

Under One Umbrella: Shared Lives of Persons with Cognitive Impairment and Carers Dyads in India

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KEY TAKE AWAY: Cognitive impairment is a co-constructed, dyadic experience where relational interdependence, preservation of selfhood and a collectivist family system reshape the lived reality of cognitive decline.

INTRODUCTION

- Major Neurocognitive Disorder (MNCD) and Mild Cognitive Impairment (MCI) are critical public health concerns that profoundly disrupt an individual's cognitive health, core personhood and relationship dynamics (1).
 - Traditional biomedical and epidemiological frameworks prioritize objective tracking of individual cognitive deficits, creating a significant gap in understanding the relational and socio-culturally embedded experience of decline (2).
 - In India, dementia care is localized within the family unit, heavily governed by collectivist values, joint family structures, gendered expectations and a cultural normalization of aging that frequently delays medical help-seeking (3,4).
- Research Question:** How do persons with cognitive impairment (PWCI) and their carer dyads collectively experience and make meaning of the realities and difficulties of navigating through cognitive decline?

METHODS

1. Design & Philosophy

Framework: Interpretivist-Phenomenology executed via Reflexive Thematic Analysis (RTA) (5).
Design Flow: Interpretivism → Research Question → Methods → Relativist Ontology → Subjectivist Epistemology

Core Stance: Cognitive impairment is treated as multiple, fluid, lived realities (**Relativism**) co-constructed through shared dyadic relationships (**Subjectivism**).

2. Setting & Participants

Setting: Cognitive Clinic, Bangur Institute of Neurosciences (BIN), Kolkata, India.
Cohort: Purposive sample of 13 Bengali dyads (N = 26 total participants). Sampling stopped at the Information Power baseline.
PWCIs: Age 56–72 (Mean: 63.76); Clinical Dementia Rating (CDR) scores 0.5 to 2 (6); middle to lower-middle socioeconomic class.

3. Data Collection & Processing

Method: Face-to-face, in-depth, semi-structured interviews
Dyadic Protocol: Two separate, sequential sessions per family unit:
PWCI Session: Explored lived experience of cognitive shifts
Carer Session: Explored functional difficulties, role shifts and coping with the changes.

Language& Integrity: Conducted in Bengali, transcribed verbatim and translated to English. Cultural equivalence verified using independent back-translation.

4. Analysis & Rigor

Analytical Tool: Manual 6-phase RTA (Braun & Clarke) using conceptual matrix charts (5).
Coding Depth: Interpretative latent coding to actively interpret psychological and socio-cultural meanings of loss and dignity.
Rigor over Metrics:

- Data Triangulation:* Cross-validating PWCI and carer narratives.
- Collaborative Reflexivity:* Deep, iterative dialogue between researchers (DB & BB) to resolve interpretive nuances.
- Reflexive Journaling:* Actively auditing researcher positionality against collectivist Indian care assumptions.

RESULTS

Theme 1: The Creeping Shadow: Navigating the Ambiguity and Belated Realization of Cognitive Decline

PWCI's Quote: *"I saw that I have bring home only 3–4 things out of five... it happened few times... then I understand I am forgetting things on a regular basis"*

Carer's Quote (Son): *"In the evening, when people return home from work, he sits quietly and keeps looking in that direction, and sometimes says, 'Look what I have become.' The fact that he can't do anything anymore causes him a lot of pain."*

Theme 2: Disrupted Livelihood: The Practical and Existential Erosion of Daily Routines and Vocational Roles

PWCI's Quote: *"There are times when I am making a pot and I... forget to take it out... so it turns into waste"*

Carer's Quote (Wife): *"If he doesn't see me for a short time, he becomes anxious... As soon as I return, he asks, 'Where did you go?'... And he gets angry over everything; I don't know what to say."*

Theme 3: Anchored in the Past: The Strained Present of Anomia and Memory Loss vs. the Sanctuary of Autobiographical Recall

PWCI's Quote: *"I sometimes forget to do daily work. Everyday household work, such as bringing the clothes from outside... I don't do much work at home these days."*

Carer's Quote (Daughter): *"She remembers old memories very well... relates everything about our relatives"*

Theme 4: Metamorphosis of Self: Navigating Affective Shifts, Personality Transformations and Relational Friction

PWCI's Quote: *"I cannot stay alone, I am fearful. I want my daughter or husband around."*

Carer's Quote (Daughter): *"My mother is becoming very childlike... If there is even a slight delay in giving her food, she gets very angry. She behaves very badly with everyone, especially with my father."*

Theme 5: Under One Umbrella: Relational Interdependence, Adaptive Coping and the Demands of Family Caregiving

PWCI's Quote: *"I am with my wife most of the day. I do whatever she asks me to do."*

Carer's Quote (Wife): *"Now I always keep him with me. For example, when I drink water, I think that since I felt thirsty, he must be thirsty too. So I give him water at that time..."*

Theme 6: The Armour of Denial: Safeguarding Dignity and Resisting the Reality of Cognitive Deterioration

PWCI's Quote: *"I don't have any problem as such. I used to have problems in remembering, now I can remember."*

Carer's Quote (Husband): *"I am standing by the fire with her until she turns off the gas... the doctor has advised me to keep her active but she forgets the steps"*

CONCLUSIONS

Relational Interdependence:

Interdependence is the defining characteristic of dementia within Indian households; a person's behavioural adaptation is thoroughly inseparable from the carer's daily involvement (1).

Behavioural Shifts: While emotional and personality transformations have an underlying neurocognitive basis, their real-world expression and interpretation within the household are profoundly shaped by family dynamics, threats to occupational identity and the psychological dread of becoming a family burden. (7).

Implications for Practice: Clinical models must move past individualistic, deficit-focused assessments. There is an urgent need for the development of culturally sensitive, strengths-based and family-focused models of dementia care in India (1).

Healthcare Recommendations: Systems must emphasize early detection, structured family psychoeducation and context-specific intervention outlines that respect dignity, continuity of “selfhood” and relational well-being (1,8).

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