

Dementia care and rehabilitation in India

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INTRODUCTION

Dementia is described as, “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease (AD), in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.”^[1] Besides cognitive dysfunction, behavioural problems like hostility, suspiciousness, stubbornness etc may also be there.^[2]

About 90% of dementia comprises of condition like Alzheimer's Disease (most common and comprises of 50-75 % of dementia cases), Vascular Dementia, Dementia with Lewy bodies and Fronto-temporal Dementia - these are neurodegenerative and irreversible.^[3] However some dementia are caused by conditions like Normal Pressure Hydrocephalus, Vitamin B12 deficiency, Folic acid deficiency, hypothyroidism etc. which are reversible and can be treated.^[3]

Worldwide, the prevalence of dementia ranges from 5-8 % in people aged 60 years and above; about 50 million people have dementia and every year there would be at least 10 million new cases as per World Health Nation.^[4] Majority of the people with dementia are from low- and middle-income countries.^[4,5]

Literature from some Indian studies mention that the prevalence of dementia among the elderly here ranges from 0.8% to 5.5%.^[6] The study by the ‘10/66 Dementia Research Group’ found the prevalence of dementia to be 7.5%.^[7] A recently published systematic review and meta-analysis that included 20 studies from 1996 to 2013 found that the prevalence of dementia was about 2%.^[8] The ‘Longitudinal Aging Study in India’ found the prevalence of dementia in the elderly aged 60 years and above to be 7.4% which translates to the fact that about 8.8 million Indians have dementia; it was more in female and those in rural areas compared to males and those in urban areas respectively.^[9] Thus a wide variation in the prevalence of dementia in India has been reported. This is due to the different methodologies applied by various studies.


COURSE OF DEMENTIA AND ITS EFFECT ON FUNCTIONALITY

In the early stage of dementia, usually in the first two years, the signs and symptoms may be missed and family members may mistake it for normal age-related issues. The affected person may have subtle problem in language, have problems in making decisions, mood changes may be there, may look disinterested, have difficulty remembering things/events and so on.^[3] However they may still be able to continue with their daily activities.^[10]

In the middle stage of dementia, usually from the second to fifth year, the neurocognitive deficits and dysfunction becomes apparent; day to day activities become challenging and dependency on care-givers to manage activities of daily living like maintaining hygiene, washing, dressing etc is frequently required.^[3]

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Access the Article Online	
DOI: 10.29120/IJPSW.2025.v16.i2.693	Quick Response Code 
Website: www.pswjournal.org	



How to Cite the Article: Das S. Thejus BR. Dementia care and rehabilitation in India. Indian J Psychiatr Soc Work 2025;16(2): Epub. Indian J Psychiatr Soc Work 2025;16(1):1-6.

In the late stage of dementia, usually after the fifth year, the disabling effect of the disease is more pronounced and such persons with dementia are almost completely dependent on others for nearly all of their activities like eating, moving about, using toilet and so on; they may have bowel incontinence and would be bedridden for most of the time.^[3]

MANAGEMENT OF DEMENTIA

To make a diagnosis of dementia, clinical assessment is very important which is complemented by investigations like neuroimaging, biomarkers and even by usage of digital tools. As of now dementia cure remains elusive and hence management of dementia involves a combination of detailed clinical assessment, usage of medicines and non-pharmacological approaches.^[11]

Depending upon the type of dementia, the usage of medicines varies. For dementia due to AD, drugs like acetylcholinesterase inhibitors- donepezil, rivastigmine and galantamine as well as NMDA receptor antagonist like memantine are often used. Antioxidants are often prescribed as well. To manage the behavioural and psychological symptoms of dementia (BPSD) drugs belonging to the SSRI class (sertraline, escitalopram etc) and antipsychotics are also used. In recent times disease modifying agents like aducanumab and lecanemab seem to show promising result in the treatment of dementia due to AD.^[11]

Non-pharmacological approaches to dementia includes providing psychoeducation, cognitive stimulation programme, reality orientation, reminiscence therapy, aroma therapy massage, animal assisted therapy etc. Role played by caregivers of persons with dementia is very important especially in the later stages of dementia when such patients are no longer able to take care of themselves.^[12] The role of caregivers and issues faced by them will be elaborated under the next two headings.

ROLE OF CAREGIVERS

Caregivers have multiple roles to play while caring for those with dementia. Such role includes providing assistance in medical, financial, emotional, legal support and so on.^[13] Caregiver should be able to understand the needs and problems of persons with dementia; understand the nature of the illness and liaise with the treating team in providing

assistance to those with dementia in various aspects (for example providing orientation cues in their conversation); understanding the behavioural symptoms associated with dementia; facilitating socialization; arrange for others to provide care when required; providing personal care-bathing, feeding, toileting etc; be involved in protecting the rights of their relatives with dementia.^[12,13,14]

ISSUES FACED BY CAREGIVERS

Most of the literature mentions that caregivers of persons with dementia face enormous burden: physical, mental as well as financial.^[3,13,14] They are vulnerable to psychological morbidity and stress; may have condition like anxiety and depression.^[3,14] Much of their time and energy is spent on caregiving, leaving very less time for themselves that lead to decreased socialization, increased isolation.^[14] Other issues like poor understanding about the illness, its associated behaviour and lack of guidance in managing such behaviour have also been reported.^[3,14] Dealing with multiple medications that has to be provided to the relatives with dementia is another challenge posed by caregivers, given the fact that many of those affected also have co-morbid physical and mental health conditions.^[11] High care giving burden was seen in caregivers who were- above 50 years of age, female, spouses, those who stayed in smaller/nuclear family and those who lacked social support.^[15] Thus caregiving in dementia is indeed very taxing and while assessing the persons with dementia, it is also essential to assess the caregivers and find out if they have any stress or burden because the caregivers themselves have to be well so that they can look after their relatives with dementia properly.

REHABILITATION IN DEMENTIA

In the initial phase of dementia, treatment modalities are somewhat predictable. When dementia is diagnosed early and it is still in mild level of severity, patients are able to maintain their activities of daily living and are usually independent to a fair degree. Gradually with the progression of the illness, multiple issues are faced not only by the patients, but also by the caregivers.

Rehabilitative measures have a key role to play in the management of people with

dementia and World Health Organization too acknowledges this. Such measures usually involve the various health care providers, the caregivers and patients.^[11] Few rehabilitative measures employed for people with dementia include following:

- a) Gait rehabilitation: As elderly with dementia have issues related to movement, including the tendency to fall, so measures to improve gait and stability in movement helps in improving the mobility of patients. Such measures include standing from sitting position, kneeling, walking, turning around, rhythmic music and so on.^[16]
- b) Strategies to reduce fall: By employing various measures like exercises to improve gait, balance and strength; tailor made exercise and other such programs that suits everyone's personal needs; enhancing safety measures at home (by removing objects that may cause injury, decluttering etc) are some of the strategies that can be employed to prevent or reduce falls.^[16]
- c) Regular physical activity and exercises: The benefit of exercise for all including the elderly with dementia is well known. Especially the benefits of physical activity and exercise in persons with dementia have been reported in terms of improving physical health, mobility, decrease risk of depression, slowing the progression of AD and reducing frailty. However, evidence of improving cognition by virtue of doing exercise remains inconclusive. Exercise that has been suggested include aerobic exercise, resistance training, balance and flexibility training; duration from a minimum of 30 minutes thrice a week to 150 minutes per week have been suggested.^[16]
- d) Cognitive rehabilitation: Rehabilitative measures to improve cognition is an important component for persons with dementia and includes various measures like Cognitive Stimulation (by including intervention like reminiscence therapy, reality orientation, sensory-motor therapy etc) and Cognitive Training have been helpful to improve cognition and functioning in persons with dementia, at least in mild cases.^[16]
- e) Assistive Technology and Devices: Simple assistive devices like walking stick, wheel chairs, walkers etc. help improve mobility

and thus enhances the quality of life in individuals with dementia. With the progress in technology devices like memory aids (digital calendar, voice reminder, medication scheduling), automatic on-off devices (for gas supply, water, electric switches etc), tracking devices, technology facilitated games and so on have seen increase in usage. These have a lot of benefit like improving functionality, reduce distress, enhances safety, improves socialization and so on.^[16]

DEMENTIA CARE AND REHABILITATION: INDIAN SCENARIO

In India most of the care for persons with dementia are provided mainly by the family members.^[15] In the initial phase of the illness where dementia management is mostly done through hospital-based facilities, resources are somewhat more compared to facilities meant for later stages of dementia where long term care and rehabilitation is required. In fact, the overall the residential facilities for the elderly with severe mental illness including dementia was also found to be very less, half of which were in the state of Tamil Nadu and Kerala.^[17] Facilities meant exclusively for care and rehabilitation of those with dementia is even less and are mostly concentrated in the southern states and in urban areas.^[3,18]

Various organization like 'Alzheimer's and Related Disorders Society of India (ARDSI)', 'HelpAge India', 'Dignity Foundation', 'Nightingales Medical Trust', 'Dementia Society of Goa', 'Sangath' etc. are providing a number of services for the care and rehabilitation of people with dementia. These include facilities like day-care centres, residential care facilities and domiciliary care services. There are about 10 Day Care Centres, 6 Residential care facilities and 6 domiciliary facilities run by these various organization as per a report of ARDSI of India.^[3] However an article published in 2019 has mentioned that there are 20 'Day Care Centres' and 30 'full time Residential Centres' for people with dementia across India and mostly in urban areas.^[19]

Day care centres for people with dementia usually would provide services for a fixed duration in a day ranging from 7 to 10 hours. Some common services provided by such day care centres usually contain activities like

exercises, music, art, recreation; counselling; therapy; behaviour management; personal care etc.^[20] Various day care centres in India provide similar services.^[15] Such services are usually for people who may not require institutional care and have need for supervised day time care only.^[3]

Residential Care Services could be nursing homes or short-term respite care services that usually cater to the basic day to day activities of the people with dementia.^[3]

Domiciliary Care Services mostly help in providing services to persons with dementia at their home itself. It may include dedicated nursing care by nursing professional especially those with experience in geriatrics. Sometimes such services are provided by assisting the caregivers through training in caregiving.^[3]

Community based rehabilitation has also been documented, mainly from the southern part of the country. Such rehabilitation for persons with dementia included measures like involvement of a multidisciplinary team; care givers support group; facilities like provision of day care; facilitation of domiciliary care; providing training to workers; generating awareness; providing medical and psychiatric services; provision of memory clinic; provision of helpline etc. The Day Care programme included activities like newspaper reading, writing, drawing, colouring, exercises etc and therapies like reality orientation, reminiscence therapy sessions. These facilities were used by relatives of persons with dementia and it helped them immensely.^[15]

GOVERNMENT SECTOR

The Government of India is aware of the needs of the elderly population, especially with regard to various health issues afflicting them. The “National Programme for the Health Care of Elderly” (NPHCE) was launched by our government during 2010-11. Through this program there is a provision of including services for the elderly from the level of sub-centre to the district level. Additionally, there is provision to start 19 Regional Geriatric Centres, National Centre for Ageing (Two in number) and a 250 bedded Geriatric Care and Rehabilitation Centre in PGIMER, Chandigarh. Though exclusive dementia related care and rehabilitation has not been specifically elaborated, this programme does

provide home based care and supportive appliances through the various sub-centres and till December 2020, a total of 14201 such instances of providing support have been reported. Further this programme also plans to start ‘home health care services’ through the Regional Geriatric Centres for the elderly who are above 75 years of age. Through such ‘services’ a team of dedicated health care professionals will visit the residence of elderly people who are on treatment and may not be in a position to go to a hospital. The team will provide nursing care, train caregivers in activities like feeding, bathing, wound care etc for the affected elderly, provide rehabilitation training in activities of daily living, physiotherapy and so on.^[21]

Centres like National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, through its ‘Geriatric Clinic and Services’ provide rehabilitation to elderly patients that includes occupational rehabilitation, cognitive rehabilitation and guidance for daily activities.^[22]

The Department of Psychiatry in Government Medical College and Hospital (GMCH), Chandigarh, through its ‘Disability Assessment Rehabilitation and Triage (DART)’ service provides intervention like neuro-cognitive rehabilitation, social skill training, vocational rehabilitation etc for persons with chronic mental illness. Particularly the ‘Neuro-cognitive Rehabilitation Clinic’ provides cognitive skills training to enhance the cognitive functions of persons who have conditions like traumatic brain injury, dementia, cognitive impairment due to chronic mental illness etc.^[23]

As far as dementia related measures are specifically concerned, Kerala was the first state to have taken initiative in dementia care as early as 2014 through its public-private model in collaboration with ARDSI. It included strategies to increase awareness on dementia among the public; empowering caregivers and health professionals; providing facilities like day care centres, residential homes etc.^[19]

The state of Karnataka recently declared dementia as public health priority. In their action plan for dementia (draft), they have proposed to start a dementia registry and also to provide homebased caregiver assistance.^[24]

The National Institute of Mental Health and Neurosciences (NIMHANS) in Bengaluru and 'Manthan platform' along with support from Central Government has also developed 'Dementia Design Studio' which seeks to develop a culturally relevant solution for better care of patient with dementia; it includes intervention like environmental modifications, use of assistive technologies, reminiscence therapy, cognitive stimulation activities etc.^[25,26]

THE WAY FORWARD

Keeping in mind the likelihood of increased prevalence of disorders like dementia in India, there is a felt need to have an exclusive national policy for dementia and this point has been highlighted by many.^[15,19,27] We need to develop a mechanism of helping people with dementia who have little or no social support by opening up government run state-of-the-art residential facilities. Provision of opening more and more day care centres or respite care centres, at affordable rates with transportation facilities to pick up and drop persons with dementia, especially for nuclear family with working family members will be very much helpful to the service users.

We should promote community-based rehabilitation for the people with dementia, as such initiative will facilitate the rehabilitation of the persons with dementia in familiar environment and is also like to be very much cost-effective. Another good idea worth deliberating is the formulation of a rehabilitation plan in the very early phase of dementia by taking the wishes of the affected individual into consideration. Provision of 'Advance Directives' as mentioned in Mental Healthcare Act-2017^[28] is likely to be useful in this regard.

Empowering the caregivers by means of training, providing domiciliary assistance as and when required is another way by which the care and rehabilitative measures for persons with dementia can be enhanced. Initiative of WHO like the 'iSupport' which is a training program for caregivers of persons with dementia and is available online as well is likely to be very helpful for such people.^[29] These are a few of the measures that we may adapt to help the people with dementia and their caregivers.

Financial support and sponsorship: Nil.

Conflicts of interest: None

CONCLUSION

The overall rehabilitative measures and facilities for people with dementia are very limited in our country. However, we have made some progress, though it is not uniform all over the country. Policies for better care of the elderly with health issues is likely to be a game changer and with time we will surely be making a lot of progress in dementia care.

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Received on: 08-03-2025

Revised on: 10-03-2025

Accepted on: 10-03-2025

Published on: 16-03-2025