

The ‘Lost Years’ of Dementia in India: Analysis of Diagnostic Latency and Barriers

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Background

- While global projections indicate that the number of people living with dementia will reach **153 million by 2050**, India faces a distinct and escalating crisis, with recent national estimates from the LASI-DAD study identifying a **7.4% prevalence** among adults aged 60 and older—translating to 8.8 million people currently living with the condition. Despite this, there is still diagnostic delay because they present late due to lack of public awareness, clinician awareness, clinical training and limited infrastructure.
- Objective:** This study investigates the barriers to early care and diagnosis in an urban Indian tertiary care context.

Methods

- Study Design:** Prospective, cross-sectional observational study (2024–2025) at an urban specialist tertiary care center.
- Cohort:** 61 patients presenting with cognitive impairment lasting >3 months.
- Cognitive Assessments:** Montreal Cognitive Assessment), Addenbrooke's Cognitive Examination-III and the Clinical Dementia Rating scale.
- Psychosocial Impact:** Caregiver burden measured using standardized scales: IQCODE.
- Delay in diagnosis:** Time taken from symptom onset to diagnosis being > 6 months.
- SES scale: **Modified Kuppuswamy scale.**

Baseline characteristics				
Baseline characteristics	Major NCD	Minor NCD	Subjective cognitive impairment	
STUDY POPULATION (61)	34	20	7	
Gender				
Male	25	14	5	
Female	9	6	2	
Age distribution at onset:				
<65 years	14	11	2	
>65 years	20	9	5	
Education status				
> 12 years	17	17	7	
<=12 years	13	2	0	
Illiterate	4	1	0	
Number of Languages known to patient				
1	19	7	1	
2	9	6	1	
3+	6	7	5	
Mean age at Onset	61.9±9.3	65.5±9.4	71.6±8.7	
Mean age at diagnosis	65.1±9.2	67.8±9.4	73.4±8.3	
Mean time from onset to diagnosis	38.7±25.5	26.3±20.3	22.3±13.9	
First Symptom:				
Recent episodic memory	20	12	5	
Behaviour abnormality	10	3	0	
Working memory + attention + executive dysfunction	4	0	0	
Parkinsonism present	20	3	1	
Positive Family History	6	3	2	
Co-morbidities	22	15	4	
Hypertension	15	10	3	
Diabetes	10	7	2	
Clinical Scores				
IQ CODE	4.47±0.6	3.51±0.4	3.37±0.3	
MOCA	13.9±12.5	22.9±13.2	27±2.6	
ACE iii	60.3±16.5	83.6±7.9	94.1±3.8	
CDR	1.9±1	0.5±0.5		
0.5	0	1	7	
1	2	15	0	
2	2	4	0	
9				
3	23	0	0	

Summary of Results

DEMOGRAPHICS & CLINICAL PROFILE

- In this cohort of 61 patients (72% male; mean education: 12.9 ± 4.7 years), the **mean age at symptom onset was 64.2 ± 9.8 years**, and the **mean age at diagnosis was 66.9 ± 9.7 years**. Cases were evenly distributed between young-onset (50.8%) and late-onset (49.2%) presentations. Among the 34 patients with Major Neurocognitive Disorder (**mean CDR: 1.9 ± 1.0**), primary subtypes included **Alzheimer's Disease (35.3%)**, **Frontotemporal Dementia (20.6%)**, **Dementia with Lewy Bodies (17.6%)**, **Vascular Dementia (17.7%)**, **Corticobasal Syndrome (5.9%)**, and **Parkinson's Disease Dementia (2.9%)**.

Severity at First Presentation (Distribution of CDR Scores)

Drivers of Diagnostic Latency (Major Neurocognitive Disorder, Delay > 6mo, n=34)

SOCIOECONOMIC PARADOX (Major Neurocognitive Disorder, n=34)

- Diagnostic Latency:** All patients experienced diagnostic delays, with a mean latency of 38.7 ± 25.5 months (Range: 8–120 months).
- The Educational Divide:** Highly educated patients experienced longer time to diagnosis (44.9 ± 33.0 months) than less educated patients (32.5 ± 13.1 months).
- The Gender Divide:** Men faced a mean time to diagnosis of 41.8 ± 27.7 months, compared to 30.2 ± 16.6 months for females.
- Primary Barriers:** Incorrect initial diagnoses and symptom neglect were the predominant barriers across all subgroups. Notably, financial constraints were reported exclusively in the female subgroup (11%).

The Socioeconomic Paradox in Major Neurocognitive Disorder (Diagnostic Latency: Mean ± SD, n=34)

CAREGIVER IMPACT

- Perceived Functional Decline:** The cohort demonstrated a mean IQCODE score of 4.01 ± 0.68. Within the Major Neurocognitive Disorder subgroup, this mean score rose to **4.47 ± 0.59**.
- Burden Distribution:** 41% of caregivers reported moderate-to-severe or severe burden. Severe burden was noted *exclusively* in patients presenting with Major neurocognitive disorder.
- The Burden Threshold:** While 38%–42.6% of caregivers reported little to no burden, this was largely restricted to patients with early-stage cognitive impairment.

Discussion

The Socioeconomic Paradox: Higher education levels paradoxically correlate with longer diagnostic delays, suggesting that affluent populations may rationalize early symptoms, whereas lower socioeconomic groups underreport illness due to limited awareness until overt functional impairment emerges.

The Clinical Burden of Late Presentation: Over one-third of the cohort presents at a severe stage of cognitive impairment, confirming that caregiver crisis often serves as the final, desperate catalyst for seeking specialized intervention.

Systemic Barriers: High rates of symptom neglect and initial misdiagnosis reveal critical failures in primary care referral pathways that stall the diagnostic journey long before patients reach a neurologist.

A Shift in Dementia Care: With increasing presentations of mild or subjective cognitive impairment in younger individuals, proactive monitoring of vascular risks and longitudinal symptom progression is essential to prioritize early brain health interventions.

Conclusions

- The "Lost Years" of diagnostic latency are not a financial failure, but a systemic one—driven by symptom neglect and initial misdiagnosis.
- It is crucial to understand that **Dementia is not synonymous with aging**.

To bridge this gap, India must prioritize:

- Primary Care Capacity:** We propose strengthening of primary care services with improved clinician network, training and awareness.
- Public Health Awareness Campaigns:** Targeted, high-impact messaging to break the stigma of dementia and promote brain health measures and initiatives
- Integrated Care Pathways:** Scaling specialized memory clinics to ensure patients are routed to expertise long before reaching severe stages.

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