

The dementia epidemic: Impact, prevention, and challenges for India

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In 1947, when India achieved independence, the average life expectancy of an Indian was 32 years, with birth rate being high and few people surviving to old age. With the advancement of medical sciences and implementation of family planning program, the crude birth rate and death rate declined significantly with the average life expectancy of an Indian going up to 68.3 years. However, living longer did not mean living well as the increased life expectancy did not translate to improved quality of life due to lifestyle-related chronic noncommunicable diseases and its sequelae. Dementia is one such disease of the elderly with high morbidity and considerable socioeconomic impact. Dementia is a neurodegenerative disease of multifactorial causation, heterogeneous presentation, and variable prognosis. It is characterized by a decline in performance and cognitive impairment in multiple domains and affects a person's independence in doing activities of daily living.^[1] It also contributes to significant health-care costs and caregiver burden, making it a public health priority.

It is projected that around one in five persons from low- and middle-income countries are going to be above 60 years of age by 2050. In countries like India, elderly are taken care by families and there is one elderly person for every 10 working-age persons, but this ratio will increase closer to one elderly for every 3 working-age population by 2100.^[2] With the increase in the elderly population, there would be a proportionate rise in elderly suffering from dementia as the prevalence of dementia in the elderly is 5%–7%.^[3] In absolute terms, there are about 35.6 million people living in the world currently with dementia and 7.7 million new cases of dementia added every year, i.e., nearly one case every 4 s with highest projections in South Asian nations such as India and China.^[4] The number of people living with dementia worldwide is projected to double by 2030 and more than treble by 2050, where majority would be in developing countries like India.^[5]

IMPACT OF DEMENTIA

Dementia is considered to be an expensive medical illness and the potential costs are huge as conditions associated with dementia are typically progressive and irreversible.

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The care of dementia patients is extremely time and cost intensive. Studies done in developed countries have shown estimates of about 600 billion dollars a year based on insurance claims.^[6] There is a dearth of information on economic costs and social burden of dementia in the Indian population. It is difficult to estimate the accurate cost of dementia in countries like India as health-care expenses are majorly borne by individual families and indirect costs such as decreased productivity of the individual, caregiver, and loss of wage days of caregiver are difficult to quantify. The time spent on informal care of a demented person is almost ten times higher than formal care. Families take over roles and responsibilities and compensate for the deficiencies of the demented, thereby masking the real burden.

PREVENTION OF DEMENTIA – CHALLENGES

As in any chronic medical illness, the objective of intervention in dementia is to prevent the onset or postpone the onset in normal population and eliminate the disease or control the symptoms in the diseased population. Prevention can be categorized into three levels.

Primary prevention

Primary prevention focuses on reducing the incidence of dementia by addressing risk factors. It is considered the best modality to decrease the burden of dementia as a mere postponement of disease will contribute to a significant decrease in prevalence and thereby morbidity, caregiver burden, health expenses, etc., Not all risk factors can be addressed as there are unmodifiable factors such as aging, women gender, genetic risk, and ethnicity (South Asian, African-Caribbean, etc.). The modifiable factors such as cardiovascular risk factors (type 2 diabetes, hypertension, obesity, and hypercholesterolemia), lifestyle factors (smoking, alcoholism, unhealthy diet, and physical inactivity), depression, and head injury are to be targeted for intervention.^[7]

Secondary prevention

It focuses on early detection before the emergence of overt dementia and halts the progression. Early identification of symptoms of cognitive decline has many advantages such as halting the disease process, addressing the reversible causes, controlling the vascular risk factors, and preparing the family to address the consequences and prevent the progress to severe dementia. Early intervention also enhances the

quality of life of the demented patient and caregiver and is known to cause less severe behavioral and psychological symptoms of dementia (BPSD). Disease process of dementia starts many years before the development of clinical symptoms and after onset of first neuropathologic brain lesion before the onset of the first clinical symptom. Mild cognitive impairment (MCI) is an intermediate prodromal stage of memory impairment with normal cognitive function. MCI often, but not invariably, precedes dementia. Identification of individuals during preclinical or prodromal stage would help in early intervention, thereby altering the course and prognosis of dementia. The different tools used are questionnaires, biomarkers, and neuroimaging. Further commonly used questionnaires in the screening of dementia are Mini-Mental Status Examination, Clinical Dementia Rating Scale, Vellore Dementia Rating Scale (VDRS), and Rowland Universal Dementia Assessment Scale. The heterogeneity of Indian population in terms of education, language, culture and etiopathogenesis of disease, presence or absence of vascular risk factors, and psychiatric comorbidities do play a role in sensitivity and specificity of questionnaires. Hence, these questionnaires cannot be used as universal screening tool in Indian population and culture-specific tools such as VDRS should be considered. The biomarkers available are pathophysiologic markers such as amyloid beta accumulation cerebrospinal fluid/positron emission tomography (CSF/PET) and Tau-mediated neuronal injury (CSF) and topographical markers such as synaptic dysfunction fluorodeoxyglucose (^{18}F) PET, functional magnetic resonance imaging (fMRI), and brain structure (volumetric MRI). Few markers such as amyloid positivity correlate very strongly with the presence of apolipoprotein E4 alleles but not others.^[8] Topographic markers alone are insufficient for identifying the presence of preclinical Alzheimer's disease. Neuroimaging techniques such as MRI with diffusion-weighted and diffusion tensor imaging, magnetic resonance spectroscopy, fMRI, PET, and single-photon emission computed tomography are also used widely for early detection of neuropathological changes, subtyping, and monitoring progress and ruling out other causes of dementia.^[9] In the absence of any clinical changes in asymptomatic subjects, these biomarkers and radiological findings can serve as the link with underlying disease. Dementia is a clinical diagnosis, and definitive confirmation is by postmortem examination of brain tissue. The biomarkers and radiological imaging are to be considered for evaluation in high-risk individuals in the presence of risk factors. They can also be used as a research tool for understanding the pathogenesis of illness. However, both biomarkers and radiological imaging are expensive, need great expertise for interpretation, and are invasive at times.

The major challenge in secondary prevention is the diagnosis of preclinical stage as it is difficult to diagnose in the absence of brain abnormalities and clinical symptoms.

The continuum of preclinical stage, MCI, and Alzheimer's dementia is not established clearly in all cases, more so not all MCIs progress to Alzheimer's Dementia and overt disease can occur even in the absence of MCI.^[10]

Tertiary prevention

It focuses on timely diagnosis and treatment of cognitive, behavioral, and psychological symptoms along with decreasing caregiver burden and improving quality of life. The pharmacological agents such as donepezil, rivastigmine, galantamine, and memantine do not have conclusive evidence in controlling the symptoms of dementia in the long run.^[11]

The challenges in tertiary prevention include the difficulties in timely diagnosis as the awareness of dementia is minimal and families attribute the symptoms of dementia to aging mostly and would not seek professional help as labeling elderly is linked to disrespect and stigma in Indian society. Dementia is not considered a life-threatening illness needing acute intervention and is also a cost-consuming and time-intensive illness, so families tend to ignore/accept symptoms of dementia and take the social roles of the demented person compensating for their deficiencies. It would be ideal to do door-to-door screening; however, considering the workforce of health workers and their inadequate training in identifying cognitive decline, it will be difficult to consider that option as of now. Furthermore, there are no disease-modifying therapies for Alzheimer's dementia at present and drugs such as donepezil and memantine alleviate the symptoms for a short period of time without reversing the neuropathological changes. Besides, there is a need for the development of a drug/strategy which can reduce deposition and facilitate clearance of amyloid beta protein, protect neuronal synaptic function, and attenuate tau phosphorylation. However, there are difficulties formulating such a strategy due to incomplete understanding of disease pathogenesis.^[12]

For effective implementation of the above preventive strategies, we need to have adequate trained workforce and financial resources. The formal training in identification and management of BPSD is scarce across different levels of medical training and added to that India has a poor doctor-to-patient ratio in general, more so with trained geriatric mental health experts. The share of government health-care expenditure in the 2.5 trillion dollar GDP of India is a meager 1.2% and the allocation to dementia prevention program is even scantier and definitely inadequate.

POSITIVE SOLUTIONS

1. Understanding the nature of the epidemic: Dementia is a syndrome of multiple etiologies, predominantly degenerative in nature. Hence, the chance of treating is very minimal unless immunomodulant therapies

and replacing neurons by utilizing the mirror neurons becomes a reality. The focus should be primary prevention of risk factors in all individuals' right from young age and universal screening for risk factor and adequate management

2. Steps for early identification and management: Programs to raise awareness to reduce stigma, and wide screening using a reliable tool should be considered. Controlling vascular risk factors during midlife and early old-age prevents or postpones or delays progression of dementia. Addressing comorbid psychiatric illness, especially depression, improves functional well-being
3. Handling the caregiver burden: Considering the increasing dependency ratio, the caregiver burden is going to be huge. The options such as dementia villages can be thought of wherein demented persons will be taken care by trained health workers and Geriatric Mental Health Professionals, thereby decreasing family carer's burden
4. Research focus: Research should focus on understanding the neuropathological changes of disease and its correlation to clinical features. It helps in finding appropriate screening and diagnostic tool along with strategies or drugs to halt or reverse the progression of disease
5. Health policy focus: Policies should address health determinants' right from birth and enhance cognitive reserve for populations by promoting education and thereby economic well-being. The GDP spending on health and education should rise significantly in upcoming years to halt the epidemic of dementia.

CONCLUSION


Dementia epidemic is going to be an inevitable consequence of ongoing demographic transition in India. However, the current understanding about dementia is inadequate for development of appropriate feasible tools for screening the population in early phase of dementia as there is a dearth of manpower and financial resources. There are also huge gaps in research, especially in areas of pathophysiology and disease-modifying pharmacological agents. Therefore, the only viable option as of now is primary prevention of dementia by addressing risk factors and promotion of protective factors. However, for effective handling of epidemic, we need to empower the health-care workers and professionals in screening and management of dementia. The research in dementia should be considered as a high priority by government and other associated organizations of health care. An effective systemic health-care model should be developed for delivery of services to the families

and patients with dementia keeping our sociocultural beliefs in mind. Every step should be taken to improve awareness regarding dementia and its preventive measures, to halt the epidemic, thereby contributing to a healthy and prosperous nation.

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