

DEMENTIA IN INDIA 2020



A REPORT PUBLISHED BY
ALZHEIMER'S AND RELATED DISORDERS SOCIETY OF INDIA (ARDSI)
COCHIN CHAPTER

WITH ACADEMIC SUPPORT FROM
KERALA UNIVERSITY OF HEALTH SCIENCES (KUHS), THRISSUR

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'The Banyan tree' has a difficult start to its life fighting for survival.

When growing old, they spread across, providing shade in large areas. Even when dead and hollow they continue to provide shelter.

No wonder, banyan tree was suggested by many as a symbol for Dementia Friendly Communities in India (DFCI).

DEMENTIA IN INDIA 2020

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FOREWORD

MY JOURNEY



It was the personal traumatic experience of my father late Rev. O.C.Kuriakose Kor Episcopa that brought me close to the area of Alzheimer's disease. Even in late 1980s none of the medical centres in India were in a position to offer any significant help to those affected with Alzheimer's disease. None knew the existence of such a deadly disease even in a state like Kerala. Those were real times of struggle for me. My father was diagnosed with frontotemporal dementia and he passed away at an early age of 63. Somewhere down the line I felt the strong need to address this disease with a serious attention. This gave me the courage to hold the first National Seminar on dementia in collaboration with Tropical Health Foundation of India (my first project) at Cochin in 1991 which led to the formation of ARDSI. Though it was a giant step outside my comfort zone, I understood the relevance of working towards this cause largely because there wasn't much awareness. With a huge struggle and relentless efforts, ARDSI was made a provisional member of ADI in 1992, and later became the first Asian country to become a full-fledged member of ADI in 1993. We were the first Afro-Asian Alzheimer Association to become a full member of ADI. I vividly remember attending the ADI Council meeting in Toronto where I was the only brown-skinned person. I mention this not because it was a problem, but to show how under-represented my part of the world was in ADI in those days. I took the role of Vice Chairman from 1998 to 2001 and continued to serve in various capacities within ADI until 2009 and in 2011 was elected as Chairman of Alzheimer's Disease International (ADI), the first Asian to be elected to this honourable post.

The 14th International Conference of Alzheimer's Disease International (ADI) was held at Cochin in 1998 and is the biggest milestone in the history of ARDSI. It was a truly a remarkable event with 750 delegates from 50 countries and was the first time it was held in Asia. It was at this conference that the 10/66 Dementia Research Group was formed and where the first Asia Pacific regional meeting was held.

By then we decided to broaden our activities and spread our wings by starting chapters across India. Though with a lot of initial challenges, we now have chapters across India. The biggest challenge that we had to face those days was the existing social stigma which made the relevance of awareness about this disease a very crucial factor. Even today only about 10% get identified. Current activities remain mostly confined to the people who already know about dementia.

In the future, I would like to see ARDSI emerges as an even stronger organisation. It is the platform for all those working for and with people with dementia and their families around the country, so it should be able to influence central government to make dementia a health priority. I would like to see a world where dementia is treated at par with other chronic diseases like cancer or stroke, where people speak openly about the condition and where all those affected receive a timely diagnosis, appropriate treatment and care.

To deliberate, discuss and impress governments, service developers, funding bodies and policy makers there should be documents which narrate the details of dementia which are contextual and relevant. Patient advocates and family members should be able to use them along with professionals and prepared by authors who know the ground realities. There I am sure 'Dementia in India 2020' will give a strong impetus to various stakeholders who care about people with dementia, their friends and relatives and those who wish and work towards a dementia friendly community. I sincerely thank all those who have dedicated their time and energy from their busy schedules selflessly for this noble cause.

Dr Jacob Roy Kuriakose

Founder, Alzheimer's and Related Disorders Society of India (ARDSI)

Past Chairman and Honorary Vice President,
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FROM THE EDITORS

There are around 5 million people with dementia in India and many more are at a high risk of developing this condition with no cure. Dementia robs the person not only his memories and personality but often his dignity as well. Stigmatisation, lack of adequate services, barriers to access available services all worsen the physical, psychological and financial hardships of the families. The total estimated worldwide cost of dementia in 2018 was US\$1 trillion which will rise to US\$ 2 trillion by 2030. The challenges associated with dementia if left unattended, can be a barrier to India's economic and social development. The true human costs of dementia cannot be measured. Undoubtedly caring for someone with dementia is one of the toughest jobs and families often do it with no meaningful support from any other sources. The enormity of the public health challenge posed by dementia and its negative impact on a rapidly ageing society is not fully understood by policy makers and politicians.

Organisations like Alzheimer's Disease International and World Health Organisation have published informative material related to dementia addressing the international audience. Dementia India Report published in 2010 gave a status update on the situation in India. We expect 'Dementia in India 2020' - to be a useful addition to the gradual but steadily growing literature on dementia in India. It is always a challenge to bring out a document equally appealing to different stakeholders: specialists, professionals, non-specialists, caregivers, volunteers and public, both in terms of content and language. Our approach has been to make sure there is something in it for all stakeholders involved. Sustained media interest and public attention on dementia is necessary to take any plans forward and gain commitment from the governance and political leadership.

We hope this would be a useful document for those who advocate and work tirelessly to improve the lives of people with dementia in India, to influence the policy makers and administrators. We are sure the information provided will help volunteers in providing information and guidance to people with dementia, their families, caregivers, public and those who deal with funds. We have included sections which the professionals find appealing as well. We anticipate the report would catch the attention of government agencies and officials who are responsible for the care of the elderly and social welfare.

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ABBREVIATIONS

AChEIs	Acetylcholinesterase Inhibitors
AD	Alzheimer's disease/ Alzheimer's dementia
ADI	Alzheimer's Disease International
ADL	Activities of Daily Living
ApoE	Apolipoprotein E
APP	Amyloid beta (A4) precursor protein
ARDSI	Alzheimer's and Related Disorders Society of India
ASHA	worker Accredited Social Health Activist
BPSD	Behavioural and Psychological Symptoms of Dementia
ChEI	Acetylcholinesterase Inhibitor
COI	Cost of illness
CVD	Cerebro Vascular Dementia
EOAD	Early-Onset Alzheimer's Disease
EOD	Early Onset Dementia
FTD	Fronto Temporal Dementia
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
LBD	Lewy Body Dementia
LMIC	Low and Middle Income Country
LOAD	Late Onset Alzheimer's Disease
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
MoCA	Montreal Cognitive Assessment
PHC	Primary Healthcare
PSEN1	Presenilin 1
PSEN2	Presenilin 2
PWD/Pwd/ PLWD	People with Dementia/ Person/s with Dementia/ Living with Dementia
QoL	Quality of Life
RCT	Randomised Controlled Trial
WAR	World Alzheimer Report
WB	World Bank
WHO	World Health Organization

CHAPTER 1

WORDS THAT MATTER- EXCERPTS FROM PEOPLE WITH DEMENTIA AND CAREGIVERS

'I started noticing the changes myself few months ago...My family was worried for over a year...I was good with language, reading and writing... but now I struggle even in conversation to get the right words. It's scary...I worry about the future.' - Mr K, Chennai

'I knew something was not right for a few years now. Was in hospital for something else. I am told I have a form of dementia. I am on tablets. I am now busy getting all the property documents in order and sorting them as per my wishes. May be tomorrow I won't be able to do it. I don't want my children to fight for my property.' - Mr S, Bengaluru

'We are lucky to live in a city with such facilities. My dad used to attend a day centre and now in severe stage. He is in a care home and his pensions fund his stay...I know we are lucky in the given circumstances to be in this city.' - Son, Bengaluru

'There is no way other than to lock my mother- in law in the house when I go for work...she wanders around and creates trouble. My husband is there and he is not well to work...if I don't work, my family will starve.' Daughter-in-law, village near Pondicherry

'Losing my husband in the middle of the train journey was the scariest experience I had. We were going to the temple...he got off at some station. He was about to die of dehydration when police found him two days later....he didn't remember our names, where he was from or even his own name.' -Wife from Telangana

'I cannot believe this is my mother who was house proud, calm, an exemplary host and a cook.... this disease robbed her everything; her personality, her charm....she is now a different person always clinging to my dad like a scared child.' -Daughter, New Delhi

'I care for him...even washing him when he dirties his clothes. He doesn't know when to go to the toilet or where the toilet is....I don't get depressed...I know this is my duty, caring for our elders that is what we do in our culture.' Daughter, Kottayam

'Both of us are working. We would like to look after my mother...we are willing to pay for carers.... but getting suitable people is so difficult...even in this big city. We had four carers changing in the last nine months.' Son, Mumbai

'Mother- in- law thinks I am there to steal her property....I understand she feels that way because of her dementia but I couldn't take it anymore when she started acting towards my husband (her son) as if he was her husband and she believed I was having an affair.' -Daughter- in -law, Ernakulam

'My grandma always lived with us since I remember. She became a widow quite young. She now has dementia, her memory is failing. She just sits in front of the television dozing off...doesn't bother what programme is on and lost her ability to use the remote. Reading about the illness worries me for her future...but at least we know what to expect.' - Grandson, Chennai

'The first doctor we took him to said it was just old age....it was only the third doctor who said my dad possibly has dementia...it's frustrating when you know something is wrong but everyone dismisses your concerns.' - Anonymous

'I knew this existed but only when I visited a centre for people with Alzheimer's as part of a college program I realised how heavy it is....it is tough.....they don't even know who they are or their family. Now I am sure my grandfather who passed away some years ago had Alzheimer's.' - Student, New Delhi

'I hope they find a cure soon. So much advances are happening in science...I hope they crack it soon...yes the families find it helpful to have the information and the psychosocial measures but they are disappointed when I say there is no cure.' Doctor (previously carer), Hyderabad

'I live abroad. My sister looks after my mother....I feel guilty for not being there for her. I speak to my mother everyday on Skype or WhatsApp. She is so happy to speak but she just repeats herself. There isn't a single day I wouldn't call because my sister says mother is very happy after talking to me and that is the least I can do' - Daughter, London

CHAPTER 2

DEMENTIA- INTRODUCTION, ASSESSMENT AND DIAGNOSIS

Sanju George, CT Sudhir Kumar, Jessy Fenn, Venugopal Duddu

INTRODUCTION

Dementia is a general term to describe a group of symptoms which occurs due to the damage and death of brain cells. The common symptoms are impaired memory, thinking, language, comprehension, judgement, decision making and orientation. It is a progressive condition and the symptoms get worse over time. Behaviour and personality changes can occur and as time goes on, the person will be unable to carry out activities of daily living. Dementia is not a normal part of ageing. Dementia can affect young people though rarely. Several different diseases can cause dementia. More than one form (mixed dementia) can exist in the same person.

Definition: The International Classification of Diseases (ICD 10, WHO, 1992) defines dementia 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 normally accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.'

The Diagnostic and Statistical Manual (DSM 5)

describes dementia as 'significant cognitive impairment in one or more domains of complex attention, executive functions, learning and memory, language, perceptual motor ability, and social cognition' (APA, 2013). For a condition to be diagnosed as dementia, it is also important that these cognitive deficits interfere with independent functioning in daily activities.

The word 'dementia' has its origins in the Latin word *dementatus*, meaning 'out of one's mind'. The word dementia was perhaps first used by Celsus in the first Century AD and later by Oribasius, Esquirol and Kraepelin, to mean different psychopathological entities. It was Alois Alzheimer in 1907, who first described a case of progressive aphasia, apraxia and agnosia, associated with the specific histopathological finding of neurofibrillary tangles and plaques. This is what we understand as Alzheimer's dementia today, the most common form of dementia (Graziane and Sweet, 2017).

STAGES OF DEMENTIA

Though there is wide variation in how dementia progresses from person to person and also based on the type of dementia, the following guide gives a rough picture of the progression of dementia through 3 stages from mild to moderate to severe.

The features of each stage is given below (Three stage Model)

EARLY STAGE - (Mild degree)

- ▶ May function independently
- ▶ Forgetfulness, misplacing things, difficulty in multi-tasking
- ▶ Some difficulty tracking time, finding the right words and names
- ▶ Some difficulty and slowing in concentration, decision making and planning

MIDDLE STAGE- (Moderate degree)

- ▶ Increasing dependency
- ▶ Symptoms of the early stage get worse, memory gets worse
- ▶ Becoming forgetful of recent events and people's names
- ▶ Difficulty recalling personal information
- ▶ Losing way even in familiar places
- ▶ Disorientation
- ▶ Having increasing difficulty with communication
- ▶ Needing help with personal care and other activities of daily living
- ▶ Behaviour changes, including wandering and aggression

LATE STAGE: (Severe degree)

- ▶ Significant dependency
- ▶ Early and middle stage symptoms get worse.
- ▶ Memory disturbances are severe
- ▶ Difficulty recognizing relatives and friends, may not identify self
- ▶ Difficulty or unable to communicate
- ▶ Severe disorientation, becoming unaware of the time and place
- ▶ Physical functions deterioration, need significant assistance, poor mobility
- ▶ Behaviour changes that may escalate

ASSESSMENT AND DIAGNOSIS

The primary purpose of the assessment process is to arrive at a diagnostic formulation, which can help plan clinical management. Psychoeducation, medications and psychosocial interventions have the potential to improve patients' quality of life and reduce caregiver burden. Early diagnosis will help the people involved to plan for future and take financial decisions. It is not possible to cure dementia but treatments can delay their progression, ameliorate their behavioural and psychological symptoms, and psychosocial interventions can support those with dementia and their care-givers. Dementia-like syndromes can also be caused by a range of metabolic, endocrine and nutritional conditions. These can affect younger people and may be more amenable to treatments than the degenerative forms of dementia.

A list of dementias and dementia like syndromes based on their aetiology is given in Table 1 below (David et al, 2009).

Neurodegenerative	Alzheimer's disease, Dementia with Lewy bodies Frontotemporal dementia, Parkinson's disease Huntington disease
Vascular	Infarction. Haemodynamic insufficiency
Neurological disease	Multiple Sclerosis Normal-pressure hydrocephalus, Brain tumour
Endocrine	Hypothyroidism, Hypercalcemia, Hypoglycemia
Nutritional	Vitamin B12 deficiency, Thiamine deficiency Niacin deficiency
Infectious	HIV, Neurosyphilis
Metabolic	Hepatic insufficiency, Renal insufficiency Wilson disease
Traumatic	Subdural haematoma, Dementia Pugilistica
Exposure	Alcohol, Heavy metals Carbon monoxide

Alzheimer's Disease (AD), Vascular Dementia (VD), Lewy Body Dementia (LBD) and Frontotemporal Dementia (FTD) account for 90% of all dementias. Alzheimer's dementia is the most common type of dementia. It is important to note that, even today, it remains difficult to arrive at a conclusive diagnosis of the sub-type of dementia during life, as a diagnosis can only be conclusive after post-mortem examination of the brain. Adding further to the complexity of arriving at a diagnosis is the fact the three most common types of dementias (Alzheimer's, vascular and Lewy body) frequently co-exist.

COMMON GENERAL CLINICAL PICTURE OF DEMENTIA

- C- Cognitive impairment, a progressive decline in intellect, memory etc
- B- Behaviour and personality changes with psychological symptoms
- A- Activities of Daily Living impairment; by loss of functional abilities

Given below are brief descriptions of the clinical features of some of the common types of dementias (David et al, 2009).

(i) Alzheimer's dementia (AD): This is characterized by its gradual onset and steady progression. Forgetfulness and memory problems are often early symptoms but as the illness progresses, patients tend to become confused, may lose their way around familiar places, have difficulties with planning and completing simple tasks, making decisions and judgment may be impaired. As the illness progresses, patients may have global impairments in all aspects of cognitive and intellectual functions. These symptoms can affect patients' ability to manage their activities of daily living. Such cognitive decline is associated with brain changes (macroscopic and microscopic), although the two need not proceed in parallel. Macroscopic brain changes include gross brain atrophy, hippocampal atrophy, widened sulci and increased ventricular size. Typical microscopic brain changes are amyloid plaques and neurofibrillary tangles. Although genetic factors (such as specific gene mutations and copy number variations within several genes) have a role in the aetiology of Alzheimer's disease (especially early-onset AD), the aetiology of AD is multi-factorial with an interplay of multiple environmental and physical risk factors and protective factors.

(ii) Vascular dementia (VD): This was previously called arteriosclerotic dementia. It is caused by an impairment in blood flow to the brain due to underlying vascular causes. Four types of vascular dementia have been described: multi-infarct dementia, small vessel disease, post-stroke dementia and specific vascular dementia syndromes. VD differs from AD in its acute or abrupt onset and stepwise progression. Patients often have a history of previous vascular events (eg., Transient Ischemic Attacks, acute cerebrovascular accidents, strokes, etc). The clinical picture of VD can be quite variable and depends upon the location of the vascular pathology. Common symptoms include confusion, slowness in thoughts and behaviour, difficulties in planning and executing familiar tasks, problems in organising one's thoughts, poor attention and concentration, gait and continence problems, as well as memory problems. Patients often have insight into their difficulties, and judgment tends to be preserved until late in the illness.

(iii) Dementia with Lewy bodies: The core clinical features of this type of dementia are fluctuating cognitive functions with pronounced variation in attention and alertness. Visual hallucinations that are recurrent and distressing, typically well-formed and detailed, motor features of Parkinsonism, and high sensitivity to various psychotropic medications may also be present. The essential pathology in this type of dementia is Lewy bodies, which are present inside nerve cells. Differential diagnosis from AD is difficult as there is considerable overlap in the symptomatology of these two dementias.

(iv) Frontotemporal Dementia (FTD): Degeneration of nerve cells in the frontal and temporal lobes of the brain results in this form of dementia. It used to be called Pick's disease. The age of onset is usually younger than in AD. In behavioural variant of FTD there are marked changes in behaviour and personality. The person may behave inappropriately, impulsively, unsympathetically etc. They lose their interpersonal skills, lack judgement and becomes disinhibited. They may neglect personal hygiene, become compulsive, lack motivation and overeat. In Primary progressive aphasia (PPA) language skills such as speaking, comprehension and writing are affected. They may use words wrongly or in the wrong order or may even struggle to produce the right sounds when saying a word. Amyotrophic lateral sclerosis (ALS), Corticobasal syndrome, Progressive Supranuclear palsy (PSP) are some other conditions included in this spectrum. Memory problems tend to occur only later. Frontotemporal lobar degeneration can be due to accumulation of a protein called tau or involving the protein TDP-43.

Diagnostic systems: The term 'dementia' as was used in DSM 4 has been replaced by 'Neurocognitive disorder' (NCD) in DSM 5 released in 2013 (however, the term dementia may still be used as an acceptable alternative). NCDs are further divided into major NCD and mild NCD, and each consists of subtypes according to aetiology such as NCD due to Alzheimer's disease, Vascular NCD, NCD with Lewy bodies, NCD due to Parkinson's disease, Frontotemporal NCD, NCD due to traumatic brain injury, NCD due to another medical condition, NCD due to multiple aetiologies and so on. 'Mild neurocognitive disorder' also known as Mild Cognitive Impairment (MCI) is also included. Reducing stigma associated with dementia, to capture the care needs of people with MCI and

The term ‘Dementia’ as was used in DSM 4 has been replaced by ‘Neurocognitive disorder’ (NCD) in DSM 5.

bringing the diagnostic guidelines into line with current clinical practice are some of the reasons for this reclassification. In the draft version of ICD 11 the groupings of “neurocognitive disorders” is in chapter 6 on mental disorders and “disorders with neurocognitive impairment as a major feature” in chapter 8 on diseases of the nervous system.

(i) DSM 5 diagnosis of Major Neurocognitive Disorder

This is based on significant cognitive decline in one or more cognitive domains eg memory, language. The cognitive performance should be documented by neuropsychological testing or, in its absence, another qualified clinical assessment. The cognitive deficits affect independence in everyday activities. It demands comparison of the individual’s performance in neuropsychological tests with population norms, adjusted for age, education, and cultural background. The absence of population norms and the lack of resources to conduct detailed neuropsychological tests in LMICs will complicate its use and prevent comparison (Ferri and Jacob, 2017).

(ii) ICD 10 diagnosis of Dementia

This requires evidence of a decline in multiple higher cortical functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement and so on and should be sufficient to impair personal activities of daily living. Symptoms and impairments should have been evident for at least 6 months for a confident diagnosis of dementia to be made. ICD 11 (draft) requires a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities).

Differential Diagnosis

A clinician’s crucial task during the assessment is to differentiate dementia from other conditions and identify the possible cause of the presentation. Some of the differential diagnoses for dementia that need to be considered while assessing are briefly described below:

1. *Delirium* is acute in onset and has a fluctuating and short course/duration. The key feature differentiating delirium from dementia is the patient’s level of consciousness – it is impaired in delirium but not in dementia. However, delirium can be superimposed on dementia, in which case, with appropriate treatments delirium can resolve while the underlying dementia persist.

2. *Mild Cognitive Impairment (MCI)* is a condition where there is ‘modest cognitive decline from a previous level of performance in one or more cognitive domains. These cognitive deficits do not interfere with the person’s capacity for independence in everyday activities. The identification of MCI is important because of a high risk of conversion to dementia.

3. *Medical conditions:* As shown in Table 1, a wide range of medical conditions may ‘present’ with symptoms which mimic dementia and hence these medical disorders have to be ruled out before arriving at a diagnosis of dementia. Examples of some such conditions include hypothyroidism, hypercalcemia, hypoglycemia, Vitamin B12 or thiamine deficiency, hepatic or renal impairment and some autoimmune disorders. Appropriate laboratory investigations and other medical tests may have to be carried out to detect/rule out these conditions.

4. Depressive disorders, usually severe depressive disorders, can also be associated with impairments in memory, concentration, and an overall reduction in intellectual abilities. The term ‘pseudodementia’ was used previously to describe this condition. A distinction can be made by careful and detailed history taking including

It is important to differentiate delirium from dementia. Delirium is a potentially life threatening condition.

Depression can be associated with impairments in memory and concentration. A detailed history is helpful to differentiate between depression and dementia. Depression is treatable.

pre-morbid personality, onset and progression, and cognitive symptoms. Note that depressive symptoms/ disorders can co-exist with dementias in which case depressive symptoms resolve with treatment.

5. There are many more conditions but we would like to discuss two disorders not generally included in the list of differential diagnosis but which have been gaining recent attention.

(i) Limbic-predominant Age-related TDP-43 Encephalopathy (LATE):

(Nelson et al, 2019. Recently a brain disorder that mimics symptoms of Alzheimer's disease has been described which is called Limbic-predominant Age-related TDP-43 Encephalopathy. It is believed to be an under-recognized condition with a very large impact on public health. LATE progresses more gradually than Alzheimer's but LATE combined with Alzheimer's, which is common for these two highly prevalent brain diseases appears to cause a more rapid decline than either would alone. The disease causing mechanism is quite different from that of AD. It is caused by deposits of a protein called TDP-43 in the brain which gets misfolded and moves from its normal cell location. Oldest old above the age of 85 are at greatest risk of LATE. It is believed to be a major contributor in a large number of people who had symptoms of dementia but without classical features of Alzheimer's disease in their brains at autopsy. Researchers call for removing people with LATE from studies of Alzheimer's drug trials which will also probably increase the response rate to medications in people with AD. More research is needed regarding this condition.

(ii) Auto Immune Dementias:

Long and Day (2018) proposes that as diagnosis

and management of patients with autoimmune and paraneoplastic encephalitis (AE) has expanded, it has become increasingly apparent that dementia may arise as a subacute or chronic complication of immune-mediated injury to the central nervous system. Hence there is a need to routinely consider the diagnosis of AE in patients with dementia, and to evaluate patients recovering from AE for clinically meaningful cognitive impairment.

In addition to the above mentioned differential diagnoses, the clinical assessment also needs to evaluate for the presence of a family history of dementia. This is especially relevant in early onset AD which can be reflective of an underlying genetic predisposition. Alcohol use disorders, other illicit substance use disorders, head injuries, infections and diseases affecting the nervous system can also cause dementia syndromes.

Young Onset Dementia (YOD)

Onset of dementia symptoms before the age of 65 is variously described as young onset dementia, early onset dementia (EOD) etc. Dementia in young people is a heterogeneous group of disorders and occur during the most productive years of life. Commonest cause is Alzheimer's disease followed by vascular dementia, frontotemporal dementia, Lewy Body dementia, alcohol related dementia etc. Other causes include Parkinson's disease Dementia, Mixed Dementia, Huntington's disease, Creutzfeldt Jakob disease, Down's syndrome etc. Marked diversity in presentations and aetiology makes diagnosis difficult. Neurodegenerative causes predominate as in the elderly and the rest are mostly due to genetic, infectious, autoimmune, vascular, nutritional, and metabolic etiologies (Devineni and Onyike, 2015).

Marked diversity in presentations and aetiology makes diagnosis difficult in young onset dementia/ early onset dementia.

Diagnostic Process

- A detailed history of symptoms and difficulties generally from the family, is important in addition to that from the patient. Key informant/s is the person who is able to give comprehensive and accurate information as they are often involved with daily care and treatment. The focus of the history is upon the nature of the symptoms, as well as their onset and progression. A medical and psychiatric history along with family and social details form part of the detailed assessment.
- Mental status examination is required to assess for depression, hallucinations, delusions etc.
- There are several cognitive tests available (eg. MoCA-Montreal Cognitive Assessment, ACE- Addenbrooke's Cognitive Examination); cognitive testing is valuable as part of the evaluation.
- A physical examination is important which will help to assess the general physical health, rule out other health problems, to evaluate possible causes of presenting symptoms. Assess nutritional status and pain. Review the medications the person is taking- prescribed ones and non-prescribed.
- Blood tests are required which help to rule out physical disorders (eg. thyroid abnormalities, anaemia, vitamin deficiencies, metabolic and electrolyte abnormalities, liver and renal problems)
- Based on the clinical situation investigations like VDRL, HIV testing, Chest Xray, ECG, EEG, Lumbar Puncture etc may be considered.
- A brain imaging (CT or MRI scan) is usually requested especially if not done before. It helps to assess the extent of any structural changes associated with the dementia.
- Neuropsychological evaluation may be needed in complex presentations.
- Instruments like NPI (Neuro Psychiatric Inventory- for assessing behavioural and psychologic symptoms), BADL (Barthel Index for Activities of Daily Living), IADL (Instrumental Activities of Daily Living), EASI (Everyday Activities Scale for India) are helpful in assessing functional status of patients.
- Finally, an assessment of the patient's living circumstances, support systems available and caregiver identification/ assessment of their understanding of the problems are important in planning management.
- An independent carer assessment may be required to assess the mental health of the carer.

DIAGNOSIS- Personnel and Settings

Who can diagnose dementia? Is dementia a specialist diagnosis? There are differing views on this. Currently it would appear, most diagnoses are done by specialists including psychiatrists and neurologists. The paucity of professionals such as neurologists, psychiatrists, geriatricians and psychologists has been well documented in resource-constrained countries like India. In resource poor settings, facilitating diagnosis at the primary care level and by general practitioners is a welcome step. The more complex diagnosis and management could be left with the specialists. National clinical guidelines to help with diagnosis and management are available (Shaji et al, 2018). It has been found that community health-care workers could, with a few hours training, identify dementia in the community with a positive predictive value of 66%, based solely upon their prior knowledge of older people from their routine outreach work (Shaji et al, 2002, Ramos-Cerqueira et al, 2005).

Alzheimer's Disease International (Prince et al, 2016) suggests a two pronged approach to improve the rates of dementia diagnosis at primary care. The first involves changing societal attitudes by raising awareness of the condition, its prevalence and impact upon individuals, families and society at large, the extent of the unmet need, and the potential for intervention to make a difference once the diagnosis has been made. The second approach is to provide knowledge and skills regarding dementia diagnosis, provision of information and support, and basic management strategies for patients, caregivers, professionals, para-professional health workers and the lay public in general. Hence the emphasis needs to be upon enhancing general awareness to identify symptoms as part of an illness (rather than normalising these as part of an ageing process), and equipping primary care workers to take up the relevant 'first-aid' work to help patients and carers (Patel et al, 2018).

Primary Care and General Practitioners

It is felt that dementia diagnosis is infrequent in primary care in India though general support may be provided as with other elderly patients. Department of Health (2009) in the UK reports a combination of three factors contributing to low rates of detection of dementia; the stigma of dementia preventing open discussion, the false

Primary care services should have basic competency in early detection of dementia.

belief that memory problems were a normal part of ageing, and the false belief that nothing could be done; that resulted in inactivity in seeking and offering help. ADI (Prince et al, 2016) proposes that dementia care health services should be provided at the primary care level and all primary care services should have basic competency in early detection of dementia, making and imparting a provisional dementia diagnosis, and initial management of dementia. In resource poor settings WHO (2016) mhGAP evidence-based intervention guide can be utilised across primary care services. The suggestion of publicising the availability of effective drug and non-drug interventions for people with dementia and their carers to health and social care professionals through initial training and ongoing professional development, and to the public through population health promotion, and health and social care facilities is very valid in India. The efforts of patients with dementia, their relatives and patient advocates are greatly laudable in this aspect in many developed countries. The medium of learning from lived experiences of carers and patients is yet to catch up in the country.

Diagnosis in general wards

Elderly patients admitted to hospital for physical problems are at a high risk of delirium and the risk is high if dementia coexists. They are usually referred for psychiatric evaluation if they present with obvious abnormal mental status or behaviour and may receive an incidental diagnosis of dementia. However if all elderly patients admitted to hospital for physical problems are screened or assessed for possible dementia, this will be a valuable measure in improving diagnosis rates and helping them access the service they need. This will be a core function of liaison psychiatry services but as we know there are manpower issues in providing such a proactive service. An alternative is to train the ward nurses in screening for cognitive impairment and an assessment of only the screen positive individuals by a specialist.

Memory Clinics

It has been shown that memory clinics improve dementia diagnosis rates in other parts of the world (Ramakers & Verhey, 2011). The essential components of dementia management include creating awareness, early identification, and education of family members regarding various strategies to deal with symptoms of dementia (Gurukartick et al, 2016; Srivastava et al, 2016). With such wide targets, it is clear a multidisciplinary approach is essential in dementia care. Memory clinics/memory teams/ dementia clinics are multidisciplinary teams usually based in hospitals. They can be based in the community as well. The characteristic feature of such a service is its multidisciplinary nature. In addition to the specialist (psychiatrist or neurologist or geriatrician etc) the team consist of professionals from other disciplines eg psychologists, nurses, social workers, volunteers etc. The service is aimed at assisting people with dementia and their families throughout the dementia journey from early diagnosis to psychoeducation to medical and psychosocial interventions to caregiver support. These interventions require time and resources more than what a medical doctor in an outpatient clinic can offer and hence the team members bring their own set of professional skills to support the families. The teams may be big or small. Some teams have a doctor, social worker and nurse working together but some other teams may have just two members while some others have bigger teams. They may be conducted daily or periodically eg. weekly.

Memory Clinics play a central role in providing dementia care in many parts of the world. Though a universal definition is not available, a memory clinic/service is defined as a multidisciplinary team that assesses and diagnoses dementia, and may provide various interventions for dementia (Royal College of Psychiatrists, 2014). This service may also contribute to training, education and research and definitely can play a major role in

Memory clinics which are multidisciplinary are aimed at assisting people with dementia and their families throughout the dementia journey from early diagnosis to psychoeducation to medical and psychosocial interventions to caregiver support.

If all elderly patients admitted to hospital for physical problems are screened or assessed for possible dementia, this will be a valuable measure in improving diagnosis rates and helping them access the service they need.

creating dementia friendly communities. These clinics are not to be confused with various establishments which promise memory enhancement or memory boosting among the general population.

In India, the number of Memory Clinics run by government hospitals is quite small. Dementia India Report (Shaji et al, 2010) quotes a figure of 100 memory clinics in India mainly in super specialty hospitals making it one clinic per 37000 population. However the details of functioning and team composition of these clinics are unknown. In India the development of such clinics has been sporadic and unplanned and is closely related to prescription and monitoring of medications for dementia as many are sponsored by pharmaceuticals. Alzheimer's and Related disorders Society of India (ARDSI) has been in the forefront in guiding and assisting various key partners and it has brought out guidelines for establishing Memory Clinics (Kumar, 2015) relevant across various settings - resource intense or scarce; government or private; rural or urban.

CONCLUSION

Strategies to address the issue of fewer number of specialists include task shifting (process of delegation whereby tasks are moved, to less specialized health workers), and task sharing (certain tasks are shared among health-care teams) but for them to work, there should be close collaboration between different professional groups. District Mental Health Programme (DMHP) is a step in the right direction to empower primary care doctors in diagnosing and managing mental and behavioural disorders but with several challenges. Dementia diagnosis can happen in various settings and it is important not to solely rely on specialists. Training and support is essential for task shifting and task sharing, with other professionals. Newer technologies like telemedicine should be explored to facilitate the process

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CHAPTER 3

PSYCHOLOGICAL AND BEHAVIOURAL INTERVENTIONS IN DEMENTIA

Keshav Janakiprasad Kumar

Introduction

Normal ageing is caused by age related micro-structural changes in the brain resulting in cognitive decline. The decline is seen in the domains of attention, memory and executive functions which include, planning, working memory, decision making and speed of processing. These cognitive abilities enable one to think clearly and maintain appropriate social interactions. The interphase between normal ageing and dementia is known as mild cognitive impairment (MCI) presenting with cognitive deficits in domains of memory or executive functions.

Dementia is a neurodegenerative disorder associated with pathophysiological changes in the brain. These changes adversely affect cognitive functions along with functional independence. The symptoms of dementia can be categorized into two major types which include cognitive and non-cognitive symptoms (Baharudin et al, 2019). The common cognitive sequelae of dementia is impairment in memory, especially learning new information and working memory resulting in difficulties at multitasking, judgement and planning. Non cognitive symptoms are known as behavioural and psychological symptoms of dementia (BPSD) as designated by the International Psychogeriatric Association. It has been suggested that there is an interplay between cognitive capacity or impairment, external environmental

stressors and the individual's psychological state. The cognitive deficits may render the individuals with dementia incapable to deal with or cope with environmental demands resulting in BPSD (Scales et al, 2018). The neuropsychiatric symptoms subsumed under BPSD include changes in the emotional experience, thought content, perception and motor functions. The neuropsychiatric manifestations are often heterogeneous and unpredictable (Cerejeira et al, 2012).

BPSD is generally classified into five syndromes, which are psychosis, aggression, psychomotor agitation, depression and apathy (Finkel et al, 1996). Studies suggest that at least 5 out of 6 patients with dementia develop BPSD during the course of their illness which could include one of the five syndromes (Carrion et al, 2018). Both cognitive symptoms and BPSD are highly distressing to patients as well as caregivers.

Current intervention practices for dementia

The recommended, first line of management for both cognitive symptoms as well as BPSD is non-pharmacological interventions followed by least harmful medications for shortest period of time possible (Gauthir et al, 2010; Cerejeira et al, 2012). Non-pharmacological interventions include cognitive retraining at the early stages (mild to moderate) of dementia. As the disease progresses, other psychological interventions such as

reality-orientation therapy, reminiscence therapy, validation therapy and behavioural therapies become more relevant.

Cognitive Retraining

There is a direct relation between cognitive functions, emotional regulation, social functions and activities of daily living. Ability to pay attention to environmental stimuli, focusing on the task at hand and attending to conversations in a social setting are basic requirements for intact functioning. Executive function impairment in working memory, reasoning, decision making and mental flexibility results as inability to remember, organize and analyze different aspects of information, adversely impacting overall functioning, and quality of life of the patients as well as their caregivers.

Cognitive retraining programmes have emerged as an efficacious method of intervention that could aid in the delay of disease progression in dementia. It was primarily developed as a neuropsychological rehabilitation method to treat cognitive impairment in individuals with acquired brain damage as well as neurological conditions. The terms cognitive retraining, cognitive remediation, cognitive rehabilitation and brain training are used interchangeably. Literature also describes cognitive rehabilitation and cognitive stimulation therapy; however, the distinction is unclear despite some differences in the theoretical assumptions (Bahar-Fuchs, 2013).

Cognitive Stimulation Therapy (CST)

CST involves activities that stimulate thinking and memory. The typical activities include discussion on personal events and other topics that the individuals may be interested in and indulgence in playing word games, puzzles, gardening, cooking etc. The activities are generally carried out by trained staff across two sessions per week, each lasting for about 45 minutes. It is a manualised and time limited intervention and has got the best evidence base

Cognitive retraining, traditionally involves repeated practice on a set of standardized tasks designed in a hierarchical manner addressing multiple domains of cognition. The tasks may be presented

in a paper-pencil format or on computer in a digital format. Successful completion of each level on different domains such as attention, memory, speed of information processing and executive functions such as mental flexibility, response inhibition and working memory are essential to proceed to the next level of the task (Bahar-Fuchs, 2013; Mowszowski, 2010).

Current approaches to cognitive retraining

Several different cognitive training approaches exist in literature. These differ based on theoretical orientations and activities used along with the progression of the training. Following is a brief description of some of these methods.

1. *Drill and Practice*: This approach is also referred to as stimulation approach. It focuses on improving cognitive processes by repetitive training on tasks arranged in a hierarchical fashion across increasing levels of difficulty. The theoretical assumption is based on neural plasticity. The approach is assumed to facilitate restoration of brain functions which could potentially generalize to everyday functions.

2. *Strategy training approach*: This aims primarily at developing new compensatory strategies that resemble daily life functioning and is targeted at relevant problem behaviors such as preparing a meal or participating in traffic as a cyclist (Fassoti & Kovac, 1995). There are internal and external strategies. The internal strategies involve re-learning information, making association while learning, using mental visualization or mnemonics. The external strategies are use of external memory aids such as using dairies, notebooks, things to-do list, use of pagers and other assistive devices.

3. *Multi-domain cognitive retraining*: Several cognitive retraining programmes have focused on training single domain such as attention alone, or memory. Training a single domain has limited potential to generalize to activities of daily living. Training multiple domains of cognition simultaneously in increasing levels of difficulty results in better generalization to everyday activities as well as possibility of improving quality of life (Kumar, 2013).

Training multiple domains of cognition simultaneously in increasing levels of difficulty results in better generalization to everyday activities as well as possibility of improving quality of life.

Before 1980s the focus of cognitive retraining was primarily on acquired brain damage. Subsequently, the principles of cognitive retraining were applied to healthy normal individuals to improve age related cognitive decline. The preferred term for cognitive retraining when used with healthy normal is cognitive stimulation or cognitive training. When used with individuals with mild cognitive impairment (MCI) and dementia, it is referred to as cognitive retraining. However, the objective of either of the intervention is to improve cognitive functions.

Cognitive retraining programmes are based on principles of neural plasticity. Neural plasticity is defined as the ability of the nervous system to adapt or change its structural organization in response to changes in the environment. Specifically designed cognitive retraining programmes serve a dual purpose. It is known to attenuate the risk of cognitive decline in healthy elderly individuals (Stern et al, 2006), and also in people with conditions like mild cognitive impairment (MCI) and dementia (Verhaeghen et al, 1992; Rebok et al, 2007). It is also known to increase the cognitive reserve by means of recruitment of alternative brain network or a more efficient utilization of brain networks in general (Stern et al, 2006).

The rationale for cognitive retraining is the notion that practice on carefully selected tasks promotes recovery of the disrupted neural circuits and possibly restore functions in the impaired cognitive processes themselves.

The rationale for cognitive retraining is the notion that practice on carefully selected tasks promotes recovery of the disrupted neural circuits and possibly restore functions in the impaired cognitive processes themselves. The tasks mediated by those circuits are then performed in a way similar to non-brain damaged individuals (Mateer & Mapou, 1996, Robertson & Murre, 1999). Research suggests that regular activation of various neural networks by means of cognitive training in different domains could contribute to maintenance of healthy brain and cognitive status (Sitzer et al, 2006; Angevaren et al, 2008). Few clinical trials have demonstrated generalization of discrete training programmes (Sitzer et al, 2006). These cognitive intervention programmes are found to be cost effective in maintaining cognitive status in healthy normal individuals, those with MCI or dementia (Knapp et al, 2006).

Cognitive retraining with specific focus on India

Cognitive retraining programmes have been developed and improvised by the Neuropsychology unit, Department of Clinical Psychology, NIMHANS, since 1986. The challenge has been to develop cognitive training programmes that could cater to the Indian population, from various socioeconomic strata, using material that is easily available in every household.

A comprehensive multimodal approach to improve cognitive functions was attempted (Kumar et al, 2000) on patients with traumatic brain injury (TBI). The basis of this rehabilitation programme was that it addressed domains of attention, response inhibition, mental flexibility, verbal fluency, divided attention, planning, working memory, and organization; encoding strategies were trained to improve memory. Patients improved on cognitive functions and psychological well-being along with significant reductions in symptoms of TBI.

The cognitive retraining programme for elderly was developed along the lines of an earlier study funded by Department of Science and Technology (DST) Tide Division, Government of India. The programme was administered to cognitively healthy normal individuals and clinical population comprising individuals with diagnosis of

The challenge is to develop cognitive training programmes that could cater to the Indian population, from various socioeconomic strata, using material that is easily available in every household.

MCI and mild dementia for 30 sessions of one hour duration each. Both the groups showed significant improvement in cognitive functions, including attention, working memory, verbal fluency, learning and memory. There was also improvement on Geriatric Depression Scale (GDS) Everyday Abilities Scale for India (EASI) and AD8 (Dementia Screening) in the clinical groups. The paper-pencil based multi domain cognitive training programme has been digitized into an app, (AGILE MIND) which can be used on android devices. The use of app based cognitive retraining programme is currently on-going. The initial results are encouraging, suggesting that this method could be used across different states and different languages in the country.

Implementation research study of Cognitive Stimulation Therapy to develop, test, refine and disseminate implementation strategies for CST for people with mild to moderate dementia in India is ongoing (Spector et al, 2019).

Interventions

Cognitive Retraining
Cognitive Stimulation Therapy
Behavioural Therapy
Reality orientation therapy
Reminiscence therapy
Validation Therapy

Other psychological interventions in dementia

1. Behavioural Therapy: Behavioural therapy has been traditionally and successfully used to reduce challenging behaviours such as wandering, aggression etc. The strategies used are based on principles of conditioning and learning theories. This approach requires a comprehen-

sive assessment of triggers (causing event or situation) and the reinforcements (maintaining or strengthening factors) associated with the behaviour that is to be modified. This is known as ABC approach which includes antecedents (situation or events prior to the behaviour), behaviour (details of the behaviour) and consequences (Dauglas et al, 2004).

2. Reality orientation therapy: The key element of this therapy is to orient and remind the individuals with dementia about themselves as well as their environment. This is done through the use of various materials such as signposts and notices in the patient's environment to facilitate orientation.

3. Reminiscence therapy: This method helps individuals with dementia to relive their experiences which were pleasurable and non-threatening. This includes revisiting previous family holidays, weddings etc with help of photos, videos, revisiting the places or people. This approach is known to improve behaviour, well-being, motivation, social interaction and self-care (Dauglas et al, 2004).

4. Validation therapy: The focus of this therapy is more on the feeling than intellect. The individuals are required to retreat into the past or the inner reality, to avoid stress, boredom and loneliness in the face of the painful present. It is perhaps, a means of empathizing with feeling and meaning of the individual's inner self from the past rather than on the current situation riddled by confused speech and behaviour. Validation may require the therapist to acknowledge a statement made by the patient regardless of it being factually true or false even by just a nod. The basic premise of validation therapy is to communicate and empathize with respect indicating that the patients' opinions are heard and valued. Though the individual may be incapable to learn new things, he or she may be able to remember how efficiently they solved problems previously. To summarize, the therapies may find usefulness with the progression of the disease processes (mild to moderate dementia). Cognitive training is helpful at the early stages to slow down further cognitive decline. All these therapies could be seen as on a continuum. The emphasis of cogni-

There is a huge gap in providing psychological interventions as there is a dearth of service providers who specialize in these interventions for patients with dementia in India.

tive intervention is to facilitate the focus of attention to the task on hand and on the outer world, while the other therapies help to seek comfort in the internal world of the patient.

Future directions

There is a dearth of service providers who specialize in these interventions for patients with dementia. Cognitive retraining methods to improve cognitive functions and other psychological interventions need to be integrated to form a comprehensive continuum of non-pharmacological interventions. Large scale studies on larger populations in different languages needs to be conducted in order to establish validity and for better implementation. Service providers need to be sensitised about the multiple psychological needs that the patient population might present with and they should be trained to meet the demands. Uniformity in service provision across the country could help reduce caregiver burden as well.

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CHAPTER 4

MEDICAL MANAGEMENT OF DEMENTIA: A REVIEW OF EXISTING GUIDELINES

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The introduction of Tacrine in the 1980s was the beginning of the pharmacotherapy for dementia, Tacrine being a cholinesterase inhibitor (ChEI) enhances the duration and action of the meagre amount of acetylcholine available in the brains of Alzheimer's disease (AD) patients[1,2]. Following the same mechanism of action, Donepezil, Rivastigmine and Galantamine became available through mid-1990s. Memantine, a later entrant, acts on N-Methyl D-Aspartate receptors (NMDA), which are important for memory and synaptic plasticity.

Methods

For this review, a search was made on Google Scholar and PubMed in June 2019. The present review is divided in to 2 parts – review of the existing guidelines from India and elsewhere including articles published subsequently till October 2019, and management of behavioural and psychological symptoms of dementia.

SECTION: I

Review of Guidelines

Guidelines from various countries since 2010 were reviewed (Table 1).

TABLE 1. List of Guidelines included in the review-

S. No.	Guideline	Country	Year of Publication	Last included report
1.	Clinical Practice Guideline- Indian Psychiatry Society	India	2018	2006
2.	National Institute for Health and Care Excellence (NICE)	UK	2018	2015
3.	British Association of Psychopharmacology (BAP)	UK	2017	2015
4.	California Alzheimer's Clinical Care Guideline	California	2017 (4th Revision)	2008
5.	Clinical Practice Guideline	Australia	2016	
6.	American Psychiatric Association (APA)	America	2014	2007
7.	Canadian Consensus Conference (CCC)	Canada	2014	Not specified
8.	Ministry Of Health- Singapore (MOH-S)	Singapore	2018	2013
9.	Clinical Practice Guideline	South Korea	2011	
10.	European Federation of the Neurological Societies- Other Dementia (EFNS)	Europe	2012	2007
11.	European Federation of the Neurological Societies- AD (EFNS)	Europe	2010	2007

Alzheimer's disease

While prescribing for AD, clinicians face issues over the choice of ChEI; whether to use single or dual therapy, and in advanced stage of the disease whether to continue or stop the medication(s). All the guidelines agree that ChEI drugs are first line therapy for mild to moderate AD[2 to 12]. The improvement in cognition is significantly more with active drug than with placebo, but the ChEIs are no better than placebo in improving neuropsychiatric symptoms as measured on Neuro-Psychiatric Inventory (NPI). There is no difference in the efficacy of the 3 agents (Donepezil, Rivastigmine and Galantamine); the difference however lies only in the tolerability of the medication. Thus no agent is superior to the other, and the selection of ChEI depends on patient profile and tolerability. Contrary to this, a recent meta-analysis including sixteen thousand patients reported the superiority of Donepezil over other ChEIs on global clinical impression scale[13, 15]. The EFNS guideline[14,16] is focussed on determining the efficacy of single (ChEI) vs. dual therapy (ChEI + Memantine). The combined effect size on Global Clinical Impression and behaviour favoured combination therapy for moderate to severe AD. The authors conclude that the 'strength of this recommendation is weak'. Thus, it is recommended that the therapy in a newly diagnosed case be initiated with a ChEI, and Memantine can be added later as the illness progresses [4,12,15,16]. The DOMINO study[17,20] further supports these findings. In addition, the patients in whom Donepezil or Memantine was changed to placebo showed faster deterioration and led to increase in institutional care[18,21]. Thus, it appears that stopping the ChEI and/or Memantine adversely affects the progression of the disease in the later stages of the disease.

A later meta-analysis concluded that Memantine may be superior to ChEI drugs as it 'improves cognitive functions and behavioural disturbances more efficiently than the placebo, both as mono-therapy and in combination with Donepezil'. Based on these findings the authors recommend combined use of Donepezil and Memantine[19]. All the guidelines have focused on ChEI and Memantine as treatment for AD. Other Medications used in the treatment of AD include intranasal insulin therapy, immunotherapy, lithium etc.

Vascular dementia

There is evidence for ChEI to show the benefits in cognitive symptoms associated with vascular dementia; albeit the benefits are small[4,23]. The improvement is seen more in patients with cortical (either single or multiple), rather than sub-cortical lesions.

BAP guidelines mention the use of Nimodipine in vascular dementia, which can beneficially affect MMSE, executive function measures and global rating in sub-cortical ischemic vascular dementia (SIVD)[24]. In the study by Moretti et al.[25] Rivastigmine improved executive function, neuropsychiatric features, depression and scores on Clinical Dementia Rating Scale in SIVD patients; and neuropsychiatric features and depression in multi-infarct dementia subjects. There was however no improvement in MMSE scores in either group.

Other Dementias

This group comprises of less common dementias like Fronto-temporal Dementia (FTD), Primary Progressive Aphasia (PPA), Progressive Supranuclear Palsy (PSP), Cortico-Basal Degeneration (CBD), Prion disease dementia and Huntington's dementia. Ministry of Health, Singapore (MOH-S) guideline supports the use of ChEIs in FTD[25], while the other available guidelines do not support the use of these drugs in FTD. Despite increased agitation been reported with their use in FTD[45], the rate of off-label use remains high. Based on trials, Memantine lacks efficacy in subjects with FTD 26, 27[35,36]. Other than ChEI and Memantine, small trial of Souvenaid and intranasal Oxytocin have shown beneficial effects in behaviour and social cognition measures over a short time period[28,29], but this requires more adequately powered studies to support its use.

In management of PPA, there has been no satisfactory trial to support use for ChEIs or coenzyme Q10. The largest PSP trial to date found that Davunetide (proposed to decrease tau phosphorylation and stabilise microtubules) was not an effective treatment[30, 39]. In patients with Creutzfeldt-Jakob disease (CJD) Quinacrine (an antimalarial drug that reduces abnormal prion protein deposits in vitro)[31] and Doxycycline[32] were tried but they lack any survival benefit. There are no adequately powered

studies of ChEIs to support the use of these drugs for cognitive impairment in Huntington's disease. Similarly, there is no evidence to support the use of other medications to treat dementia associated with Huntington's disease though several disease-modifying avenues are being pursued, including compounds to reduce metal-induced aggregation of the Huntingtin protein[33].

Other adjuvant medications addressed by different guidelines

Ginkgo Biloba is the most studied adjuvant medication, with over 4 systematic reviews published till date. Although it has been used in number of trials it is not recommended by any of the guidelines [4, 15, 23] owing to its low efficacy. A recent systematic review however supports its efficacy in high doses (240 mg and above) for mild cognitive impairment (MCI) and dementia[34, 43]. All guidelines refute treatment with omega-3 fatty acids[4,5], folic acid[3, 4,6,7], Vitamin B12 and Vitamin E[3,4,6,7]. Even the latest Cochrane review[21] found no evidence that vitamin E prevents progression to dementia, or that it improves cognitive function in people with MCI or dementia due to AD. However, there is moderate quality evidence from a single study in the review that it may slow functional decline in AD. Vitamin E was not associated with an increased risk of serious adverse events or mortality in the trials in this review. These conclusions have changed since the previous update, however they are still based on small numbers of trials and participants and further research is quite likely to affect the results. There is inconclusive evidence against the use of steroids[25], non-steroidal anti-inflammatory agents[4,17,44], acetylsalicylic acid[3,35,44], statins[3,4,6,7,23], H3 antagonists[19], eicosapentaenoic acid and docosahexaenoic acid supplementations[20], Selenium[22] and hormone replacement therapy[3, 4, 6, 7, 23,35].

SECTION: II

Behavioural and Psychological Symptoms of Dementia

Nearly 90% of the patients with dementia experience BPSD symptoms during the course of illness (frequency increases with the severity of dementia)[36, 37]. More than the cognitive complaints these symptoms are the reason for patient and carer distress, increased service use and an unwanted move to a care home or hospitalization[37, 38].

Challenges

The difficulties these symptoms pose to patients and others lead to the terminology 'challenging behaviour'[39] while the term BPSD is widely used in clinical settings and research[40]. The presence of these wide range of symptoms and behaviours, is in fact a language of distress through which a person with dementia communicates his or her unmet needs[41]. In a 5-year prevalence study, the most prevalent BPSD symptoms were apathy, depression and delusions, while the most enduring symptom of BPSD was agitation[36]. These symptoms not only limit the ability to sustain everyday activities and reduce quality of life (QoL) for all those affected[40]; but also increases the chance of mortality[42].

Management

Surprisingly, even with so much at stake the evidence to manage BPSD effectively is quite scarce. A review of different existing international guidelines concludes that behavioural and psychological symptoms of dementia (BPSD) should be assessed at diagnosis and at regular intervals thereafter[2,3,6,10,11,15,23,35,44,45,46,47]. Almost all guidelines advise to evaluate and act upon the precipitants of behaviours[15] and to identify and treat delirium, which is the most common differential[11,43,48]. The consensus is that BPSD should be initially treated with non-pharmacologic interventions and complemented by pharmacologic therapies only when essential[15,23,43,45,49,50,51,52]

Pharmacotherapy

Introduction of pharmacotherapy should be tried with strict risk benefit analysis and involving patient and family through informed consents[3,12,15,23] A diverse range of medications from typical and atypical antipsychotics, antidepressants, anticonvulsant-mood stabilizers, cognitive enhancers (ChEI/NMDA antagonist), benzodiazepines to other preparations like analgesics, anti-inflammatory agents and Memantine have been used to manage the wide spectrum of BPSD symptoms. According to the existing evidence the efficacy and effectiveness of these drugs depend both on the sub-type of dementia and on the type of symptoms being targeted.

Tabulated summary of evidence based pharmaco-

logical management of challenging behaviours in different dementias (Table 2&3) with list of approved drugs and their corresponding dosages (Table 4&5)

Summary

- ▶ Involve patient and family in pharmacotherapy decision, including discussion of medication risks, benefits and side-effects.
- ▶ Assess and monitor changes in medications, the effects and adherence at every visit.
- ▶ AD- consider ChEI to treat mild–moderate dementia, Memantine may provide benefit in moderate–severe dementia.
- ▶ VD, identify and treat vascular risk factors.
- ▶ DLB, both ChEI and Memantine can be used to manage cognitive.
- ▶ PDD ChEI can be considered for cognitive symptoms.
- ▶ FTD neither ChEI nor Memantine is recommended.
- ▶ BPSD use medications judiciously and only after trial and failure of non-pharmacologic approaches.
- ▶ Atypical antipsychotics are preferred for Psychosis and agitation (strongest recommendation being for Risperidone).
- ▶ Patients with DLB are very susceptible to extra-pyramidal side effects of antipsychotics: therefore, ChEIs (Rivastigmine) are the first line.
- ▶ For moderately challenging behaviour, evaluate for co-morbid depression. Recommend use of antidepressants, especially SSRIs in cases of failure of non pharmacological management.
- ▶ Recommendation is to evaluate for pain and give trial of analgesics (Paracetamol) when and where possible.

Table 2. Behaviour and Psychological Symptoms in Alzheimer's Dementia

Symptoms	First line	Second line
Depression	Citalopram (2)	Sertraline, Mirtazapine
Emotional lability	Citalopram	Mirtazapine
Psychosis	Risperidone(1)	Olanzapine, Haloperidol
Aggression	Risperidone(1)	Olanzapine, Haloperidol, Memantine
Severe Anxiety	Mirtazapine	Trazodone
Severe Agitation	Risperidone (1)	Olanzapine or Memantine ± short term Lorazepam
Vocalisation/shouting	Sleep Hygiene & CBT	Zopiclone(3), Temazepam
Wandering	No specific drug treatment.	
Level of evidence in (), 1 = Meta-analysis 2 = RCTs 3 = Other studies 4 = Expert opinion		

Table 3. Behaviour and Psychological Symptoms in Dementia with Lewy Bodies and Parkinson's Disease Dementia		
Symptoms	First line	Second line
Depression	Citalopram (4)	Mirtazapine
Psychosis	Stop Dopamine Agonists, consider reducing L-DOPA	Rivastigmine(3)
Aggression	Quetiapine	Rivastigmine(3), Memantine
Severe Anxiety	Citalopram (2)	Rivastigmine(3), Donepezil
Severe Agitation	Citalopram	Rivastigmine(3) or Memantine ± short term Lorazepam
REM sleep behaviour (nightmares, hyperactivity)	Clonazepam (3)	Melatonin
Poor Sleep	Sleep Hygiene & CBT	Zopiclone(3), Temazepam
Vocalisation/shouting	Identify underlying symptoms or problems. No specific drug treatment	
Wandering	No specific drug treatment.	
Level of evidence in (): 1 = Meta-analysis 2 = RCTs 3 = Other studies 4 = Expert opinion		

Table 4. Different Drug Classes recommended for use in BPSD

Drug Class	Treatment option	Comments
Analgesics	Paracetamol 500 mg- 1gm-QID	Treatment of potential cause of pain is important therefore, a trial of Paracetamol should be considered for all patients with non-cognitive symptoms, even where there are no overt symptoms of pain.
Acetyl-cholinesterase Inhibitor (ChEI)	<ul style="list-style-type: none"> • Donepezil 5mg-10mg/day • Rivastigmine 3mg-12mg/day • Galantamine 8mg-24mg/day 	<p>If not already prescribed for cognitive symptoms, then could be considered for non-cognitive symptoms, which cause significant distress or potential harm, in:</p> <ul style="list-style-type: none"> • Patients with mild to moderate dementia. • Patients with Lewy Body Dementia.
NMDA antagonist	Memantine	<p>If not already prescribed for cognitive symptoms, then could be considered for non-cognitive symptoms, which cause significant distress or potential harm, in:</p> <ul style="list-style-type: none"> • Patients with moderate to severe dementia. • Patients with mild to moderate dementia where ChEI have been ineffective or contraindicated
Benzodiazepines	Lorazepam 0.5mg-2mg	<p>Benzodiazepines should be avoided where possible.</p> <ul style="list-style-type: none"> • ONLY use in short term severe acute distress. • Lorazepam is the preferred choice (due to quick onset and short half-life). • High risk of sedation. Care in patients at high risk of falls
Antidepressants	<ul style="list-style-type: none"> • SSRI Low dose Sertraline- 25mg-100mg/day OR Low dose of Citalopram- 10-20mg/day • Mirtazapine 15mg-30mg/day • Trazodone 50mg-150mg/day 	<p>Low dose SSRI or Mirtazapine may be helpful in patients with moderate to severe depressive symptoms.</p> <ul style="list-style-type: none"> • Low dose Sertraline may be a possible first line option. • Please be aware of contraindication between Citalopram and all other medications known to cause QTc prolongation (this includes ALL antipsychotics) mixed evidence. • Be aware of sedation as an adverse effect of Mirtazapine. Trazodone may be beneficial in patients with increased restlessness and agitation. • Be aware of sedation is a possible side effect. Care in patients at high risk of falls. • Trazodone can be given as a single or divided dosage.
<p>Anticonvulsants Carbamazepine (upto 400mg) Sodium Valproate (100mg-500mg/day) Very low grade evidence in cases with aggression where antipsychotics are contraindicated but have to be careful with drug indications. Gabapentin and Pregabalin</p>		

Table 5. Antipsychotics dosage and indications		
	Dosage	Comment
Risperidone	0.25 – 2mg/day	First line antipsychotic. Only antipsychotic licensed for use in BPSD in the UK and Australia
Olanzapine	2.5mg-10mg/day	Second line antipsychotic, where Risperidone is either contraindicated or ineffective.
Quetiapine	12.5mg-300mg/day	Could be considered for first line for patients with Parkinson's Disease or Lewy Body Dementia as lower risk of movement disorders. or • May be considered third line where Risperidone and Olanzapine are ineffective or contraindicated.
Aripiprazole	5mg-15mg/day	• Could be considered second line for patients with Parkinson's disease or Lewy Body Dementia as lower risk of movement disorders (where Quetiapine is ineffective or contraindicated); or • May be considered third line where Risperidone and Olanzapine are ineffective or contraindicated.
Amisulpride	25mg-50mg/day	• Should only be considered where all other antipsychotic options have been ineffective or are contraindicated.
Clozapine	12.5mg-25mg/day	Not routinely recommended for treatment of BPSD. • For reference in Parkinson's Disease psychosis licensed dose is between 12.5 – 50mg/day (with the potential to increase in severe cases doses can be increased to a maximum of 100mg/day). Patient should be closely monitored for sedation and other adverse effects at any dose increase. • Very slow titration needed in patients with Parkinson's Disease or Lewy Body Dementia, e.g. 6.25mg for 7 days then 12.5mg for 7 days then review and any further increase should be done in steps of 12.5mg every 7 days.

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CHAPTER 5

DEMENTIA PREVALENCE IN INDIA - ESTIMATING THE NUMBERS

Sen Varghese Kallumpuram, CT Sudhir Kumar

This section is intended to give a basic understanding of prevalence rates in dementia and how they are calculated, for a non-specialist reader with interest in dementia. For further information please refer to the documents referred to in the section which give comprehensive information about various aspects of epidemiology in dementia.

Epidemiology is the study of diseases in a population. It is the foundation upon which the prevention and management of diseases is based. Identifying the number of people affected by a disease and the risk (and protective) factors that contribute to it are important aspects of epidemiology. Prevalence is the number of people affected with the disease at a given point in time. Incidence is the number of people who newly develop the disease over a period of time (eg. one year). Prevalence and incidence figures are important in estimating the impact of dementia and economic burden on the society. This information is crucial in formulating public health policies to deal with the disease. Updated figures are hard to come by as good quality epidemiological studies are expensive to conduct and time consuming.

There is a wide variation in the prevalence rates for dementia reported by the studies from India. Why is it so? The possible reasons could include (i) methodological differences of the studies ie the study population chosen, ways used to measure cognitive impairment, how dementia was diag-

nosed etc (ii) real difference in the prevalence of dementia eg. increased risk factors, more protective factors in the population studied. In an ideal world the most accurate estimate of the prevalence of dementia would be to identify everyone with dementia living in the country. But we know this is impossible to do, given the very scale of the task. Studies using nationwide representative samples encompassing the diversities of a large country like India are also lacking. Hence currently the popular methods to estimate the national prevalence is to use figures obtained from the few studies conducted in various parts of the country (and using them in statistical analysis) or figures arrived by consensus among experts. Using these figures, census data and future projected population, national estimates are calculated. For example, in south Asia (Afghanistan, Bangladesh, Bhutan, India, Nepal and Pakistan) the number of people above the age of sixty was 139.85 million in 2015. There were 14 eligible publications studying a total population of 19673 which was used by the Alzheimer's Disease International (ADI) in estimating the prevalence of dementia in this region. Though the generalisability (extent to which these findings can be applied to settings other than that in which they were originally studied) of these figures can be challenged, they are the best available data currently.

Understanding the global figures

With every new report there is a change in the estimated number of people with dementia. World

Alzheimer Report (2015) is an independently researched and the most comprehensive document published by ADI on the global impact of dementia.

The Global prevalence of dementia was estimated based on a systematic review of 273 studies. The report in 2015 estimated that 46.8 million people lived with dementia worldwide, This number is expected to increase to 74.7 million in 2030 and 131.5 million in 2050.

The estimated prevalence of dementia in the 2015 report was 12-13% higher than the previous report in 2009. In the World Alzheimer Report (2009) the global prevalence of dementia based on a systematic review of 154 studies was estimated by ADI to be 36 million in 2010, nearly doubling every 20 years to 66 million by 2030 and to 115 million by 2050. It was acknowledged in the World Alzheimer Report (2015) that changes in estimates were due to the changes in the quality of the evidence and the significant increase in the number of the older population. Much of this projected increase is attributable to the large estimated increase in the number of people with dementia in low and middle income countries. When calculating these projections, there is an assumption that age-specific prevalence in each region will remain constant over time, which is unlikely to be the case. WHO (2017) estimated that dementia affects approximately 50 million people worldwide; a number that is projected to grow to 82 million by 2030 and 152 million by 2050.

Dementia is the second largest cause of disability for individuals aged 70 years and older, and the seventh leading cause of death. **There are an estimated 10 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds (WHO, 2019).** These new estimates are almost 30% higher than the annual numbers of new cases estimated in the WHO/ADI (2012) report (7.7 million new cases, one every 4.2 seconds). Majority (63%) of those affected reside in low- and middle income countries (LMICs). Increase in life expectancy (number of years a person is expected to live) is associated with increased prevalence of conditions like dementia. Between 2015 and 2050, the number of older people living in lower middle income countries is expected to increase by 185%. Projections of dementia prevalence figures assume that prevalence of dementia will not vary over time, and that population ageing will drive the projected increases. The prevalence of any condition is a product of its incidence (new cases in a time period) and

There are an estimated 10 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds (WHO, 2019).

the average duration of the disease episode. As ADI (2015) discusses, in reality, future prevalence could be affected by changing incidence and disease duration

ADI estimated prevalence of Dementia (World Alzheimer Report 2015) Top ten countries	
China	9.5 million
USA	4.2 million
India	4.1 million
Brazil	1.6 million
Germany	1.6 million
Russia	1.3 million
Italy	1.2 million
Indonesia	1.2 million
France	1.2 million
Japan	3.1 million

UNDERSTANDING THE INDIAN DATA

The main documents which help us to understand the prevalence data in India are (i) the population projections (Office of the Registrar General and Census Commissioner, India 2006), (ii) Dementia India Report (2010) which estimated the prevalence based on 6 studies and (iii) World Alzheimer Report (2015) which made the estimates based on 11 studies.

(i) Population projections of India

The following are some of the relevant observations made in the Population Census (2011) and population projections for India and its states 2001-2026. There are nearly 104 million elderly persons (above the age of 60 years) in India, 53 million females and 51 million males. More than 73 million elderly persons (71%) live in rural areas. The proportion of elderly persons has increased from 5.8 per cent to 8.8 per cent in rural areas, and from 4.7 percent to 8.1 percent in urban areas during 1961 to 2011. Kerala has

the highest proportion of elderly people in its population (12.6 %) followed by Goa (11.2 %) and Tamil Nadu (10.4 %) as per Population Census 2011. Nearly 69% of the households did not have a person aged 60 years or above in their household. Around 22% of households had one elderly person, 9% had 2 elderly people in the households and 0.5% household had 3 or more elderly members. 5.2% of the elderly lived alone, 12% lived with their spouse, 44.8% lived with a spouse and other family members, 32.1% lived with their children and 4.4% lived with other relatives and non- relations.

(ii) Dementia India Report (2010)

Dementia India Report (2010) conducted a detailed review of literature and found 7 out of possible 86 publications obtained using valid search strategies in databases, reported prevalence of dementia in India. Of these, six publications were included in the meta-analysis. It was estimated that 3.7 million people lived with dementia in India in 2010 and this figure was estimated to increase to 4.41 million in 2015, 5.29 million in 2020, 6.35 million in 2025, 7.61 million in 2030, 9.07 million in 2035, 10.69 million in 2040, 12.47 million in 2045 and 14.32 million in 2050

(iii) World Alzheimer Report (2015)

The crude estimated prevalence rate of dementia (total number of cases in the population irrespective of subgroups like age) for those aged above 60 years of age in south Asia was 3.7% and the standardised prevalence rate (number of cases adjusted for difference in age distribution between population groups) was 5.63 % based on meta-analysis of eligible studies. The countries in the south Asia region are India, Afghanistan, Bangladesh, Bhutan, India, Nepal and Pakistan. The rates calculated by ADI, were based on 11 studies found eligible to be included in the analysis. Following rigorous methodological and reporting criteria, ten Indian studies (and one study from Bangladesh, with a prevalence rate of definite dementia of 3.6%, Palmer, 2014) were included by ADI to estimate the prevalence rate of dementia in south Asia. Based on these calculations there were an estimated 4.1 million people with dementia in India in 2015. (Current state-wise estimate is shown in Table 5)

Table 1: Age-wise estimates of Dementia prevalence

Age group	60-64	65-69	70-74	75-79	80-84	85-89	90+	Standardised prevalence for those aged 60
Males*	1.2 %	1.9%	3.0%	5.1%	8.5%	13.8%	26.2%	5.63
Females*	1.6%	2.5%	4.0%	6.7%	11.2%	18.1%	34%	

*Based on ADI (2015) dementia prevalence estimates

It is estimated that 5.3 million people above the age of 60 have dementia in India in 2020

It equals to, one in 27 people above the age of 60 in India, has dementia

Table 2: Studies from India included in review and meta-analysis by ADI (2015) to estimate prevalence rates

Study	Year	Region	Prevalence rate (%)
Shaji et al	1996	Ernakulam-rural	3.19 (60+)
Rajkumar et al	1997	Madras	3.5 (60+)
Chandra et al	1998	Ballabgarh-rural	0.84 (55+) 1.36 (65+)
Vas et al	2001	Mumbai –urban	2.44 (65+)
Shaji et al	2005	Ernakulam-urban	3.36 (65+)
Rodriguez et al	2008	Chennai, urban	8.2% (65+)(7.5%-crude)
Rodriguez et al	2008	Vellore, rural	8.7% (65+) (10.6-crude)
Mathuranath et al	2010	Trivandrum, urban	4.86 (65+)
Seby et al	2011	Pune, urban	14.9 (65+)
Raina et al	2013	Tribal area, Himachal Pradesh	0 (60+)

Table 3: Some other notable studies useful for understanding prevalence are shown below

Study	Year	Region	Prevalence (%)
Saldanha et al	2010	Urban Pune, Maharashtra	4.1
Raina et al	2010	Ethnic Dogra population, Rural Jammu and Kashmir	1.83
Sathyanarayana Rao et al	2014	Suttur, rural Karnataka	10
Banerjee et al	2017	Kolkata	1.53

Gender difference in dementia prevalence

Dementia India Report (2010) concludes that there was no difference between men and women in age specific incidence of dementia and hence it may appear that gender is not a risk factor for dementia. It explains that the higher proportion of women having dementia may be due to the fact that women live longer than men. Similarly, ADI (2015) reports that women predominate amongst older people with dementia because of their greater life expectancy. However, it was also noted that age-specific prevalence and incidence of dementia are also higher among women, particularly at older ages. The reasons for this are not clearly established and there is a need for more research. Research across several other

countries are closely looking at the differences in pathways leading to dementia between men and women. The influence of risk factors also may be different between men and women. For example, more men are smokers while more women have depression, both being risk factors for dementia. Hence better understanding of the influence of gender is important. As more data becomes available from across the world, there usually is a reduction in the variation of prevalence figures in dementia and it is quite possible this is applicable in gender difference as well.

Young onset dementia

When the symptoms of dementia start before the age of 65 it is variously described as young onset dementia (yod), younger onset dementia, early

It is important for those with Mild Cognitive Impairment (MCI) to have an assessment by a doctor as the symptoms may also be due to reversible causes

onset dementia (eod) etc. It is not a common condition and as quoted by ADI report (2015) around 2 to 8 % of all patients with dementia have an early onset. The prevalence rate is not expected to increase over time. The delay in receiving an accurate diagnosis is much longer than in late onset dementia possibly due to unusual symptoms. Also more neurological conditions need to be ruled out when younger individuals are affected. Due to a relative lack of high quality data and the perception that it contributes little to the overall burden, the special needs of those affected and their families are often neglected. This is an area where further research is needed.

Mild Cognitive Impairment (MCI)

Pathological changes start in the brain many decades before the onset of first dementia symptoms. Mild cognitive Impairment (MCI) is considered to be a transitional phase between normal cognitive functioning and dementia. In MCI cognitive faculties like memory, language, reasoning etc are mildly affected but not to the extent of affecting their activities of daily living. Research into MCI is gaining momentum. Early identification and further research can help to develop prevention strategies. Early interventions including lifestyle changes and managing risk factors can impact upon conversion rates into dementia. The prevalence rate of MCI in studies from India widely varies (Table 4) depending on the setting, age of the sample, definition of MCI and instruments used etc. The annual conversion rate ie the percentage of people with MCI who develop dementia in a year in community samples is reported to be around 3 to 10 percent (Michaud et al 2017) and the few available Indian studies also report around similar ranges. It is important to have an assessment and diagnosis of MCI as the cognitive impairment may also be caused by

treatable conditions and need not necessarily be a precursor of dementia.

While estimating the prevalence rate of dementia it is essential to consider and include this hidden population with MCI who are at a high risk of progressing to dementia. Even with modest assumptions of 15 % prevalence of MCI and an 8% annual conversion rate of MCI to dementia the number of persons likely to develop dementia among those with MCI in India in one year would be around 1.7 million. (Table 5 at the end of the Chapter)

We felt it is important to discuss this data as people with MCI are at a high risk of developing dementia but potentially may benefit from risk reduction interventions. The information provided here should be seen only in this context of public health significance.

Table 4: Prevalence of MCI in selected Indian studies

Study	Year	MCI Prevalence (%)
Das et al	2007	14.89%
Sosa et al	2012	4.3%
Singh et al	2013	19.26%
Kaur et al	2014	31.53%
Ghose et al	2019	39.2%
Mohan et al	2019	26.06% 18.5% (among non-depressed)

Table 5: Estimated number of people with dementia among elderly persons (aged 60+) in states *of India during 2020-2021

	Percentage of elderly people in total population of State (%) 2020-21	No. of elderly persons (in 1000s) 2020- 21	No. of elderly persons with Dementia (in 1000s) 2020-21 ***	No. of elderly persons with MCI likely to develop dementia in one year (in 1000s) #
Andhra Pradesh	12.2	11152	413	134
Assam	9.1	3098	115	37
Bihar	9.5	10365	384	124
Chhattisgarh	10	2729	101	33
Delhi	8.7	2131	79	26
Gujarat	11.6	7687	284	92
Haryana	9.7	2862	106	34
Himachal Pradesh	12.9	953	35	11
Jammu &Kashmir	10.5	1364	50	16
Jharkhand	9.7	3456	128	42
Karnataka	12.5	8074	299	97
Kerala	16	5833	216	70
Madhya Pradesh	8.9	7379	273	89
Maharashtra	11.2	14247	527	171
Odisha	11.8	5185	192	62
Punjab	12.6	3814	141	46
Rajasthan	9.4	7266	269	87
Tamil Nadu	14.8	10507	389	126
Uttar Pradesh	8.7	20369	754	244
Uttarakhand	10.4	1172	43	14
West Bengal	11.9	11573	428	139
India	10.7	143244	5300	1719

* Except Goa

** Based on population projections, Census of India, 2001- report of the technical group on population projections, 2016

*** Based on a prevalence rate of 3.7%

Projection based on a prevalence of MCI of 15% among whom the annual rate of conversion to dementia is taken as 8%.

CONCLUSION

Large scale epidemiological studies representative of the diversities of a country like India will give more meaningful information useful for prevention strategies and service development. We acknowledge that the clinical utility of the concept of MCI is a hotly debated topic but we thought it warranted discussion as identifying this group of people would help in secondary prevention of dementia.

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CHAPTER 6

DEMENTIA CARE COSTS IN INDIA

Venugopal Duddu, Sanju George

Background

Dementia is a chronic and progressive condition. It is characterised by global decline in cognitive abilities like memory, thinking, new learning, spatial orientation, and so on. A number of risk factors have been identified for the development of dementia. Some of these, like age, gender, family history and ethnicity, are not modifiable, but some others like Diabetes, hypertension and obesity, can be modified to lower the risk of dementia. Other modifiable risks include various lifestyle factors like lack of exercise, excessive alcohol consumption & smoking and unhealthy diet.

Age is an important non-modifiable risk factor for dementia. As age increases, so does the risk of cognitive decline and dementia. This aspect is especially pertinent in growing economies like India which has seen an increase in its greying population in the last few decades. The problem is compounded by the absence of uniformly well organised and accessible health-care systems. As a result, the majority of the cost and burden of the illness is borne by care-giving family members.

This chapter will provide a brief overview of the costs of dementia in India. The following sections will touch upon the challenges in costing illnesses like dementia in India and the available evidence of the costs of dementia in an Indian setting.

India spends only about 1.2% of its GDP on healthcare. This is substantially less than many other developing and developed countries. Only a small fraction of this budget is allocated to mental health, and an even smaller fraction to illnesses affecting the elderly.

Costing an illness- key considerations and challenges

India spends only about 1.2% of its GDP on healthcare. This is substantially less than many other developing and developed countries. Only a small fraction of this budget is allocated to mental health, and an even smaller fraction to illnesses affecting the elderly. The cost of an illness is an important measure of its societal impact, and individual and family burden. This is relevant from an economic perspective as it can inform resource allocation from a finite healthcare budget- be it at the State level or an individual household, especially given that healthcare expenses are primarily borne out-of-pocket in most Indian families today.

Broadly speaking, Illness costs are categorised into three main components- costs of direct care, costs of indirect care and intangible costs

Table 1

Types of Costs included in a Cost of Illness study			
Direct costs	Direct costs	Indirect costs	Intangible costs
Actual costs of medical care:	Non-medical expenses:	Loss of earning	Effects upon Quality of life of patient
Consultation	Cost of healthcare assistants	Loss of productivity	Effects upon QOL of carers, etc
Investigations	Travel	Absenteeism, etc	
Admissions	Accommodation		
Treatment costs, medications, etc	Day care costs		
	Institutionalisation costs, etc		

Costing dementia in a country like India is uniquely challenging. There are a number of reasons for this. Firstly, significant variation has been reported in the prevalence of dementia (and its subtypes) across different parts of the country. This could be due to differences in the screening tools and methodology used, but the ethnic and cultural diversity could also be a factor. Equally, these differences could also reflect true differences in prevalence across different regions of the country (Das et al 2012). Secondly, the costs incurred depend upon how the healthcare system is organised locally, and what resources are available. Health is the state's responsibility (as opposed to the Central government's responsibility). As such, the organisation and financing of healthcare services, and the availability of resources varies significantly across different parts of the country, as well as between rural and urban areas. In a similar vein, the cost of a service can vary substantially across different parts of the country. Much of the care for people with dementia in rural and many urban parts of India is provided by family members. Allocating a monetary value to the time and effort of such informal care is very difficult, if not impossible. Such an exercise will involve a number of assumptions which may not be universally applicable across the country. For example, should it

be costed based upon the country's hourly wage rates? What about family members who give up employment in order to care for an ill person? Or a retired spouse undertaking this role? Further, any attempt to study the actual costs incurred in the care of a person with Dementia is likely to be coloured by individual differences in health-care seeking behaviours too. (Wimo, et al, 2006; Prince 2004)

There are a number of stakeholders involved in the care of people with dementia. While the individual with dementia and his family bear the primary brunt of the illness, the society within which the illness manifests, and the state which has responsibility to care for people with the illness also have an economic stake in the costing exercise. The ascertainment of the costs of dementia could therefore be done from the standpoint of any of the involved stakeholders. Further, there is much debate as to which costs should be counted in the analysis, and how distal and intangible costs are measured. Even in situations where there is consensus on which service costs should be included, there can be significant differences in how these are actually measured in practice, there is much geographical variation in cost of care across India. As an example, the cost of home care for a person with dementia can be

very different in a city like Chennai or Hyderabad, as compared to a smaller town or village in Kerala. Whilst in a city, there may be an established hourly or daily tariff for home assistance (depending upon what is provided), the same cannot be extrapolated to a rural or semi-urban area where the service may not even be available and the role may be performed by different family members for short periods throughout the day. The absence of well-organised pathways-through-care and standardised unit costs are therefore, a particular challenge in a costing exercise for conditions like dementia in India.

In view of all these challenges, the WHO has recommended an algorithmic approach to draw inferences on the economic costs of illnesses like

Dementia. This needs to take into account multiple perspectives and methodologies that have been adopted in various studies (WHO, 2009). The following section will attempt to summarise this research in reference to India (or other LMIC).

Dementia care costs in India- the evidence

There is little research on the cost of dementia in India. Some information can however, be gleaned from a series of research reports by Wimo and colleagues, who estimated the worldwide costs of dementia over a period of several years. (Wimo et al, 2006, 2007, 2010; Wimo and Prince, 2010).

Table 2: Summary of evidence

		Types of costs studied	Estimate applicable to India/ economic bracket	Costs per person per year: DC	Costs per person per year: DC+PADL	Costs per person per year: DC+ all ADL	Costs per person per year: DC+ ADL + Supervision
Wimo et al 2006	Societal	Direct care only	LIC	USD 216			
Wimo et al 2007	Societal	Total costs	India	USD 1447	USD 2229	USD 3254	USD: 5061
Wimo et al 2010	Societal	Total costs	India	USD 1925	USD 2964	USD 4327	
Wimo et al 2017	Societal	Total costs	LMIC/ G20	G20: USD 20187 (total costs) per person LMIC: USD 3865 (total costs) per person			
Rao and Bharath 2013	Households with an ill person	Direct and indirect costs	India	Rural: INR 20300-66025 (total costs) per household Urban: INR 45600- 202450 (total costs) per household			

DC: cost of direct care

PADL: cost of caring for personal ADLs (1.6 hours/d)

ADL: cost of caring for Activities of Daily Living- Personal and Instrumental (3.7 hrs/d)

LIC: Low Income country

LMIC: Lower-middle income country

Wimo and his colleagues (Wimo et al, 2006) presented estimates of the worldwide cost of dementia based upon two parameters: the estimated age-class prevalence of dementia and the direct societal costs of the illness. This prevalence-based approach is preferred when assessing the economic burden of an illness, as opposed to an incidence-based approach which is a better indicator of the economic impact of an intervention. In the absence of reliable cost-of-illness studies in most countries, costs were imputed from a macroeconomic premise that healthcare expenditure is significantly correlated with the country's GDP. Using this approach, the authors found the cost of dementia in Lower income countries (in which India belonged in 2003) to be USD 216 per patient per year. This cost referred only to direct costs at a societal level (as opposed to costs incurred by individual households), as the authors felt it was not possible to quantify indirect and intangible costs in their study.

The same researchers extended their work to estimate the total costs of dementia worldwide in 2005 (Wimo et al, 2007). Three types of informal care were identified- care for Personal activities of daily living (ADL), Instrumental activities of daily living and Supervision of the ill person. Based upon existing studies (of which there was only 1 study from India), the authors estimated care needs of 1.6 hours per day for Personal ADL, 3.7 hours per day for all ADL, and 7.4 hours per day for all informal care (including ADL and supervision) (Dias et al, 2004). The estimated costs per ill person per year for India were: USD 2229 for Direct care and Personal ADL, USD 3254 for Direct care and all ADL and USD 5061 for Direct care and all informal care (including ADLs and supervision costs). The estimated costs escalated to USD 2964 for Direct costs and Personal ADL care and USD 4327 for Direct costs and all ADL care per ill person by 2009 (Wimo et al, 2010). These numbers were also reflected in the World Alzheimer's report 2010 (Wimo & Prince, 2010).

Wimo and colleagues (2017) updated these costs again in 2015. Unfortunately, their article does not give country-wise data of costs, but the mean costs incurred per person with dementia in

The CPI (Consumer price index) rose by 1.442 between 2012 (when the Bharat and Rao study was conducted) and July 2019. Based upon this, the estimated household costs of caring for a person with dementia have risen to Rs 29272- 95208 per household per year in rural areas, and Rs 65755- 291933 per household per year in urban areas.

the G20 group (of which India is a member) was USD 20187. On the other hand, the estimated per person per year cost incurred in Lower-middle Income countries (which includes India) was USD 3865. This report found a decrease in the estimated costs of dementia care, which is probably attributed to various methodological issues (including re-classification of countries based upon their income) rather than a true cost reduction.

Rao and Bharath (2013) conducted a costing exercise of dementia using a household budget approach. They initially identified all the possible cost components that could be incurred. A modelling exercise was undertaken to estimate which costs would apply at different levels of illness severity. Thus, the authors arrived at household costs of care for persons with varying severity of dementia from two different settings- one of which was a rural setting and the other was urban. The study found that the annual cost of caring for a person with dementia ranged between INR 45,600 to INR 2,02,450 in the urban setting and between INR 20,300 to INR 66,025 in the rural setting. When extrapolated to the entire country, Indian households spend over INR 23 crores to care for people with dementia. Costs, especially indirect costs like home care and residential care, increased with severity of the dementia. Medical costs, like the costs of medications, consultation and hospitalisation accounted for 20-35% of the total costs.

To summarise, there has been little Cost-of-Illness research in dementia in India. Findings from international studies do not always allude to Indian

Medical costs account a smaller proportion of the total care costs, therefore improvements in medical technology and health care alone will have a limited impact upon the overall cost burden of dementia.

estimates, partly because of absence of robust Indian epidemiological data, as well as the absence of standardised unit costs. The large variability in prevalence, available resources, health-care infrastructure, costs of services and roles taken up by informal carers (spouses or children or children-in-law) render costing estimates even less reliable. The only Indian study to have approached the topic has used a household budget approach to estimating costs. The results are likely to be more applicable to the settings where the study was conducted, but there are important take-home messages. Medical costs account a smaller proportion of the total care costs, therefore improvements in medical technology and health care alone will have a limited impact upon the overall cost burden of dementia. Parallel developments in social support systems to care for persons with dementia are needed, and these need to be accessible, available and affordable on a wider scale, in order to make a dent on the cost burden of the illness.

Summary and Future directions

Cost of illness studies provide useful information on the economic burden of an illness. They can have a role in guiding health policy and budgets. Unfortunately, little attention has been paid to studying the cost of dementia in India. This chapter has attempted to summarise the available literature on the costs incurred in the care of a person with dementia per year in India. Future work needs to focus upon addressing the aforementioned challenges so as to provide usable information for policy-makers to plan effective, accessible and acceptable services for the care of persons with dementia in India.

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CHAPTER 7

LEGAL AND ETHICAL ISSUES IN DEMENTIA: INDIAN SCENARIO

Guru S Gowda, Palanimuthu T Sivakumar

Case Vignette 1

75-year-old elderly lady Mrs X is a retired teacher and widow from a middle socio-economic urban background. She presented to us with a history of progressive cognitive decline for more than a year. She also had agitation, intermittent aggression, disorganized behavior, decreased sleep and impaired Activities of Daily Living (ADL) for 3 months. Mrs X lives in her own house and her youngest daughter lives in the same compound in a separate home. There are conflicts among her three children about managing the finances, and decisions around shifting the patient to a residential care facility. Mrs X's youngest daughter took the responsibility to look after her mother and sought guidance from the treating team with respect to the legal aspects of managing Mrs X's finances and the decision around shifting her to a residential care facility.

The team advised Mrs X's daughter to consult the Free Legal Aid Services run by the Karnataka State Legal Service Authority and Forensic Psychiatry Services. She was advised that she could either establish a 'trust' under the name of Mrs X or apply for Legal Guardianship from the concerned authority if Mrs X lost the legal capacity for making a financial and property-related decision. If she wanted to proceed with making a trust, then she and her siblings could be Trustees of the Trust. Together they could make financial and property-related decisions through the trust. If, on the other hand, she wanted to claim for legal guardianship for Mrs X, then she needed to approach the City Civil Court under Right to Person with Disability Act, 2016

Case Vignette 2

Mrs. C is an 80-year-old graduate, a retired government employee, a widow, living alone in the city in her own independent house. She has no children of her own and has infrequent contact with her sister's children and other relatives. She was brought for evaluation after her relatives (sister's children) came to know that she has been admitted to an old age home by the neighbor. On evaluation Mrs C had a significant cognitive impairment, she was not able to identify her relatives. She had no recollection about details of recent financial transactions. She still believed that she is continuing to work.

Her relatives found out that the patient's house had been sold for a meager amount (compared to market value), and the money had been transferred to multiple bank accounts over the last few days. Mrs C's neighbor had taken the power of attorney to manage her finance after the property was sold. Her relative asked the treating team for certification about the patient's legal capacity to manage these transactions and assistance in the legal process related to alleged cheating. The relatives (sister's children) of Mrs C were referred to the Free Legal Aid Services, run by the Karnataka State Legal Service Authority and Forensic Psychiatry Services. They were advised to seek Legal Guardianship from the concerned authority, as Mrs C had lost the legal capacity to make a financial and property-related decision. They were also advised to register a complaint in police station and to file a case in criminal court under financial abuse.

Case Vignette 3

Mr D was a 76-year-old elderly male graduate. He was a widower and lived alone in the city. He was brought for evaluation by a neighbour as his children were not looking after him. On evaluation, Mr D was found to suffer from mild depression. He was also found to have multiple psychosocial stressors, particularly with his finances and had difficulty in handling day to day affairs.

The neighbour and Mr D were referred to the Free Legal Aid Services, run by the Karnataka State Legal Service Authority and Forensic Psychiatry Services. Mr D was advised to seek maintenance from his children to manage his day to day affairs, and to approach the City civil court for the same under a) Maintenance and Welfare of Parents and Senior Citizen Act, 2007; b) Section 125 of the CrPC; c) The Hindu Adoptions and Maintenance Act; and d) National Council for Older Persons (NCOP).

1. Introduction

In India, there is a rapid increase in the proportion of older adults (aged 60 years and above) due to population aging. It is due to an increase in life expectancy and reduced early and mid-life mortality due to communicable disorders like infections. Older adults constitute 8.6% of the total population of India (104 million) as per census 2011. Mental health issues like Depression, Delirium, and Dementia are common in older adults (United Nations Population Fund; 2017)

The Dementia India report estimated the prevalence of dementia in India in 2010 as 3.7 million, with a predicted increase to 4.1 million in 2016 and 14.3 million in 2050 (Shaji et al 2010). The 10/66 Dementia Research Group study, has estimated a higher prevalence of dementia in an urban and rural setting using an education and culture fair methodology that is appropriate to the Indian population (Khan, 2011).

As Dementia is associated with significant cognitive impairment, those affected by dementia are more dependent on caregivers and they have unique needs. They are more vulnerable to loss of mental capacity, homelessness, wandering in society, neglect, exploitation, abuse, violence, institutionalization, inadequate medical and psychiatric care and violation of their human rights (Sivakumar et al 2019). In this scenario, there is a need for focused health-related policies and programs as well as legal and ethical frameworks to protect the interests of elderly people with dementia. This article attempts to provide a brief overview of the legal and ethical issues related to dementia in the Indian scenario.

2. Mental Health Care Act, 2017 and Dementia

The Mental Healthcare Act (MHCA) was enacted in 2017. It replaces the Mental Health Act 1987. It was enacted to address the lacunae of the previous Act and to be in line with the United Nations Convention on the Rights of Persons with Disabilities in 2007. The provisions of MHCA, 2017 that are relevant to the care of persons with dementia are a) Psychiatric Advance Directives; b) Nominated Representatives and c) Consent for Admission and Treatment and d) Right to access mental health care (Sivakumar et al 2019, MHCA, 2017).

People with dementia are more vulnerable to loss of mental capacity, homelessness, wandering in society, neglect, exploitation, abuse, violence, institutionalization, inadequate medical and psychiatric care and violation of their human rights.

2.1 Psychiatric Advance Directive - An advance directive is a document in which persons with dementia can explicitly state their wishes about receiving mental health care, and is applicable when they lose the capacity to make health-related decisions. It is a legal procedure and needs to be registered in the Mental Health Review Board of their jurisdiction, which is assigned by state mental health authority. Advance directives are important in the context of dementia, especially as the condition is associated with progressive cognitive decline and can incapacitate the affected individual from making competent decisions. The purpose of advance directives is to promote autonomy and beneficence (MHCA, 2017).

2.2 Nominated Representative – A person with Dementia can nominate a person (not a minor and after the consent from the nominee) to act as his/her Nominated Representative (NR) to discharge duties related to his/her mental health care and treatment (including admission-related decisions). The appointed Nominated Representative will discharge these duties when the Person with Dementia loses the capacity to make health related decisions (and there is no prior Advance Directive). The Central rules and regulations of the MHCA have provision to appoint one or more Nominated Representatives and to specify the order of preference (Example – First NR - Mrs. X (Wife), Second NR – Mr. A (Son) and Third NR - Mr S (Friend)). If a person has neither made an Advance Directive nor appointed a Nominated Representative as prescribed by law, then MHCA considers the following as the deemed Nominated Representative, (in a descending order of preference): a family member, if family member not willing to be NR then a caregiver, if family member and caregiver not willing to be NR then person appointed by concerned board (Director, Department of Social Welfare) (MHCA, 2017).

2.3 Consent for Admission and Treatment– The MHCA assumes that every person (including persons with dementia) has the capacity to make admission and treatment-related decisions unless it is proved otherwise by a Psychiatrist or another Mental Health Professional. The professional has to determine capacity based on the person's a) comprehension; (b) understanding

An advance directive is a document in which persons with dementia can explicitly state their wishes about receiving mental health care, and is applicable when they lose the capacity to make health-related decisions.

the consequences of the decision, and (c) communication of the decision domain, using Capacity Assessment Guidance Document issued by the Ministry of Health and Family Welfare, Government of India (MHCA, 2017).

2.4 Right to access Care - Persons with Dementia have the right to access mental health care and community living. They have a right to be protected from cruel, inhuman, and degrading treatment; and to equality and non-discrimination under the MHCA 2017. The Act also specifies the duties of the government to promote mental health and develop preventive programs, create awareness, reduce stigma and develop human resources. MHCA advocates for the provision of old age mental health services and comprehensive rehabilitation services at each district level. If services are not made available by the government, a person with dementia can apply for compensation. This is a revolutionary health statute for bringing in the compensatory mechanism to make the state responsible for providing care (MHCA, 2017).

3. The Rights of Persons with Disabilities Act, 2016

India signed the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and subsequently ratified the same on October 1, 2007. To comply with UNCPRD, the Government of India ratified the Rights of Persons with Disabilities Act, 2016 (RPWD Act 2016) to replace the Persons with Disabilities (PWD) Act 1995. It has provisions for persons with dementia, who have a disability, for a) Guardianship; b) Disability welfare and social benefits provision and c) Right to access to justice. (The Rights of Persons with Disabilities Act. RPWD Act; 2016, UNCPRD, 2006)

3.1 Disability – A Person with Dementia who has a disability greater than 40% is considered as having “Benchmark Disability” under RPWD Act 2016. The person with Benchmark Disability can avail of the welfare and social benefits under this Act (c).

3.2 Guardianship - Persons with Dementia having a disability, or their family members / caregivers can seek limited or total guardianship from the designated authority. The designated authority will grant guardianship based upon the extent of support a disabled person with Dementia requires (The Rights of Persons with Disability Act; 2016).

3.3 Right to access to justice - Person with Dementia having a disability can exercise the right to access to any court, tribunal, authority, commission, or any other body having judicial or quasi-judicial or investigative powers without discrimination (RPWD Act, 2016, Math et al 2016).

3.4 Legal Capacity - Person with Dementia having a disability will continue to have rights, which are equal to others, to own or inherit property, movable or immovable; to control their financial affairs; and to have access to bank loans, mortgages and other forms of financial credit (RPWD Act, 2016, Math et al 2016).

4. Rights, Welfare and Self Respect issues and Dementia

There is no specific legislation for persons with dementia with respect to their rights, welfare, and self-respect, but legislation specific to the elderly is equally applicable to a person with dementia. In the Indian Constitution, the directive principle of state policy, Article 41 states that, “The State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want.” Even though it is a directive principle, which is not enforceable (unlike Fundamental Rights), it places an obligation upon the State to provide job opportunities and other help to the elderly so that they can earn and live a respectful and independent life.

In 2007, the Government of India enacted a new legislation for the protection of senior citizens

‘Maintenance and Welfare of Parents and Senior Citizens Act, 2007’ makes a legal obligation for children and heirs to provide sufficient maintenance to senior citizens / older adults.

called ‘Maintenance and Welfare of Parents and Senior Citizens Act, 2007’. This Act makes it a legal obligation for children and heirs to provide sufficient maintenance to senior citizens / older adults. This Act also proposes to make provisions for state governments to establish old age homes in every district with a minimum capacity of 150 senior citizens per home. In a recent judgment on public interest litigation (PIL) related to the implementation of the MWP Act, 2007 (Ashwani Kumar Vs Union of India) delivered in the Supreme Court of India, the Right to health care and Shelter was upheld as a fundamental right.

The National Policy on Older Persons, 1999 recognized that older persons and their concerns were of national importance. It looked into provision of a) financial Security (old-age pension, retirement benefits); b) healthcare and nutrition; c) shelter; d) welfare; and e) protection of life and property. A new policy was formulated in 2011 called “National Policy for Senior Citizens 2011”. It refocused on priority to issues of older women, poor and rural elder population.

The National Council of Senior Citizens is an autonomous body headed by the Minister for Social Justice & Empowerment, Government of India. This was set up to identify and address the concerns of older persons. The council advises Governments on issues related to the welfare of senior citizens like a) Policies, programs and legislative measures related elderly; b) Promotion of physical and financial security, health and independent and productive living; and others. Through this council initiated a new program like a) Vriddh Jan Grah, b) Rashtriya Vayoshree Yojana, c) Vayoshreshtha Samman.

5. Mental Capacity and Dementia

Mental Capacity is the ability of an individual to understand, appreciate and manipulate information and form rational decisions. A capacity as-

assessment is context and situation-specific, relating to the particular decision under consideration of the person at that point in time. The complexities of capacity assessment and its implications render it a challenging task for professionals. (Darby et al 2017, Hegde and Ellajosyula, 2016). Dementia can affect a number of cognitive abilities and processes like attention, memory, language, behaviour and executive functions. These cognitive abilities /processes are involved in reasoning and decision-making, which are in turn, important components of many Capacity Assessments. Essentially, capacity is a functional assessment made by a clinician to determine if a patient is capable of making a specific decision. For a patient with dementia, it is used to determine whether the patient is capable of a) making a will, b) participate in research, c) managing their finances, d) living independently, and e) driving safely (Darby et al 2017, Hegde and Ellajosyula, 2016).

As mentioned previously, the assessment of capacity is situation and context-specific. It involves a direct interview with the person with dementia using both informal and formal methods. Assessment can be planned at different points of time, rather than doing at a single point and the clinician has to keep meticulous records of assessment. The key components of the capacity assessment are: firstly, to ascertain whether the person has a disorder of the mind or brain (for example dementia), and secondly, whether such a person understands the nature of the index decision, options available to him/her, weighs up the pros and cons of these options, arrives at a decision, communicates the same, and is consistent over a period of time.

5.1 Testamentary Capacity - The Indian Succession Act, 1925 (sec 59) says a person of sound mind can make a will and execute a will, with regard to distribution and disbursement of assets and property after one's death (The Indian Succession Act, 1925). As testamentary capacity

is both task-specific and situation-specific and it includes the ability to understand the nature and effect of making a will, the extent of his or her property and assets, consequences of his or her actions, and claims of the expected beneficiaries. Testamentary Capacity is usually assessed by specific legal criteria called 'Banks v Goodfellow criteria'. (14) These criteria are as below

Banks v Goodfellow criteria for Testamentary capacity

- a) Understanding the nature of the act of making a will and its consequences.
- b) Understanding the extent of one's assets.
- c) Comprehending and appreciating the claims of those who might expect to benefit from the will, both those to be included and excluded.
- d) Understanding of the impact of the distribution of the assets of the estate.
- e) That the testator is free of any disorder of mind or delusions that influence the disposition of assets.

5.2 Consent for Research, Genetic testing and Newer Modalities of treatment

- As per Indian Council for Medical Research, National Ethical Guidelines for biomedical and health research involving a person with dementia participants considered vulnerable population. During the consent procedure, the participant and family must be adequately informed about relevant facts of the research and genetic testing and newer modalities of treatment. The family (spouse, adult child, parents, siblings) or Legally Authorised Representative consent is necessary during the above-said procedure if a person with dementia is incapable of giving expressed consent (Indian Council for Medical Research, 2017).

5.3 Institutionalisation / Admission to an Old Age Home

- Admission of a person with Dementia in an Institution or old age home requires informed consent from the person. Sometimes a brief stay at the home can help the person to make an informed decision on whether he/she would like to be admitted there in the longer term. The clinician can engage the person in a discussion on the possible benefits, risks and discomforts of living in old age home or Institution and alternative options, and thus encourage the

Capacity is a functional assessment made by a clinician to determine if a patient is capable of making a specific decision

person with dementia to make an informed decision. In situations where the person lacks the capacity to make this decision, the advance directive (if available) should be consulted. If the same has not been written, the Nominated Representative should be consulted to ascertain the person's wishes and best interests, before admitting him/her to an Institution/ old age home.

5.4 Fitness for Driving - Driving a motor vehicle is considered a complex task, as it involves visuospatial orientation, traffic awareness, maintaining appropriate speeds, and staying in lane. Dementia is characterised by cognitive decline and may impair driving ability. Impaired driving ability can pose a risk to the person himself/herself and other road users. The clinician is often called upon to provide certificate related to fitness. Clinicians may need to check about visuospatial orientation, right-left orientation, reaction speed, and judgment, determine if there have been any recent accidents or episodes of disorientation (Croston et al, 2009). If a person is fit for driving, certificate can be issued for a short time interval, as disease can have a progressive decline over a period of time. However, as per the new Motor Vehicle (Amendment) Act 2019, there is no specific discussion about driving fitness in relevance to dementia (Motor Vehicle (Amendment) Act 2019).

5.5 Handling property and financial transaction - As per the Rights of Persons with Disabilities Act, 2016, a person with Dementia having a benchmark disability will continue to have rights, which are equal to others, to own or inherit property, movable or immovable; to manage their financial affairs; and to have access to bank loans, mortgages and other forms of financial credit. He can transact, sell or gift the property (RPWD Act, 2016, Math et al 2016). He can ask for limited Guardianship from the concerned authority if she /he needs support in decision making. The clinician is often required to assess the capacity of a person with dementia with respect to handling property and financial transactions, when he/she is seeking Limited Guardianship for supported decision making. The clinician has to determine capacity based on individual awareness about the extent of the property, nature of transactions, the contract he/

she is making, impact and outcome of transactions / contract on his property.

5.6 Palliative Care - In Palliative Care, the goal is to improve quality of life. A person with Dementia may require palliative care in advanced stages of the dementia. The clinician should discuss this issue with the person with Dementia at an early stage and encourage him/her to make an Advance Directive or nominate a Nominated Representative to assist with decision making in this circumstance. It helps Person with Dementia, when incapable of giving expressed consent to proceed with palliative care. If he/ she has not identified a Nominated representative or written an Advance Directive and is currently incapacitated to make a decision about palliative care, the clinician will need to discuss this with the family (spouse, adult child, parents, siblings) or Legal Authorised Representative regarding their preference, decision, and consent about palliative care (Darby et al 2017, Hegde and Ellajosyula, 2016).

6. Conclusion - Dementia is associated with significant cognitive impairment. Persons with dementia are often dependent on caregivers and they have unique needs. They are vulnerable to loss of mental capacity, homelessness, wandering in society, neglect, exploitation, abuse, violence, institutionalization, inadequate medical and psychiatric care and rights violations. To deal with legal and ethical issues are challenging for professionals who work with dementia. There is a need for specific legislation, policy, and program which looks into self-respect, health care rights, care, rehabilitation, testamentary capacity, handling property, financial transaction, and palliative care.

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CHAPTER 8

DEVELOPMENT OF COMMUNITY RESOURCES FOR DEMENTIA CARE

KS Shaji

A society is considered relatively old when the fraction of the population aged 65 and over exceeds 8-10%. Kerala is spearheading India's demographic transition and the pace of demographic aging will increase in other states too. The long-term care needs our population will keep rising. This obviously will add to the escalating costs of health care.

Dementia is a common health problem among older people. The affected individuals would need prolonged assistance and support from others. There are both direct and indirect costs due to dementia. Loss of productivity and cost of care adds to the economic burden. The societal costs of dementia are enormous according to the Dementia India Report (Shaji et al, 2010).

Family is the usual source of support for People Living with Dementia (PLWD). However, families are becoming smaller in size across India. More women are taking up employment outside their homes to supplement the family income. We cannot leave the responsibility of home-based

care to the families and then hope that the traditional family network is capable of absorbing any amount of stress. Families need assistance and support especially when engaged in care of PLWD in their household. There is a need to share responsibility among individuals, families, and the government. Support to caregivers is crucial for sustaining long term care. Governments and the society at large, should step in and support these families. A public health framework will help in strengthening the existing infrastructure for informal care.

How can the society or the government be of help? We can mobilize social forces to foster the interdependence which exists in our culture. The willingness to offer and provide much needed assistance to a functionally impaired person is a virtue and a social responsibility. This is very much part of our cultural resource. Palliative care movement in Kerala and other parts of India had promoted this interdependence which is the essence of our social capital and created a network of volunteers backed by profession-

als, to facilitate community care. Similarly we too can generate a pool of volunteers to support home-based dementia care. The 10/66 Dementia research group had shown the need for development of such resources and its feasibility (Shaji et al, 2002 & 2003; Dias et al 2008). The mh-GAP Intervention Guide developed by the World Health Organization can be used as resource materials for training of non-specialist health care providers like volunteers and community health care workers (WHO, 2016). The department of health or social justice can take the lead in this. Social organizations and organizations like ARDSI can support and collaborate with governmental agencies.

Role of Local Self Governments (LSGs)

The Panchayathi Raj system of governance and the decentralized planning allows opportunities to build community resources for care of chronic diseases and disabling conditions like dementia. This allows scaling up of services to reduce the treatment gap that exists. The proximity of the LSGs to the potential beneficiaries allows them to have better understanding about the needs of the community and develop user friendly services. LSGs are also in a position to periodically review and monitor the benefits of the projects which they themselves undertake to implement. They are also entrusted with the powers to redesign, change the funding pattern and add value to these projects. This allows them to make best use of the available financial resources. People's plan campaign in Kerala had led to many projects to help older people. We have many District Panchayaths (eg Ernakulam & Thrissur) engaged in implementation of projects to support home-based dementia care. Three Block Panchayaths in Thrissur District provide dementia care services (Talikulam from 2001 Onwards, Mulllassery from 2016 and Ollukkara from 2019) as part of their ongoing projects.

We can build community resources for dementia care with people's participation and this in turn can lead to enhancement of skills and knowledge needed to provide home-based care of older people with disabling conditions in general and those with dementia in particular.

There are a certain general preparatory efforts

which might help in designing and implementing various projects in the field of geriatric health care. This includes periodic exercises at mapping of resources and identification of unmet needs. Mapping of resources should necessarily include evaluation of the availability, cost and nature of health care infrastructure, manpower and relevant information about other sectors which will have to collaborate with the health services.

Identifying and facilitating the involvement of private and voluntary sectors is extremely important. Otherwise most of the projects will remain designated as "Governmental Health Program". Liaison and collaboration with these two sectors will ensure that health care services remain active and sensitive to the needs of the people. The Government Medical College at Thrissur, Kerala had collaborated with many LSGs to develop and implement many community based health care projects. Based on this experience we propose a brief training of Volunteers to support home-based dementia care. This may be considered as a general guideline which can be adapted to the local needs.

A DEMENTIA CARE TRAINING PROGRAM FOR HEALTH VOLUNTEERS

Time frame:

- There shall be two phases for the training
- First phase shall be for a day and the focus shall be on identification and assessment of cases
- Specific task of visiting suspected cases will have to be undertaken by the trainees after this initial phase.
- The second phase shall take place on another day after a gap of 10- 20 days. The trainees are to make visits to the community during this interval to meet and evaluate possible cases of dementia. Their doubts would be clarified and their need for more knowledge and skills shall be addressed during the second day of training.
- Five hours on each of these two training days shall be spent on interactive formal training. An hour can be reserved for informal interaction between the trainees at the end of each day's training. The group shall be encouraged to remain networked and a mechanism to get more support and training shall be decided later on.

Core content

Day -1 (1) Identification of Dementia (2) Assessment of Dementia

Day -2 (1) Management of Dementia (2) Providing Caregiver Interventions

Who should attend the training program?	Who should conduct the training program?
Health Volunteers willing to be part of a community care program	Team of Health Professionals (Doctors, Nurses, Psychologists, Social Workers)
Accredited Social Health Activists (ASHAs)	They should have good knowledge and experience in dementia care.
Community Health Workers	They should have access to training modules.
Public Health Nurses	
Social workers, Health Visitors	

Feasibility Issues

- Demand/Need: Increasing need for services is now more apparent in Kerala and urban India. The nuclear family households may need more help and probably for longer period. The pool of non-specialist health care providers, especially those who form part of the out-reach services will benefit from this training. They can act as home care advisors
- Cost: Affordable. Training can be made simple and costs can be contained by using existing infrastructure and volunteers
- Manpower for Training: Available; can get support from the community mental health programs in the districts as well as from the Medical Colleges
- Integration with other programs: This needs to be established with careful collaboration between departments of health, medical education and social justice

Overview of the Training Program

	Pre-training session: Introduction and distribution of Training Material : 30 minutes
Section: 1 (Day -1)	<p>Identification of Dementia (brief, interactive sessions which uses slides, case vignettes, cartoons and handouts)</p> <p>Normal Aging Cognitive functions Aging and cognitive decline Forgetfulness in dementia Other symptoms of dementia Causes of Dementia Diagnosis of Dementia</p>
Section: 2 (Day -1)	<p>Assessment of Dementia (brief, interactive sessions which uses slides, case vignettes, cartoons and handouts)</p> <p>Assessment of cognitive functions Assessment of behavioural symptoms Assessment of Activities of Daily living Assessment of for other illnesses Assessment of the setting of care Assessment of Burden of care</p>
Section:3 (Day -2)	<p>Management of Dementia (brief, interactive sessions which uses slides, case vignettes, cartoons and handouts)</p> <p>Need for specialist care Need for medical care Need for nursing care Information and Education Drugs Non-drug interventions</p>
Section: 4 (Day -2)	<p>Providing Caregiver Interventions (brief, interactive sessions which uses slides, case vignettes, cartoons and handouts)</p> <p>Counselling skills Supporting the caregiver/s Tips for better care Health and well-being of the caregivers Need for sustained support Need for specialist support</p>

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CHAPTER 9

COMMUNITY BASED REHABILITATION OF PEOPLE WITH DEMENTIA - AN INDIAN EXPERIENCE

S Shaji

The public in general perceived dementia or Alzheimer's disease as a problem of the Western world and sceptical about its existence in India.

Introduction

Alzheimer's and Related Disorders Society of India (ARDSI) began to function in Kerala in 1992 during a period when awareness about dementia or Alzheimer's disease was very low. The public in general perceived dementia or Alzheimer's disease as a problem of the western world and sceptical about its existence in Indian community. Though awareness existed among local people about a condition of 'senile degeneration' called 'chinnan', it was perceived as a part of normal ageing. Dr K Jacob Roy, a paediatrician by profession, based on his experience as a caregiver, felt the need for developing services for Dementia. As a result, the first National Seminar on Dementia was organised in Kochi in 1992, in which experts from various parts of India assembled and discussed the various problems associated with dementia and its possible interventions. This conference created the intellectual background for the organisation ARDSI and its activities.

Norman Vincent Peale Centre for Community Mental Health and Dementia

The first community-based project for dementia was started in Tiruvaniyoor panchayat of Ernakulam district in 1992. The project had multiple components and a multi-disciplinary team for its implementation.

The activities of the project included (1) Epidemiological survey and identification of people with dementia for intervention (2) Training of Community Geriatric Health Workers (3) Community based intervention for people with dementia (4) Geriatric clinic Support group for the carers (5) Awareness programmes

The Rural Epidemiological Study

A door to door survey was conducted to identify elderly people, aged 60 and above, a total of 2067 elderly persons were screened with the vernacular adaptation of the MMSE (Mini Mental Status Examination) and all those who scored 23 and below had a detailed neuropsychological evaluation by Cambridge Examination for Elderly (CAMDEX- section B), and the caregivers of the people with confirmed cognitive impairment were interviewed using CAMDEX- section H to confirm the history of deterioration or impairment in social or personal functioning. In the third phase the subjects with confirmed cognitive impairment were evaluated at home as to whether they satisfied the DSM-III-R criteria for dementia. Sub-categorization of dementia was done based on ICD-10 diagnostic criteria. Five percent of those whose screening was negative were randomly selected and evaluated during each stage. The prevalence rate of dementia was 33.9 per thou-

sand. 58% of the dementia cases were diagnosed as vascular dementia and 41% satisfied the criteria for ICD-10 dementia in Alzheimer's disease. There were more women in the Alzheimer's disease group. Smoking and hypertension were associated with vascular dementia while a family history of dementia was more likely in the Alzheimer's group.

A multidisciplinary team

A multidisciplinary team consisting of a consultant psychiatrist, clinical psychologist, a medical officer, social workers, staff nurses and community geriatric health workers and the administrative staff worked in coordination to fulfil the objectives of the project.

Training of Community Geriatric Health Workers

A certificate course in geriatric healthcare was started with the recognition of Christian Medical Association of India (CMAI). The minimum qualification for joining the course was SSLC or matriculation. The course was of twelve months duration. Twenty candidates were trained in the initial batch and the main objectives of the training program were:

1. To prepare personnel to render comprehensive care for the aged, in their homes in the community settings and in institutions.
2. To help family members to take care of the elderly people in their homes and to maintain a healthy and comfortable life at the optimum level.

Domiciliary Care

Most of the patients with dementia live at their homes with their family. Many a times, the support given by the family may be inadequate or inefficient due to the lack of understanding about the disease process, inability to deal with behavioural problems associated with dementia or due to interpersonal problems or caregiver distress. The identified cases were subjected to detailed assessment. Once the diagnosis was confirmed, an intervention strategy was formulated for the identified medical, psychological and psychosocial problems. An individual care plan was important considering the needs of a particular patient and family. Social workers and community geriatric health workers under the supervision of a staff nurse implemented the care in the

community. The identified medical, psychological and psychosocial problems were managed by the experts from the centre. The frequency of visits by the geriatric health workers depended on the needs of the patient and the family. They educated the family regarding the management of behavioural and psychological symptoms and physical care was provided to those who were in need of it.

Support Groups (Caregivers Meeting)

Caregivers meetings were organised once in a month. A venue that was convenient to the family members was selected. Usually the meetings were convened at a patient's house or in a local institution. The average attendance in these meetings varied from eight to ten persons. The experts from the centre provided clarification and guidance to their problems in these meetings.

Support groups/ Caregivers' meetings provided a forum for the caregivers to share their problems, to ventilate their feelings and to formulate coping strategies to overcome their difficulties.

The caregivers who were in need of individual attention were referred for counselling services at the centre. The counselling service was provided to the primary caregivers by the psychologist and psychiatric social worker from the centre.

Geriatric Clinic

This clinic was managed by a team of a medical officer, staff nurse, lab technician and an attendant. This was basically meant to ensure acceptance and participation of elderly people in the community.

Urban Community Dementia Services (UCDS)-Cochin

UCDS was a pilot project for developing community based comprehensive healthcare services for patients with dementia. It was situated at South Kalamassery- a small town 10 kilometres from the city of Cochin. This centre provided healthcare to about five thousand elderly people of thirteen divisions of corporation of Cochin. The project started in January 1996. The main objectives were: (1) To identify the persons with dementia (2) To provide comprehensive healthcare which included domiciliary care, day care, medical and psychiatric services to the persons with dementia (3) To train community geriatric health

workers (4) To organise support groups and (5) To disseminate information about dementia

A multi-disciplinary team worked coordination to fulfil the objectives of the project. The clinical team consisting of a medical officer, psychiatrist (part time), clinical psychologist, psychiatric social workers, staff nurse and community geriatric health workers. The administrative staff included a project officer, accountant and driver. The community geriatric health workers were the key persons involved in providing services in the community.

The Urban Epidemiological Study

A door to door survey was conducted in the city of Cochin to identify the elderly people aged 65 years and above using cluster sampling. Of 1934 people screened with a vernacular adaptation of MMSE, and those screened at or below the cut off of 23 were evaluated further and those with confirmed cognitive and functional impairment were assigned diagnosis according to DSM-IV criteria. The identified cases were categorised by ICD-10 criteria. 10% of those screened as negative were evaluated at this stage. Prevalence of dementia was 33.6 per thousand. Alzheimer's Disease was the most common type (54%), followed by vascular dementia (39%) and 7% of cases were due to causes such as infection, tumour and trauma. Family history of dementia was a risk factor for Alzheimer's disease and a history of hypertension was a risk factor for vascular dementia.

Day Care

The day care provided respite to the caregivers and rehabilitation to the patients. This program was very helpful for those families where all the members of the family were working and those who were unable to take care of the patient due to family disharmony or lack of personnel. The day care centre was furnished to accommodate fifteen patients.

Day Care Programme

The day care centre functioned from 9.30 AM to 4.30 PM. The patients were picked up from their houses by 9 AM and dropped back by 5 PM. The routine for a typical day started with a group prayer followed by reading of newspapers

and other recreational activities. These included reality orientation, reminiscence therapy sessions, light and passive exercise, group singing and activities like writing, drawing, colouring, etc. The whole program was flexible, designed to meet the needs of the individuals. The conveyance to and from the centre was provided in a mini bus. The day care activities were coordinated by a care manager with the help of four Geriatric Health Workers. The centre provided a therapeutic environment to the patients. Regular attendance in this programme enabled close monitoring of physical and psychiatric status of the patients so that early intervention and treatment was possible.

Forty-six patients have availed of day care services in 1996. Diagnostic break up of 46 patients was as follows: Alzheimer's Disease-69%, Vascular Dementia- 14%, Mixed-2%, Age Associated Cognitive Decline- 6%, Others- 6% (for example, Parkinson's disease, normal pressure hydrocephalus). The persons belonged to all social economic status (upper class-29%, upper middle class- 18%, middle class-10%, lower middle class- 10%, lower class- 33%). Most of the patients belonged to the age group 70-89. An evaluation study of the project was undertaken by an independent agency, Rajagiri College of Social Sciences. The result indicated that the intervention didn't much have impact on the course of the illness but was contributed to the welfare of caregivers.

Main reasons given by the caregivers for sending their relatives to the day care

1. For better and skilled care with the expectation of some improvement.
2. Unable to manage behavioural problems at home (e.g. wandering, aggressiveness).
3. Inadequate caregiving facilities at home e.g. lack of manpower.
4. For better social and physical stimulation
5. Interpersonal conflict.
6. Neglect.

The main barriers for sending their relative to the day care were the stigma attached to the illness, difficulties in transportation, severe behavioural problems and incontinence.

Memory Clinic

ARDSI in collaboration with the neurology department of Indira Gandhi Cooperative Hospital, Cochin started a Memory Clinic in the year 1999. This was the first memory clinic established in India. The people with memory disorders were referred to this clinic through various sources like general practitioners, other hospitals, NGOs and general public. The referred cases were screened by the psychiatric social worker and potential cases were referred to the neurologist for further investigation and management. The care team of ARDSI carried out the liaison work with the clinic and the community.

Dementia Care Fund

This fund was being utilized for alleviating the financial burden of the caregivers. It was supplied either in the form of income generating programmes for the caregivers or in the form of geriatric care items. Donating sewing machines, helping the caregiver to get a driving license, providing items for setting up a small shop were some of the examples. Clothes, medicines, walker, bed pan, sputum mug, rubber sheet, etc. were supplied to the needy patients. In total, 56 persons with dementia and their caregivers benefited from this fund.

Comprehensive Dementia Care Project - Palarivattom- Cochin

The centre was located at the centre of the city, so that accessibility to the clients was better. The target population was elderly people of Cochin Corporation. In this project, trained volunteers from the community were utilised for identifying people with dementia and their needs assessment. The interventions included domiciliary care, day care, support groups and helpline. The community care was implemented through community geriatric health workers under the supervision of trained nurses. Training program for carers given by National Institute of Social Defence (NISD).

The main barriers for sending their relative to the day care were the stigma attached to dementia, difficulties in transportation, severe behavioural problems and incontinence.

Epidemiological Study of Dementia in Thrissur District of Kerala - The Study Sponsored by Indian Council of Medical Research (ICMR)

The study investigated the prevalence, biopsychosocial correlates and risk factors related to various dementias in Thrissur district of Kerala. A total of 2200 elderly people aged 65 years and above were identified using cluster sampling technique, from both rural and urban areas of Thrissur district. They were assessed by Geriatric Mental Status Examination (GMS- B3), History and Aetiology Schedule (HAS-B) and Community screening instrument for dementia (CSI-D-informant interview). GMS- B3 was used as a screening test for cognitive impairment. All those screened positive and 10% of the negatively screened people were evaluated by a psychiatrist at their household and diagnoses were made as per DSM- 4 criteria. Identified cases were categorised as per ICD-10 diagnostic criteria. The overall prevalence was found to be 33 per 1000. The prevalence rate in rural and urban areas were 26 per 1000 and 37 per 1000 respectively. 65% of cases were due to Alzheimer's disease, 24% cases were due to Vascular dementia and 11% of cases were due to alcoholism, head trauma, parkinsonism and malignancy. Age, past history of depression, past history of stroke and unmarried state were identified as risk factors for dementia.

Lessons from these Projects

1. Epidemiological studies conducted in various parts in Kerala confirmed the presence of dementia as elsewhere in the world.
2. Experience from the rural community revealed that traditional systems of care were still existing. Majority of cases of dementia were undiagnosed and un-intervened. Dementia symptoms were mostly considered as a part of normal ageing, and not as a clinical condition. Family members

were not much worried about cognitive impairment as such but were mainly concerned about the management of behavioural and psychological symptoms of dementia and they required assistance especially for bedridden patients and those with severe physical problems like urinary and faecal incontinence and prevention of bed-sores. The geriatric clinic functioning along with the dementia care project facilitated the conceptualization of dementia care as a part of geriatric problem and ensured community participation. Caregiver's stress was a problem in a subgroup and family intervention and support groups were beneficial for them. Attending a support group in relation to a health condition provided a novel experience for the members of that rural community. The rural project revealed that selecting geriatric health workers from the same community is important. When the people are selected from the same community, their access and acceptability was more.

3. Experience from urban community revealed that a significant proportion of identified patients had previous consultation with a neurologist or a psychiatrist and received some sort of intervention. Many people were investigated with neuro-imaging. Even for patients who had interventions, majority didn't receive proper information regarding the nature, course, progress and various other aspects pertaining to the illness. People in the urban community felt more distress in caring people with dementia due to the limitations in living arrangements and lack of human resources. Many people got relief by sending their relatives to the day care centre. The day care centre provided monitoring of medical and psychological symptoms and addressed the needs of the family. The transition from homecare, day care to institutional care was more visible in the urban community. More people from institutions caring for the elderly people attended the training programs in urban community so that they could provide better care to the residents of the institution. The helpline started was utilised by many carers in the urban community. Utilisation of services by patients and family members indicated that these were indispensable need for the community which was practically non-existent in the country. Training of volunteers was vital in Indian context. These

The rural project revealed that selecting geriatric health workers from the same community is important.

community projects provided models which are community based, family oriented, cost effective, culturally appropriate and comprehensive.

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CHAPTER 10

CAREGIVING FOR DEMENTIA IN INDIA: CHALLENGES AND SOLUTIONS

Sridhar Vaitheswaran, Shruti Raghuraman, Thara Rangaswamy

Introduction

While there is a slow but growing recognition that dementia is a major public health problem in India with the estimated number to be around 10 million persons with dementia (PwD) by 2040 (Jotheeswaran, Williams, & Prince, 2010), the impact on the caregivers of those with dementia has not received much attention. Caregivers of PwD appear to experience higher levels of burden compared to caregivers of elderly without depression, those with depression or psychosis (Dias et al, 2004 & Sinha et al, 2017). The psychological morbidity in India and other developing countries was found to be ranging from 40 per cent to 75 per cent (Dias et al, 2004). Other consequences of caregiving also include social isolation (Brodaty & Hadzi-Pavlovic, 1990) and physical health problems (Schulz & Martire, 2004; Vitaliano et al., 2003) for the caregivers. Higher caregiver burden can also translate to poorer quality of care received by the person with dementia and early nursing home placement as shown in a review by Etters, Goodall, & Harrison (2008).

Most PwD in India are cared for by their families in their homes. The 10/66 Dementia Research Network (Prince et al, 2004) reported that 98% of caregivers in India were residing with persons with dementia. Most families seek expensive private medical help for dementia in India and many caregivers also report cutting back on their employment to care for their family member with dementia (Prince et al, 2004). Rao and Bharath (2013) report the estimated annual household cost of caring for a person with dementia ranged from INR 45,000 to INR 2,02,450 in urban regions and INR 20,300 to INR 66,025 in rural regions of India (to provide context, per capita income in India in 2013 was estimated to be INR 68,747; Press Information Bureau, 2013). The household health expenditure including insurance contributions in India is around 65% of the total health expenditure (National Health Systems Resource Centre, 2018), indicating that the families depend on their own income or savings to contribute to 2/3rd of any health care expenditure. Thus caregiving for dementia in India has a significant economic impact on the families. While there is

little published data from empirical studies on the cost of caregiving for dementia in the nation, we can safely estimate that given the number of persons with dementia in India, this will not be insignificant.

In India family members provide majority of care for persons with dementia. Caregiver burden not only has adverse effects on the quality of care received by the persons with dementia but also impacts on the caregivers as individuals, their families, and the nation as a whole. However, there is a large gap in our understanding of Indian experiences in caregiving for dementia (Emmatty, Bhatti & Mukalel, 2006).

Understanding caregiver burden

Traditionally caregivers can be classified as “formal” (professional caregivers being remunerated for their work) and “informal” (family members or other persons providing care for someone they know without being paid for providing care). Our focus here is on “informal caregivers,” that is, a family member of a person with dementia assuming the role of a caregiver and this individual is not paid to provide care (Greenwood et al, 2008). The term caregiver burden has been used extensively in literature but there is no single agreed definition (Chou et al, 2003). It has been conceptualised from varying perspectives and this has contributed to the heterogeneity in its definition. The lack of agreement on the concept and definition of caregiver burden in research has limited clinicians and policy makers from offering appropriate interventions both at the individual level as well as the public health level (Braithwaite, 1992). More recently caregiver burden is widely acknowledged to include multiple domains including the physical, emotional, social and economic consequence of provision of care on the caregiver (Gaugler et al, 2000).

Montgomery et al (1985) describe the subjective and objective aspects of burden faced by caregivers. Emotional reactions, such as anxiety or depression, and attitudes experienced by the caregiver due to caregiving constitute the subjective burden. On the other hand, the physical or instrumental provision of care that can be measured objectively, such as number of hours of providing care or number of meals assisted, is referred to as objective burden.

Caregivers experience burden when the expectations from the various roles they hold are incompatible with each other or if the caregiver perceives that they have limited resources or time to fulfil all the obligations associated with each role.

Many theoretical models have been proposed to explain the concept of caregiver burden. In Pearlin's stress process model (Pearlin et al, 1990), caregiver burden is the primary stressor, which is influenced by the caregiving context and the caregiver's background. Caregiver burden, in turn, influences secondary stressors such as role strains and intrapsychic factors (competence, role captivity, etc.). These contribute to outcomes including depression or anxiety experienced by the caregivers.

Another model proposed by Yates et al (1999) considers objective factors such as levels of cognitive or functional impairment as well as behavioural problems as primary stressors. Amount of time spent by the caregiver providing care is the primary appraisal. Both the primary stressors and the primary appraisal are influenced by the mediators (perceived social support, availability of formal services and frequency of respite from care responsibilities) and correlate with the burden experienced by the caregivers.

According to the “role theory” (Biddle, 1986) caregivers experience burden when the expectations from the various roles they hold (for example, an adult daughter caring for her parent with dementia also having the responsibility to care for her own children as well as performing her role as an employee at her work) are incompatible with each other or if the caregiver perceives that they have limited resources or time to fulfil all the obligations associated with each role.

Figure 1 below is adapted from the theories described above and provides a framework for understanding the multi-factorial nature of caregiver burden in the context of dementia.

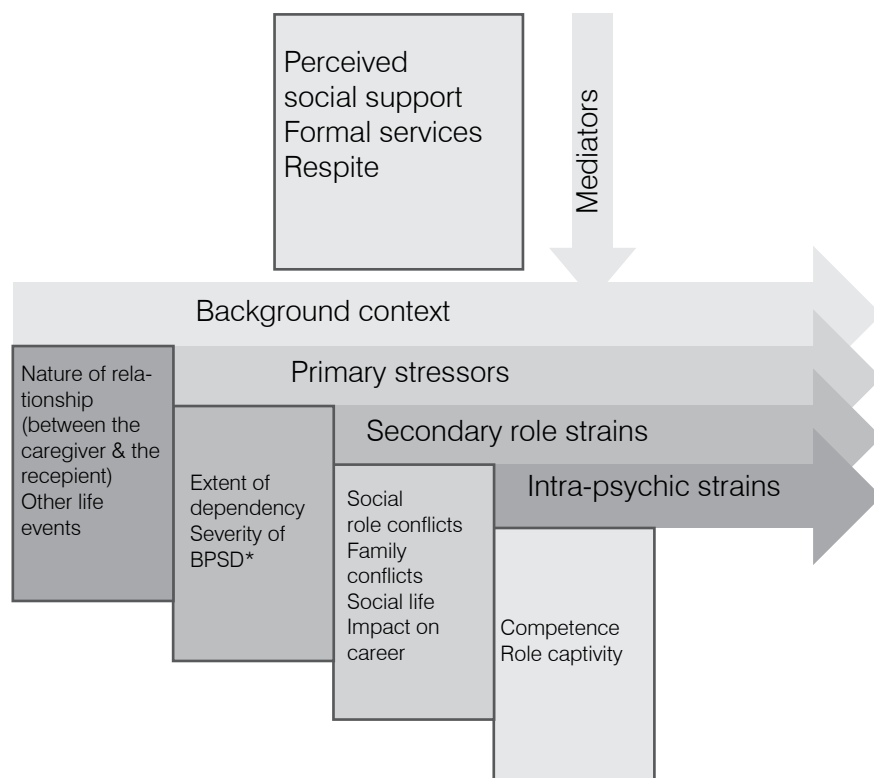


Figure 1: Factors associated with caregiver burden in the context of dementia

Instruments and measurement of caregiver burden in dementia

A crucial issue in measurement is that studies do not employ uniform instruments of measurement to study caregiver burden. Many measures are available and are discussed below.

1. *Zarit Burden Interview (ZBI)* (Zarit, Reever, & Bach-Peterson, 1980): The Zarit Burden Interview is a widely-used caregiver self-report measure. The original instrument was a 29-item questionnaire and the revised version contains 22 items. Each item on the interview is a statement, which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). While ZBI has been used extensively across the globe, it has not been formally validated in Indian populations. Authors found that most of the studies employing ZBI generally reported lower burden scores than expected. The 10/66 research group's cross-cultural comparisons of burden among several developing countries (Prince, et al., 2004) reported

lower burden scores in the Indian sites (Chennai and Goa) when compared to other sites studied using the same instruments of measure. The authors report that while the items of ZBI suggested high face validity, they were concerned regarding the use of ZBI among Indians who are known for their reverence of duty and responsibility towards the elderly. Some items in ZBI may be semantically challenging for Indian participants.

For instance, question 1 of the ZBI states –“Do you feel that your relative asks for more help than he/she needs?” In the Indian cultural context, caregivers consider their caregiving role to be a part of their familial/filial duty and not something that is offered upon request. In India, elderly are expected to do less at home and depend on their family for most of their needs. When elderly relatives do ask for help from their family, it is considered to be the duty of the family to help them. Further, the concept of ‘asking for help’ may be difficult to interpret in more advanced dementia as the persons with dementia may be unable to articulate their needs and requirements. These could also be the reasons for low mean scores in the aforementioned studies.

2. *Modified Burden Assessment Schedule (BAS)*: This is a modified version of the BAS, which is used to measure burden of caregiving for persons with chronic mental illness (Thara, Padmavati, Kumar, & Srinivasan, 1998). The original BAS is a 40-item questionnaire that was developed to quantify the subjective burden as perceived by caregivers of persons with psychotic illness.

3. *The Family Burden Interview Schedule (FBIS)* (Pai & Kapur, 1981): The FBIS is used to measure burden experienced by caregivers looking after a family member with any chronic illness. The instrument has 24 items under 6 areas: financial burden, disruption of routine family activities, family leisure, family interactions, effect on physical health and effect on mental health of others. Each item is scored on a 3-point scale and the

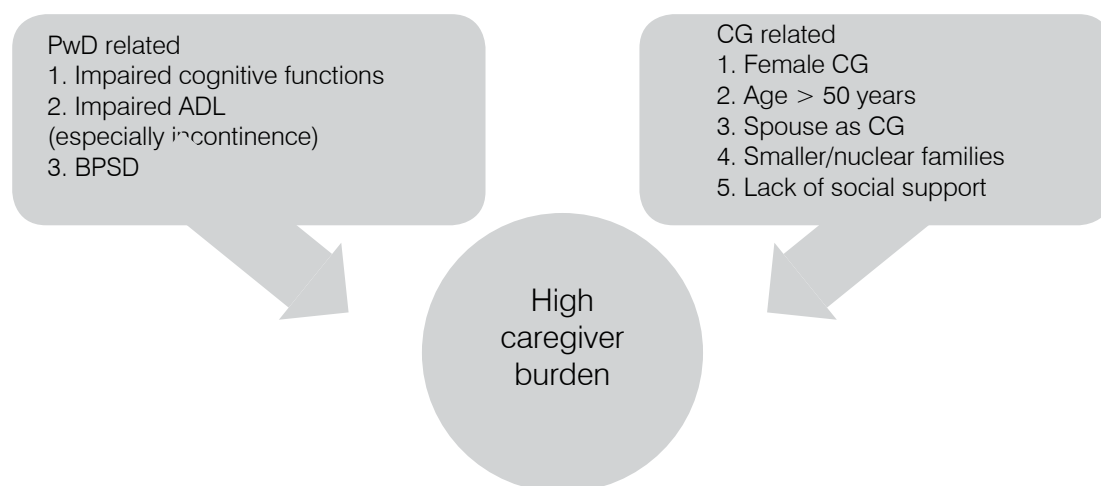
participant is asked to score subjective experience of burden as well.

4. *Perceived Stress Scale (PSS)* (Cohen, Kamarck, & Mermelstein, 1983): The PSS is used to measure subjective perception of life situations that one may find as stressful. The instrument has 10 items and the responses are measured on a Likert scale.

Correlates of burden

Presence of incontinence, impaired basic activities of daily living, wandering, agitation, aggression and violence have been associated with increased caregiver burden (Shaji, et al., 2003). Prince, et al. (2012) also showed that the severity of dementia and presence of behavioural and psychological symptoms (BPSD) had a linear relationship to burden.

Figure 2 below highlights the factors in persons with dementia and the caregivers associated with higher levels of burden



PwD: Persons with dementia; ADL: Activities of daily living; BPSD: Behavioural and psychological symptoms of dementia; CG: Caregiver

Figure 2: Caregiver and persons with dementia factors associated with high caregiver burden
Research on caregiver burden in the India faces many challenges. Availability of multiple measures, lack of standardised measures for India, lack of theoretical frameworks about burden specific to the Indian context to guide research and low priority for dementia research as well as research on caregiver burden are some of the issues that need to be addressed. Even though research on dementia caregiver burden in India is fraught with limitations it is important to acknowledge that caregiver burden in dementia is a significant problem. Public health

policies should provide guidance and health services must endeavour to provide suitable evidence based interventions to address caregiver burden.

Education/advice, social support, behaviour management, emotional support and respite are effective interventions tested across the world. Technology has been considered to help in reaching out to the caregivers.

Interventions for caregiver burden

Brodaty, Green and Koschera (2003) recommend that interventions to address caregiver burden in dementia work best when they are tailored to the needs of the caregiver, address subjective burden experienced by the caregivers, involve both the caregiver and the person with dementia in the intervention, and offered as long-term solutions. In a systematic review Clarkson et al (2018) identified education/advice, social support, behaviour management, emotional support and respite as effective interventions tested across the world. Technology has been considered to help in reaching out to the caregivers.

A Cochrane review (Lins et al, 2014) on use of telephone based support for caregivers showed evidence for reducing depression in caregivers, and internet based interventions, especially when offered as part of a multi-component intervention has shown benefits especially in reducing caregiver depression, anxiety and burden (Hopwood et al, 2018).

To our knowledge the home based, flexible, stepped care intervention for persons with dementia and their caregivers in Goa (Dias et al, 2008) is the only study from India that followed a systematic and rigorous protocol to assess the effectiveness. In this study trained home care assistants who were supervised by a lay counsellor delivered the interventions. This consisted of regular visits every fortnight for six months by the home care assistants. The caregivers were offered basic education about dementia, education about behaviour problems and their management, support in activities of daily living and referral to specialists when necessary. There is an urgent need for more studies to address caregiver needs in India that are multi-modal, culturally and socially acceptable to all stakeholders, tailored to the needs of the population, pragmatic, replicable and cost effective. Public health policy

Caregiver burden is a multi-domain experience that is influenced by and affects the physical health, emotional and social wellbeing of caregivers as well as financial aspects of caregiving.

should support implementation of suitable interventions in the community.

Conclusion

Caregiver burden is a multi-domain experience that is influenced by and affects the physical health, emotional and social wellbeing of caregivers as well as financial aspects of caregiving. The severity of symptoms and level of dependency in persons with dementia along with the availability of formal as well as informal support contribute to either exacerbate or mitigate caregiver burden. Heterogeneity of measures used and paucity of use of theoretical models underpinning research limit our understanding of caregiver burden in India.

There is an urgent need to conduct research to conceptualise the construct of caregiver burden within the socio-cultural milieu in India. This will be a pre-requisite to develop culturally valid and reliable assessment measures for caregiver burden in India. Further, appropriate interventions should be developed and implemented to address the needs of caregivers of persons with dementia in India.

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CHAPTER 11

DIGITAL INTERVENTIONS TO SUPPORT FAMILIES

Swapna Kishore

Introduction

The huge gap in dementia support in India is obvious when we consider the coverage of conventional interventions available to the over four million families coping with dementia. Many population segments cannot access any existing intervention. Capacity constraints severely limit scaling of conventional interventions while the need for support continues to grow.

Digital interventions offer an opportunity to reach many more segments of the population. These interventions are scalable. However, their potential remains untapped in India. Informal discussions with stakeholders reveal reasons such as a gross underestimation of the possible reach and lack of experience in implementing digital interventions.

Use of digital interventions needs to be integrated in the national dementia approach. A comprehensive strategy can be derived based on resources on digital health, eHealth and mHealth^{1,2,3}, “e-Health India”⁴, and other digital development resources. The process will require multiple stakeholder meetings and understanding the strengths and limitations of technology. A comprehensive approach will take years to reach consensus, roll-out the elements and benefit families affected by dementia.

There is also an urgent need to find practical ways to support families in the short term. In this chapter, we consider digital interventions for families that can be implemented quickly and without the use of specialized technology.

Digital interventions cannot replace direct interventions, but they can support those living with dementia in many ways. They can provide education on dementia and care and information related to dementia experts, organizations, products, services, facilities and other resources. Digital platforms can be used to make tasks easier, improve quality of life for persons with dementia and their caregivers and enable connecting with experts and peers.

This chapter is relevant for persons involved in formulating policies, funding or creation of interventions or looking for other ways to contribute.

Suggested interventions are discussed under “Online and Mobile Interventions”, “Mobile Apps” and “Assistive Products”; note that these domains have overlaps and that terminology may be used differently by others.

Most dementia care in India is done by families and they have to make the best use of existing resources. Suggestions for them are included in clearly demarcated boxes.

Note: This chapter does not discuss larger interventions that require specialized knowledge or

more funds, such as medical technology, tele-medicine, artificial intelligence, advanced technologies and healthcare management systems.

Current and projected data on connectivity and Internet use

Usage data in published reports varies depending on the year and methodology used. However, as the summary below shows, the reach is huge and the big picture is consistent enough to take informed decisions on possible digital interventions.

The outreach possible through mobiles and the Internet is huge: The percentage of Internet users in 2017, at 34.45⁵, (lower than most countries in percentage terms) translates to over 400 million users. The percentage of individuals with cellular subscriptions in 2017 was 87.28 (1168.9 million connections)⁶. However, 87.28% does not represent the percentage of connected India because some persons have multiple subscriptions. A 2018 survey indicates that 70% Indian adults own a mobile phone, 13% share one, and 17% do not use mobiles⁷.

Digital reach spans multiple demographics.

There are also digital divides: While connectivity is growing in all demographic segments, it is not uniform. For example, in December 2018, India's urban teledensity (subscriptions per 100 persons) was 159.98 while rural lagged at 59.50⁸. India's Internet users were estimated as having a female/male ratio of 42 to 58⁹. A 2018 survey found that Internet users are more likely to be younger, male and more educated⁷.

Mobiles are the go-to device for access. Data of 2017 shows that the overall share of Internet users using mobiles for access is 78%; 99% of Indian language users use mobiles for access¹⁰. Phones used for Internet access include both smartphones and inexpensive Internet-enabled phones¹¹.

Video availability and usage of digital media is growing. Videos are emerging as a mode for information and education. In 2016, in urban India, digital video reach was 2/3 of TV and expected to continue growing¹¹. 54% users viewed videos to learn something new; "how-

to" searches on Youtube increased threefold in 2016¹¹. Video searches in categories including education and business have grown 1.5 to 3 times in the last 2 years. Online video audience will grow to 500 million by 2020¹².

There are more Indian language users than English users. In 2016, there were 234 million Indian language users compared to 175 million English users; by 2021 they will be 536 million compared to 199 million for English. Over 90% Indian language users use chat and digital entertainment; their use of social media and digital news is also increasing. More regional content in various categories and more services in Indian languages will lead to more usage¹⁰.

Rapid growth is expected, driven by Indian language users and non-metro users. 9 out of 10 new users will be Indian language users. Voice searches (now also possible in nine Indian languages) have shown a year-on-year growth of 270%¹². Digital divides are reducing. One estimate says that by 2020 half of all internet users will be rural, 40% will be women, and 33% will be 35 or older¹³. Online behaviour will change as users grow in digital age (years spent online) and digital maturity (better devices for access)¹¹. Growth is supported by improved ICT and multiple enablers, notably the improved digital infrastructure and digital empowerment of citizens under the flagship programme, Digital India.

Current availability of online and mobile support

Current online dementia support is available through websites, videos, online forums and other online initiatives. Box 1 suggests existing support that families can use.

Unfortunately, current support has many significant gaps as identified below:

Online support is mostly in English and useful but inadequate for families in India.

Authoritative international websites contain useful educational material for dementia and care. However, their country-specific information is not relevant for India (such as helplines, support services, insurance, laws and hospital systems). Some examples and suggestions are difficult to relate to. Some caregivers have called the cultur-

al mismatch “alienating”.

Indian websites, usually created by dementia organizations, contain announcements for services and events. Their educational content is often basic. Very few sites provide detailed information on dementia and care and reliable resources (such as for diagnosis, training, counselling, services, facilities and products). Most care suggestions are geared for metro-based middle-class families. Fake news and misleading/ exaggerated claims circulating in India remain unchallenged.

Support in Indian languages is very poor.

Indian language content is available in some languages but overall coverage is very low and lacks multiple perspectives, shared stories, and practical tips applicable for multiple profiles. Better support is needed, and in more languages.

Videos (YouTube). English videos on dementia are available from reputed international organizations but there are relatively few care-related tips and stories from India.

Regarding Indian language videos for dementia, some dubbed/ subtitled versions of English videos are available. Some Indian language videos are suitable for the Indian context. However, the overall coverage is very low. More videos in multiple Indian languages are needed, especially “how-to” videos for typical problems faced.

Forums from India are negligible in coverage.

While Indians can benefit from some large international online forums (English), and there are some small local Indian forums, there are no large Indian forums providing safe, moderated spaces. Indian language forums are needed. Spaces are needed to gather voices of Indians with dementia and their caregivers.

Indian dementia phone helplines provide limited support.

These can be helpful but are usually limited in terms of their working hours, languages supported, topics addressed, and data they provide on dementia resources-cum-services.

Box 1: For families to access reliable and useful material

(All weblinks included were last accessed in July 2019)

Use only reputed sites or ask dementia resource persons for suggestions. Some specific suggestions below:

English, International: Standard international websites contain reliable explanations of dementia and its care. Notable are the ADI website <https://www.alz.co.uk/>, the national sites of USA <https://www.alz.org/>, UK <https://www.alzheimers.org.uk/>, Australia <https://www.dementia.org.au/> and USA's National Institute of Aging <https://www.nia.nih.gov/>. Ignore country-specific information. WHO's iSupport program is available at <https://www.isupportfordementia.org/en>

English, India: Some standard sites are those of Alzheimer's and Related Disorders Society of India <http://ardsi.org/> and some of its chapters (such as <http://ardsihyd.org/>, <http://www.dementiabangalore.in/>, <http://ardsiguwahati.org/>, <https://alzheimersdelhi.org/> and <http://ardsikolkata.org/>). Other sites from India include <http://www.dementiaindia.org/>, <http://alzsupportpune.org/> and a comprehensive site <https://dementiacarenotes.in> that has detailed discussions for caregivers as well as curated lists of Indian dementia resources.

Indian language material. Indian language material is available from ADI, countries catering to Indian-origin residents, countries with shared languages and India. A few websites with extensive content are: <https://dementiahindi.com> (Hindi) and <http://alzheimerbd.org/> (Bengali). A good starting point is the compilation for online content in Assamese, Bengali, Gujarati, Hindi, Kannada, Konkani, Malayalam, Marathi, Punjabi, Tamil, Telugu, and Urdu at: <https://dementiacarenotes.in/resources/indian-languages/>

Videos: See videos of reputed organizations on their YouTube channels or videos recommended by experts.

Online forums: See Alzheimer's Society, UK's Talking Point <https://forum.alzheimers.org.uk/>, Alzheimer's Association, USA's AlzConnected <https://www.alzconnected.org/> and Facebook Group Memory People <http://www.facebook.com/groups/180666768616259/>. Ask volunteers about local,

Online and Mobile Interventions

Based on the current and projected mobile and online usage and gaps in dementia support, here are some suggested interventions:

Focus on Indian language content and video content. Indian language content is the only way to reach several million non-English Internet users. Videos can help people looking for answers on videos. Select languages relevant for the intended audience, and ensure content is relevant and helpful for the Indian context. Examples:

- Create Indian language versions of existing English material. Dub/ subtitle videos in Indian languages.
- Create simple, easy to understand new Indian language content, including experience-sharing, “how-to” videos and articles that address queries and concerns people may have.

Improve content and accessibility of existing online interventions. Examples of possible enhancements:

- Add risk reduction tips, examples of dementia impact, caregiving explanations and tips, videos and real-life stories.
- Add information on events, resources and services in various cities, subsidies, insurance options and tax rebates.
- Squash fake and misleading news.
- Make existing information, education and communication (IEC) material available online.
- Create new content for multiple demographics; use a “mobile first” approach. Add graphics, audio and video to bypass literacy barrier.
- Ensure all interventions are mobile-friendly and are accessible by persons with impaired vision or hearing problems and persons with less powerful devices.

This improved content can be used to create Indian language versions.

Create special modules in multiple languages, such as:

- Online training for care skills and stress reduction.
- Moderated forums to connect with peers in a safe and culturally familiar space.
- Modules to connect with experts through calls, chat and webinars.

Create phone-based interventions for mobile users who don’t use the Internet. Use these to explain healthy lifestyles, help people reach experts

and send reminders. Cater to multiple languages. Consider voice and text-based systems using features like missed calls, SMS text messages, USSD and IVRS.

Make interventions visible to potential beneficiaries. Content needs to be visible to people coping with dementia when they search using ways that they are familiar with and for the terms they may use to search.

- Spread information about interventions through social media, existing campaigns for dementia or other relevant domains, targeted advertisements and interactions with families.
- Optimize sites and videos for better visibility in text and voice searches in English and Indian languages.
- Match topic name and presentation to queries people may have.

Even simple interventions can be challenging to implement if there is no prior experience of such projects. Difficulties are faced in identifying vendors for developing and maintaining digital interventions, communication and coordination between stakeholders, funding/ resources, planning and monitoring all required tasks for development and maintenance. Interested persons can refer to available discussions¹⁴ to be better equipped to handle such work.

Mobile Apps

“Mobile Apps” (also called “apps”) are often assumed to be a transformative digital intervention for providing support. Apps are software applications developed specifically for use on smartphones and tablets. They should not be confused with mobile-friendly websites (websites that work well on Internet-enabled mobiles).

Currently, apps are available for cognitive stimulation, engagement and improved quality of life of persons with dementia and for some care aspects. Only a few dementia-related apps are available from India, and these are in initial stages. (Health-care management apps used within healthcare facilities are not discussed here).

App design, development, publicity and maintenance depend heavily on developer skills and reliability. Design and related decisions require informed involvement of the management team. It is difficult to ensure that apps will be noticed, downloaded and used regularly. People with low experience in implementing digital interventions can support more easily and effectively using good online content on mobile-friendly sites. This is espe-

cially so because app use is limited to smartphone users, currently mostly younger, more educated and male⁷.

The effort versus potential benefit of app development can be re-evaluated once smartphone penetration is higher in required audience segments and expertise for technical projects improves.

Wherever relevant, families can consider existing apps or find alternate ways to achieve the required function (See Box 2).

Box 2: For families considering apps

Smartphone/ tablet users can consider free and paid apps for engaging persons in early-stage dementia, getting caregiving tips, planning and monitoring daily tasks, coordinating tasks with well-wishers and tracking and fall prevention, etc. Ask peers and experts for suggestions.

Evaluate options for suitability.

Examine other means to get the desired functionality, such as creating custom playlists, using private Facebook/ WhatsApp groups to coordinate tasks with well-wishers and using WhatsApp location share for tracking.

Assistive products

Products and systems that use technology (ranging from low-tech to sophisticated) can help in dementia care. They can be used to maintain or improve the functional capabilities, independence and quality of life of persons with dementia. They can improve their safety inside and outside home and make care easier and less stressful. Examples include automated prompts and reminders, clocks and calendars, medicine dispensers, tracking devices, hearing, vision, and mobility aids, safety devices, detectors, telecare systems, communication devices, virtual assistants, reminiscence and entertainment devices and others^{15,16}.

Those interested in assistive products can look for discussions under terms like “assistive technology”, “assistive products”, and “assistive devices.” They may find it helpful to see the cognitive impairment products included in WHO’s “Priority Assistive Products List”¹⁷, discussions on the Alzheimer’s UK site¹⁵, the practitioner’s guide from Genio¹⁶ and similar discussions elsewhere.

Designing, testing, and productionizing assistive products requires time and investment. Products

should be safe, usable, and affordable. Effort is needed to ensure adoption by potential beneficiaries. Such products have limited reach and benefit and their priority has to be compared to other interventions.

Those considering use of existing assistive products can see Box 3

Box 3: For Families Considering Assistive Products

Information on possible products is available from books, sites, peers and dementia resource persons.

Typical areas where Indian families seek solutions are safety, fall prevention, tracker devices and support for remote care.

Evaluate possibilities based on potential benefits to the person with dementia or the caregiver, safety, comfort, usability, ease of learning and costs. For costs, in addition to cost of the product, consider installation, training, ongoing costs and maintenance. Check whether any discounts or subsidies are available.

Conclusion

Families living with dementia have to make the best of what is already available; Boxes 1 –3 can help them use existing interventions.

Most families in India get no support for dementia. Given the rapid growth in ICT across India, digital interventions can reach currently unsupported families from multiple demographics. Based on the usage patterns and trends and existing support gaps, two digital intervention areas to focus on are Indian language content and videos. Mobile-friendliness is essential. Other possibilities include phone-based interventions, online forums, training, content and design enhancements, app development and assistive products.

Choosing simpler interventions and releasing modules incrementally will provide earlier benefits compared to waiting for completion of complex solutions. This approach is particularly relevant when expertise with digital work is low. Delivering usable outcomes sooner makes feedback available early. This helps to refine interventions and build expertise for future work. For example, make websites mobile-friendly before considering app development. Release content on specif-

ic subtopics as it gets ready.

The overall support coverage can be better if those working on various interventions pool their initiatives and learnings to improve their effectiveness and avoid overlaps.

Families, even if connected and active Internet users, can only benefit from digital interventions they reach and use. The intervention should be visible when they look for answers for their problems. People searching for solutions use modes they are familiar with and frame queries using terms that match their layperson understanding of the situation. For example, they may search for “how-to” tips for a behaviour or symptom that worries them; they may not look for “dementia.” And after reaching an intervention, they should find it engaging and useful. On digital platforms, distraction is just a click away.

The management effort for development and maintenance should not be underestimated, especially selection of vendors and effective communication and coordination across all stakeholders. Applicable legal and ethical requirements must be met and appropriate disclosures and disclaimers included. For paid interventions (usually for services, apps and assistive products) users’ perceived need, price sensitivity and the expected market size must be considered.

Digital interventions are part of an empowering dementia-friendly environment and the overall healthcare scenario. They will be more effective if they work well with other interventions. Also, as technology and its usage changes rapidly, interventions need ongoing reviews and adaptation. In the larger context, interventions should integrate with policy and programs in health and other development areas for better synergy. This also enables possibilities for funding, data exchange and partnerships. Examples are Digital India, National Health Policy, the National Digital Health Mission and initiatives of local government, reputed NGOs and trusts. Ideas to adopt or adapt may be available from existing guidelines and experience-sharing of initiatives from India and other developing countries.

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(all weblinks last accessed July 2019)

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CHAPTER 12

DEMENTIA: RISK AND PROTECTIVE FACTORS

Baby Chakrapani PS, Dania Alphonse Jose

A complete understanding about the cause of dementia remains elusive. It commonly occurs after middle age as a result of neurodegenerative and cerebrovascular processes beginning earlier in the life course. Developing agents that can slow down or cure these diseases causing dementia continues to be a challenge. Therefore, there is an urgent need to gain more insight into the risk factors of this neurodegenerative condition which might lead to main pathological processes responsible for disability and dependency. That will help either to prevent the processes of neurodegeneration or in slowing down the pathological processes. Based on epidemiological, clinical, genetic and biochemical studies researchers have reported several risk factors that affect the likelihood of developing one or more kinds of dementia. There are several potentially modifiable and non-modifiable risk factors associated with cognitive decline or Alzheimer's disease (AD) in dementia. It is generally considered that a fifty percent reduction in population prevalence of dementia can be achieved by a five year delay in the onset of symptoms (ADI, 2014). Primary prevention (interventions applied before the condition occurs) plays a major role in prevention of dementia.

Non-Modifiable Risk Factors

Age and Gender

Alzheimer's disease and other forms of dementia are not a normal part of ageing but the likelihood of developing Alzheimer's disease increases as you get older. This has been very clear in various epidemiological studies. There is some research to suggest dementia has a gender effect (Mielke, 2018). The lifetime risk of AD dementia is greater for women, AD is not a disease unique to women but about two thirds of people diagnosed with AD dementia are women ("2016 Alzheimer's disease facts and figures," 2016). But the interaction between gender and risk for AD dementia is still unclear.

Family history and Genetics

In general a person with family history of Alzheimer's disease is considered to be at a heightened risk of developing the disease themselves. At the same time many people who have relatives with Alzheimer's disease never develop the disease, and many without a family history of the disease do get it. This is due to the complex interaction among multiple susceptible genes and other factors, including environmental contributions and chance occurrences. Systematic

In recent years, molecular genetic studies have identified several candidate genes in Alzheimer's Disease.

search for the genetic basis has involved twin, family, linkage and association studies. Twin studies have observed consistently higher rate in identical twin pairs (22-83%), than dizygotic (not identical) twin pairs (0-50%) (Bergem, Engedal, & Kringlen, 1997; Breitner et al., 1995). Family studies have found higher prevalence of AD in first degree relatives of people with AD with an ancestral history than in first degree relatives of control subjects. Among family studies, early-onset families, patterns of AD inheritance have been consistent with classical Mendelian autosomal dominant inheritance, while the late-onset families have tended to suggest a multifactorial inheritance involving both genetic and non-genetic factors.

The underlying risk factors remain largely unclear for this heterogeneous disorder. In recent years, molecular genetic studies have identified several candidate genes in AD. The mutations in three different genes are found to be associated with dominantly inherited or EOAD: amyloid beta (A4) precursor protein (APP), presenilin 1 (PSEN1) and presenilin 2 (PSEN2). However, in LOAD, the strongest risk is associated with Apolipoprotein E (APOE), $\epsilon 4$ allele, located on chromosome band 19q13. It is a unequivocally established "susceptibility" gene in late onset AD. ApoE is a lipid-binding protein and is expressed in humans as three common isoforms coded for by three alleles, $\epsilon 2$, $\epsilon 3$, and $\epsilon 4$. A single APOE $\epsilon 4$ allele is associated with a twofold to threefold increased risk; having two copies is associated with a five-fold or more increased risk (Tosto & Reitz, 2013). In addition, each inherited APOE $\epsilon 4$ allele lowers the age at onset by 6–7 years (Ungar, Altmann, & Greicius, 2014). APOE $\epsilon 4$ is also associated with lower cognitive performance, in particular the

memory domain, is associated with mild cognitive impairment (Reitz & Mayeux, 2010), and is associated with progression from mild cognitive impairment to dementia. Although the population attributable risk of APOE $\epsilon 4$ is estimated at 20–50 %, the presence of $\epsilon 4$ is neither necessary nor sufficient for development of the disease (Bekris, Yu, Bird, & Tsuang, 2010)

Modifiable Risk Factors and Dementia

A number of modifiable risk factors in dementia have been described by observational studies but a substantial proportion of it remains as unexplained risk with moderate evidences. Here we explain some of the common risk factors which are found to be important in the pathogenesis of dementia reported by various studies. These factors independently or combined may account for more than half of the attributable risk for AD and related disorders.

Low Early Education

Low early education has been shown as a risk factor for dementia across studies. Early educational experience plays a significant role in developing dementia later in life.

Diabetes Mellitus

Midlife diabetes or a longer duration of diabetes is found to be associated with an increased risk of AD. Several studies showed that long-term direct effect of uncontrolled hyperglycemia (uncontrolled glucose level in blood) or along with one or more condition such as hypertension and dyslipidemia (abnormal levels of blood lipids) may cause neurodegenerative changes in the brain. Population based studies identified that people who have type 2 diabetes are, on average, twice as likely to develop dementia compared to those without diabetes (Muller et al., 2007).

Obesity

Higher body mass index (BMI) and obesity are well established risk factor for type 2 diabetes (T2D), cardiovascular diseases, cancer and it has also been proposed as an independent risk factor for cognitive decline, brain atrophy, reduced white matter and integrity of the blood-brain barrier, and elevated risk for dementia. Findings from case-control studies found that high BMI in midlife was the only midlife vascular risk

factor that demonstrated a significant association with increased late-life brain amyloid deposition (Gottesman et al., 2017). Also various other epidemiological and observational studies identified mid-life obesity as a risk factor for dementia and AD.

High blood pressure and High cholesterol

Elevated and uncontrolled high blood pressure and excess cholesterol in the blood stream affects the heart, arteries and blood circulation by inducing atherosclerosis and impaired blood flow. This may increase the risk of dementia and also can directly induce neurodegeneration. Evidences has been consistently implicated these risk factors in midlife are associated with higher risk of dementia and Alzheimer's disease later in life in both the sexes (Kivipelto et al., 2001; Launer et al., 2000).

Depression

Depression is a remarkable risk factor for AD. It affects a large number of elderly people, late-life depression and anxiety disorders are considered as significant behavioral aspect of the symptomatology of AD but a frequently underestimated risk factors of AD (Wragg & Jeste, 1989). Depression generally affects the cognitive and functional status of patients with dementia and leads to a condition traditionally termed as depressive pseudodementia. Several studies showed an association between history of depression and risk for AD. A growing body of evidences suggests that depressive symptoms appearing a year prior to the onset of dementia might be considered as an early symptom indicating the onset of a disease or illness. In the last decade several studies revealed many molecular pathways in the background of AD (Green et al., 2003). But the pathophysiological relationship between late life depression and risk for development of AD is entirely not clarified.

Smoking

Case control and longitudinal studies produce conflicting results about the association between smoking and AD. Tobacco use has long been known to increase the risk for cardiovascular diseases, cancer, stroke etc. Current research studies identified that smoking-related disease conditions extends beyond this and includes

brain neurobiological and neurocognitive abnormalities (e.g., hippocampal volume loss, learning and memory deficits). These smoking-related neurobiological abnormalities may represent risk factors for Alzheimer's disease. In addition, findings from a meta- analyses study showed sustained smokers had increased risk for Alzheimer's disease pathophysiology and associated dementia than people who had never smoked (Hernan, Alonso, & Logroscino, 2008).

Alcohol abuse

Alcohol is ranked fifth among the most important risk factors for death and disability worldwide and it has been implicated as one possible risk factor for AD. The World Health Organization (WHO) defines, consuming more than 60 g of pure alcohol per day for men and more than 40 g of pure alcohol per day for women was associated with an increased risk of being diagnosed with either cognitive impairment or dementia in both sexes. In addition case control studies reported majority (57%) of early-onset dementia (before the age of 65), were related to chronic heavy drinking. Heavy alcohol consumption accelerates shrinkage, or atrophy, of the brain, which in turn is a critical determinant of cognitive decline and neurodegenerative changes as well superficially very similar to those seen in aging or AD (Meyer et al., 1998). But in contrast to aging and AD, alcohol's effects on the brain may be reversible. Majority of observational studies suggest light to moderate drinking was associated with the risk of AD. In contrast to this, some studies observed an association between mild to moderate alcohol use and a lower incidence of dementia.

Other Factors

The major environmental risk factors for dementia are categorized into six groups: Air quality, toxic heavy metals and other metals, occupational-related exposures, trace elements, and miscellaneous environmental factors. The evidence has not been strong as the other risk factors previously discussed.

Protective Factors

Micro and macronutrient deficiencies can contribute to dementia and supplements have been studied also for their protective effects. B-vitamins, antioxidants, omega 3, vitamin E etc have

It is estimated that the proportion of dementia cases that are theoretically preventable through elimination of the nine identified risk factors is 41•2% in India.

been studied and ADI (2014) concludes that in late life with the exception of Mediterranean diet findings from supplementation trials have not been strong. However the trials did not always focus on those with deficiencies. The following factors have also been studied: other vitamins, use of anti-inflammatory drugs, estrogen supplements in women, use of turmeric, healthy diet-whole grains, fruit and vegetables, fish and olive oil, bilingualism- 'fluency in or use of two languages' etc. Education especially in early years, physical activity and cognitive stimulation are considered to be significant protective factors.

Dementia: Indian Scenario

The average life expectancy of an Indian was 32 years in 1947 when India achieved independence but the current average life expectancy is 68.3 years. India is one among the fastest growing countries in the world and its rapidly growing societies are the sources of global development. However accompanying this rapid growth, there is also a rapid epidemiological transition of increase in aging population. The current life style changes and disorders like Type 2 diabetes, hypertension, stroke etc., along with increased age might be the major risk factors for dementia in India. The published Indian literature on various aspects of dementia have been on the rise, but unfortunately there are no systematic longitudinal studies which discuss the exact epidemiology, risk factors, and genetic studies on dementia.

The most frequent form of dementia in our population is AD. The prevalence rate is higher in women than in men and rural prevalence is higher than the urban settings. Lack of awareness leads to a delay in diagnosis or no diagnosis at

all. As in any chronic medical illness, early detection and diagnosis will be helpful in dementia. Dementia is a condition with no cure available but prevention is possible; so early intervention to prevent the onset or postpone the onset in normal population is important. It is estimated that the proportion of dementia cases that are theoretically preventable through elimination of the nine identified risk factors is 41•2% in India. The nine potentially modifiable risk factors are less childhood education, midlife hearing loss, hypertension, obesity, later-life smoking, depression, physical inactivity, social isolation, and diabetes (Mukadam et al, 2019).

Conclusion

Currently there is no cure for dementia but there is good evidence that a healthy lifestyle can help reduce your risk of developing dementia. The strongest evidence exists for low education in early life, hypertension in midlife, and smoking and diabetes across the life course.

Reduce Dementia Risk

- Effective intervention and management of mid-life high blood pressure, obesity, diabetes
- Moderate and regular exercise
- High education- 'More education is a protective factor for dementia'
- Maintaining a healthy and balanced Diet
- Practice cognitive stimulation exercises
- Get quality sleep and if required get screened for sleep apnea
- Manage stress, depression and nourish inner peace
- Watch your weight
- Avoid excess alcohol consumption
- Stop smoking
- Eat healthy food
- Maintain more socially integrated lifestyles by establishing extensive social networks and frequently participating in social, physical, and intellectually stimulating activities in middle age and later in life.

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CHAPTER 13

EXPERTS' AND STAKEHOLDERS' CONSENSUS ON CHALLENGES AND PRIORITIES IN DEMENTIA

Gowtham Dev, CT Sudhir Kumar

An experts and stakeholders meeting was hosted by Kerala University of Health Sciences (KUHS) Thrissur on 22 May 2019. Dr MKC Nair, Honourable Vice Chancellor, Dr Jacob Roy Founder ARDSI, Dr. Harikumaran Nair GS, Dean Research, KUHS and Convenor, Dr VV Unnikrishnan, Dean Academic, KUHS and Dr Tina Jaicob spoke on the occasion. Dr Sanju George and Dr Roy K George chaired the scientific session and the presentations were by Ms Deepika Nair, Dr KS Shaji, Dr Thomas Iype, Dr S Shaji, Dr CT Sudhir Kumar. There were around 40 participants were divided into four groups and the consensus opinions are presented here. Dr Indu PV, Dr Ninan Kurian, Dr Steve Paul, representatives from Kannur Dementia Care Society, ARDSI Kottayam, ARDSI Pathanamthitta, CUSAT, KUHS etc actively participated in the discussions.

Consensus opinions of stakeholder groups

Group 1 NGOs, SOCIAL WORKERS, VOLUNTEERS

1. Focus of action: Improve the quality of life of patients and caregivers, physical health of the patients, help families cope with dementia, tackle stigma, involve families socially, supportive physical environment for patients.

2. Action plan: Awareness programmes at grass root level, awareness events at residential associations, educational institutions, old age homes. Training of trainers programmes, House visits, medical camps, stress tolerance techniques for caregivers, mass programmes creating demen-

tia friendly panchayaths and districts, help with domestic care.

"Patients are not giving anybody a hard time, they are having a hard time themselves with poor memory"- Volunteer

Group 2 FAMILY CAREGIVERS

1. Top Challenges: Behavioural changes, memory problems, poor recognition of family and friends, dependence, unable to leave patients without proper support, taking for consultations.

2. Situations when felt completely helpless and/or exhausted: Constant vigil, taking for consultations, how to give priority to the person's happiness while caring for them, finding adequate time to care, long distance travel especially at night, advanced stages when bed ridden.

3. Biggest support/help in extending caring work in the family: spouse, siblings.

4. Outside support services on a regular basis: Social organisations, palliative care.

5. Support you wish for and not receive: No support for people with dementia from government agencies.

6. Needs: More awareness campaigns for public on early diagnosis and care giving, documentaries for public in layman language, separate department for patients with dementia in government hospitals, minimum one day care centre for dementia in all local bodies.

Group 3 RESEARCHERS AND ACADEMICIANS

1. What do you think the priority areas are for research in dementia in our setting?

Biomarker detection, genetic tracking, dementia friendly design, daily assisted living suitable to India, psychosocial support system, health system intervention and course design.

2. How do we attract attention and funding for dementia research in India?

Making funding agencies aware of economic burden of the family and society, make them aware of the importance of early detection and biomarkers, target prevalence, prevention and delaying the onset.

3. What challenges do you see?

Lack of the following: research centres, funding, medical practitioners in research, multidisciplinary research, clear definition of dementia, data sharing, use of technology.

4. Needs: Caregiving advocacy and policy making, helplines, dementia friendly state level policies, separate disability categorisation of dementia, creating dementia friendly environments.

Group 4 DOCTORS, NURSES, PSYCHOLOGISTS

1. Enlist top challenges that you face in the field of dementia care

Lack of awareness, lack of manpower, ageism, lack of trained manpower, lack of day centres especially for females.

2. What are the future opportunities in the field of dementia care?

Increased interest in geriatric medicine, geriatric nursing, trained home care support.

3. How do we reach out to the very poor and population that are difficult to reach?

Equitable distribution of resources, effective community based outreach programmes, financial assistance, caregiver aid, pensions.

4. What challenges do you think patients and families face in accessing existing ser-

vices and where do you think improvements are needed?

Transportation, financial hardships. Improve access initiatives by panchayaths, local hospitals, resident associations, pensioners, voluntary organisations, students. Make the services affordable.

5. What other allied services need to be introduced?

Helplines for emergency, for sharing information, bedside laboratory services, home care support.

6. Any other points you would like to document.

Service provision for destitute, widows, wanderers. Nutrition support, meals on wheels.

Kerala State Initiative on Dementia (KSID) - Smruthipadham

Government of Kerala launched this comprehensive dementia care model in 2014. It exemplified the state's prioritisation of making dementia care a public health and social welfare priority. It is a public-private partnership between Kerala government Department of Social Justice and ARDSI. The initiative focuses on providing Information, Education and Communication materials, establishing day care and residential care facilities for people with dementia and includes plans for establishing memory clinics, community care and support etc. This partnership initiative is unique and innovative and probably the first of its kind in India. We hope this will be a forerunner of many such projects across India and hopefully lays the foundation for states wide dementia plan and strategy.

ACTION PROPOSAL

Following is the summary of the discussions which occurred at various levels during the meeting and its preparation.

1. Dementia plan, policy and stakeholder collaborations

Stakeholder alliances to advocate for national and state level dementia policies and district level plans.

Stakeholder collaboration of NGOs, voluntary organisations, health and social care professional organisations, caregivers etc

Existing programmes where dementia can be sited need to be closely looked into.

2. Awareness and sensitisation

Improve awareness among all sections of society. Targeted sensitisation of politicians, administrators, journalists and media.

3. Information

Information about dementia and associated issues and caregiving guides should be available in local languages. Information about services available should be accessible. Information about risk factors and how to address them should be disseminated.

4. Training

Training health and social care professionals to identify people with dementia in community and hospitals and how to support them.

Training doctors at all levels in dementia diagnosis and management.

Consider screening questions for dementia to be used by health professionals during consultations irrespective of the presenting problem.

Establish training systems to ensure targeted training for health professionals, caregivers etc including training of trainers from different backgrounds eg, doctors, teachers, social workers, nurses, palliative care workers, volunteers.

5. Service development

Establishing multidisciplinary Memory Clinics in district hospitals and medical colleges.

Developing agreed referral pathways of patients with dementia from community and primary care level for further care.

Developing domiciliary services for monitoring and care at home by voluntary sector and government agencies.

Establishing day centres for people with dementia with transportation.

Establishing residential care centres for those with severe and complex issues unmanageable at home and for those who do not have caregivers.

Developing respite care in the form of temporary residential care for patients with dementia at times when caregivers are not available.

6. Financial Support

Financial support to be provided for people in low socioeconomic strata.

7. Building Dementia Friendly Communities

Effectively utilise locally available community resources- manpower and otherwise eg. volunteers.

CHAPTER 14

DEMENTIA INDIA STRATEGY AND PLAN FOR INDIA- THE ROAD MAP

CT Sudhir Kumar, KS Shaji, Mathew Varghese

National health strategy provides direction for improving health and is used for planning purposes. It is a document that outlines a country's vision, priorities, budgetary decisions, and a course of action. National plans are made taking into account the unique culture and demographics of the country. WHO published the Global Action Plan (2017) which aims to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries. It envisages a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality. National plans can either be stand alone, integrated with existing programmes or be combined. While standalone strategies reduce the risk of fragmentation and ensure dedicated resources, integrated policies attract attention along with already identified priority areas and optimises the use of limited resources.

Dementia India Report 2010

The first major step which brought in the discussion of a national dementia strategy was the publication of the Dementia India Report. It clearly set out recommendations to form the basis for a comprehensive strategy.

They are (i) make dementia a national priority and this must be reflected in the plans for service development and public spending and should be an inter-agency, inter-departmental strategy. Dementia must be prioritised in the Five Year plans of the Ministries of Health and Social Welfare.

(ii) Increase funding for dementia research, review Indian medical and social research funding to establish a more ambitious funding program into the causes, prevention, cure and care of dementia. There is a need to have a national consultation to evolve research strategies and delineate specific directions.

(iii) Increase awareness about dementia, education of the general public as well as training health service providers and social services sector is important. There is a need to have regular and national campaigns to educate the public about evaluating for memory problems in old age.

(iv) Improve dementia identification and care skills. Dementia 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. 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 col-

leges and district hospitals and an integrated geriatric services with delineated referral mechanisms needs to be evolved.

(v) Develop community support and the number and extent of low level community home care packages must be increased. Home help services, social insurance and other social defence measures must be established.

(vi) Guarantee carer support packages, psychological therapies including carer training and support groups and quality respite care for people with dementia and carers. Provisions must be 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 people with dementia and carers to access direct payment and carer pension benefits must be explored.

(vii) Develop comprehensive dementia care models eg. bridge the gap between care at home and care in a care home.

(viii) Develop new national policies and legislation for people with dementia.

WHO Global Action Plan (2017)

The Global action plan on the public health response to dementia 2017-2025 was adopted by World Health Organization (WHO) member states at the 70th World Health Assembly in May 2017. The plan follows 10 years of advocacy for a global response to dementia by Alzheimer's Disease International and others worldwide.

WHO Global Action Plan (2017) seven cross-cutting principles

Human rights of people with dementia

Empowerment and engagement of people with dementia and their carer

Evidence-based practice for dementia risk reduction and care

Multisectoral collaboration on the public health response to dementia

Universal health and social care coverage for dementia

Equity Appropriate attention to dementia prevention, cure and care

The action areas identified by the WHO are (1) Dementia as a public health priority, (ii) Dementia awareness and friendliness, (iii) Dementia risk reduction (iv) Dementia diagnosis, treatment, care and support (v) Support for dementia carers (vi) Information systems for dementia and (vii) Dementia research and innovation. They target for increased policy, awareness, prevention and diagnosis, research, care and treatment of dementia. The WHO Global plan urges 146 countries (75% of Member States) to develop a dementia plan by 2025 and the expectation is that a comprehensive government plan will address the needs of people with dementia and can provide a mechanism to consider a range of issues including promoting public awareness of dementia and improving the quality of health care, social care and long-term care support and services for people living with dementia and their families.

Among others, WHO research prioritisation exercise suggested the following which are extremely relevant to the Indian context. (i) identify clinical practice and health system-based interventions that would promote a timely and accurate diagnosis of dementia in primary health care practices (ii) determine the most effective interventions for educating, training and supporting formal and informal carers of people with dementia (iii) understand the contributions of vascular conditions to neurodegenerative diseases causing dementia (iv) explore single and multi-domain approaches for primary and secondary prevention of dementias based on evidence on risk/protective factors and the relationship with other chronic diseases (v) identify strategies to anticipate and deliver effective and cost-effective late life and end of life care for people with dementia, including advance care planning (vi) evaluate the relative effectiveness and identify the optimal models of care and support for people with dementia and their carers in the community across the disease course WHO identifies stigma/lack of public awareness, lack of political will, lack of human and financial resources, lack of integration across government levels and sectors and lack of dementia diagnosis as major barriers in forming a dementia plans. Hence the importance of improving awareness and identifying people with dementia cannot be overemphasised. Many developed countries evaluate the success of a dementia plan

by assessing the delay in admission of patients with dementia into residential and other formal care services, avoiding unnecessary admission to hospitals and preventing crisis interventions which are all costly to the government. However for India the focus is different. Most national plans have keywords including coordinated action, integrated approach, person centred care, modernisation of the care home sector etc. But we have to define carefully what these entail for a developing country like India.

ARDSI Dementia India Strategy Report (2018)

ADI reports, 32 countries and territories have adopted a plan on dementia, including 27 WHO Member States. Non-governmental strategies are generated by private non-governmental groups that can serve as the case statement to persuade governments to create a national or sub national governmental plan and includes the National Dementia Strategy of ARDSI.

Based on the WHO action areas, ARDSI (2018) published a National Dementia strategy plan as an initial step to bring transformation in ensuring comprehensive dementia services. This outlines a plan to commit resources that are necessary to address the problems of dementia and the hope and expectation is to receive a commitment from the government on yearly basis for funding, capacity building and research to transform the dementia care and support services at State and national levels.

There are seven core areas identified to be set out as national priorities in the strategy. Key targets and priority actionable issues are identified across the seven WHO action areas. The plan is ambitious and sets targets to be achieved in a few years and an overview of activities to reach them. Budgetary allocation of 0.5 % each from Human Resources Department (HRD) budget, National Program for Prevention and Control of Cancer, Diabetes, Cardio Vascular Diseases and Stroke (NPCDCS) budget, health budget and social welfare budget is envisaged to set the plan in motion.

ARDSI Dementia India Strategy Report (2018) Seven Actionable Areas, Inspired by the WHO global Dementia action plan

1. Make dementia a national health and social care priority: Declare dementia as one of the national public health priorities
2. Dementia Awareness and dementia friendly communities: Develop comprehensive sustainable awareness information packages to address multi-stakeholders including service providers
3. Risk reduction and dementia prevention: Reduction of Non communicable diseases (NCD), alcohol consumption, salt intake, hypertension, tobacco, indoor air pollution, Increase Physical activity, availability & affordability of NCD drugs.
4. Improve access to best medical care, strengthen standard treatment protocols: Strengthen and augment tertiary care regional centres for elderly/dementia care, develop patient centric care plan and continuity of care plan.
5. Social support services: Inclusion into health insurance, standard civil dispute settlements, create dementia friendly environment in transport, welfare services, old age pension, legal service and medical care, develop area specific community friendly memory clinics/community models
6. Research and Development: Develop/discover/deliver new innovative dementia friendly devices, processes, drugs
7. Strengthen dementia disease surveillance system: Improve database/information management system through effective surveillance

Improving awareness about dementia among all sections of the society, will lead to better identification of people living with dementia and this in turn will create an increased demand for dementia related services. More visibility, discussions and demands for services should open the eyes of the policy makers and governments. While working towards a national endorsement of the Dementia strategy by the government, there is scope for action at state level and collaborative work with multiple stakeholders.

State Plans

Regional plans at state level are equally relevant in dementia strategy and planning. The targets may include raising public awareness regarding dementia, identifying people living with dementia in the community providing treatment, developing services for people with dementia, developing and delivering support services for caregivers, training the workforce, and improving public health research. The strategy needs to be built on early identification of people with dementia, providing care and support of people with dementia and palliative care during advanced stages. The strategy shall also include long-term measures to prevent dementia by developing and implementing public health interventions to reduce the incidence of dementia. Raising public awareness about dementia and its management is important.

We need to have a workforce who is capable of providing care and support for people with dementia. Capacity building of the formal care providers shall be taken up. A formal training program shall be developed and the opportunities for skill building has to be made available across the state. Many healthcare providers are reluctant to make a diagnosis of dementia as they think they have nothing to offer once the diagnosis is made. This scenario should change. Health care providers, especially those who have had no specialist training in psychiatry or neurology often do not recognise the important role for non-pharmacological interventions in dementia care. They often do not initiate simple basic interventions like provision of information about dementia and support for caregivers. These services are simple, basic and should be given to all. These interventions are in fact mandatory and those

affected by dementia and their caregivers will find it very useful.

Investing in the national health care system to develop an infrastructure to encourage and help healthcare staff to identify people with dementia is essential. Anyone above the age of 60 who comes in contact with any healthcare staff for any reason should have a brief screening to identify cognitive disorder. This shall be done by asking appropriate questions regarding their memory, executive functions and ability to carry out activities of daily living.

Multiple stakeholders

Dementia care and research involve multiple stakeholders including health and social care sectors, professional groups, university and research organisations and voluntary organisations. Hence a national strategy and plan endorsed by these stakeholder groups is likely to gain more attention and visibility. A Dementia alliance formed with multiple stakeholders like patient groups, academic communities, civil society representatives, professional organisations like Indian Psychiatric Society, Indian Neurological Association, Indian Psychological Association, Indian Social Workers Association, to name a few would make the strategy more participatory with a shared ownership and accountability. A mandatory political approval makes the way forward less difficult.

Dementia care spans across various national programmes and the use of available resources should be optimised. The plan should be a concerted approach by the local self, state and the central governments along with non-governmental agencies. There is a small but dedicated cadre of people who work tirelessly for the cause of dementia but there is a dire need to expand this base by attracting more people to join hands cutting across educational, economic and professional backgrounds to attain more credibility, visibility and attention.

ADI reports that it is waiting for a written letter from India's Ministry of Health affirming their commitments towards the national strategy. Creating better awareness about dementia and the challenges it brings and the consequences, among all sections of the society and developing a wider stakeholder base to attract political will are probably the strongest drivers to make the National Dementia Strategy a reality.

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USEFUL RESOURCES

Please verify the authenticity of information before using it.

<http://ardsi.org/>- Official website of ARDSI.

Helpline numbers: 9846198473/ 9846198471/ 9846198786

<https://dementiacarenotes.in/>- Comprehensive information on resources, tips, caregiver stories for dementia caregivers in India

<https://www.patientsengage.com/condition/dementia-> PatientsEngage- caregiver focused healthcare platform useful for India

<https://www.who.int/news-room/fact-sheets/detail/dementia-> World health Organisation resource for dementia

<https://www.alz.co.uk/>- ADI, international federation of Alzheimer associations around the world

<https://www.alz.org/>- Alzheimer's Association-leading voluntary health organization in Alzheimer's care, support and research in the USA

<https://www.alzheimers.org.uk/>- Alzheimer's Society- UK charity that campaigns for change, funds research into dementia

<https://www.dementia.org.au/>- Dementia Australia- represent Australians living with dementia and those involved in their care.

<https://www.alzscot.org/> - Alzheimer Scotland- Scotland's Dementia Charity

<https://alzheimer.ca/en/Home-> Alzheimer Society, Canada- not-for-profit health organization

<https://alzheimer.ie-> Alzheimer Society of Ireland-leading dementia specific service provider

<https://www.ninds.nih.gov/Disorders/All-Disor->

[ders/Alzheimers-Disease-Information-Page](#)

The National Institute of Neurological Disorders and Stroke

<https://www.alzheimersresearchuk.org/>- Alzheimer's Research UK - UK's leading Alzheimer's research charity

<https://www.youngdementiauk.org/> Young Dementia UK- dedicated national charity for younger people with dementia and their families.

<https://www.lbda.org/> Lewy Body Dementia Association- nonprofit organization whose vision is a cure for Lewy body dementias and quality support for those still living with the disease.

<https://www.theaftd.org/> - AFTD- The Association for Frontotemporal Degenerationimprove the quality of life of people affected by FTD

ARDSI Dementia Day care / Full Time Care Centre- Information available at

<http://ardsi.org/NationalofficecareCenters.aspx> (Accessed in October 2019)

KERALA

ARDSI Cochin Harmony Home, Old NKN Hospital Building Pazhangadu, Kumbalanghi South Cochin - 682 007, (Thopumpady). Project Officer, Mob: 9496592922 / Tel. 0484 224 0705 Email: cochinharmonyhome@gmail.com

ARDSI Comprehensive Dementia Day Care Centre, 2/115/B-B1/ Puthenkulangara Mana Road, Eroor North P.O, Mathur, Cochin-682306, Kerala. Social Worker Cum Care Manager
Tel. 0484-2775088

Email: ardsicochin@gmail.com

Dementia Respite Care Centre Ramavarmapuram P. O,Villadam, Milma stop, Thrissur -680 631. Project Officer, Mob: 8848950058 / Tel. 0487 2693232. Email: rccharmonyhome@gmail.com

ARDSI Malabar Harmony Home P.O. Marikunnu, Near NGO Quarters, Ambalaparambu Colony (via), Kozhikode - 673 012. Project Officer, Tel: 8893270500/9745907653 E-mail: mhhcalicut@gmail.com

Full Time Dementia Care Center, Snehasadanam, Lion's Bhavan, N.H.BYE Pass Road, Thiruvallam, Thiruvananthapuram – 695027. Administrator Phone: 0471-2384151 Mob: 9745097872/ 8281554872 Email: georgemathew_in@yahoo.com

KSID SMRUTHIPADHAM Day Care center, Kurukkenpara Via, Kavilakkad. Chittanjoor, Kunnamkulam - 680 503 SW-cum- Administrator Mob No.: 8592007762. Email: smruthipadhamgvr@gmail.com

KSID SMRUTHIPADHAM Full time care center, Illathupady, Edavanakkad, Ernakulam - 682 502. SW-cum- Administrator Mob. No. 9744795428 Email: ksidekm@gmail.com

KOLKATA

Dementia Day Care Centre P-5, Regent Estate, Ground Floor, Kolkata - 700092 Pro-gram Officer Mob: 9331039839/ 9830460306/ 8232014540 Email: ardsikolkata@yahoo.co.in

NEW DELHI

Dementia Day Care Center RZ-62/9, Tughlakabad Extension, New Delhi-110019. 9810829559 / 91-11- 29994940, 64533663 E-mail : ardsi_dc@hotmail.com

HYDERABAD

Dementia Day Care Center Zeba Bashiruddin Centre for Healthy Aging, # 8-2- 332/5, Road No. 3, Banjara Hills, Hyderabad - 500 034. Mob: 9618527072 Email: ardsihyd@gmail.com

GUWAHATI

Dementia day care center H/No-35, Arunudoipath, Opp. Hatigaon Namghar, Hatigaon, Guwahati-781038 (Office In Charge) Mob.7035907918 Email: djgoswami78@gmail.com

Dementia Day Care centre, SMRITIVISHWAM Universe of Memory 2, Ganesh Niketan No.1,- Prof. Agashe Road, Dadar (West), Mumbai - 400028. Secretary General, ARDSI Hon. Secretary, ARDSI- Mumbai Chapter Tel: 8286126890, Mob: +91 9757095327 Email: vishvidya9@gmail.com

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