Dementia: Indian scenario

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Abstract

As per the estimates of the World Health Organization, aging population is increasing in developing countries and dementia is going to become epidemic among elderly in the coming decades. This demands early action to prevent the disease and treatment of the affected persons, which is poorly existent in middle- and low-income countries. The need of the hour to tackle dementia in India is to estimate disease burden in the community, search for risk and protective factors of dementia, and undertake measures to provide social benefits to the sufferers and those who are at risk. Raising awareness among the public and general physicians is an important task ahead. In India, there is lack of good longitudinal studies which can provide true trend of the disease and determine risk factors, paucity of basic and clinical researches on dementia, poor awareness, and inadequate availability of social benefit. India, being a country of diverse ethnicity and cultures, has great advantages to carry out genetic epidemiological study. The information may be useful for undertaking remedial measure. This article will highlight the existing state of the above medical and social issues and deficiencies, so that the stakeholders can make adequate preparation to provide relief to the dementia patients and those who are at risk. It is expected that the medical and scientific community will draw attention to the medical problem with the help of governmental and non-governmental agencies, and the political leadership will be motivated to undertake the issue of providing socioeconomic benefit to families of the victims.

Key words: Caregiver burden, dementia, epidemiology, genetic study, India, risk and protective factors

Introduction

Dementia is usually a disease of the elderly and is characterized by progressive loss of memory and other mental faculties such as language, judgment, and planning, impairment of daily activities, and deficiency in social interaction. Dementia impacts personal, family, and societal life. It reduces life span, induces caregiver's strain at family level, and utilizes health care facility, inflicting strain on national income. It is expected that the burden of dementia will be increasing in developing countries due to increase in longevity and increasing prevalence of risk factors such as hypertension and stroke and lifestyle changes.[1,2]

India has a unique situation characterized by rapid epidemiological transition leading to increasing aging population and higher prevalence and incidence of non-communicable diseases such as stroke and cardiovascular diseases, similar to other developing countries in the world.[3] Fortunately, the published Indian literatures on various aspects of dementia have been on the rise, but still far short of the actual need. In this review, we highlight the present Indian scenario of dementia in relation to its epidemiology, risk factors, genetic studies, peculiarity of clinical and neuroimaging characteristics if any, awareness, and care of the affected persons, as documented in Indian studies. We want to exclude pharmacological management issues in dementia since the literature on these aspects from India context is almost limited.
Das, et al.: Dementia in India

Epidemiology

Global picture
The World Health Organization (WHO) predicts that by 2025, about 75% of the estimated 1.2 billion people aged 60 years and older will reside in developing countries.[3] It is estimated that the number of people living with dementia will almost double every 20 years to 42.3 million in 2020 and 81.1 million in 2040.[4] The rate of growth will be the highest (around 336%) in India, China, South Asia, and western Pacific regions, 235-393% in Latin America and Africa, and the lowest (100%) in developed regions. Based on 2001 global population, about 24.3 million have dementia and 4.6 million incident or new cases are added yearly.[4] As per global burden of disease study by WHO and World Bank, dementia contributes 4.1% of all disability-adjusted life years (DALYs).[9]

Prevalence of dementia in India
Prevalence rates (PRs) [Table 1] from different regions of India differ widely.[6-14] The rate may possibly be related to adoption of different methodology, screening instruments, defining criteria, multiethnicity, and multicultural and environmental factors. The prevalence of dementia of rural population in South India and that in North India showed a widely varying rate from 3.39 to 0.84%, respectively.[6,9] There are few urban studies from several regions of India showing similar varying rates: From 2.44 to 4.1% in West India,[11,12] 1.83% in North India,[10] 0.8-1.28% in East India,[13,14] and 3.6% in South India.[8] The differences may be true considering the multiethnic, multicultural, and environmental differences. Utilizing a common protocol and undertaking multicentric study on dementia prevalence and incidence may overlook distinctive differences across regions.

Mild cognitive impairment
Mild cognitive impairment (MCI) is a transitional phase between normal aging and dementia. Understanding (MCI) is important, and many cases may progress to dementia, though some may revert to normal cognition. Very few studies on MCI have been carried out in India. One of these was a community-based study and another was a clinic-based study.[15] The community prevalence of MCI in India is about 14.89% (95% CI: 12.19–17.95%) and that of multi-domain type (8.85%) was higher than amnestic type (6.04%). Interestingly, this data is comparable to a study from a developed country.[16] Another longitudinal study from India has recorded a conversion rate of MCI to dementia, which is similar to western countries and varies from 8 to 14%.[14,17] It might indicate the dynamic factors for conversion of MCI to dementia are possibly the same in developed and developing countries. In the clinic-based study, out of 194 referral cases with cognitive dysfunction, 65.5% cases had dementia based on clinical, neuropsychological, and imaging evidences and about 22.14% cases had MCI.[18]

## Table 1: Prevalence studies of dementia from India

<table>
<thead>
<tr>
<th>Region</th>
<th>Study</th>
<th>Age/gender</th>
<th>Number of subjects</th>
<th>Prevalence rates (%)</th>
<th>Instruments used</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>South India</td>
<td>Shaji et al., 1996[6]</td>
<td>≥60</td>
<td>2067</td>
<td>3.39</td>
<td>Screening: MMSE and CAMDEX</td>
<td>Rural South Indian population in Kerala</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>965</td>
<td>2.8</td>
<td>Confirmation: Clinical and DSM IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td>1102</td>
<td>3.54</td>
<td>Geriatric Mental State Examination</td>
<td></td>
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<tr>
<td></td>
<td>Rajkumar et al., 1997[7]</td>
<td>≥60</td>
<td>750</td>
<td>3.5</td>
<td>Screening: Hindi MMSE</td>
<td>Rural South Indian population in Madras</td>
</tr>
<tr>
<td></td>
<td>Shaji et al., 2004[8]</td>
<td>&gt;65</td>
<td></td>
<td>3.36</td>
<td>Screening: Hindi MMSE</td>
<td>Urban South Indian population in Madras</td>
</tr>
<tr>
<td>North India</td>
<td>Chandra et al., 1998[9]</td>
<td>≥55</td>
<td>5126</td>
<td>0.84</td>
<td>Screening: Hindi MMSE</td>
<td>Rural North Indian population</td>
</tr>
<tr>
<td></td>
<td></td>
<td>≥65</td>
<td></td>
<td>1.36</td>
<td>Confirmation: CDR and DSM IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td></td>
<td>1.8</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td></td>
<td>1.25</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Raina et al., 2010[10]</td>
<td>&gt;60</td>
<td>1856</td>
<td>1.83</td>
<td>MMSE and EASI</td>
<td>Migrated population in Jammu region of J and K</td>
</tr>
<tr>
<td>West India</td>
<td>Vas et al., 2001[11]</td>
<td>&gt;40</td>
<td>24,488</td>
<td>0.43</td>
<td>Sandoz clinical assessment geriatric scale and MMSE</td>
<td>Urban western Indian population in Mumbai</td>
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<td></td>
<td>≥65</td>
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<tr>
<td></td>
<td></td>
<td>Female</td>
<td>12,613</td>
<td>0.15</td>
<td></td>
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<td></td>
<td>Saldanha et al., 2010[12]</td>
<td>&gt;65</td>
<td>2145</td>
<td>4.1</td>
<td>Community screening instrument</td>
<td>Urban population in Pune</td>
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<td>East India</td>
<td>Das et al., 2008[13]</td>
<td>60</td>
<td>5430</td>
<td>0.8</td>
<td>BMSE and KCB-Kolkata cognitive battery</td>
<td>Urban Kolkata</td>
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<tr>
<td></td>
<td>Banerjee et al., 2008[14]</td>
<td>≥50</td>
<td>6129</td>
<td>0.62</td>
<td>Screening questionnaire for cognitive dysfunction, KCB-</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>≥60</td>
<td>2720</td>
<td>0.128</td>
<td>Kolkata cognitive battery</td>
<td>Urban Kolkata</td>
</tr>
</tbody>
</table>
Stroke dementia
Increasing stroke prevalence and incidence has led to the expectation that stroke dementia will be higher in India. Recently, a prospective community study from East India documented PR of post-stroke dementia at 13.88% (95% CI: 9.91-18.90%). The prevalence was higher than the rate calculated from a meta-analysis of the studies on stroke dementia worldwide (overall rate 7.4%; 95% CI: 4.8-10.0%). Higher rate in the above study may be due to inclusion of pre-stroke dementia subjects. In a clinic-based study from South India, the pattern of vascular damage and underlying vascular risk factors were documented among subjects with vascular dementia (VaD). Out of the different patterns, subcortical, cortical–subcortical, strategic infarcts, and cortical dementia were documented in 52.4%, 26.2%, 14.3%, and 7.1% of cases, respectively.

Incidence of Dementia in India
Long-term study on dementias and cognitive dysfunction are few from India. One study from North India on Alzheimer disease (AD) has shown an incidence of 4.7 per 1000 person-years as compared to 17.5 per 1000 person-years in Monongahela valley, USA. Both were sister studies with similar methodology, but differing in life expectancy and literacy of the studied samples. Another incidence study in Dogra population of North India documented an incidence rate of 5.34 per 1000 person-years.

The study on stroke dementia has also documented an annual progression rate of 3.53% of stroke survivors into dementia, indicating that 1 out of every 28 stroke survivors become demented each year. Thus, it is estimated that one-third of stroke survivors will become demented if they remain alive for a decade after stroke. Chance of having dementia becomes more pronounced when they have recurrent and thrombotic stroke.

Mortality of Dementia
The study from India, conducted in South India, investigated predictors of mortality among older people living in the community. Mortality risk was 2.3 times more for older people with dementia and linearly correlated with the severity of cognitive impairment. Similarly, another study has shown higher mortality by 2.65 times in patients with post-stroke dementia than in stroke survivors without cognitive dysfunction.

Risk Factors of Dementia
The traditional risk factors of dementia are advancing age, illiteracy, addiction, hypertension, diabetes, poor socioeconomic status, trauma, familial or genetic factors, nutritional factors, and stroke.

A study from West India has documented advancing age, poor literacy level, low socioeconomic status, and positive family history as the risk factors for dementia. On the other hand, marriage was found to be protective in the same study. Marriage is possibly linked to health and economic benefit. Married individuals tend to have better physical health and psychological well-being, and a lower mortality risk. Chandra et al. speculated, based on their study of elderly rural persons from North India, that the risk factors for cognitive dysfunction not amounting to dementia were nutritional deficiencies and certain common infectious diseases. The neurologic factors which may be resultant of nutritional disturbances were history of impaired consciousness due to head injury or seizure disorders, gait disturbances, diminished tendon reflexes suggestive of neuropathy, and presence of at least one primitive reflex indicating diffuse forebrain dysfunction. A study from South India has documented family history of dementia as a risk factor for AD and smoking and hypertension as the risk factors for VaD.

From East India, a community study has shown that the risk factors for MCI were hypertension, diabetes mellitus, and smoking which included both inhalant and chewing tobacco, as compared to the control population. Among the stroke survivors, stroke dementia is commoner among the elderly and in those with cortical atrophy. Recurrent stroke and thrombotic stroke were the other risk factors for stroke dementia.

Protective Factor
Animal studies have shown the protective effect of curcumin, a yellow curry paste (turmeric) which is almost consumed universally by Indians. It has antioxidant and anti-inflammatory effects and decreases amyloid protein synthesis. Possibility of lower prevalence of dementia among Indians may be related to this dietary protective factor in the diet.

HIV Infection and Dementia
HIV is an important cause of cognitive dysfunction among young and middle-aged persons. One study from South India documented cognitive dysfunction in about 60.5% of HIV subjects. Prevalence of AIDS dementia is however lower among Indian (approx. 2%) is much lower than Americans (15-30%). This has been related to “TAT” protein which is stable in Indian variants of HIV C type virus than in western countries. This also indicates existence of protective factor in Indian environment and probably needs to be probed further.

Genetics of Dementia in India
ApoE gene polymorphism has important association...
with dementia and has been confirmed in both clinic- and community-based studies. In the western countries, APOE gene has been shown to be increasingly associated with dementia. Frequency of APOE4 gene polymorphism (ApoE genotypes with at least one e-4 allele) is less common in the Indian population (around 0.07). However, a clinic-based study from South India confirmed the increased frequency of ApoE4 in patients with dementia (0.18), especially among those with AD (0.21), and also in VaD. The frequency was higher than that reported in the other rural community-based study from North India (0.15 in all dementias) and the hospital-based study. A study from Central India has shown positive influence of presenilin gene (PS1, allele 1) and ApoE gene e-4 alleles, increasing the susceptibility for degenerative dementia as compared to VaD. APOE4 polymorphism does not influence the magnitude of clinical and functional deficits. Other than AD group, VaD group has also shown higher frequency of APOE4 alleles (0.17), though the study from urban northern India has shown higher positivity of APOE4 allele among VaD patients (0.34) than among AD patients (0.29). Occasional cases of familial dementia have been recorded, but no genetic report of established mutation in presenilin 1 and presenilin 2 has been published. A family of autopsy-proved AD has been documented. We have not encountered and found any report on specific mutation of known genes of AD dementia. In a study on 81 patients with frontotemporal lobe degeneration, microtubular associated protein gene, progranulin gene, and APOE genes have been found to play limited roles in the pathogenesis among Indian population as compared to European and North American populations.

**Neuropathology of Dementia**

Since autopsy is optional in India for non-medicolegal cases, there is dearth of reports on the pathology of brain in subjects with dementia. It is a serious deterrent in validating the antemortem diagnosis of dementia and its subtypes. However, a study on the pathological finding of aging brain has been carried out in West India and this was compared with similar studies from a center in USA, utilizing the same methodology. Mean brain weight of Indian sample was lower and mean diffuse plaque density was higher. Differences in mean density and counts of neurofibrillary tangles and neuritic plaques were not statistically significant. This is at variance with the expected lower AD-related lesion burden based on the clinical/epidemiological studies, suggesting lower prevalence of AD in India.

**Problems in Recognizing early Dementia Cases in Indian Context**

In Indian social scenario, forgetfulness in the elderly is often recognized as normal variation of aging. When it is recognized, it is often in advanced stages. Commonly, the responsibility of household instrumental activities such as marketing, office work, monetary transaction, etc., is shouldered in next generation family members. Consequently, milder problems remain unrecognized. Another important hurdle is to get proper and chronological history. Being a multilingual country with significant proportion of illiterate people, formulating and validating different evaluation scales is a challenging task.

**Dementia Subtype and Indian Perspective**

Subtyping of dementia has been carried out in many studies from India. Community-based studies have shown that the frequency of AD varied from 0.34 to 1.5% above 60 years of age. However, clinic-based studies have one advantage that they are well investigated. A clinic-based study from South India found AD in 38.3%, VaD in 25.4%, frontotemporal dementia (FTD) in 18.7%, diffuse Lewy body disease (DLB) in 8.9%, and mixed dementia in 8.6% of the patients. Prevalence of overall dementia and its subtype from India is 2.7% [95% CI (1.4-4.0%); AD, 1.3% (0.8-1.8%); VaD, 1.1% (0.2-1.9)]. Proportionately VaD is higher in Asian countries than in western countries. In clinically diagnosed dementia cases, 75% were AD and 13% were VaD from a North American country. The mean age at presentation in India is about 66.3 years, about one decade younger than in developed countries. The proportion of patients with early-onset dementia was high (49.9%), compared to 7-30% in developed countries. This may be related to younger age of Indian population as compared to western population or ethnically related. The two clinic-based studies from two regions have shown subjects with dementia showing similarity in age group, but differing in subtypes and etiologies, indicating possible contribution by varied environmental factors and possible referral bias. [Table 2]

Thus, the two studies evaluated the cases based on clinical, biochemical, radiological, and neuropsychological assessment. Significant finding was the noticeably lower frequency of AD from Central India. One of the explanations was that frequency of mixed dementia might be overestimated in this study. Possibly many of the cases might be categorized as degenerative dementia if autopsy could be performed.

A study on early-onset dementia (≤65 years) from East India documented higher frequency of possible AD (30%), followed by FTD (27%), VaD (20%), Huntington disease (HD) (4%), and miscellaneous causes in 11% of cases. Higher frequency of family history was noted in 30% of cases with AD, 20% in FTD, 5% in VaD,
Behavioral and Psychological Symptoms of Dementia

Overall, the patients can present in two ways, either with cognitive deterioration or with behavior and psychological symptoms of dementia (BPSD), and thus can present to either neurologist or psychiatrist. Rarely, degenerative dementias, particularly AD subtype, may present with unusual clinical phenomenon such as visual disturbances.

Though cognitive symptoms are the main focus for diagnosis and management of dementia, recent years have seen growing importance of BPSD particularly from the point of management, caregiver’s burden, quality of life, and outcome of dementia. However, most of the studies have been carried out in developed countries. Recently some studies have also been done in the developing countries including India by the 10/66 group.[41] This group reported that at least one BPSD was present in 70.9% of cases and the commonest psychiatric abnormalities were depressive syndrome (43.8%) followed by anxiety neurosis (14.2%) and schizophreniform/paranoid psychosis (10.9%). In contrast, a community study from North America documented that 61% had exhibited one or more mental or behavioral disturbances in the past month. Apathy (27%), depression (24%), and agitation/aggression (24%) were most common in subjects with dementia.[42] Thus, higher depression in developing countries may be related to cultural and socioeconomic influences. A recent community study from western India has documented varied BPSD such as irritability (15.1%), agitation (9.3%), apathy (8.1%), hallucination (8.1%), depression (7%), disinhibition (5.8%), and somatic symptoms such as poor sleep (5.8%), poor appetite (2.3%), and suspiciousness (2.3%).[12] Pattern of BPSD differs depending on the subtypes of dementia. A study from West India recorded that AD patients have significantly more delusions, hallucinations, anxieties and phobias, and caregiver distress than patients with VaD.[43] Another study from South India had found that over 96% patients of dementia had one or more BPSD and certain delusions such as delusion of theft or that one’s house is not his own.[44] Similarly, in a study from South India, the neuropsychiatric symptoms between AD, VaD, and FTD were compared and it was observed that aberrant motor behavior, disinhibition, and appetitive/eating behavior differentiated FTD from AD and VaD.[45] No significant difference was found between AD and VaD. Mean total psychopathology scores increased in tandem with dementia severity regardless of dementia type.[46] In another study from East India, higher frequency of utilization behavior in subjects with FTD was noted and the actual underlying cause was not known.[47] It may be related to the pattern of degeneration in frontal lobe with secondary release phenomenon of underlying repetitive behavior.[46] Interestingly, one European study had found more psychiatric symptoms in FTD cases and all were diagnosed as primary psychiatric disorders at the onset.[47] It emphasizes early need of recognition of BPSD.

Neuroimaging

Study on functional neuroimaging pattern in patients with dementia showed similar picture as standard literature.[48] AD has been found to be the most frequent form of dementia. However, a significantly higher proportion of frontal lobe involvement was noted in the Indian population, as compared to global literature. No occipital cortex extension was found in Indian patients. In another community-based study, magnetic resonance imaging (MRI) has shown increase in prevalence of infarcts and more extensive white matter change indicating possible vascular changes. Frontal lobe atrophy was dominant in FTD cases. In 74.5% of cases with AD, both gray and white matter involvement was noticed. Only prominent cortical gray matter involvement was noted in a small number of cases of AD (8.1%) and VaD (7.7%). This report indicates that dementia subtyping based on neuroimaging is not reliable.[12]
**Awareness**

Interestingly, systematic study on awareness about dementia is infrequent. The awareness about dementia is poor among common people and also general practitioners. One study from India has recorded that dementias are considered as neglect by family members.[49] Dementia subjects are often stigmatized. Poor awareness leads to poor recognition, resulting in delayed diagnosis and sometimes catastrophic situation may arise. There is little help from health service sectors which do not provide the needed information and support for carers and family members. Print media and electronic media have started to raise awareness among the general public in India. Alzheimer Related Disorder Society of India is taking part in this process through its different chapters nationally.

**Caregiver Burden in India**

The caregivers have to bear the brunt of the dementia patients and BPSD is the most important factor predicting the caregiver burden in dementia. In India, the majority of the caregivers are women in 70% of cases, and are mostly wives, daughters, and daughters-in-law.[50] The principal sources of caregiver strain are BPSD and incontinence. Strain is exacerbated by the lack of supportive response from local health services and of family support resulting from adverse behaviors from other family members, and they suffer significant mental strains indicating clear need for support and more education.[51] A study from Goa, West India has shown that community-based interventions have considerable potential to improve the quality of life of the caregivers and the subjects with dementia. Home-based care is preferred to daycare program for the caregivers of persons with dementia.[52] The study has shown that the use of locally available, low-cost human resources in tune with socio-culturally acceptable method is feasible and leads to significant improvement in caregiver’s mental health and burden of care.

**Socio-Cultural Context of Dementia: Kerala Model**

Kerala, an advanced state in terms of literacy and human development index, has undergone rapid urbanization and modernization in 80s and 90s of the last century.[53] As a result, there is exodus of earning member for economic reason. Traditionally in Indian culture, the elderly persons are taken care of by the next generation family members. Urbanization leads to disruption of joint family due to migration and older people are left in rural communities with meager or absence of family support in many cases. Thus, demographic changes characterized by increasing elderly population and modernization have led to negative influence of people with dementia. In such a situation, non-governmental organizations have come in the forefront. They are attempting to arrange awareness program and daycare and homecare centers for the patients as well as for the caregivers. In this state, many institutions have been set up to take care of patients with dementia.

**Conclusion**

India lacks much information such as incidence of VaD which is basically avoidable by preventing stroke and controlling its risk factors such hypertension, diabetes, smoking, and dyslipidemia. It is expected that without autopsy validation of dementia diagnosis, the true picture of underlying disease burden cannot be estimated. The real problem is management of AD. In the last 25 years, the biological groundwork of AD has been unraveled, but no disease-modifying agent has been discovered. Considering the lower prevalence and incidence of AD as compared to that in western countries, long-term research plan to identify the protective factors and subsequent research application in animals and human should be urgently undertaken. One of the neglected areas is social support and establishment of health care services, though government has taken note of this situation and it is expected that adequate measures for treatment and prevention of dementia in patients will be taken in the near future.

**Acknowledgment**

We are obliged to Mrs Surmadas Ghosh for literary corrections and Mr. Dipankar Bhattacharya for literary material supply.

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How to cite this article: Das SK, Pal S, Ghosal MK. Dementia: Indian scenario. Neurol India 2012;60:618-24. 
Source of Support: Nil, Conflict of Interest: None declared.