

Towards a Dementia-Friendly India

India is the second most populous country in the world and is home to 1.2 billion people.^[1] Of this, 8.6% or 104 million are 60 years old or over. Furthermore, with increasing life expectancy in a developing country like India, this figure is anticipated to grow higher. Prevalence rates of dementia in India have been found to vary greatly between studies, ranging from 1% to 10%. This is in part due to the diversity of the populations studied and the methodological differences between studies. Prevalence rates are higher in studies which used instruments appropriate for populations with low awareness of dementia and where relatives are less likely to report symptoms even in the presence of objective evidence.^[2] Added to this the fact that the prevalence of dementia doubles every five years after the age of 65. Taking all the above into account, it is estimated that there are about 4.1 million people with dementia in India^[3] and this is expected to double by 2030 and treble by 2050.^[4]

“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.”^[5] Dementia is a disease mostly of the old, though young people can get affected as well. Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia account for 80% of all dementias, with Alzheimer’s type being the most common.^[4] As dementias are degenerative brain diseases, it is not possible to alter the course of the disorder, but treatments can delay the progression of the disease and ameliorate its behavioural and psychological symptoms, and psychosocial interventions can support those with dementia and their carers.

Dementia adversely affects not only the individual (ill health, disability, impaired quality of life and reduced life expectancy) but also his/her family (significant carer burden and poor quality of life) and society (economic and social costs), and is a significant cause of disability in late - life. The World Health Organisation’s (WHO) Global Burden of Disease Report^[6] calculated 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 Years Lived with Disability (YLD) and Years of Life Lost (YLL), and found dementia to be a major contributor. The 10/66

dementia study,^[4] among other things, also looked at the care needs of people with dementia and found that, in India, between 50 and 70% of those with dementia needed care, and most of these needed ‘much care.’ It also noted that between 40% and 72% of primary caregivers (usually family members) reported high levels of psychological morbidity. In addition to the individual disability and carer burden, the social and economic costs borne by the wider society are also huge, some hard to quantify.

A rough estimate in 2010^[4] pegged the total societal cost of dementia for India to be US\$ 3.415 billion (INR 147 billion); with its 56% (INR 88.9 billion) being the informal care costs and 29% being direct medical costs (INR 46.8 billion). Rao and Bharath^[7] estimated the annual household cost of caring for a person with dementia in India, depending on the severity of the disease, to range from INR 45,600 to INR 2, 02,450 in urban areas and INR 20,300 to INR 66,025 in rural areas. Costs increased with increasing severity of the disease.

In this article, we emphasize the need to view dementia as a public health problem, and elaborate on public health-based prevention models^[8] gaining popularity in dementia. Primary prevention though refers to efforts to prevent the disease; in neurodegenerative conditions like dementia the aim may be to delay the onset of symptoms. Secondary prevention targets delay in the progression of symptoms and covers screening, early identification and treatment. Tertiary prevention focuses on reducing the disability and its impact on the family. We aim to approach the public health prevention model using pragmatic strategies relevant to Indian situation. Synthesizing the current evidence available in this field, we then propose a model for delivering dementia care services in India.

PREVENTION STRATEGIES

Minimising risk

With no major breakthroughs imminent in the medical treatment of dementia, primary prevention strategies are crucial. There are seven potentially modifiable risk factors that have been shown to be associated with Alzheimer’s disease, and hence these are ideal targets for primary prevention: diabetes, midlife

hypertension, midlife obesity, physical inactivity, depression, smoking, and low educational attainment. It was proposed that relative reductions of 10% per decade in the prevalence of each of the above seven risk factors could reduce the prevalence of Alzheimer's disease by 8.3% worldwide in 2050 and that the incidence of Alzheimer's disease can be reduced through improved access to education and the use of effective methods targeted at reducing the prevalence of vascular risk factors and depression.^[9] Multimodal interventions that include more than one behavioural or lifestyle intervention (physical, mental, cognitive, diet, etc.) may have a greater likelihood of influencing neurobiological mechanisms underlying cognitive decline than any one activity alone.^[10] The WHO^[11] proposed linking dementia with other programmes, policies, and campaigns on Non-Communicable Diseases (NCD) risk reduction and health promotion across relevant sectors. In a country like India, when there are competing needs for the scarce resources available, demands should be realistic and pragmatic. It is clear that inter-sectorial collaboration is the best way forward in addressing the complex challenges associated with dementia care and organising services. Although strengthening health and social care systems will form the backbone of many of the components described above, and because policy decisions are essential for sustainable regional or national strategies, successful small scale collaborations can be forged at local levels. Mental health professionals (psychologists, social workers, and psychiatrists) have a crucial role in facilitating such collaborative models at regional, state and national organisational levels. Vehicles such as the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) can be used to include dementia piggyback on to other NCDs. NPCDCS, launched in 2010 in 100 districts across 21 states, focuses on health promotion, early diagnosis, management and referral besides strengthening the infrastructure and capacity building.^[12]

Awareness raising

There are two essential aspects in identifying people with dementia: the general public should be aware of dementia and its symptoms, and be ready to seek appropriate help and when an individual approaches a professional, he/she too should be aware and competent to make a correct diagnosis of dementia. This emphasises the importance of awareness creation among the public and skills development among various professional groups. Actions in this regard could include finding ways to make opinion-leaders, media, and celebrities to talk more about dementia and organising ongoing dementia awareness programmes.

Awareness programmes should be contextual and culture specific. Cultural practices and beliefs play a major role in shaping attitudes and behaviours. From understanding dementia as a disease process as against a part of normal ageing and recognising symptoms of dementia, would enable and break barriers to seek help and support by families affected by dementia. Stigma and discrimination against people with dementia occur at various levels. Even health professionals can be perceived as unhelpful and dismissive. Advocacy is important to increase awareness in the political sphere, which should be collaborative and include families, health care professionals, non-governmental organisations (NGO), social service, etc., The campaigns should be structured and long term. Risk reduction strategies should be an inevitable component of awareness programmes. A dementia-friendly community approach, which aims at building a society where people with dementia have a good quality of life, is the way forward.^[13]

Early diagnosis

Early identification and diagnosis of dementia and providing support to the person and his/her carer/s are essential to ensure a good quality of life. However, the treatment gap (the difference between number of people with the condition who need care and the number of people who receive care) for dementia in India is about 90%.^[14] Acquisition of skills to suspect and identify people with dementia is important for all professionals likely to come in contact with the elderly people. This includes nurses, doctors, social workers, occupational therapists, physiotherapists, etc., and a range of non-healthcare professionals. Lack of a medical cure and the worrisome impact the diagnostic label can have on the patient and the relatives are reasons for low rates of diagnoses by medical professionals. However, often, the families are relieved to realise that their relative suffers from a medical condition and that they are not being 'purposefully difficult.' A medical diagnosis often allays several other anxieties and often shifts attitudes positively.

In addition to people presenting specifically with memory/cognitive problems, screening for memory problems among elderly people in other settings such as medical and surgical outpatient clinics and those admitted in hospital wards will help identify more people with dementia. Periodic screening for cognitive problems among the elderly people in the community can be conducted by primary health centres in collaboration with local NGOs. Cognitive screening may also be combined with various other health intervention programmes in the community as part of the NCD strategy. Community workers should have the basic knowledge to offer appropriate advice regarding

dementia and there ought to be pathways in place to ensure an appropriate and timely response.

Memory clinics

The core functions of such clinics/services are to assess people with suspected memory difficulties, make a diagnosis, and come up with a treatment plan. They should also be equipped to treat comorbid conditions and to offer a range of medical and psychosocial interventions to patients and their caregivers. Some such clinics also offer inpatient stay and take on non-medical work in this field such as running awareness-raising campaigns and training programs. Such clinics can be located in general hospitals or community centres and need to have multi-disciplinary input from doctors (neurologists, psychiatrists, geriatricians, etc.), nurses and social workers, depending on the available resources.^[15]

Services for those with dementia and their carers

Once a diagnosis is made, patients and their carers will need a range of help and treatment/support services. They need information about the condition and skills to manage the situation. It becomes difficult to deal with the challenges of dementia without appropriate knowledge and skills.

There should be an identified source where they can turn to. This could be the local health centre, a local NGO or a local self-government body. Information is plentiful in some areas and languages but rather scarce in others. Social work institutes, preventive medicine departments and so on are best positioned to translate, adapt and provide such information in collaboration with specialists. Community-level health workers should be able to train the family caregivers to deal with the daily stresses of dementia care. Most people would want to try cognitive enhancers, which should be considered after providing information about the moderate effectiveness of these agents in improving the condition.

In early stages of illness, many relatives find that day centres (where people with dementia are cared for during working hours) are effective alternatives to leaving them home on their own and provide breaks for caregivers who have other responsibilities as well. These centres offer leisure activities and cognitive stimulation. Day centres which provide free or subsidised places should be available locally or regionally. As dementia is a progressive condition and as symptoms get worse, caregiving demands go high, and the distress levels tend to escalate. In India, the primary caregivers are often women and elderly partners. National Mental Health Policy^[16] acknowledges that the unmet needs of elderly caregivers have a negative impact on their lives as well

as the lives of those for whom they provide care. Dias *et al.*^[17] showed that home-based support for caregivers of persons with dementia, which uses locally available, low-cost human resources, is feasible and acceptable, results in significant improvements in caregiver mental health and lessens the burden of caring.

The advanced stage of the condition requires palliative care approaches. Community-level palliative care teams^[18,19] may have transferable skills to care for patients with dementia. Where it is no longer possible to look after those with dementia in their own homes, they will need to be admitted to care homes. Nursing homes with qualified and skilled staff members with a safe, stimulating environment are important in such centres. Although there are some private agencies that provide such care, albeit few and far between, the government sector needs to step up too. Though precise official data are not available, it is estimated that there are only 20-day care centres and 30 full-time residential centres that cater to the needs of people with dementia across India and they are mostly concentrated around major cities.^[20]

Families caring for those with dementia will also benefit from support in the care of their loved ones. Those who can afford may utilise paid caregivers but those who cannot, rely on informal support from relatives, friends and the wider community. One needs to be innovative in mobilising community support – examples include volunteers, senior citizen groups or local networks of people small or big. There is no ‘one-size fits all’ approach as there are cultural, social and attitudinal factors associated with this type of help-seeking and provision.

The specific role of community workers is important, and the inclusion of members of the local community in a semi-formal network of care is one way forward. The idea is to create a network of community members to provide psychosocial support in strengthening mental health services at the primary care level.

Care of people with dementia also comes under the new Mental Healthcare Act 2017.^[21] It is considered to be a progressive and revolutionary piece of legislation intended to provide mental healthcare and services for persons with mental illness and to protect, promote and fulfil the rights of such persons. It has several positive aspects^[22] and measures such as opportunities to make advance directives (AD), nominated representatives, regulating all facilities that provide psychiatric care irrespective of systems of medicine practiced or nature of service provider, and setting up systems to ensure due process when personal liberties are restricted. These

are hoped to bring about significant changes in the care of patients with dementia as well. However, there seem to be several ambiguities and gaps which need to be reviewed to bring it in line with the principles followed in other countries but adapted to local situations.

A national dementia plan and more research

Dementia should be acknowledged not only as a national public health priority but also as a social care priority. A national dementia plan with allocated funds to see it through has to be in place. The key components of an effective dementia plan include: making dementia a national priority, increasing awareness about dementia, improving early identification and treatment, developing home care and community support, building carer support packages, developing comprehensive dementia care models, and increasing funding for dementia research. As the needs of people with dementia are multiple and varied, and because they fluctuate over time, it would be impossible for a single professional or agency to address all their needs. This is what calls for partnership between families, government agencies and voluntary sector organisations.^[23]

Research in dementia from India is either small-scale independent studies or studies that are part of international research collaborations. Whether regional variation of dementia rates shown in some studies is related to a lower prevalence of certain risk factors or higher prevalence of certain protective factors need to be explored further.^[24] We need answers to questions such as what interventions do families find useful? How can effective interventions be delivered in low resource settings within existing infrastructure? And what would ease the burden of caregivers of people with dementia? Long term research plans are needed to address the complex challenges associated with dementia.^[25] Intersectoral collaborations between government departments (e.g., health and family welfare and social justice), NGOs, community workers, academicians, and researchers are the way forward.

Proposed model for delivering dementia care services: Seven core strategies

Dementia India Report^[4] proposes a model for effective dementia care based on seven core strategies focusing on awareness creation, demanding services for people with dementia; capacity building of health care teams; providing affordable treatment; effective long-term care through community-based programmes and residential, respite and day care facilities; and developing legal services and training services. These strategies echo the propositions by international organisations. Alzheimer's

Disease International (ADI)^[26] emphasises that national dementia plans are the single most powerful tool to transform national dementia care and support, but India does not have one yet. ADI identified ten areas that should feature in any future National Dementia Plan, which are: improve awareness and education, improve early diagnosis and treatment, improve support available at home, strengthen support available to family caregivers, improve residential/institutional care, better integrate care pathways and the coordination of care, improve training for healthcare professionals, monitor progress, commitment to research, and recognise the role of innovative technologies.

Although there have been no significant national level programmes focusing on dementia, there are a few good models of practice which could easily be replicated in other parts of the country. A classic example is Kerala State Initiative on Dementia. Taking cognizance of dementia as a major public health problem affecting the community, Kerala became the first state to launch a state-wide dementia initiative in 2014. Kerala State Initiative on Dementia used a public-private partnership model linking various government departments with Alzheimer's and Related Disorders Society of India (ARDSI). It has several components including creating dementia awareness among all sections of the society, equipping health personnel and professional caregivers with knowledge and skills for dementia care, establishing memory clinics for diagnosis and care of people with dementia, opening care homes and day-care centres in all districts for dementia patients, and so on.^[27]

To upscale such innovative ideas to the national level in the form of a national plan, commitment from the government is essential. Multidisciplinary models and collaborative working with other health and social care professionals is the way forward. Caregiver support should be provided not only using formal systems but informal system as well, utilising local community resources, with all stakeholders included. There should be more emphasis on chronic health problems, NCDs, and long-term care. The focus should be on improving the quality of life.

CONCLUSION

Dementia not only affects the health, and quality of life of the individual but also has huge impact on the psychological and emotional well-being of the caregiver in addition to the socio-economic burden of the family and society at large. Furthermore, with the number of people who have dementia in India expected to double from the current 4.1 million by 2030 and treble by

2050, there is no denying that it is a significant public health issue. Given this, public health-based prevention strategies need to be in place – i.e. prevention at primary (intervention strategies prior to the onset of dementia), secondary (interventions covering screening, early identification and treatment), and tertiary (treatments for the chronic condition, including psychosocial and rehabilitation needs of the individual and the carer) levels. Recognising dementia as a priority health and social care issue by the policymakers, specific government funding allocation, active engagement of voluntary organisations, strong patient advocacy movements including networking, media attention and utilising existing local community level initiatives and infrastructure are the crucial drivers in building a dementia-friendly India.

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