# Assessment of Dementia Under Prevailing Indian Laws and Its Implications

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ementia is the main cause for clinically significant cognitive impairment among older people. We should be aware of the implications of current Indian laws when assessing and managing persons with dementia (PwD).

The diagnosis of dementia can be challenging at times. The use of standard diagnostic criteria with evaluation for reversible causes is mandatory. As dementia is a serious diagnosis with medico legal implications, the diagnosis needs to be backed by documentation of clinical features and relevant investigations leading to the diagnosis.

This viewpoint paper describes the issues related to the assessment of capacity and disability in PwD and its relevance in the context of Indian laws by collecting the relevant literature and the authors' clinical and forensic psychiatric experience and expertise. According to the Mental Health Care Act (MHCA) of India, 2017, all persons with mental illness are presumed to have the mental capacity to understand the information,

appreciate the foreseeable consequences of a decision, or communicate the decision by speech or gesture or any other means. The key components of the decision-making process are understanding, appreciating, reasoning, and communicating. Capacity assessment must be comprehensive. Indian disability evaluation and assessment scale (IDEAS) may be used to assess and certify disability in dementia. Clinicians need to be aware of the issues and implications related to advance directives, selection of nominated representatives, driving, and other prevalent Indian laws concerning PwD.

Awareness of medico legal aspects and relevant implementation during clinical practice and medical board evaluation will help protect the interests of PwD and reduce avoidable litigation, and protect the clinicians and service providers.

#### Introduction

Cognitive decline is common in late life. A significant proportion of community resident older people lives with clinically

cognitive impairment. Dementia is the main cause of cognitive impairment among people aged 65 years and over. The prevalence of dementia increases with age. It is essential to differentiate dementia from other clinical states like mild cognitive impairment (MCI) and other prevalent mental health conditions like depression. Dementia is a clinical syndrome that many diseases can cause. The onset and progression vary depending on the etiology, but onset is usually insidious with slow progression. Dementia often remains a hidden problem, more so in societies with low public awareness about dementia. Often, people with mild to moderate dementia do not get identified. Clinical recognition of dementia is easier in the clinical setting when its severity is moderate or severe. However, the diagnosis can be challenging in the case of MCI and mild dementia. As dementia impacts the individual's mental capacity, a thorough understanding of the implications of such impairments is necessary to clarify the issues related to the application of the current Indian laws.

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This viewpoint paper attempts to synthesize the relevant scientific literature in the light of the clinical and for ensic psychiatric experience of the authors ranging: early career psychiatrist (NC), mid-career neuropsychiatrist (MC), senior geriatric psychiatrist (KSS), and late-career psychiatrist with international experience (RK). We held discussions among ourselves and focused on certain areas relevant to people with dementia in India. We identified and reviewed relevant articles from PubMed and other electronic resources and deliberated on issues related to clinical practice. This paper describes our opinion and point of view on some of the many issues which clinicians encounter. The key considerations are described below.

#### **Diagnostic Challenges**

Clinicians should know the guidelines regarding the diagnosis of dementia and be familiar with International Classification of Diseases, Tenth Revision (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM 5).<sup>1,2</sup> The most important differential diagnosis of dementia is age-associated cognitive decline. This is much more common among older age groups, which is considered part of normal aging, and has no clinical significance.

MCI is another clinical condition that must be differentiated from early dementia. Further, MCI is more prevalent than dementia in the community. Behavioral impairment is also seen in persons with MCI. One study from a tertiary care center in India found impaired impulse control problems, emotional regulation problems, and reduced motivation in patients with MCI.3 Investigators have found written arithmetic, confrontation naming, immediate visual memory, and visual attention as significant correlates of declining financial capacity of persons with MCI.4 However, more research is needed about the nature of real-life problems faced by people with MCI.

In the case of dementia, the documentation of clinical features and investigations leading to the diagnosis is vital in every case. The diagnosis of dementia as per ICD-10 needs the symptoms to be present for a minimum period of six months. The duration criteria were designed to help avoid confusion with reversible states with identical

behavioral syndromes such as traumatic subdural hemorrhage, normal pressure hydrocephalus, and diffuse or focal brain injury. There could be a difference of opinion regarding this ICD-10 position, considering more cases are present earlier in the disease. Yet, it does highlight the need to rule out reversible causes, especially when the duration is short. In any case, the clinician shall make sure that reversible dementia is managed appropriately. Early diagnosis of reversible dementia is important not just from a clinical and social perspective for PwD and their caregivers; it is also critical from the medico legal perspective.

Only in metropolitan cities with public awareness or individuals with family history and experience of dementia may present themselves early in the course of the disease. In most cases, family members bring them when the condition has progressed to moderate or severe stages or behavioral symptoms. Whenever needed, the clinician shall facilitate the further clinical or neuropsychological evaluation of the PwD. A history of a clinically significant decline in cognitive functioning is essential for the diagnosis of dementia. A coresident family member is usually able to give such information. Multiple informants may have to be interviewed to get reliable information. The source of information needs to be documented and corroborated with other family members. It is essential to document the persistence or progression of cognitive dysfunction during follow-up visits. In case of any diagnostic uncertainty, especially regarding the differentiation between early dementia and MCI, it must be documented unequivocally. One could use the guidelines provided by ICD-10 or DSM-5 to grade the severity of dementia or use instruments like the clinical dementia rating scale.5

#### **Cognitive Assessment**

A baseline cognitive evaluation can be done with a simple test like mini-mental status examination (MMSE).<sup>6</sup> It is a commonly used screening tool for cognitive functions in usual clinical practice. It has many advantages such as it is easy to administer and requires no formal training. But, it has education bias leading to low scores for illiterate or less educated people even when they do not have

dementia. MMSE score does not directly correlate with the decisional capacity of the patient.<sup>7</sup> Patients with high scores can also have impaired capacity, although high scores may indicate better decision-making ability in general. It is better to use the MMSE in conjunction with other neuropsychological tests and clinicians' decisions based on the interview. The utility of an expert neuropsychological assessment has increasingly been recognized in supplementing the clinical evaluations to determine the decision-making capacity related to dementia.<sup>8</sup>

Hindi mental state examination and everyday abilities scale for India can be used as part of the assessment.9,10 Addenbrooke's cognitive examination can also be used to assess people with cognitive impairment.11 Montreal cognitive assessment can also be used as it has high sensitivity (0.96) and specificity (0.95) and good validity for the diagnosis of MCI, mild dementia, and dementia because of Parkinson's disease.12 Apart from English, it is also available in several Indian languages like Hindi and Marathi. Further, it is available in three versions to diminish learning effects if repeat testing is needed to be performed within three months of initial testing.13

Cognitive tests like the executive interview and formal neuropsychological tests such as trails A and fluency tests are also useful for measuring executive function and correlated with competency and mental capacity by previous researchers. 14-16

The assessment of capacity for everyday decision-making is another useful tool to understand the everyday decisional capacity of the patient. It uses a semistructured interview pattern with questions framed for caregivers to get information and to understand the patient's functional capacity. This tool can be tailored to access how a patient understands and appreciates a problem, the risks and benefits of the possible solutions, and the ability to reason through the choices involved in solving this problem.<sup>17</sup>

## Mental Capacity Assessment and Legal Implications

All individuals can make decisions independently, which is the fundamental

presumption as per Article 12 of the UN convention on the rights of persons with disabilities. Capacity is the ability to understand the benefits and risks of available alternatives, make and communicate an informed decision independently. According to the MHCA of India, all persons with mental illness are presumed to have the mental capacity to decide on their treatment decisions if they can understand the information, appreciate the foreseeable consequences of a decision, or communicate the decision by speech or gesture.18 The act stipulates the need for informed consent before admission, discharge planning, and various procedures and interventions.

There is a related construct called competence, which refers to the legal aspects of decision-making, especially regarding the ability to make a valid contract, financial and personal decision-making. While capacity is a clinical, task-specific, and dynamic construct (capacity can vary over time) for therapeutic decision-making, competence is a legal construct, not task-specific, but broad in outlook, and stable unless revoked or reestablished by a court of law.

It is also accepted that capacity is a spectrum, not a unitary, concept, which means a person has capacity in one domain and may lack capacity. For example, a PwD may make some therapeutic decisions such as clinical follow-up consultation with a treating psychiatrist but may need assistance for more serious therapeutic decisions like invasive procedures (supportive decision-making). However, it retains legal personhood. On the other hand, competence is a categorical construct, which is either present or not. Being declared legally incompetent limits a gamut of financial, professional, and personal decisions and allows for proxy decision-making with no legal role of supported decision-making.

As per Section 4 of MHCA 2017, memory loss or cognitive deficits or even a diagnosis of dementia does not imply incapacity automatically but emphasizes establishing capacity. MHCA provisions give preference to choices and wishes of a person for therapeutic decisions if the patient has the capacity. If a PwD lacks capacity, interpretation of choices and wishes, advance directives, nominated representatives can make decisions for such a patient.<sup>19</sup>

Therefore, the capacity assessment must be thorough and carefully formulated in each case. The importance of a comprehensive evaluation and keeping a good account of the clinical information in the medical records have been highlighted.20 A review of records on the decision-making capacity in adult guardianship found inadequate documentation of the person's cognitive, psychiatric, or functional abilities and their values and wishes. Merely their medical condition was often cited as evidence of impaired decision-making capacity.21 Clinicians shall therefore give due importance to documentation whenever a diagnosis of dementia is made. A diagnosis of dementia is a serious one and needs to be backed by sufficient and clear information leading to that diagnosis.

Assessing mental capacity is challenging for PwD. The mental capacity of PwD can be affected by multiple cognitive deficits. Only around 53 percent of patients with Alzheimer's dementia were found to have the capacity for everyday decision-making, as per one study from China.<sup>22</sup> Mental capacity can also vary from time to time depending on factors such as the presence of superimposed delirium, the effect of medications, concomitant stroke or lacunar infarcts, episodes of hypo or hyperglycemia, hypoxic states, and in cases of reversible dementias.

### Mental Capacity Assessment of a Person With Dementia

Capacity evaluations should be situation-specific, giving due consideration to the decision to be made. The decision to make may be financial, writing a will, driving, consent to participate in research, preparing an advance directive, appointing a nominated representative, or for admission and treatment for physical and psychiatric disorders. The clinician should understand the complexities of assessment and the implications of impaired capacity for particular situations. The clinician should work in the patient's best interests and spend adequate time with the patient and the family members during the evaluation. Sociocultural factors are also taken into consideration during the assessment process. It is imperative to keep detailed records of all such assessments. There is no gold standard test for capacity assessment. The report should be based on the clinical assessment carried out through direct interviews with the PwD and family members, and the results of neuropsychological assessments.

The following are the components needed for decisional capacity.<sup>23</sup>

- 1. The person should have the ability to comprehend the presented information, risks and benefits associated with it, and the decision to make.
- 2. The person should understand the personal implications related to the decision to take. The person should appreciate the risks and benefits and should give the reasoning for the decision.
- 3. The person should be able to make a decision and should be able to express it.

Assessment can begin with a direct interview with the person using openended questions followed by leading questions depending on the situation and the context. Sufficient efforts must be taken to simplify the process. Breaking the information into components, using easily understandable language, and repeating the information as and when needed are strategies that can be adopted. Providing opportunities for clarification of doubts and addressing concerns of the PwD are crucial to the process. We need to ensure the active engagement of the person and the family in the process of decision-making. It is important to give due consideration to the persons' autonomy and balance it with the duty of care. Further, clinicians should follow the other two key principles-beneficence and nonmaleficence. The expected temporal variations in the capacity should be considered and noted.

In hospital and resource-constrained settings, involving a multidisciplinary team can be very useful.<sup>24</sup> In most Western countries, impaired decision-making capacity is fundamental in declaring when people can't decide about various aspects of their lives.<sup>23</sup> If it relates to psychiatric treatment, the Mental Health Act takes care of such a situation, whereas the Guardianship Act takes care of medical conditions. For example, when a PwD has associated mental dysfunction with impaired

decision-making capacity and is a risk to himself or others, that person can be admitted to a public hospital under the MHA. And if such an individual needs immediate medical treatment, his best of kin could act as his or her health attorney or guardian to assist with the decision-making. If such an option is not available, the Guardianship board will appoint a public guardian to decide on behalf of the person. The law regarding this varies in different countries and even jurisdictions.<sup>25</sup>

#### **Advance Directive**

According to MHCA Chapter III, 5, every person has the right to make an advance directive. It helps persons decide how the person wishes to be cared for and treated for a mental illness. The way the person wishes not to be cared for and treated in the future.<sup>18</sup> There are practical challenges in the implementation of an advance directive in the case of dementia. In India, unlike many countries, the family members may be reluctant to discuss the prognosis of the illness with the affected person creating difficulties in care planning.<sup>26,27</sup> An advance directive and advance care planning must be done in the early stages of dementia. PwDs are often diagnosed in the later stages of the illness. The affected person would have developed significant cognitive impairment by that time and will not participate in an advance directive and advanced care planning.

Another controversy is that while considering the advance directive, the present wishes of the patient are not considered according to the MHCA. Once the patient loses the capacity to decide, their current wishes may not be considered, and only an advance directive will be considered. As advance directive is prepared in "normalcy/cognitive intact status" or earlier dementia, the patients may not be aware of their possible life course in the future. It is a possibility that the patient's preferences may change over time.28 There is a lack of research focus on the life experiences and preferences of PwD. Periodic revision of the advance directive can be done till the person loses his ability to make decisions and should be routinely offered in clinical practice. Senior citizens and the community also need to be given more information to raise awareness of this new concept of advance directive.

#### **Nominated Representative**

According to MHCA, 2017, every person shall have the right to appoint a nominated representative. There is a lack of clarity regarding selecting a nominated representative when there are conflicts in the family and the prospect of undue influence by a caretaker or family member.27 Elderly persons and their family members should be educated regarding the concept and procedures for selecting the nominated representative as per MHCA, 2017. The nominated representative may have to face many difficulties while taking decisions for the patient, giving due consideration to the previous wishes and the current health status of the PwD 29

### People With Dementia and the Criminal Justice System

A few studies in India examined psychiatric morbidity in prisons, but none had information on cognitive impairment or dementia in prisoners.30-32 With the aging population in many Western countries, there have been several PwD serving sentences.33 Of note, there are two reasons for this: Prisoners with a criminal history serving a long-term sentence might grow old in prison and develop dementia. Another being a small number of elderly being sent to jail were unable to plead "not guilty because of dementia" when committing their crimes. A survey in UK prisons found that 12 percent of prisoners aged 50 years and over had cognitive impairment.34 It has been pointed out that the current prison environment is not suitable for the elderly, and there need to be separate facilities for the elderly offenders.35

Another critical aspect to consider in this context is the fitness of the elderly offender to plead and stand trial. The trial procedures are often complicated and time-consuming, and the elderly offender with cognitive impairment may not understand the process well. In addition to impairment in several cognitive domains, their physical conditions such as frailty, hearing, and visual impairment might also affect their ability to instruct their lawyers.

Several associated factors such as delusions, mood disorders, misidentification syndromes, disinhibition, or impulsivity can lead to incarceration in PwD. While these disorders (aka behavioral and

psychological symptoms of dementia) can occur in any stage of Alzheimer's disease, such presentations are typical in patients with frontotemporal dementia (FTD) at a very early-stage disease. The behavioral variant of FTD can present with severe impairment in social cognition, moral processing, and decision-making.<sup>36</sup> The most common offenses by patients with dementia include violence, sexual offense, and drugs-related offense. Others include theft, sexual harassment, and traffic offenses.

Most prisons do not have a psychiatrist. The medical officer may be visiting the prison, and symptomatic patients may be taken to a hospital for psychiatric consultation. There is a need for further research into this issue to develop better cognitively impaired older people in prisons.

#### **Driving and Dementia**

It is pertinent to note that several people with dementia drive vehicles, as having a diagnosis of dementia is not enough to stop someone from driving. Driving requires several abilities, including an intact neurocognitive system, adequate sensory-motor, and visual functions.<sup>37</sup> An assessment of various cognitive domains will become a requisite when PwD are required to be assessed for fitness to drive. Besides, the stage of dementia and the type of dementia also need to be considered. For example, a patient with MCI may still be able to drive, although careful monitoring of the progression of the diseases is needed.

The need for training for the primary care physicians who often come across a patient with dementia has focused on western countries' attention. General practitioners are expected to consider several factors in determining the fitness for a demented person to drive.<sup>37</sup> It is mandatory for PwD or relatives to inform the licensing authority about the diagnosis in many Western countries. In the UK, a person can be fined up to 1000 pounds if such information is undisclosed. Once a diagnosis is made, the clinician should advise the patient about this rule.

In India, the scenario is different. The Motor Vehicle Act, 2019, has continued the traditional focus on visual acuity, hearing ability, and locomotor disability for granting or not granting a driving license and its renewal without considering the psychological competence required to drive. Hence, there is no legal

basis for allowing or denying a driving license to the PwD even though clinical advice is often given to PwD and their carers to refrain from driving depending on their severity of dementia, slowness reflexes, and visuospatial deficits. Future regulations may look at how to include cognitive assessments for older adults who want to drive.

#### Dementia and Research

Research participation of patients with dementia is a contentious topic. A recently conducted conference focused on this topic, and it deliberated on its many facets and how to protect rights of people with dementia when participating in research.38 Dementia patients in palliative care setting lacking the capacity to make decisions to participate in research is a matter of concern. In such situations, it is important to get the family members involved from the inception of the study design throughout the research.39 It is the responsibility of the researchers to protect the rights of PwD participating in research. This aspect is being elaborated in another paper in this special issue of the journal.

#### **Undue Influence of Person** (Coercion) and the Legal **Implications**

In many legal situations, the clinician may need to investigate the undue influence of an older adult by a caretaker or any other person. Undue influence must be suspected if the excessive persuasion of another person overcomes the person's free will or decisions contrary to personal well-being or stated positions are taken. This is particularly important in the case of making a living will and power of attorney. It is tough to determine the role of the influencer in the decisions of the older person. The clinician should carefully consider the history of the PwD, evaluate any supporting documents (like previous communications, previous will, diaries, and journals), and evaluate the dynamics of the influencer's ongoing relationship. This is no easy task as in the collective forensic psychiatry, the experience of the authors who have individually called on to assess provide their opinion on such cases as expert witnesses in the court of law.

#### **Dementia and Disability**

Disability is a complex interaction of individual impairment on account of illness, attitudinal and environmental factors vested in the societal domain.40 Disability because of dementia depicts this complex interaction as a daily reality for PwDs and their caregivers. Perhaps, dementia being a neuropsychiatric illness falls in the domains of both psychiatrists and neurologists. This probably had resulted in fragmented advocacy for the rights of PwD. Nevertheless, dementia was among the initial four neuropsychiatric disabilities for which the IDEAS was created for its assessment 41

The unique issues of PwD had not been adequately addressed in the Rights of People with Disability Act, 2016 (RPWD Act, 2016). The RPWD Act, 2016, a law compliant with the united nations convention on the rights of person with disabilities (UNCRPD), took into account the unique sociocultural issues and resource constraints faced by the disabled population in India.42 However, the Act's focus is limited emphasizing operationalizing definitions, assessment and certification of various disabilities, and ensuring the rights of persons with disabilities.<sup>43</sup> However, there is a definite under emphasis on "nonvisible" disabilities because of mental illness and dementia, especially in legal decision-making, safeguards, and facilities to fulfill basic needs. The issues of guardianship and custodianship of assets of the PwD are not adequately covered. The conventional legal position rests on establishing competency and testamentary capacity to manage self and assets. It does not consider the unique nature of the diagnosis of dementia, which is often a progressive disorder affecting an older person with multimorbidity.

#### Indian Laws About PwD

Some laws are of special interest to PwD. The Maintenance of Parents and Senior Citizens Act, 2007, while commendable in its vision, does not address senior citizens' unique psychosocial and legal concerns with dementia. Because of the nature of the illness, they may not invoke legal processes to get maintenance.44 Likewise, the Protection of Women from Domestic Violence Act, 2005, does not have any special provisions for female PwD whose cognitive issues make them even more vulnerable while also impeding their chances of seeking redressal.<sup>45</sup>

#### Conclusion

Dementia is a devastating disease, and we will see an increase in the number of people with dementia in the coming decades. Therefore, clinicians need to be aware of the prevailing laws that have implications for assessing and managing older people with dementia. The health and social care of people with dementia is a social responsibility. We need to look at the prospect of making improvements in the existing legal framework to protect the interests of older people affected by disabling health conditions like dementia, which rob people of their capacity to lead an independent life.

This viewpoint paper describes the issues related to assessing capacity and disability in PwD and its relevance in Indian Laws. According to the MHCA of India, 2017, all persons with mental illness are presumed to have the mental capacity. Capacity assessment must be comprehensive. IDEAS may be used to assess and certify disability in dementia. Clinicians need to be aware of the issues and implications related to advance directives, selection of nominated representatives, driving, and other prevalent Indian laws concerning PwD.

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