. Effective numerators and denominators (taking account of the design effect) were then calculated from either of these combinations.

Meta-analytical methods for estimating dementia prevalence:

A random effect exponential (Poisson) model to assess the effect of age, and age and gender on the prevalence of dementia was used. Age was coded as the mean for each age group as reported in 10/66 dementia India study. Modelling exercise for the effect of age, main effects of age and gender, and an interaction between age and gender was undertaken. Relevant mean age and gender coding were applied to the coefficients estimated from the models. Prevalence was estimated in five year age-bands from 60 – 89 years, and for those aged 90 and over, for both genders combined (from the age only model), and for men and women separately (from the age and gender model).

2.3 RESULTS

After the detail review, 7 out of a possible 86 publications reported prevalence of dementia. One publication was excluded due to lack of a diagnostic, and remaining 6 publications were included in the meta-analysis (Table 2.1).

Table 2.1: Indian studies on Dementia

Studies – setting (reference)	Design, sample size	Outcome	Sex	Age specific prevalence (%) with 95% confidence intervals							Overall prevalence (age range)
				60-64	65-69	70-74	75-79	80-84	85-89	90+	
1. Ernakulam (rural) (Shaji et al, 1996)	Three phase N=2067	DSM-III-R	-	0.33 (0-0.79)	0.99 (0.55-1.43)	1.5 0.3-2.7	3.24 1.16-5.32	12.88 (7.78-17.98)	16.28 8.48-24.08	32.14 14.86-49.42	3.19 (60+)*
2. Thiruporur (semi-rural) (Rajkumar et al, 1997)	Two phase N=750	ICD-10		2.5 1.25-3.75		5.5 1.5-9.5		16	1.6-30.4		3.5 (60+) 2.2-4.8
3. Ballabgarh (rural) (Chandra et al, 1998)	Two phase N=5126	DSM-IV CDR>=0.5		-	0.7 0.38-1.18	1.68 0.81-3.10		9.85 5.24-16.84			0.84 (55+) 0.61-1.13 1.36 (65+) 0.96-1.88
4. Mumbai (urban) (Vas et al, 2001)	Three phase N=24488	DSM-IV		0.28 0.05-0.51	0.8 0.38-1.22	2.42 1.54-3.30	4.99 3.04-6.94	5.06 2.72-7.40	3.85 1.24-6.46		2.31 (65+) 1.84-2.78
5. Ernakulam, Kochi (urban) (Shaji et al, 2005)	Three phase N=1934	DSM-IV		-	0.66 0.29-1.53	2.04 1.18-3.54	5.22 3.73-8.10	7.14 4.16-12.07	11.86 5.94-22.57	13.33 4.05-38.35	3.36 (65+) 2.73-4.07
6. Kolkata Municipal Corporation (urban) † (Das et al, 2006)	Two phase N=5430	DSM-IV	M	0.38 0.18-0.82		0.79 0.39-1.63		2.27 1.12-4.60			1.02 (60+) 0.78-1.32
		DSM-IV	F	0.32 0.14-0.75		0.78 0.36-1.68		3.04 1.68-5.50			
7. Chennai (urban) (Rodriguez et al, 2008)	One phase N=1005	DSM-IV	M	-	0.6 0.0-1.7	1.6 0.0-3.8	No cases	No cases	No cases		0.9 (65+) 0.3-1.5
		10/66 Dementia	F	-	0.8 0.0-2.0	1.1 0.0-2.5	No cases	No cases	3 0.0-7.3		
			M	-	2.9 0.4-5.4	5.5 1.5-9.6	4.5 0.6-9.6	25 12.8-37.2			7.5 (65+) 5.8-9.1
			F	-	5.5 2.5-8.4	7.4 3.6-11.2	8 1.7-14.3	21.2 11.0-31.4			
8. Vellore (rural) (Rodriguez et al, 2008)	One phase N=999	DSM-IV	M	-	0.7 0.0-2.1	1.3 0.0-3.1	No cases	No cases	1.4 0.0-4.1		0.8 (65+) 0.2-1.3
			F	-	0.5 0.0-1.6	1 0.0-2.4	No cases	No cases	1.5 0.0-4.4		
		10/66 Dementia	M	-	4.3 0.9-7.7	5.8 2.1-9.6	5.7 0.7-10.6	11 3.6-18.3			10.6 (65+) 8.6-12.6
			F	-	7.8 4.0-11.6	14.8 9.8-19.8	15.7 8.0-23.5	29.4 18.3-40.5			
9. Tiruvannur (Urban)* (Mathuranath PS et al, 2010)	Two phase N=2466	DSM-IV	M	1.7 0.2-3.2	1.8 0.2-3.3	2.1 0.06-4.1	5 1.1-8.8	3.4 1.2-8.0	11.1 2.7-19.4		3.7 (65+) 3.02-4.52
			F	1.5 0.4-2.6	1.7 0.4-3.0	3.3 1.1-5.4	7.3 3.6-10.9	18.4 10.2-26.5	22.4 11.7-33.1		4.86 (65+) 3.83-5.89

Note: Confidence Intervals for studies 1, 2, 4, 5 and 6 were calculated from numerator and denominator data provided in the papers, with no account taken of the two or three phase design and the multi-stage sampling. This will have led to underestimation of the standard error, i.e. the robustly estimated confidence intervals would be wider.

*Trivandrum study was published after the systematic review was conducted; hence not included in the meta-analysis. † Studies which did not fulfil the inclusion criteria

The DSM IV criteria has been widely used in both clinical and epidemiological research in India. 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 unreliability.

The 10/66 dementia diagnosis 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. 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. The final dementia diagnosis was made in two ways. The main dementia outcome was defined as those scoring above a cut off 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 involved 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. The DSM-IV dementia criteria had selectively missed mild and moderate cases.

Methodological constraints in Indian studies

One of the main methodological problems with Indian studies was assessment of dementia. For example, the informant / carers in India, despite the presence of objective memory impairment, are less likely to report cognitive decline (like memory problems) and social impairment (an essential criterion for DSM IV dementia diagnosis). Hence, using DSM IV dementia criteria in population survey may underestimate true prevalence, particularly where awareness about dementia is low;

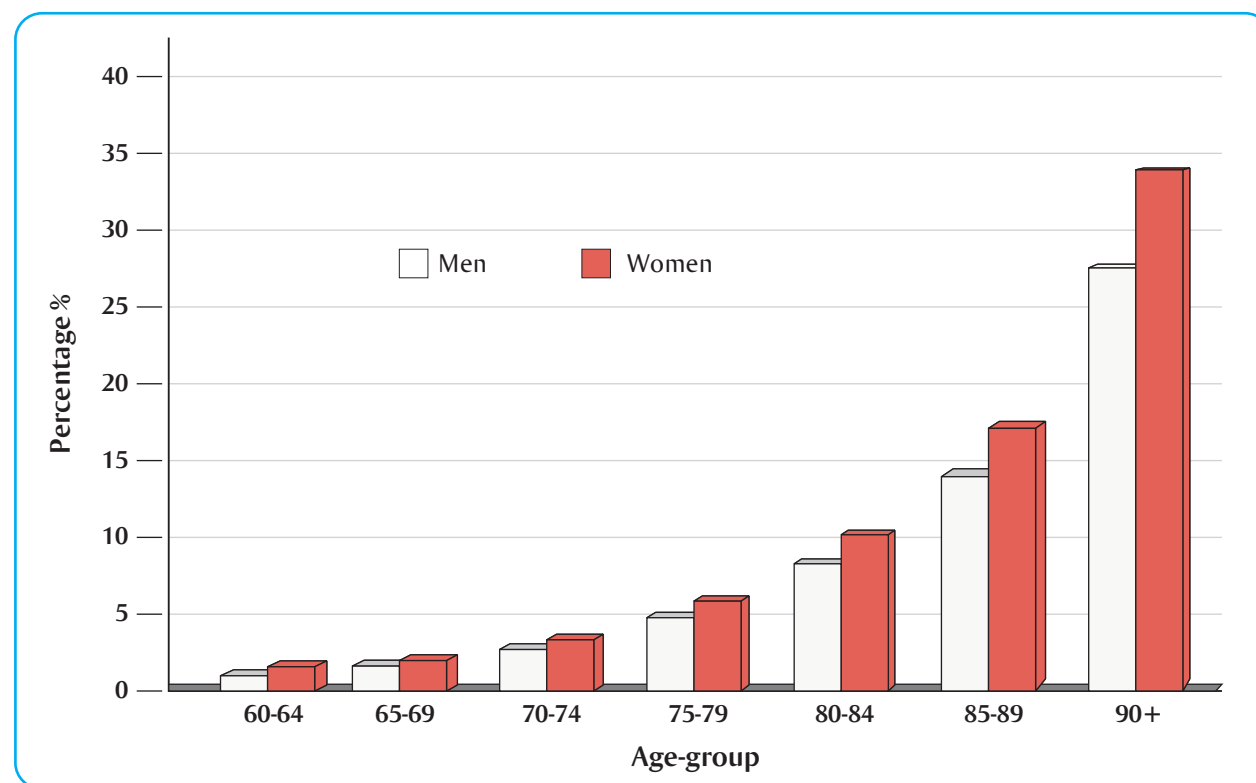
The majority of studies have used two and three phase study design and DSM-IV criteria for dementia diagnosis, and the 10/66 studies conducted in Chennai and Vellore used one phase dementia diagnosis which is a much simpler method. While multi-stage sampling permits prevalence estimates for much larger base populations (for example, the whole population of city), sample weights need to be used to calculate prevalence and confidence intervals, and it was not clear whether this was done for several studies. One phase diagnosis offers several advantages over two or more phases (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 have not been applied in the desirable manner: either screen negatives were not selected for the second phase or weighting back was not carried out properly or not carried out at all; . The end result is either under or over-estimation of true prevalence.

Current Estimation and Future Projection

Prevalence of Dementia by Age and Gender

For the year 2010, 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 increased steadily with age and higher prevalence was seen among older women than men (figure 2.1). These estimates are higher than those previously estimated by Delphi consensus .

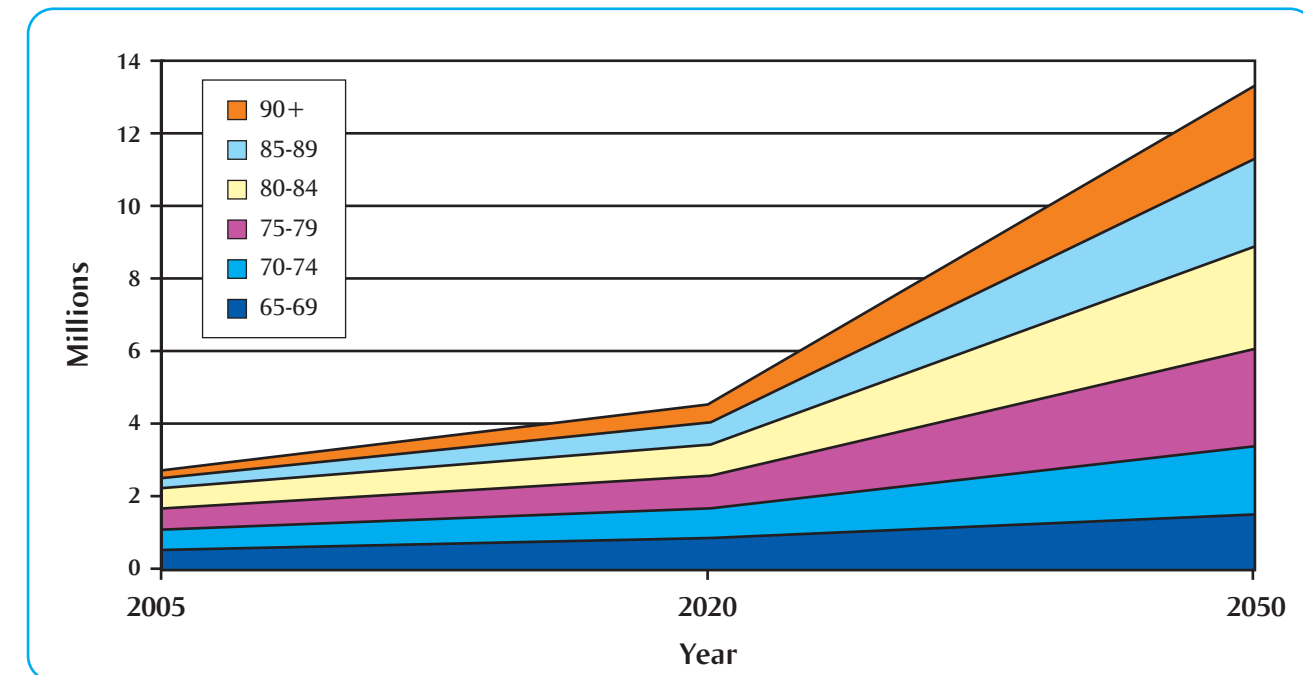
Figure 2.1: Prevalence of Dementia in India, 2010



The larger proportion of older women than men who have dementia may be due to the fact that women live longer in India. However, 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 dementia among older people.

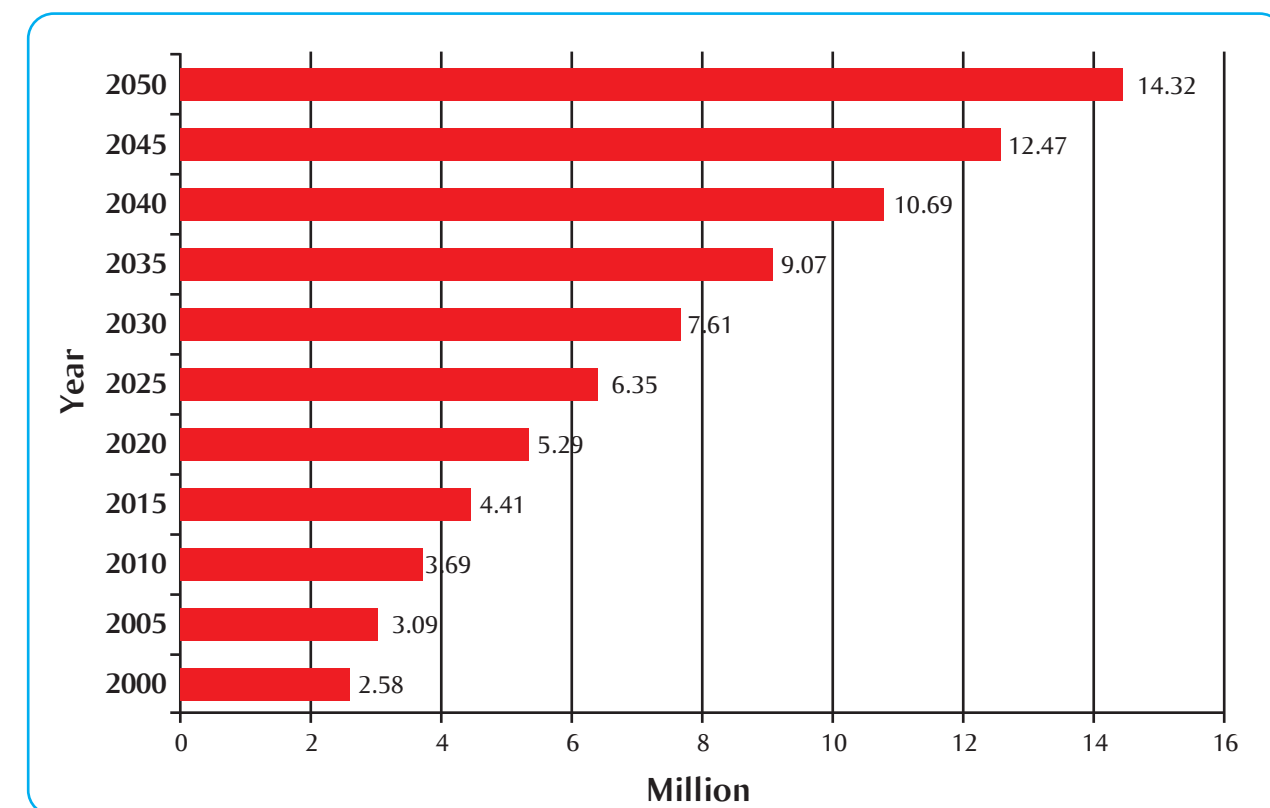
The persons with dementia in younger age groups, 60-75 years, are expected to increase steadily over time; and a steep increment amongst age groups over 75 years can be predicted after 2030. (Figure 2.2)

Figure 2.2 Trend in dementia prevalence by age over time (2010-2050)



Future Projections

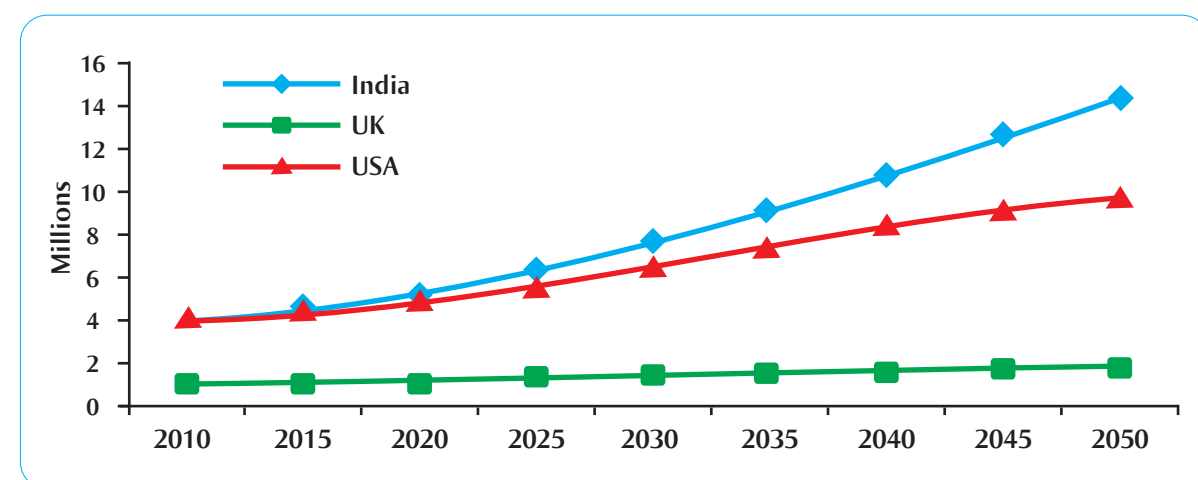
Figure 2.3: Estimation of number of PwD over 60 years in India between 2000 and 2050



The future projections are estimated on the assumption that prevalence of dementia is stable over time, which may not be true. If the incidence of dementia or with increasing life expectancy the number of older people increases, 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 2.3). Thus, an estimated twofold increase by 2030 and threefold by 2050 can be expected. By the year 2025 UK is projected to have 1 million people with dementia (Dementia UK Report, 2007). According to current estimates, India has more than 3 million PwD and is expected to overtake USA in number of PwD by 2015 (figure 2.4)

Figure 2.4: Estimated of number of PwD >60 years in India, UK and USA



State-wise estimates of numbers of PwD in India

State-wise estimates were made using meta-analyzed prevalence estimation for India and the 2001 Census data future projection (Census, 2006). The projected number of people aged 65 and older with dementia for years 2011, 2016 and 2026 varied by state and region in India and corresponding variability in number of people with dementia was also observed. The percentage change in dementia between base year 2006 and each of the subsequent time periods was calculated (Table 2.2).

By 2026, more than 500,000 older PwD are expected to be living in Uttar Pradesh and Maharashtra. In other states, Rajasthan, Gujarat, Bihar, West Bengal, Madhya Pradesh, Orissa, Andhrapradesh, Karnataka, Kerala and Tamil Nadu around 200,000 to 400,000 PwD 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 (Figure 2.5). 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 people older PwD.

The increased numbers of PwD will have a marked impact on the states' infrastructures and healthcare systems, which are at present ill prepared in many regions. The projected increases in the Southern region are not as marked as those in other regions of India, however, large proportion of people aged 65 would result in more PwD.

Figure 2.5: Projected changes between 2006 and 2026 in number of people living with dementia by State

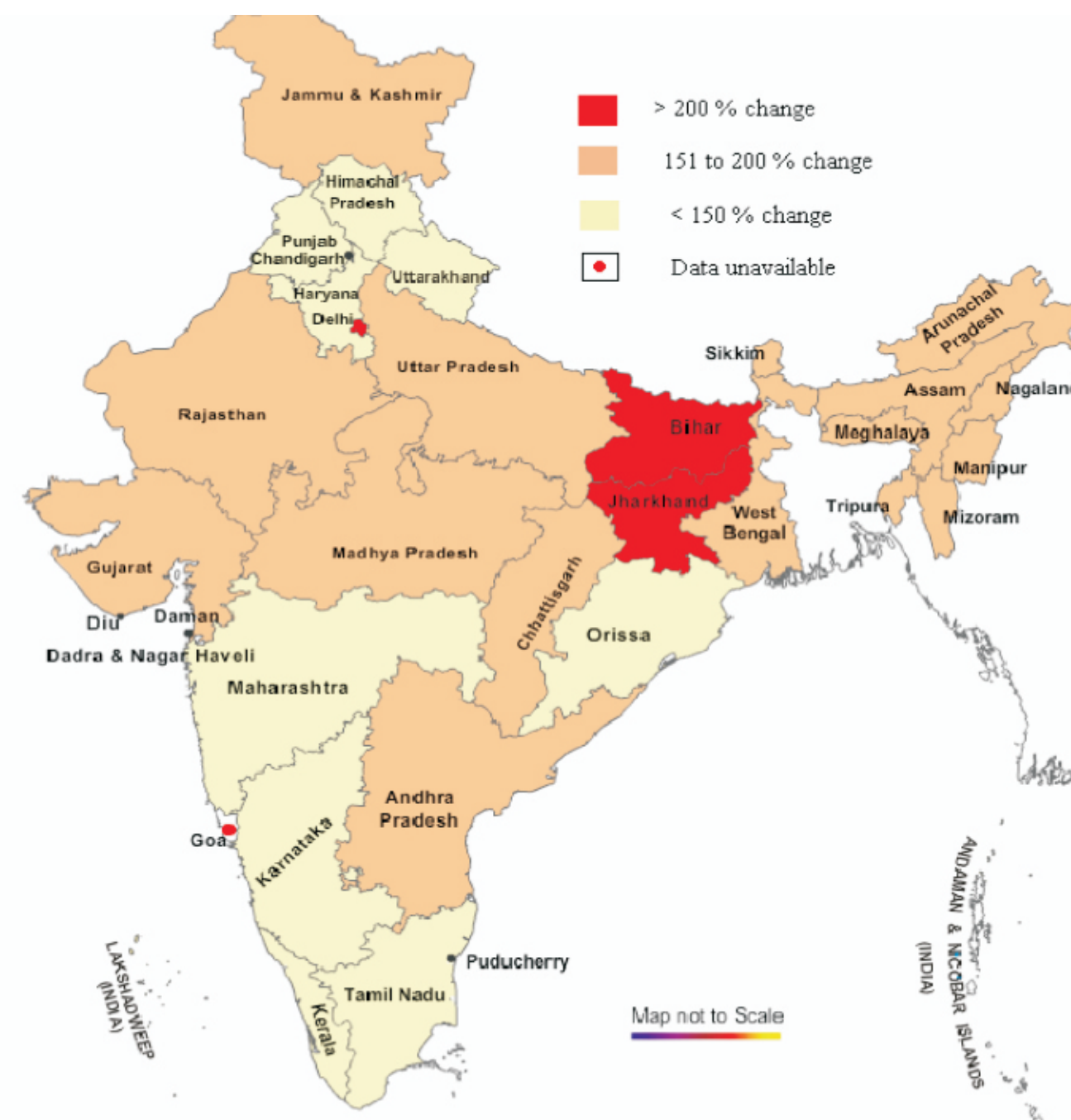


Table 2.2: Estimation for number of people living with dementia by State (except Goa) between 2006 and 2026

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

Conclusion:

This report clearly identifies the importance of dementia in India, and the growing number of PwD in the coming years. More epidemiological studies are needed to close the gap between regions uncovered, where more number of older people are residing. Further studies should take into consideration, regional, cultural, ethnic, religious and socioeconomic diversities and more importantly appropriate study design should be chosen, two phase design do not seem to work as it is more expensive, difficult and time consuming. Therefore, one phase design seems to be more feasible at community level. Apart from 10/66 dementia group studies, other studies mainly focused on estimating dementia prevalence. However, there is growing need to explore co morbid chronic diseases, disability, needs for care, care arrangements, health service utilization of PwD in India. Moreover further prospective studies should explore risk factors for dementia, with biological samples (DNA, haematology, fasting glucose and lipids and frozen serum for later evaluation), other middle age cardiovascular risk factor exposures, diet and anthropometry measure. There is a greater need to move beyond numbers to action. Community based intervention targeting older PwD and their carer should be developed and their cost-effectiveness and feasibility have to be established.



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Chapter-3 The Impact of Dementia

THE DEMENTIA INDIA REPORT

The report for improving dementia care in India

The Impact of Dementia

India is a diverse country with geographical and socio-cultural differences. We have a rapidly aging population which currently exceeds a 100 million people. This number will steadily increase in the coming decades. Age related disabling conditions like dementia will increase and have a wider impact depending on the socio-cultural context. This chapter makes an attempt to outline the overall impact of dementia in India.

The estimated number of PwD in India is an important indicator of the impact of the disease. However numbers do not convey the effects on the quality of the individual experience, or the wider consequences on the society. Hence the impact of dementia needs to 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 one of the family members has an overall impact on the entire family. At this juncture, the family and kinship form the cornerstone of care and support of the PwD in India.
3. The society: The cost of providing care and support to the PwD is met by the society, either directly through government expenditure, or in other ways. The cost of lost productivity needs to be accounted for. Other social impacts, like burden may be harder to quantify, but still have to be borne or endured.

This section of the report provides information about the consequences of dementia with respect to disability, mortality and dependency, and, at the societal level, 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 will also be described.

3.1 DISABILITY, DEPENDENCY AND MORTALITY

The World Health Organization's (WHO) Global Burden of Disease Report (GBD), first published in 1996, and currently updated in 2004, provides important evidence on the relative impact of health conditions worldwide. The key indicator is the Disability Adjusted Life Year (DALY), a composite measure of disease burden calculated as the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). Thus, DALY summarizes the effects of disease, both on the quantity (premature mortality) and quality of life (disability).

Mortality

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 for females. For India and the WHO South East Asia 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 (ADI 2006). A 15 year community-based follow-up study in the United States of 1670 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 people . A systematic review reported a direct relationship between the level of cognitive impairment and increasing risk of mortality; a two-fold mortality risk for severe cognitive impairment .

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 PwD. A Brazilian observational study conducted on 1,656 individuals aged 65 and over reported a 51.3% death rate for the dementia group and concluded that dementia was the most significant predictor of mortality among Brazilian elderly . A larger population study from Nigeria on 4,699 persons aged 65 and older also reported an increased risk of mortality for those with dementia. This association of dementia and mortality persisted with 70% of elderly over the age of 75 with dementia, dying within five years of diagnosis .

The only study from India, conducted in Chennai, investigated predictors of mortality among older people living in the community (Jotheeswaran et al, 2010). After adjusting for age and gender, the risk for mortality was 2.3 times more for older people who received a diagnosis of dementia at the baseline survey and that risk was linearly correlated to the severity of cognitive impairment.

Disability and Dependency

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

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. Table 3.1 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. The same data is provided graphically in Figures 3.1 and 3.2.

Table 3.1: Relative contribution of different chronic diseases and conditions to the total global burden from chronic diseases, for those aged 60 years and over, expressed as years lived with disability and years of life lost

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

Figure 3.1: Contribution of chronic diseases to Years Lived with Disability

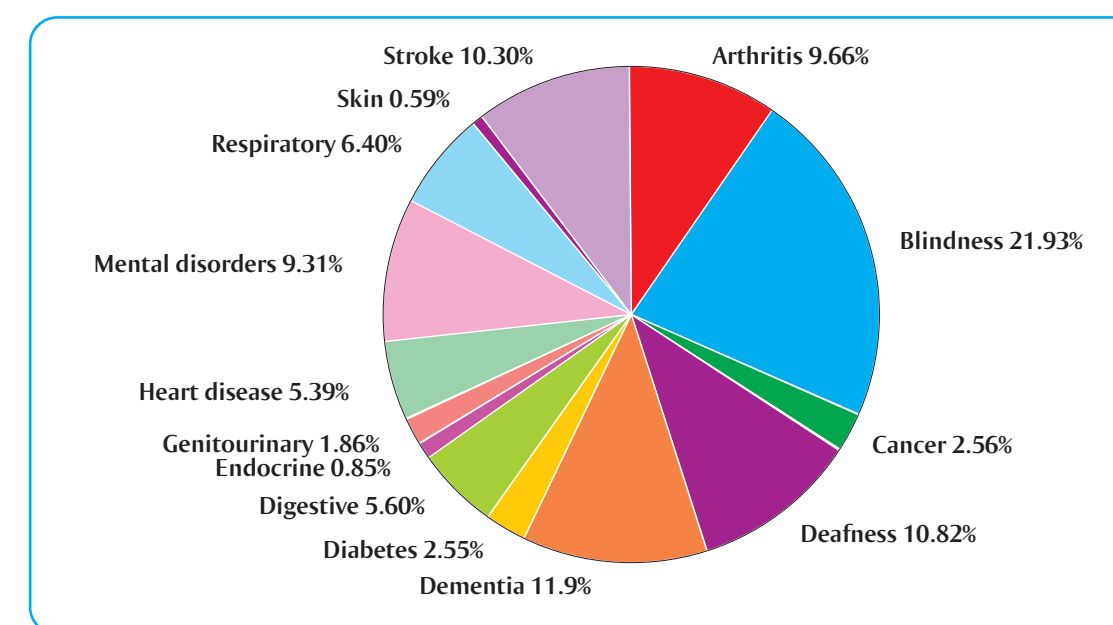
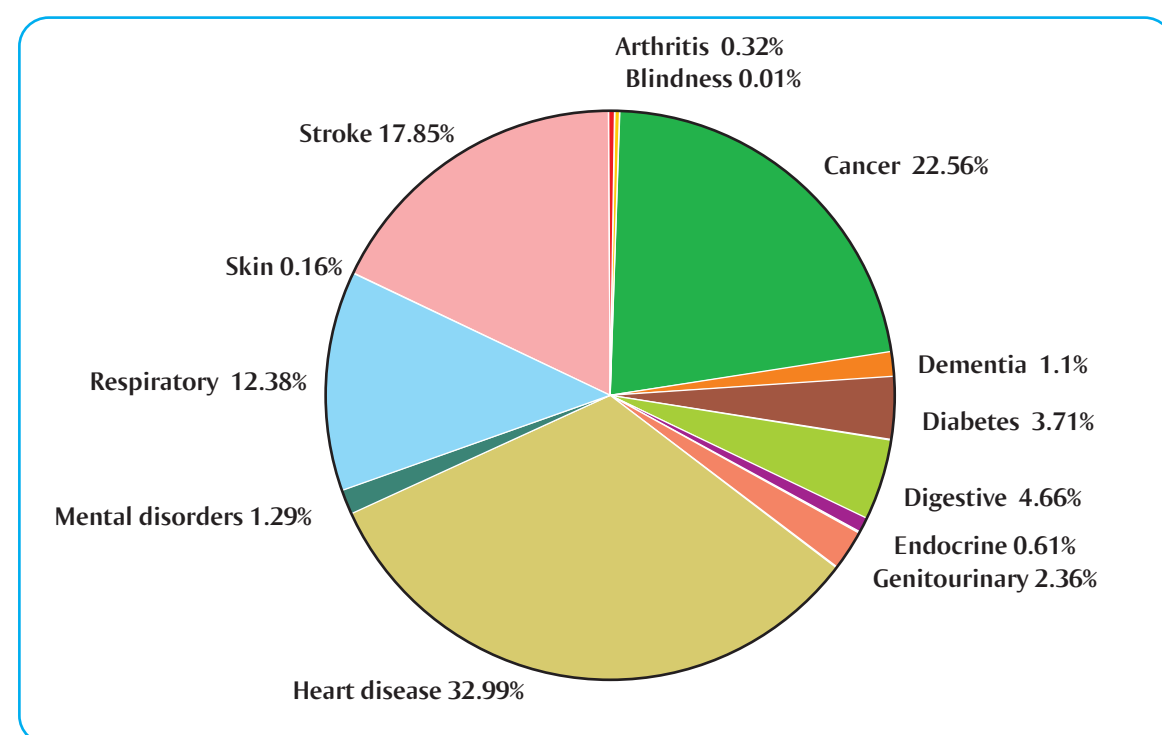


Figure 3.2: Contribution of chronic diseases to Years Life Lost



The World Alzheimer Report (Knapp and Prince, 2009) highlights the importance of co-morbidity in the causation of disability and dependence. Older people are particularly likely to have multiple health conditions. PwD often have serious co-morbid physical and mental health problems. These multiple pathologies will interact in complex ways to create barriers to activities of daily living (disability), hence determining need for care (dependence). It is not easy to assess the relative contributions of these conditions to the resultant impairments. This issue is not addressed by the Global Burden of Disease methodology. GBD assumes that the impact of different conditions can be estimated quite separately from each other, ignoring issues arising out of co-morbidity. In three recent publications, the 10/66 Dementia Research Group has assessed the impact of dementia, depression and physical impairment on dependence in Cuba, the Dominican Republic, and Nigeria. Those with needs for care were characterised by co-morbidity with dementia/cognitive impairment and physical and mental disorders. The 10/66 Dementia Research Group has carried out an extensive analysis across all 10/66 study sites (urban sites in Cuba, Dominican Republic and Venezuela, and both rural and urban sites in Peru, Mexico, China and India), using a more detailed breakdown of chronic diseases, similar to that used in the GBD report. These included six diagnoses: dementia, depression, stroke, ischaemic heart disease, hypertension, and Chronic Obstructive Pulmonary Disease (COPD), and six self-reported physical impairments: weakness or loss of a limb, eyesight problems, stomach or intestine problems, arthritis or rheumatism, hearing difficulties or deafness, and skin disorders. The findings are summarised in the World Alzheimer's Report 2009. Dementia emerged as the leading independent cause of both disability and dependency, followed by limb weakness, stroke, depression, eyesight problems and arthritis. Neither ischaemic heart disease nor hypertension, nor chronic obstructive pulmonary disease was associated with

disability or dependency. Dementia was the only health condition to be consistently strongly associated with dependency in all sites.

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

Chronic diseases appear to have different impacts on disability and mortality. Cardiovascular disease and cancer contribute much more to mortality than to disability. Successful interventions in such conditions can add years to life. Of course, it is important to save a life and add years to life. It is equally important to compress morbidity to make the Quality of Life (QoL) less affected by the ensuing disability.

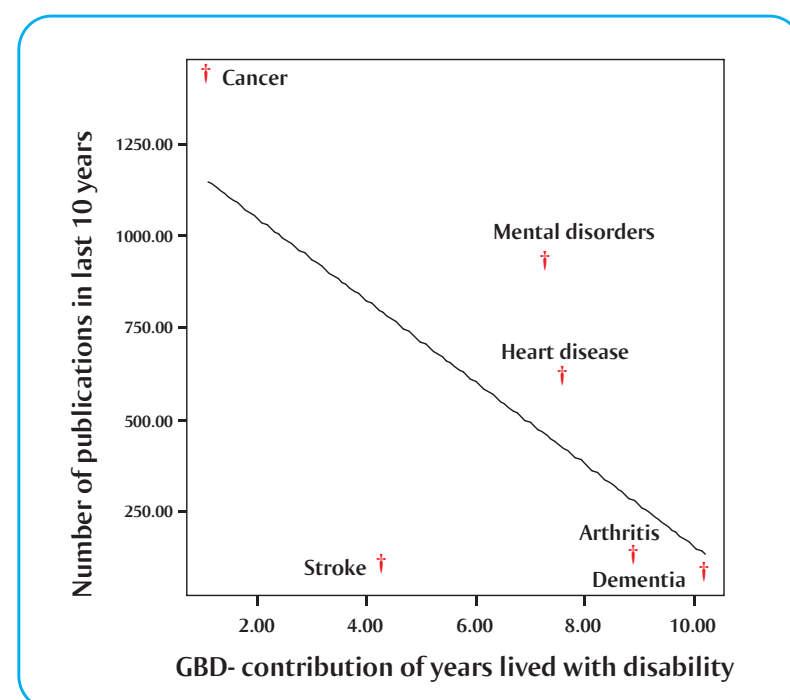
By preventing and delaying the progression, it is theoretically possible to reduce the disability thereby adding 'life to years'. In practice, prevention or postponing disability is often ignored, both by policy makers and health care practitioners. Governments world over continue to give priority to 'prevention of mortality' than 'prevention of disability'. More money is spent to prevent and provide interventions for diseases which cause sudden and premature death than for diseases which result in longer life with chronic disability.

Dementia is a typical example of such a chronic disabling condition which is often neglected by all concerned in the health care sector. Even in economically developed countries like the UK, much more is spent on healthcare for cardiovascular diseases and cancer, than on healthcare for dementia. Obviously, 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. However, better understanding of the scientific evidence is the key to this need.

Another index of the priority accorded to different chronic diseases is the research effort that is contributed to each. In the USA, the National Institutes of Health report research expenditure in 2008 was \$5.6bn on cancer, \$2.0bn on cardiovascular disease, \$0.3bn on stroke, and \$0.4bn on dementia. There is no comprehensive data on research spending from India on dementia. However it appears that only very limited amount of money is spent on dementia research. The list of the extramural research approved for funding by the Indian Council of Medical Research (ICMR) from April 2007 to March 2009 had a total of 6 projects related to dementia. Only two such projects were allocated during the 4 year period prior to this (<http://icmr.nic.in> - list of the extramural research accessed on 23-04-2010). A compilation of ICMR funded research work in the field of mental health for two decades from 1984-2004 was reviewed (Shah et al, 2005). Two projects relating to elderly were done under the leadership by Prof. Venkoba Rao. They studied elderly seeking psychiatric help in a clinical setting and also health problems of old people in a rural locality. Both these studies were in Madurai in Tamil Nadu. There were no other studies on geriatric mental health or dementia. Dementia needs to be recognized by the Indian Council of Medical Research as a priority health condition for future research. At present, the research money is allocated under the category of aging, mental health or neurological sciences.

Analysis of research effort from India, 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 from India (number of publications), YLL and YLD is presented in Figure 3.3.

Figure 3.3: Research efforts in India and Years Lived with Disability, YLD (%)



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 it has been researched. Conversely, there is a strong positive correlation between years of life lost and research effort. This mindset can be particularly problematic in countries like India where health care continues to be guided by the needs of acute care than long-term care. When planning for services for our aging population, it is important to invest money on research. Only good quality research can provide proper guidance to service development. There is also the need to develop inexpensive, effective interventions with scope for scaling up over time.

3.2 CARE OF OLDER PEOPLE

Though the biological phenomenon of aging is universal, the daily life of an old person varies considerably according to social, economic, and cultural contexts. Aging and health has many socio-cultural determinants. There are more women than men in the older age groups. Most women are widows as they tend to outlive husbands who are older to them. This is particularly evident in India and other Asian countries and poses special social issues pertaining to care and quality of life during widowhood.

The term 'healthcare' is often used in the context of doctors, nurses and hospital settings. Most of the healthcare in old age is home-based - outside clinical settings. Such care is supervised or provided by a co-resident family member or relative. This is commonly referred to as informal care. Informal care is a natural social resource which allows members of a social unit to offer and take help. This important resource is available in all societies but its value is not well recognized. Informal care plays a huge role in the care of older people in India. The experience of limitations or disability happens in the contexts of partners, family and friends.

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

Care giving has been defined as "...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Care-giving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting." (Care giving is a life-long experience. It is essential to understand the processes involved in care giving and realize its public health importance. The social context of care is also important.

In India, older people, typically live with their families in multi-generational households. This is a desirable social situation as there are more people in the household to share the responsibility of care. However, traditional family and kinship structures are widely perceived as under threat from the social and economic changes that accompany economic development and globalization across the world. Populations are becoming increasingly mobile in developing countries. So, old parents stay at home, but with less social support. Social changes associated with urbanization necessitate more people to join the work force. More women are taking up employment outside their homes in order to supplement the family income. Consequently, the care giving responsibilities at home will have to be shared by all, and no more the exclusive responsibility of the traditional house wife.

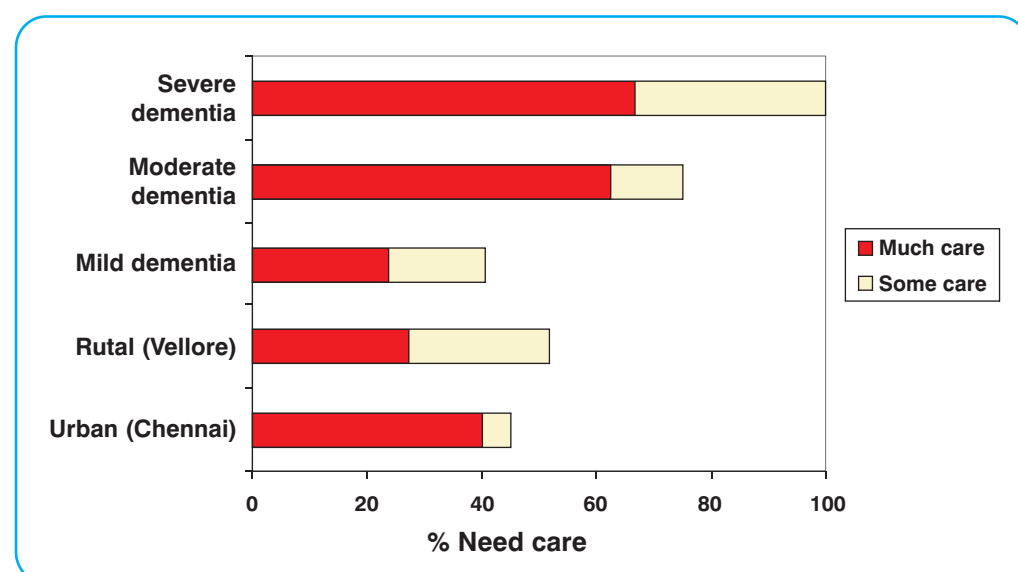
Care of People with Dementia

Most research into care giving for PwD is cross-sectional. But care giving is a long-term evolving process. The onset of caring is often hard to define. The need for care may precede or post-date a formal diagnosis of dementia. Need for care tends to escalate over time, from increased support for household, financial and social activities, to personal care. Later on, in several cases, it could involve almost constant supervision and surveillance.

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 (Clinical Dementia Rating 1 or above indicating mild or > mild dementia) from the Indian centers are summarized in Figure 3.4.

Figure 3.4: Need for care among people with dementia



Source: 10/66 Dementia Research Group population-based studies, data release 2.2

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%.

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. It is also common that one person among them would be more involved with the care at any given point of time and that person can be considered as the primary carer.

The 10/66 Dementia Research Group's multicentre pilot study included 706 primary carers of PwD in Latin America, India and China. This 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 the vast 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. Similar findings were noted by an earlier carer study by the 10/66 centre at Thrissur India. Living arrangements for PwD, and the characteristics of their carers were also assessed in the 10/66 Dementia Research Group's population-based studies. These data are summarized in Table 3.2. This study included 181 subjects from India (urban sample of 75 from Chennai and a rural sample from Vellore; both the centres were in the southern state of Tamil Nadu). Most PwD lived with adult children and/or children-in-law. Living alone, or with spouse only was very uncommon. Carers were most often women (urban 69% & rural 80.2%) and spouses (urban 26.7% & rural 23.3%), children or children-in-law (urban 40% & rural 70%). Half of these households had at least one child below the age of 16 years living there.

Table 3.2: Household living arrangements and characteristics of the main carer for PwD in urban and rural sites in India. (10/66 Dementia Research Group population-based studies – data release 2.2)

10/66 DRG study site	N	Household living arrangements				Characteristics of the main carer			
		Alone	Spouse only	Adult children	children under the age of 16	Spouse	Child or child-in-law	Non-relative	Female carer
India (urban)	75	4.0%	13.3%	72.0%	49.2%	26.7%	40.0%	0%	69.3%
India (rural)	106	15.1%	5.7%	67.0%	52.8%	23.3%	70.0%	0%	80.2%

As pointed out earlier, it is important to recognise that, other family members and friends are often routinely involved in providing care. Thus, in the 10/66 Dementia Research Group population-based studies, a fifth to a third of main carers acknowledged receiving substantial additional help from other unpaid carers. Paid carers were involved in dementia care in many sites particularly in urban Peru and urban China. However paid carers were not involved in dementia care from the Indian centres at Chennai & Vellore. But then, additional unpaid help was available in urban setting (6.7%) and in rural setting (19.8%) in Tamil Nadu (table 3.3).

Table 3.3: Additional care inputs reported by carers of PwD in urban and rural sites in India (10/66 Dementia Research Group population-based studies – data release 2.2)

Site	n	Main carer cut back on paid work to care	Additional unpaid care	Paid day-time care	Paid night-time care
India (urban)	75	14.7%	6.7%	0%	0%
India (rural)	106	10.3%	19.8%	0%	0%

There is an 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. These workers are usually women and they stay along with other members of the household. They generally take up the nursing and other caregiving responsibilities. The Red Cross Society of India organises such services in parts of Kerala. Though these workers are generally referred to as “home nurses” they are not nursing professionals. They are not trained in health care or community health work. Though untrained, some of them assume the carer role easily and provide good assistance to the families. Many families find them useful and that makes them much sought after. As these services remain unregulated, families at times could end up facing more problems. Formal home based short training programmes for these workers are very much needed. The placement agencies need to be registered and regulated. This is also an employment opportunity, especially for women.

3.3 HOUSEHOLDS: THE SETTING OF CARE

Dementia care in India is almost entirely home based. It is prudent to strengthen home based care for more than one reason. Greater focus on the households in India is required since they hold the key to the care and support of PwD.

According to the data available from the 2001 census, the rate of growth of the households is surging ahead of the population growth. The average household size at national level has declined slightly from 5.5 in 1991 to 5.3 in 2001. It is worth noting that the pattern is similar for the rural as well as the urban households. This is indicative of growing proportion of nuclear families, now more evident in urban than in rural India.

India in 2001 had 194 million households with 1028 million people. Of the total households, 193 million households were designated as normal households excluding the homeless and the institutional dwellings. More than 70% of them were in rural areas. The number of older people in the population, as per 2001 census, was more than 70.6 million. There were about 58.4 million households with at least one older person. This means that every third or fourth household has a person older than sixty years living at home. The estimated number of PwD in India in 2010 is 3.7 million. Assuming that it is very unlikely that there is more than one PwD in a given household, it means that 3.7million households have with a PwD. This would indicate that 1 out of 50 normal households will have a PwD and 1 out of 16 households with at least one older member will have a PwD. These figures indicate that dementia is not uncommon among Indian households. Dementia, directly or indirectly affects all members of a household. The estimated number of people indirectly or directly affected by dementia would then be around 20 million.

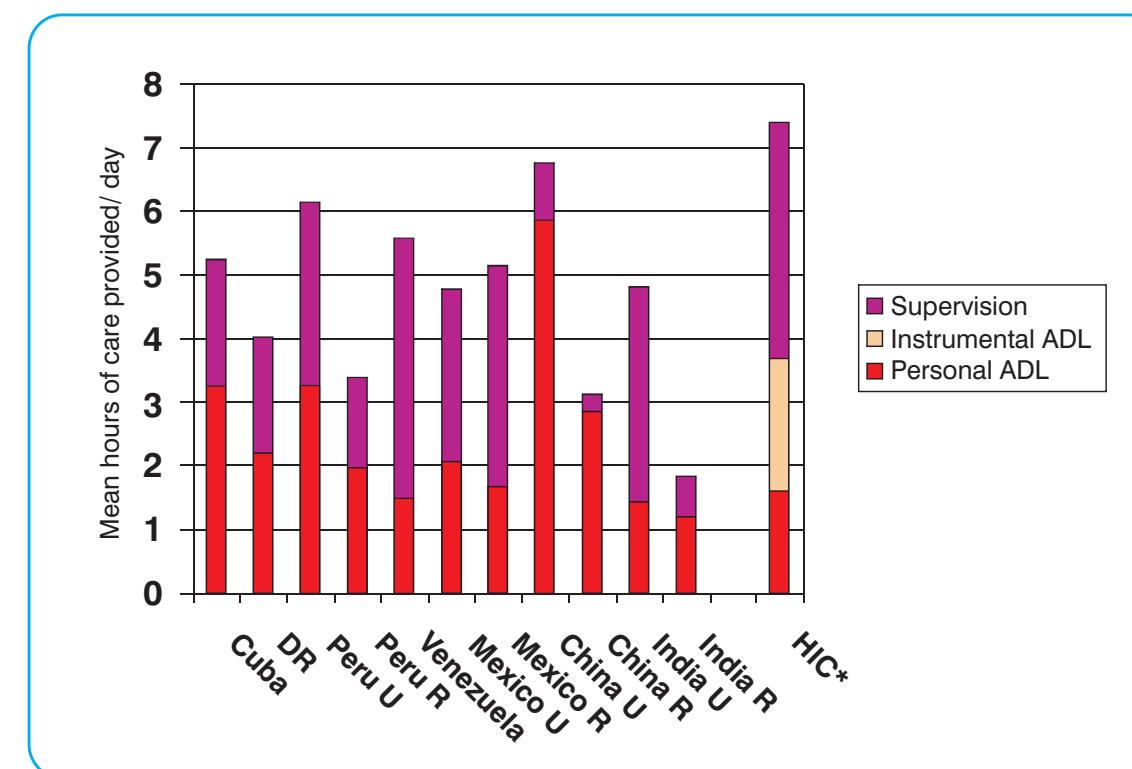
3.4 DEMENTIA: NATURE OF CARE

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 identified 27 studies, that provided information on time spent caring. Most of the studies were from high income countries. 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 in Figure 3.5. 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.

Figure 3.5: 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, data release 2.2)



3.5 THE IMPACT OF DEMENTIA CARE

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. Carer perceptions of strain are often assessed using Zarit Burden Interview (ZBI) ; ; . It has 22 items that assess the carer's appraisal of the impact of their involvement in care. 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 (Prince et al, 2004a).

Psychological impact on carers

Many studies have reported very high levels of psychological morbidity among carers of PwD; 40% to 75% in EURO CARE ; with the same range of prevalence observed in 21 of the 24 10/66 pilot centres globally . All the six 10/66 pilot study sites in India too 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. A recent systematic review identified 10 studies that assessed the prevalence of major depressive disorders among carers of PwD using structured clinical interviews, which varied between 15 and 32%. In six of these studies, the prevalence of major depression was compared with that of a control sample, which found that the prevalence in carers was 2.8 to 38.7 times higher. The studies which compared depressive symptoms in carers and non-carers have also been meta-analysed, and show a fairly consistent and significant tendency towards higher symptom levels among carers . The difference is larger for studies of dementia carers when compared with studies of mixed groups or people caring for those with physical disorders.

Impact on the physical health of carers:

It has been suggested that the prolonged stress and physical demands of care giving, coupled with the biological vulnerabilities of older carers may increase their risk for physical health problems . There is some evidence for small decrements in subjective and objective physical health and impaired immunity . One study shows an increased risk of mortality for carers who experience strain .

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

Much of the carer studies to date have been on convenient non-representative samples and this has been its main weakness. In the 10/66 Dementia Research Group sites, where representative samples were studied, the prevalence of psychological morbidity was consistently higher among carers of PwD, than among co-residents of older people (Table 2.4). In most sites, one fifth to one third of carers had significant psychological morbidity.

Table 3.4: The prevalence of psychological morbidity among co-residents of older people with and without dementia, and among carers of older PwD who needed care. (10/66 Dementia research Group population-based studies data release 2.2)

10/66 DRG study site	The prevalence of psychological morbidity (an SRQ score of 8 or more) among carers/ co-residents of:					
	all older people free of dementia		all older people with dementia		older people with dementia needing care	
	N	%	N	%	N	%
India (urban)	930	2.2%	75	8.0%	15	20.0%
India (rural)	893	9.2%	106	9.4%	30	16.7%

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. Results of these analyses are summarized in Table 3.5.

Table 3.5: The independent effect of dementia upon carer/co-resident psychological morbidity meta-analysed across 11 10/66 Dementia Research group population based study sites – Prevalence ratios (PR) and Population Attributable Prevalence Fractions (PAPF) (data release 2.2)

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

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

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 effect of dementia on the carer's mental state was partly but not entirely explained by the older person's needs for care – after adjusting for either disability or dependence the pooled effect was reduced to 1.5 (95% confidence intervals 1.3-1.8). Physical impairments, stroke and depression were also each independently associated with carer/ co-resident psychological morbidity. In fact, physical

impairments made the largest contribution (mean PAPF 18%) followed by dementia (10%), depression (8%) and stroke (3%). Taken together, the chronic disease health state of the older person accounted for a remarkable 30% of the prevalence of psychological morbidity in their carers/co-residents.

3.6 THE COST OF DEMENTIA

Undoubtedly, the impact of dementia is considerable and consequent social-economic-health burden on the individual, family and society is huge. The previous paragraphs indicate the several facets of the impact: ranging from the impact on the individual to that on care giving, economic losses for the family members / carers, increased psychological distress, etc. 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. A distinct advantage of this approach is that it helps policy makers, health planners and health administrators to assign relative priorities. However, the final estimate of the cost depends on available data and is therefore liable for several limitations which include representativeness of the population studied, sample size, cost components included, methods of eliciting cost, etc.,. Indeed based on the methodology adopted, the estimated costs can vary substantially.

Care for management of dementia has been considered either as 'formal' or 'informal' care. 'Formal care' includes institutionalised activities related to providing health services, social / community care, respite and long-term residential or nursing home care, etc., while 'informal care' is the unpaid care by family members or others including their lost opportunity to earn income. As noted earlier, in countries like India, a greater part of caregiving is informal care particularly by the members of the family. While formal care is relatively easier to cost, costing informal care poses several challenges. Apart from difficulty in defining the number of hours spent for care, there is substantial difficulty in defining the various components of informal care, costing lost productivity, etc (for details see Jonsson and Wimo, 2009 and Wimo et al,2007).

Traditionally, cost estimates are from cost of illness studies; cost-benefit and cost-effectiveness analyses are carried out to evaluate interventions, wherein costs estimates are an integral part. Cost of illness studies generally classify, costs into direct costs, indirect costs and intangible costs (Kapur, 2007). Direct costs 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. Direct costs could be further divided into direct medical costs (consultation, investigations, medicines, etc.,) and direct non-medical costs (long term care / day care, transportation, assistive devices, etc.). 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.,) (CDC, 2010, Alzheimer Europe, 2009).

The cost of dementia: global evidence

Worldwide, the annual cost of dementia has been estimated to be US\$ 604 billion for the year 2010 (1.01% of world GDP) (Wimo and Prince, 2010), an increase by 43% of the 2009 estimate (US\$ 421.6 billion) (Wimo et al, 2010) and almost double (92%) of 2005 estimate (US\$ 315.4 billion) (Wimo et al, 2007). 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) (ADI, 2009); just this increase would push the cost by 85% in 2030 (Wimo et al, 2007).

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 had highest cost per person (US\$48,605) and South Asia region the lowest (US\$903): a difference of nearly 53 times. Reflective of the need for continued and long term care, direct social costs was 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 one-third (40%) in high income countries (Wimo and Prince, 2010). This is indicative of the critical and relatively dominant role of family care in resource-poor situations (see earlier section).

Costs of dementia in select countries / regions

United States of America: The total payment made by persons with dementia in the USA for the year 2010 was estimated to be US\$ 172 billion (Alzheimer's association, 2009). Earlier, estimates (2002) revealed that, American businesses incurred about US\$ 36.5 billion, due to lost productivity, missed work or towards replacement expenses of employees who were carers who had to reduce their working hours, take time off or quit working. Coexisting medical conditions (Coronary heart disease, Diabetes, Congestive heart failure, Cancer, etc.,) enhanced the hospital stay pushing up the costs of health care (Koppel, 2002).

United Kingdom: The health and social care, informal care and productivity losses due to dementia for the year 2008 for UK was estimated to be £23.0 billion. Long term institutional care and informal care constituted nearly 95% of these costs. While, health and social care costs were estimated at £10.3 billion, health care cost alone was estimated to be about £1.2 billion, of which 44% was due to inpatient care. The annual cost per case of dementia was estimated to be £27,647, which was much more than the median salary in UK (£24,700) and was several times greater than that for Cancer (£5,999), Stroke (£4,770) or Heart disease (£3,455). An asymmetry in research priorities was also observed. Assuming that £1 million was spent on dementia care, the amount spent on dementia research was less than 1% (£ 4,882). On a similar note, it was 13% for cancer research and 7% for research in heart diseases (Luengo-fernandez et al, 2010).

Canada: The total economic burden for Canada due to dementia was estimated to be C\$15 billion for 2008 by its Alzheimer's society (2008) and was expected to increase more than 10 fold (C\$ 153 billion) during a 30 year period (2008 to 2038). The unpaid-carer lost-opportunity-costs was estimated to be nearly one - third of the total economic burden. The simulated 30 year period cumulative economic burden for the year 2038 was found to be a whopping C\$ 872 billion. Direct health costs have been expected to double every 10 years with the cumulative costs approaching C\$ 500 billion in 2038 (Alzheimer's Society, 2010).

Australia: The total financial cost of dementia was estimated to be Au\$ 6.6 billion for the year 2002, which was nearly Au\$ 40,000 per person with dementia. The financial impact has been estimated to rise to nearly 3.3% of the GDP by 2051. While family carers were providing 80% of the value of informal care without compensation, 1 in 40 Au\$ spent in health care was on dementia (Alzheimer's Australia, 2008). Expenditure for dementia was estimated at Au\$ 1.4 billion and projected to reach Au\$ 4.5 billion by 2031 (Nepal et al 2008).

Korea: Interestingly it was observed that the family's perception of their socio-economic status mattered more and predicted better the outcome rather than the actual costs for care of dementia (Kim et al, 2008). The economic evaluation revealed that for the 272,000 dementia sufferers in South Korea, the estimated total costs per year was more than US\$2.4 billion (Suh et al, 2006). Full time long term care in the community cost US\$ 44,121 and estimated costs for those who did not need long term care was US\$ 3,986. While 96% of the total annual costs were in the community, 56% of the total costs were costs due to informal care and because of missed work of carers.

Argentina: Allegri et al (2007) in their case comparison approach report that family costs of dementia care were significant and most of the direct costs were paid by the family members. The estimated cost for managing mild dementia per year was US\$ 3,420 and increased to US\$ 9,658 in severe cases. Costs increased with cognitive deterioration and with hospitalisation (US\$ 3189.20 outpatient vs. US\$ 14,447.68 institutionalized).

China: The Shanghai study estimated the annual costs to be US\$ 2,384 per patient for the year 2005-06 with a direct cost of US\$ 1058 and an indirect cost of US\$ 1326 (Wang et al, 2008).

Turkey: The observational pilot study reported the annual cost per patient to range between US\$ 1,766 and US\$ 4930. The costs increased with decreasing cognitive function and a major portion of the costs were due to carer costs (Zencir et al 2005).

Europe: The total cost of illness for whole of Europe (including Turkey) was estimated to be €177.2 billion of which €96.6 (55.0%) billion was due to informal care. The annual cost per PwD was €12,000 and ranged between €6796 in Eastern Europe and € 15,280 in Western Europe. Republic of Moldavia (€1286), Albania (€2844), Serbia and Montenegro (€3680), Romania (€4033) and Belarus (€4800) had per case costs less than €5000 (PPP), while Ireland (€20,374), Denmark (€20,915), Norway (€ 21,593) and Luxemburg (€29,179) had greater than €20,000 (PPP). Interestingly, institutional care or direct costs predominated the cost component in

northern Europe as against a predominant informal care in southern Europe (Alzheimer Europe, 2009).

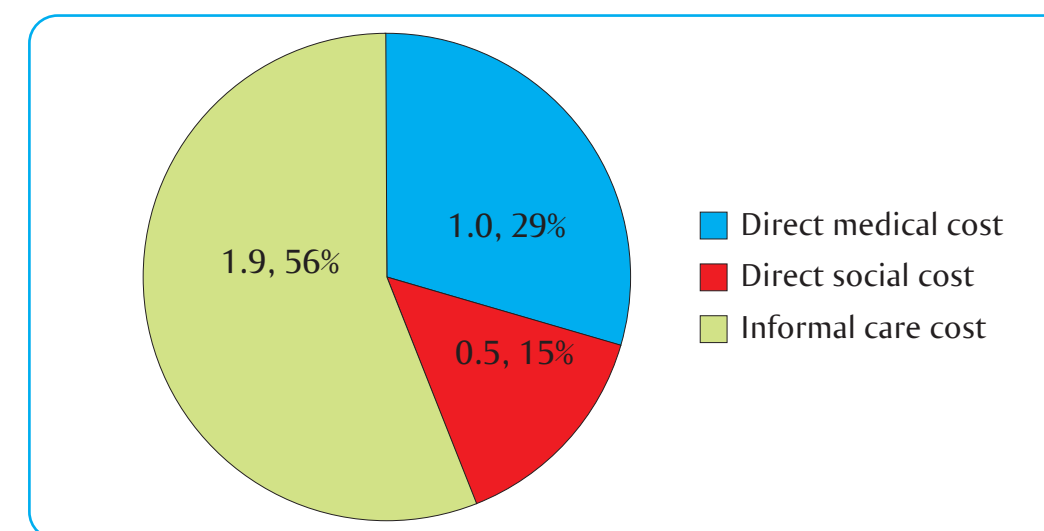
South Asia: There are nearly 4.48 million PwD in the South Asian region which includes India; this is 12.6% of the total global prevalence of dementia and 28% of the regional burden. The number of PwD would double by 2030 (9.31 million) and treble (18.12 million) by 2050. The total cost of dementia (US\$ 4.04 billion) is about 0.25% of the GDP and contributes to less than 1% of the total global cost. The cost per PwD is US\$903 and the predominant cost is due to informal care (57%). Direct medical care costs are nearly one-third (28.7%) of the total costs while the remaining is direct social costs (Wimo and Prince, 2010).

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 one-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) (Wimo and Prince, 2010).

Wimo et al (2010) updating costs of dementia for 2009 from 2005, 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%. In an earlier paper Wimo et al (2007) observed that the 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.

Figure 3.5: Dementia care: total societal costs (billion US\$) India, 2010



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 inter-quartile 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 (The 10/66 dementia research group, 2004). 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. This underscores the need for good quality economic research and operational research, particularly in the Indian context.

Challenges for costing dementia care in India

The diverse landscape of India precludes estimating uniform average costs. The huge urban – rural divide, the ongoing process of rurbanisation (urbanisation or rural areas) and globalisation pose methodological challenges in cost estimation. Cultural differences in help seeking, difference in health and social care systems and other ecological parameters (changes in awareness, availability of specific services, promotion of early diagnosis, and access to benefits linked to diagnosis) (Wimo and Prince, 2010) influence cost estimations. Examining costs for treatment of Epilepsy (Thomas et al, 2001) (Epilepsy even to this date carries greater stigma) and Diabetes (Kapur et al, 2004) (the need for continued and long term care is huge for diabetes) (Table 3.6), it can be inferred that the annual cost of about INR 20,000 and INR 15,000 for Diabetes and Epilepsy respectively is very low.

Table 3.6: Costs of Diabetes and Epilepsy

Item	Cost(INR)	
	Diabetes (2004)	Epilepsy (2001)
Doctor	853	329
Monitoring & Lab	1,609	271
Treatment (AEDs)	2,262	2,150
Hospitalization (annualized)	2,434	316
Travel to services	-	659
Mean Direct Cost	7,158	3,725
Mean Indirect Cost	12,756	10,031
Total estimated annual cost	19,914	13,756

Amidst a faster pace of globalisation and with Indian families shrinking in size, the joint families which have given way to nuclear or two generation families pose peculiar challenges in care related issues. Health care services, particularly for the geriatric population is often neglected both by the families and by the health systems. Studies from South East Asia have revealed that while 86% of the carers for Dementia are females, 8% of the main carers are spouses. Studies from India have observed that 90 – 94% of PwD in urban areas and 95 – 99% of PwD in rural areas

are at home (The 10/66 Dementia research group, unpublished) and the treatment gap is huge (>90%) (Dias and Patel, 2009). The increasing cost of health care in India and equally so in other low and middle income countries is an additional burden on the families not just in the present but also in the near future.

Cost of Caring for PwD

Box 3.1

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)

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, data from two day care centers (Trivandrum and Bangalore), two residential centres (Trivandrum and Kottapadi) and a hospital running an old age clinic (NIMHANS) 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 3.1).

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 3.7). 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 carer 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.

Table 3.7: Needs and components of cost of care for a PwD

	Components	PwD (Mild)	PwD (Moderate)	PwD (Severe)
1	Consultation	++	++	+++
	Consultation for initial diagnosis, confirmatory investigation and subsequent follow up. Followup ideally once in 2 months (6 times a year) particularly for moderate cases. Transportation cost for each visit is critical.			
2	Medication	++	++	++
	Medications (Donepezil, Memantine and Quetiapine) are needed in the management of PwD at different stages along with medications required for management of co-morbidity.			
3	Hospitalisation	-	+	++
	In the case of Moderate Dementia the BPSD would make caring difficult hence may require hospitalisation for managing the symptoms while in Severe Dementia as the person may require Hospitalisation for other associated medical complications			
4	Informal care	-	++	+++
	Informal care is generally by one or more family members (spouse or daughter in law/ daughter/ son/ son-in-law). The costs are related to the wages lost on days of consultation, hospitalization or shifting from a full time job to a part-time job or even giving up the job totally to care of PwD.			
5	Paid carer	-	±	++
	Paid care is a trained health/ nursing aide who would support the family at least for 8 hours in a day. The person would be semi skilled – trained in feeding, care of the catheter, some physiotherapy. The extent of support depends on stage of illness and most importantly the affordability issue.			
6	Residential care	-	±	++
	Residential Care is high intensive nursing care particularly needed for persons with severe dementia.			
7	Day care	++	+	-
	The day care facility provides supervision wherein the PwD is looked after during the day and return home, thus not needing institutionalisation. It is also a therapeutic set up. However, such facilities are sparse and generally not available currently.			
8	Special food	-	+	++
	PwD may require some special food like more liquids like juices, milk, soft food. Those with Severe Dementia may need very special food like soups, high calorie or protein liquid preparations, processed semisolid food porridge etc.			
9	House modification	+	++	+++
	Most places and homes in India are not elder-friendly. However when there is a person in the home with dementia, certain modifications become mandatory at every stage – in Mild Dementia bright lights, clocks, name plates for plates, non skid bathroom floors, certain changes in the dresses etc. In Moderate Dementia better safety arrangements for the person with dementia especially in toilet like high commode. In Severe Dementia – special bed with side rails, bed pans, throw away nappies etc.			
10	Lost Productivity	+	++	+++
	A person at 60 years will be functioning adequately in various roles and capacity in the house even if she/he is not working for a salary. The loss consequent to the illness need to be costed and is a big challenge in itself.			

Note: -, ±, +, ++, +++ indicates the priority from lowest to highest.

Considering the minimum amount suggested by this model and the recent estimates (Wimo and Prince, 2010), India is currently spending INR 15 to 16,000 crores 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 nominal and do not include the huge infrastructure (Prince et al, 2009) 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.

3.7 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 carers (17% primary carers and additional 6% of other carers) cut back on work and nearly a quarter of all carers 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 carers 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 (Table 3.8).

Table 3.8: Income security for older people with dementia in India (%)

	India (Urban)	India (Rural)
N	75	108
Receiving a government or occupational pension	13.3	26.9
Receiving income from family transfers	28.0	44.4
Receiving a disability pension	2.7	0.0
Experiencing food insecurity	28.0	17.6

Source: 10/66 Dementia Research Group Population-based studies (data release 2.0)

Conclusion

Dementia is definitely a greater problem for low income countries. The current work indicates the enormity of the 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 toll, enhancing the economic vulnerability and making the poor poorer. The time is not far off when the service providers and policy makers would be forced to note and take steps to tackle 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 PwD in our midst.

The impact and cost analysis clearly foresees a 'wake-up call' in terms of planning and providing services, infrastructure, capacity building and training at every level. Further prospective work focusing on cost of dementia is mandatory so as to enable and empower the service providers and policy makers to make reality based plans for India in terms of the PwD.



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Chapter-4
Services for People with
Dementia

**THE DEMENTIA INDIA
REPORT**

The report for improving dementia care in India

Services for People with Dementia

4.1 THE TREATMENT GAP FOR DEMENTIA IN INDIA

There are a number of essential issues that need to be addressed while planning the services for people with dementia in India. In the previous chapters, we saw that there are an estimated 3.7 million people with dementia in this country and the numbers are rapidly expected to rise. We also learnt about the huge impact the disease has on the carers, both psychosocial as well as financial. Services in this country should be carefully tailored to suit the special needs of PwD taking into consideration the strengths and weakness of the care arrangements in this country. The Alzheimer's and Related Disorders Society of India (ARDSI) arranged for several consultative meetings of experts on dementia from various parts of the country to understand the services available and the possible interventions to bridge the service gap in India. The service gap for dementia, which is defined as the difference between the numbers of people with dementia and the numbers which receive at least evidence based care, is estimated to be much over 90%. This chapter, will deal with the suggestions from the experts and evidence from research on the means of bridging the service gap for PwD . We will specifically look at the following areas:

1. The services for people with dementia in India
2. The help seeking behaviour of people with dementia in India
3. Proposed strategies for closing the service gap for dementia
4. Training and developing manpower for dementia and elder care

4.2 DEMENTIA CARE SERVICES IN INDIA

ARDSI dedicated to care, support and research of dementia, is actively involved in developing services for dementia across the country. The 14 chapters across India, along with other organizations like Helpage India, Dignity Foundation, Nightingales Trust, the Dementia Society of Goa, Sangath, Silver Innings Foundation, Christian Medical College Vellore, St. John's Medical College Bangalore and Voluntary Health Services Chennai are also providing care services either alone or in collaboration.

To overcome the limited information about dementia services in the country, ARDSI made an effort to map the dementia services available in India by contacting all chapters and other partners in the country.

The services available in the country that cater exclusively to people with dementia are provided in table 4.1. There are half a dozen residential care facilities exclusively for people with dementia. Around ten day care centers offer professional care for people with dementia. Domiciliary care is provided in around five centers. Memory clinics are functioning all over the country; some of them are sponsored by pharmaceutical companies. The number of memory

clinics run by government hospitals is quite small compared to the number of government hospitals in India. The available services are grossly inadequate to meet the needs of the over 3.7 million PwD in India.

Table 4.1: Services exclusively for people with dementia in India

Type of service		Approximate number of such facilities in India
Residential care facilities	This facility is suited for those families who find it difficult to manage the basic day-to-day activities of the PwD. They could opt for long term care in a nursing home facility. This also includes respite services where the PwD is looked after for a short period to give the carer a break.	6
Day Care centres	Dementia Day Care facilities are designed for those PwD who have a need for medical attention and supervision, but who do not require institutionalization in a nursing home. In these facilities, the PwD are looked after during the day after which they return home.	10
Domiciliary care services	The services are provided to the PwD at their residence. Services could range from education, to providing tips on caregiving to actual formal care. Could be provided by geriatric home nurses or other trained personnel. There is evidence that non specialist community workers can also be engaged in providing this service.	6
Support groups	Support groups are groups of people who have lived through the same difficult experiences and try to help themselves and others by sharing coping strategies. Recommended for carers of PwD.	Exact data not available
Memory clinics	Memory Clinics are specialized clinics that offer assessment, support, information and advice to those with memory problems and their carers.	100
Dementia Help Lines	These are special phone numbers dedicated to address queries on dementia. The calls are handled by trained personnel.	10

Residential care services

There are six full time residential care facilities exclusively for PwD:

1. Harmony Home, Kottapadi, Kerala
2. Malabar Harmony Home, Calicut, Kerala
3. Snehasadanam, Trivandrum, Kerala
4. Nightingales Dementia Care, Bangalore, Karnataka
5. Cochin Harmony Home, Cochin, Kerala
6. Dignity Lifestyle Home, Neral. Maharashtra

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 centres range from 5 to 20. One centre has its own premises. Three of them are run on rented premises while one has a rent free building. The ratio of staff to patients in most of the centres is 1:3. Three of the centres have vehicles that have been donated or sponsored. Professional care is provided to the patients by trained carers round the clock. Food is prepared in the premises and nurses take care of the medication. The health of the patients is constantly monitored by visiting physicians, neurologists, psychiatrists and psychologists. Volunteers, social workers, family members, students from nursing colleges and schools of social work pay regular visits to these centres. The staff provides various therapies to the residents such as reminiscence therapy, music therapy, art therapy, pet therapy, yoga, light exercises and reality orientation. Several cognitive stimulation exercises are also practiced. Picnics are organized occasionally and all major festivals are celebrated by the staff together with the people with dementia and their family members. 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 PwD. There are a few day care services for the elderly where PwD 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 PwD.

At these centres, the patients are looked after professionally by trained carers. Reminiscence therapy, reality orientation, music therapy and other cognitive stimulation exercises as mentioned above are also practiced depending on the stage and capacity of the PwD. All these centres are run as registered non-profit organizations. Except for one centre at Bangalore (premises from city corporation), all the centres are run at rented premises. Transport facilities are provided by most of the centres. Four centres have their own vehicle for this purpose. The number of people attending the day care centres range from 3 to 21. The staff to patient ratio is 1:3. Apart from the paid full time trained staff, services of visiting physicians, psychiatrists, nurses, psychologists, volunteers and social workers and members of ARDSI are also available.

Many of the day care centres also provide extended services like carer training and awareness programmes.

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 PwD and provide assistance in the form of counselling, guidance and sometimes physical help like bathing, grooming, and simple exercises. The number of people benefiting by this programme varies from 5 to 100 per centre. Home Care services are available at the Nightingales Dementia Care, ARDSI Hyderabad Deccan Chapter, ARDSI Greater Mumbai Chapter, ARDSI Kolkata Chapter, Cochin Dementia care project and the ARDSI Chapter in New Delhi. Counsellors and Volunteers respond to requests from families and offer advice, guidance and counselling to the ones in need. Early detection of PwD in the community is one of the challenges in providing domiciliary care. An effective case finding strategy for PwD in the community was developed by the Thrissur centre which involved sensitizing Anganwadi workers. In addition to this, a Randomized Controlled Trial was conducted in Goa on home based interventions for families of PwD called the Dementia Home Care Project. The results showed a significant effect on the carer mental status and the quality of life of the PwD (Dias et al 2008). The details are provided in Box 4.1.

Box 4.1: Delivering evidence Based Services at low cost: The Dementia Home Care Project

A randomized controlled trial was conducted in Goa on evaluating the benefits of a low cost, home based intervention aimed at supporting families affected by Alzheimer's disease and related dementias. The intervention was driven by a community team, each comprising of a full time Home Care Advisor (HCA), supervised by a part time local psychiatrist from the Public health services, and a part time lay counsellor. The minimum requirements of the HCA were knowledge of the local language and an aptitude for community based geriatric service. They received intensive training to provide the intervention. The intervention was delivered through a stepped care, flexible model which was specifically tailored to suit the individual needs of the PwD and their families. The HCA provided information on the disease and its progression, improved care giving skills by providing tips on management of problem behaviours, assistance in activities of daily living, provided emotional support and networking. They were supervised by the counsellor and the psychiatrist once every fortnight. The interventions demonstrated a significant impact in reducing the carer burden, mental stress, distress due to behavioural and psychological symptoms of dementia. It also showed a non significant reduction in the total number of deaths of PwD in the intervention arm which could indicate an improvement in the quality of their life. The programme demonstrates that it is possible to introduce a community dementia outreach programme as part of the existing primary health care set up, relying on trained non specialist community health workers supervised by mental health or other appropriately trained specialists.

The intervention won the Fondation Médéric Alzheimer and Alzheimer Disease International Prize for being the best evidence based psychosocial intervention for families of people with dementia in 2010.

Support Groups

While there is no definite data about the number of support groups that are helping the families of PwD, they are functioning in an informal basis all over the country. They provide solace and support to the carers and family members. Many of the Chapters of ARDSI have affiliations with such support groups and some of the memory clinics provide patronage to such support groups. These groups serve as a forum where family members can share their problems and experiences and can gain strength and practical coping methods from each other.

Memory Clinics

It is estimated that there are nearly 100 memory clinics functioning all over the country and two-thirds (67) are supported by a pharmaceutical company. Almost all the super specialty hospitals run by the central government in the field of neurology and psychiatry have a special memory clinic or specialty clinic for PwD. In contrast, a very small percentage of the other government hospitals have memory clinics. This has led to a situation when the vast majority of the population is denied the access to basic diagnosis of dementia.

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 (Appendix 1) are available in Cochin, Kolkata, Mumbai, Bangalore, New Delhi and Hyderabad. This shows that almost the entire county has no recourse to local help lines and support.

4.3 HEALTH SEEKING BEHAVIOUR OF PEOPLE WITH DEMENTIA

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, 2004a). 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. This is mainly because the services are home based which is not the case in most other health services. The details are provided in table 4.2

Table 4.2: Health seeking behaviour of people with dementia in four developing regions of the world.

Type of service opted	India and S. Asia n=179	China and S.E.Asia n=91	Latin America and Caribbean n=416	Nigeria n=20
Government primary Care	5%	36%	45%	5%
Government Hospital	5%	54%	51%	90%
Private doctors	56%	10%	42%	80%
Hospital admissions	11%	7%	14%	15%
Traditional healers	1%	12%	2%	40%
No Services	33%	18%	11%	5%

A study conducted in Goa and Chennai, compared the health seeking behaviours of PwD with that of people with depression (yet another common mental illness in the elderly) and those who did not have dementia or depression. 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 free of dementia and depression. Similarly in Chennai, 47% visited a private doctor compared to 23% each in those with depression and controls without dementia and depression. 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 PwD, 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.

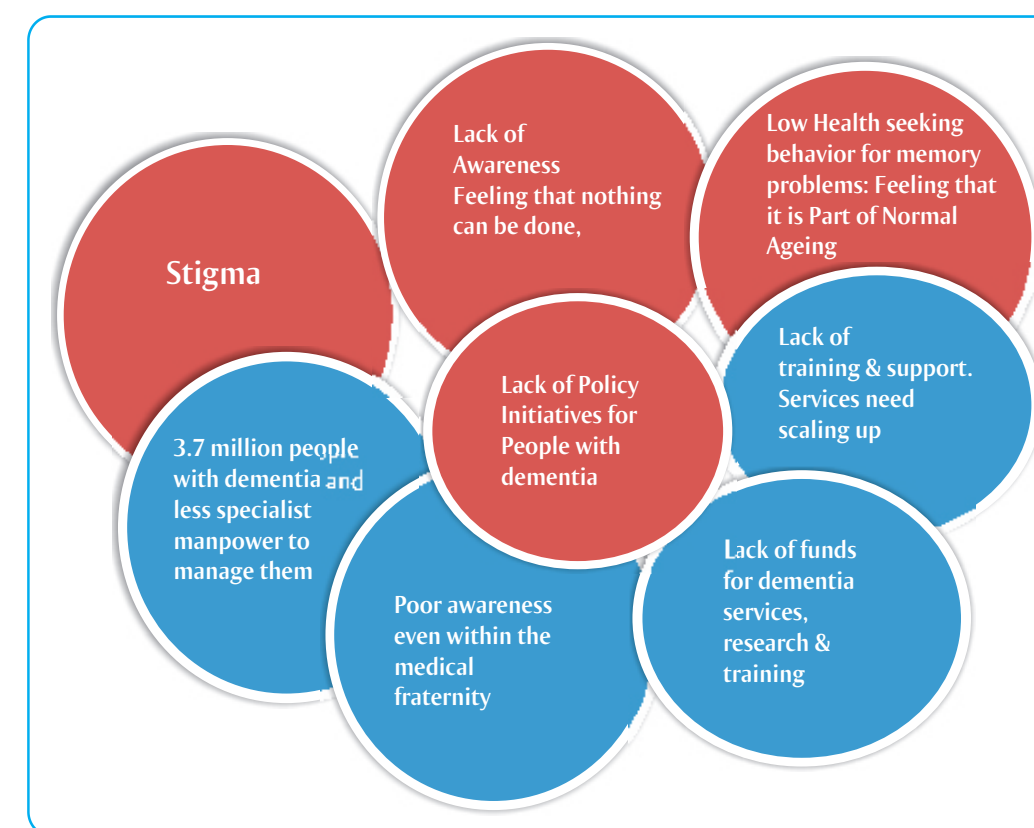
4.4 PROPOSED MODEL FOR DELIVERING SERVICES FOR PwD

Special considerations for service development in India

There are several barriers to providing appropriate care for PwD in India. Figure 4.2 depicts some of the major barriers one would have to overcome while developing the services.

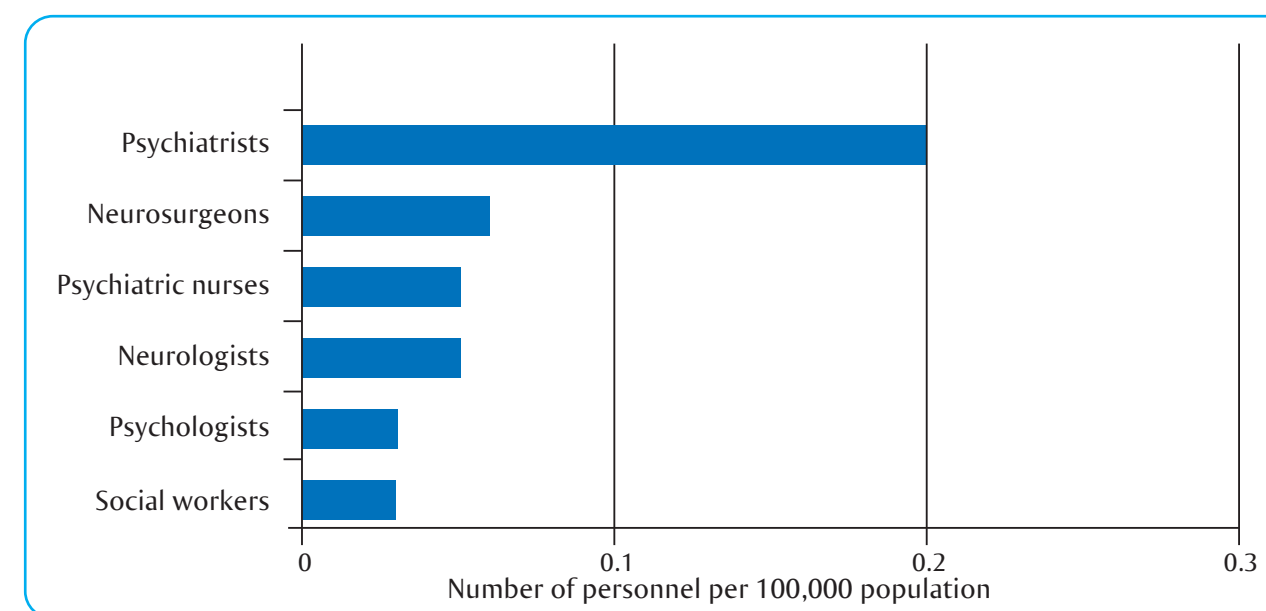
Service development for PwD in this country has to take into consideration the fact that the awareness regarding the disease is very poor in the community as well as the medical fraternity. It should also consider the help seeking behaviour of PwD. As mentioned earlier, research conducted in various parts of India revealed that families of PwD would prefer to take the PwD to a private doctor as compared to a hospital or the Primary Health Centre. Care of a PwD should take into consideration the impact it has on the carer as seen in the previous chapters. Quite often, the carers themselves need a lot of help and support. Caring for someone with dementia is vastly different from caring for an aged person or for a person suffering from any other disease. What starts off as memory problems in the beginning, will lead to the person gradually losing one faculty after another and eventually become totally dependent on the carer for all activities of daily living. The carer will also have to deal with the emotional aspect of coping with this degenerative disease. While there may be no obvious change in the physical appearance of the PwD, he or she will exhibit various behavioural changes and at times become aggressive, abusive and even violent. The physical strain of caring 24 hours a day, along with the emotional stress, makes it a very complex and difficult challenge for the carer.

Figure 4.2: Barriers to Dementia Care in India:



However, the most significant barrier to closing the service gap for dementia is the very low human resource capacity for the care of those with the disease. Scarcity of human resource (Neurologists, Psychiatrists, Psychologists etc) is true for all mental disorders across the continuum of life and has been systematically documented in a recent Lancet series on Global Mental Health. Furthermore, specialist services tend to focus mainly on medical interventions which have a limited role in the long term care of PwD. Figure 3 illustrates the availability of specialist human resources for dementia care per one lakh people.

Fig. 4.3 Availability of Human resources per one lakh people in India



The immediate challenge for India is to develop culturally appropriate services which can be delivered within existing resources (Dias et al, 2008). Also, the fact that community care has better results than institutional treatment on the outcomes and quality of life of people with chronic mental illness needs to be considered. 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 in Table 4.2.

Table 4.2: 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	Effective use of media, films, provide disability benefits to PwD and carers, fight stigma, improve quality and accessibility of services	Government, NGOs, health professionals, media	Community, primary care, memory clinics
Capacity building of health care teams	Training medical nursing fraternity in dementia management, train health care workers, Anganwadi ⁽¹⁾ workers ASHA ⁽²⁾ in delivering 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 (pharmacological and psychological)	Develop and use cheaper generic versions of anti dementia drugs Use existing resources for care- Integrate long term care and support interventions into programmes for all dependent elderly.	Patient on anti dementia drugs can follow up 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	workers, or staff specially appointed for community elder care	Primary Care, Community

Residential, respite and day care facilities	Specialized facilities with trained personnel could be established for this purpose. This will cater to the severe cases of dementia or those who do not have any support	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

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. A district model of care needs to be developed, implemented and evaluated. In the next section we will take a look at the services that are currently available in the country for training manpower for dementia care.

4.5 TRAINING AND DEVELOPING HUMAN RESOURCES FOR DEMENTIA CARE

One of the most important components of developing dementia services in the country is training health human resources. Over the past few decades, the government has begun to realize the implications of the increasing aging population in the country, and responded by creating care programmes and delivery services aimed at meeting the needs of older persons. For example, the National Policy for Older Persons, the National Council for Older Persons and more recently the National Initiative for Caring for Elderly (NICE). However, these efforts have not produced the expected results.

Training of personnel should be considered as a prime pillar for dementia care. While, the dementia care training should be a part of geriatric care training, it is rather unfortunate that Geriatric training itself is lacking in India. The pyramid of training should include carers and community health workers as the base of the pyramid, professionals like nurses, dieticians, social workers, occupational, speech and physical therapists and doctors – general physicians and specialists. The focus for training should be both short term as well as long term

Short term focus

- Training existing personnel to improve care of PwD.
- Train the Trainers of programs for carers and community health workers.
- In service training for professionals

The above training can be done by

- Identifying agencies already training personnel and delegating responsibility in a structured manner.
- Using web based training regularly, which will save on resources for the short term.
- Build on existing programs like that of NISD training of carers, Helpage India and ARDSI, CMAI, RCI programs.

Long term focus

Long term focus should be on changing the existing training curricula for professionals and modifying health sciences education (medical, nursing etc.) with emphasis on both theoretical knowledge and practical skill development in caring for PwD. Assistance of professionals from both India and abroad who have expertise in this area should be taken to develop training curricula and a schedule to train at all levels to be drawn. There is a need to co-ordinate the efforts of the various government and non governmental agencies that are working towards the same goals of caring for PwD.

Currently, there is no established system that the community can use to plan and implement collaborative personnel training. To assist in meeting this need, this section of the report outlines the development of a “National Dementia Training of Personnel Program” that will:

- 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 institutions in development of online and distance education training
- Collaborate with personnel preparation programs in dementia care that currently exist in the country and make these resources available to augment training activities.

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

- Those who work with the elderly, at home or in institutions, should receive basic training for their tasks.
- Training in gerontology and geriatrics should be encouraged and given prominence at different 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 ageing 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. (This can be done in the lines of the Anganwadi worker and Child Development Officers training conducted by NIPPCD – National Institute of Public Policy and Child Development.)

Despite the need for and proven efficacy of geriatric care, there remains a critical shortage of specialised health care professionals in geriatrics. The discipline, currently is woefully lacking in medical schools and nursing programs. Primary care and specialty health care professionals, who are likely to care for large numbers of older patients, continue to receive inadequate training in geriatrics.

Training Programmes:

ARDSI has taken the initiative to conduct several training programmes with special emphasis on dementia.

Training and Capacity Building Programmes on Old Age Care:

- **Six Month certificate Course:** The six month certificate course in geriatric care has been conceptualized to develop a cadre of frontline geriatric carers to meet the demand for carers in old age homes, hospitals, and homes for the needy elderly.
- **One Year Post-graduate Diploma in Integrated Geriatric Care:** This is a specialized diploma course in integrated geriatric care focusing on supervisory / managerial level of service providing institutions with inputs on geriatric management, geriatric counselling, social policy and planning, geriatric research etc.

Training of NGO Functionaries

One Month Certificate Course and a Five Day training Programme on geriatric counselling with special reference to dementia care for those managing residential care or day care facilities and other care centres for dementia.

ARDSI School of Geriatric Care

ARDSI has been running a school of Geriatric Care in Cochin, since 1993. The school aims at developing cadres of skilled personnel in elder care. The centre offers various certificate programs in geriatric care with an emphasis on dementia. The following courses are conducted:

- Certificate and Diploma Courses in care giving and Geriatric Care Management.
- Training for medical professionals in dementia care
- Training for the Managerial Functionaries of Geriatric and Related Institutions

The Courses are conducted in association with other organisations such as

- o Christian Medical Association of India (CMAI) – 10 Months Certificate Course in Community Geriatric Care
- o Rehabilitation Council of India (RCI) – 6 Months Certificate Course in Geriatric Care.
- o National Institute of Social Defence (NISD) – 6 months certificate course in Geriatric Care and one month Certificate course on basic issues in geriatric care

4.6 DEVELOPING GERIATRIC SERVICES IN INDIA

While there is a need to develop specific services for PwD, there is also the need to consider developing the geriatric services as a whole. The experts attending the ARDSI consultative meetings strongly felt the need for a National Institute of Ageing for the country which could spearhead the development of geriatric services in India and recommended that every health care worker must have some training in elder care and access to experts in the field of geriatrics. It was observed that only 3 of the nation's 206 medical schools have a department of geriatrics. Those caring for the elderly are physicians, nurses and other health care professionals who are certified in geriatrics or mostly, non-geriatric practitioners who have gained some degree of default competence in geriatric while caring for the elderly.

What training should be provided? Ideally, every training program for any health care practitioner needs to incorporate some level of competence in geriatrics. All programs in nursing and medicine require a rotation posting in Paediatrics, but a similar commitment to geriatrics is yet to emerge.

Addressing the dual goals of every health care worker having some training in geriatrics and every care provider having access to geriatric expertise can be achieved by meeting four objectives:

- (1) Training more personnel as experts in geriatrics,
- (2) Getting more health professional programs to increase their emphasis on geriatrics,
- (3) Getting more health care providers to employ practitioners with training in geriatrics, and
- (4) Getting more health care settings to provide geriatric-specific care.

Achieving these objectives is dependent on creating effective coalitions among professionals and professional organizations, state and central agencies, and other interested parties with ARDSI, HelpAge India, NISD, Indian Academy of Geriatrics, Geriatric Society of India,

Gerontological Society of India, Indian Association for Geriatric Mental Health (IAGMH) and other voluntary organizations working for geriatric care.

A crucial step in designing effective geriatrics education programs is to obtain better data about current and projected geriatric care workforce, their needs, including information regarding what would be an appropriate balance of numbers and geographic distribution between geriatric specialists and generalist providers. Among the questions to be answered are: How much time do people who are trained in geriatrics spend taking care of older adults? What is the appropriate ratio of such providers to the older population? What types and proportions of patients need access to geriatric specialists rather than generalists with some geriatrics training?

Even without an estimate of the precise number of specialists needed, a reasonable goal is that students in health professional education programs should have required content in their syllabus on old age care. At a minimum, all medical schools, nursing programs and schools of social work must have faculty who have specialty training in geriatrics. There should be similar goals for other health disciplines' training programs.

Sources of support: Many current advances in geriatrics education and workforce preparation are attributable to support from HelpAge India, Indira Gandhi Open University, Chennai Medical College, Christian Medical College, Vellore, NISD, and ARDSI. With support from such organisations, substantial steps to attract additional students to careers in geriatrics must be made. Collaborating with the corporate world to fund training and involving departments of geriatrics in medical colleges and nursing colleges will be beneficial. Several initiatives are under way, by various non-governmental and governmental organizations all over the country. An effort to coordinate and collaborate the various different sources will help streamline the training in the long run.

Role of the State and Central government: A start can be made to identify current position regarding 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 and coordinate state and national government efforts toward training personnel. Each district hospital to initiate dedicated geriatric clinical services, focus on establishing memory clinics and begin a systematic effort for developing geriatric/dementia services in a phased manner.

Need for further research: As in many areas of health care, there is a continued need for research in geriatric health care workforce and the organizations in which they work. This research includes factors associated with specialty and work setting chosen, as well as the association between geriatrics training and patient outcomes. Particularly important is research comparing the benefits of patients cared for by geriatric specialists with those cared for by generalists. It also includes 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.

Conclusions

India has a huge burden of people with dementia and meeting all the challenges in closing the service gap needs a multipronged approach. The family is the primary support for the PwD. The care arrangements in the country are unique and service development needs to take advantage of the same, improve carer support and make use of locally available resources to address the need. There is definite evidence from research carried out in India that locally available non specialist volunteers can be trained in detecting cases and providing effective non pharmacological interventions for the elders with dementia. In practice, such interventions will need to be incorporated into horizontally constructed programs addressing the generic needs of frail, dependent older people and their carers, whether arising from cognitive, mental or physical disorders. Good quality training, research and strong political commitment to the cause is central to achieving this goal.



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Chapter-5
Recommendations

**THE DEMENTIA INDIA
REPORT**

The report for improving dementia care in India

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

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 of 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.

Recommendation 1: Make dementia a national priority

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

- An inter-agency, inter-departmental strategy for dementia must be developed by the government to respond to the growing need for care from early diagnosis to end of life care.
- Dementia care and research must be prioritised in the Five Year plans of the Ministries of Health and Social Welfare.
- Health and Social Welfare departments must develop local plans to support increasing numbers of PwD and their families. Current government policies, including the National Policy for Older Persons, National Mental Health Program, the Persons with Disabilities Act and the National Trust Act could be starting points.
- Although mental health is a national clinical priority along with cancer and heart disease, dementia has not received the attention it requires. A coordinated national dementia plan with manifest political commitment is now a necessity. This will require co-ordination and planning across public and other related sectors.

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.

- Increasing the quantum of dementia research is an urgent priority. Improving the management of PwD now and in future, facilitate evidence-based strategies to provide better quality care to meet the evolving needs could be undertaken under the National Institute of Ageing.
- There is a need to have a national consultation to evolve research strategies and delineate specific directions to investigate the etiology, treatment and care provisions for PwD and their families.

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 training health service providers and social services sector is required for early identification of the disease.

- There is a need to have regular and national campaigns to educate the public about evaluating for memory problems in old age.
- The print, radio, television, web based and other A-V media may be used for education at different levels.
- Simple web based tools may be used to help elders and their families to self evaluate their memory problems.

Recommendation 4: Improve dementia identification and care skills

Early identification of PwD and care training should be made a core and substantial part of the training curriculum for physicians, other medical specialists, nurses, health workers, ASHA and other non-specialist health workers.

Minimum Standards must be developed to include dementia specific requirements on dementia identification and care training.

- Poor understanding of dementia and its consequences is currently leading to under diagnosis, late diagnosis and an inadequate care response. This creates an inefficient use of resources.
- Without significant focus on improving care across health and social care, outcomes will worsen and resources will be squandered.
- The aim should be for the early identification, diagnosis and management of dementia in the primary health care settings. It is necessary to use simple tools for early diagnosis and standard treatment guidelines depending on our socioeconomic and cultural situation.
- Memory clinics and dementia treatment centres are required in medical colleges and district hospitals
- An integrated geriatric services with delineated referral mechanisms needs to be evolved.

Recommendation 5: Develop community support

PwD need improved home care support packages, including low-level support to retain their independence and dignity.

Hardly any home care support exists for the majority of PwD. Some support is available in the big cities for persons who can pay for such services. As the population ages and the number of PwD increases, this situation is bound to worsen. PwD can stay at home with their families if the right support system is put in place for them and their families.

- The number and extent of low level community home care packages must be increased.
- Home help services such as help with cleaning, shopping, cooking, and child care must be encouraged in the community.
- Establish social insurance and other social defence measures (providing services and health insurances packages).

Recommendation 6: Guarantee carer support packages

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

- 1. Psychological therapies including carer training and support groups**
- 2. Quality respite care for PwD and carers.**

The Dementia India report has identified that family carers of PwD per year save the public purse over thousands of rupees. Although the total proportion of people who are able to care for relatives may decline in the future, there will remain a substantial proportion of people eager to continue providing informal care for PwD. The report demonstrates that the financial cost to society is on average about Rs fifty thousand per person with dementia per year.

- There must be formal commitments to an improved package of support for carers, so that more family carers will be able to continue caring and pressures of long-term care will decrease.
- Respite care in the form of day care centres and short term care must be made available.
- Currently the majority of this cost of care is met by PwD and their families through informal care and care charges, whereas other long-term medical conditions receive far more support from the state. There must be provision made to compensate carers with benefits like carer pension or medical insurance or benefits that are available under the National Trust Act.
- The opportunities for PwD and carers to access direct payment and carer pension benefits must be explored.

Recommendation 7: Develop comprehensive dementia care models

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

The direction of the health and social care policy should be to increase the proportion of older people who can be supported in their own homes in the community. Nevertheless there will be some need to have long-term care for PwD without families and for those who have complex medical conditions. Many of the elders in old age homes have some form of dementia. More effort is required from the public, private and voluntary sector to find good quality, cost effective options to meet the needs of PwD and their families.

Recommendation 8: Develop new National Policies and Legislation for PwD

Existing policies and programmes do not adequately address issues and concerns of PwD; there is a need to be comprehensive and also evolve a strategy.

- There is a need to relook and review existing policies and laws for elders and PwD and develop anew. The National Policy for Older Persons may be amended to include PwD.
- There is a need to develop a separate department or division under the Ministries of Health and Social Welfare (viz., an ageing welfare department) to take care of elders and PwD.
- The amendments to the Mental Health Act and the Persons with Disabilities Act should take into consideration the rights and benefits for PwD and the protection of their property and estate.
- The national strategy for training should include a national and state level programme for human resource development under the aegis of a National Institute of Ageing.

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ANNEXURE

ARDSI Chapter Addresses

1. **ARDSI - Delhi Chapter**
163, Kailash Hills
(Ground Floor, Back Portion)
New Delhi-110 065.
Telephone No. 011 2692-2940, 6453-3663(O)
Email: arsidc@hotmail.com
2. **ARDSI Calicut Chapter**
32/2405, Radhas, P.O. Kottamparamba,
Calicut - 673008, Kerala.
Tel. : 0091-495-2355388, Mob: 09388870500
3. **ARDSI Kochi Chapter**
Madavana Temple Road ,Vennala.P.O
Palarivattom N.H.By Pass
Kochi-28 Kerala, India.
Phone 0484 2808088, Mob: 098460 56001, Office: 0091 484 2665739
4. **ARDSI Hyderabad Deccan**
Room No. 3, Memory Clinic,
Millennium Block, Ground Floor,
NIMS, Punjagutta, Hyderabad – 500 082.
Tel. 040 6610-3413, Mob: 09885069539
5. **ARDSI Chennai Chapter**
The Memory Clinic,
D-89, III Street, Anna Nagar East,
Chennai – 600 102.
Tel./Fax: 044-26633143, Tel. 044-26201123, Mob: 098410 19910
6. **ARDSI- Trivandrum Chapter**
Snehasadanam, Lions Bhavan,
N.H. BYEPASS Road,
Trivandrum – 695 027
Tel. 0471 2134151, Mob: 09895355177
7. **ARDSI, Bangalore Chapter**
337, 1st Block, 2nd Cross,
R T Nagar, Bangalore - 560032
Ph: 91 080 23548444/555, Fax: 91 080 23548999, Mobile: 09243100560

8. ARDSI Kolkata Chapter

15/3C Naskarpara Lane
Kolkata 700031, West Bengal
Ph # 033-2405-4959, Mob: 09331039839

9. ARDSI Kottayam Chapter

Thundathil House,
Malam P.O, Manarkadu, Kottayam.
Mob: 0944730 6586

10. ARDSI- Mumbai Chapter

Room No.:27, BMC School Bldg
(2nd Floor), JJ Hospital Complex
Byculla, Mumbai-400008.
Mob 09820074476

11. ARDSI Coimbatore Chapter

Villa No.10, Santhosham Comfort Homes,
Pachapalayam, Kalampalayam P.O,
Perur, Coimbatore – 641 010.
Tel. 097861 33333

12. ARDSI Goa Chapter

H. No. M1, Housing Board Colony,
Alto Porvorim, Bardez, Goa – 403 521
Ph: 2414027, Mob: 09822382842

13. ARDSI Pathanamthitta Chapter

Thazhayil Kudumba Yoga Mandiram
Elanthur – P. O.- 689 643
Tel. 0468 2361398, Mob:09846185475, Tel. 0468 2312737

14. ARDSI Greater Mumbai Chapter

Bldg: ARENA - 3, Flat: 801/802,
Poonam Garden, Near S.K. Stone,
Off. Mira Bhayandar Road,
Mira Road (East), Mumbai - 401107
Tel. 09819819145



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.



ARDSI National Office

P.B.No. 53, Gururvayur Road,
Kunnamkulam - 680 503,
Thrissur Dist, Kerala State.
Email: ardsinationaloffice@gmail.com
Tel: 04885 223801 (off)
Tel. 098461 98473 (Helpline)

ARDSI National Office

163, Kailash Hills
(Ground Floor, Back Portion)
New Delhi-110 065.
Email: ardsi.no@gmail.com
Tel: 2692-2940, 6453-3663(O)