

Framing Alzheimer's Disease in India Through Self, Familial, Social, and Governmental Perspectives

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Conceptualizing the Disease

- AD awareness is increasing among the public, yet the condition is **not yet widely recognized as a disease** at the local level. This leads to alternative means of explaining symptoms by **bypassing the biological aspect**.
- Individuals with memory and cognitive issues may be described as *sathyavaana* ("being in the 60s)," normalizing elderly memory loss as part of the aging process. Symptoms are not perceived as surpassing the **threshold of normal aging** into the diseased state.
- Symptoms have been attributed to age, overwork in the office, loneliness, black magic, and punishment from God – none of which are tied to a particularly specific disease.
- Typical conversations about medicalizing AD do not translate into some communities because there is not as much of a **social distinction between the normal and the pathological in the elderly**. From a feasibility standpoint as well, there is no equivalent phrase to describe AD in vernacular languages.



Self and Social Perceptions

- AD introduces **loss of self-autonomy and respect** – transforming affected individuals into a "nonperson." As they progress through the disease stages and begin to lose control of their mental and bodily functions, they increasingly rely on caregivers (mostly family members) to care for them. This immobilization aspect can be considered a "sign of the loss of selfhood," and the disease ends up transforming into a "critical metaphor for death."
- Because surrounding community members witness the progression of symptoms but may not understand that the symptoms constitute AD as a medical problem, the ill person experiences **social stigma, shame, and embarrassment**. This can make it difficult for the ill person themselves or their family members to help seek needed support. Based on local beliefs, some families may wish to **prioritize their dignity and social perception** in the community by ignoring the condition and avoiding medical care.
- Traditionally, **intergenerational** relationships are at the heart of Indian households, but this structure is **dissolving** due to industrialization and urbanization. As a result, the elderly feel that they do not command as much respect in their family as the intergenerational hierarchy leader when compared to past traditions. This not only catalyzes internal conflict about the elderly's role in the family, especially as their symptoms become more intense and debilitating, but also brings about new fears.



"Masimas" as Transitional Caregivers

- Masimas* ("aunties") are hired female caregivers who relieve family caregivers of day-to-day household responsibilities, allowing them to recuperate from the difficult physical and emotional demands of caregiving. Patients and *masimas* may build meaningful social bonds, so *masimas* can **support well-being** of both patients and family members.
- Unlike hospital-based care, the *masimas* work within the family's home environment, and their salaries are much lower compared to professionally-trained caregivers. Even though family members pay *masimas* to provide care, there is **reduced perception that care is being commodified**.
- Usage of *masimas* has increased due to **urbanization** and fewer family members residing in the same household.
- Hiring a *masima* could help **maintain community perception of parental responsibility**, since children are not entirely abandoning their parents. However, this comes with a certain level of **financial affordability** that typically is experienced by upper-middle-class families.



- Alzheimer's Disease (AD) is a **leading causes of illness and mortality** among elderly, with an estimated **3.7 million Indians** over the age of 60 years old living with dementia; this number may nearly quadruple to 14.3 million individuals within the next few decades.
- Therefore, it is important to consider the impact of Alzheimer's disease on the elderly population, both from a medical and social standpoint.
- This study integrates a **medical anthropology** lens (heavily centered on analysis of Lawrence Cohen's *No Aging in India: Alzheimer's, The Bad Family, and Other Modern Things*) to explore the impact of Alzheimer's Disease in India, encompassing self and social conceptualizations of the disease, familial caregiving, the role of healthcare professionals, as well as government policies.
- Overall, this study advocates a **multifaceted approach** to addressing Alzheimer's in India through deconstructing social stigma, sustaining family-based caregiving with "senior recreation daycare models," and expanding institutional elderly care. Addressing the rural-urban access gap and bridging traditional and biomedical perspectives are further crucial steps in combating the impact of the disease.

Policies and Governmental Support Frameworks

- The public health sector has primarily focused on preventive child and maternal health issues, and the number of aging AD individuals could **overwhelm the already strained system**.
- The government is pushing for more elder care to take place at home through **policies** such as the Senior Citizens Act, which provides tax relief for family members who are taking care of elderly relatives. This has resulted in only 2.73% of elderly care nationwide taking place through formal institutions.
- Governmental care institutions are based in large cities, which is exacerbating the **rural-urban access divide**. The Rural Unit for Health and Social Affairs Department has proposed establishing a "**senior recreation day care**" and "**social clubs**" model, which is constructed with aging individuals' needs in mind and serves as a support system for family caregivers. Mobilizing this model can combat social isolation and build resilience for both the patients and family caregivers.
- A national-level challenge to address the public health burden of AD is **cultural diversity**. Each individual family, neighborhood, community, region, and state fosters their own local traditions and norms, which makes it difficult to account for all possible factors when designing interventions and policy frameworks.



Familial Caregiving

- Filial piety** as *seva* ("service") is centered on respect and care for parents as a form of divine worship. Caregiving can lead to extreme expectations and burnout, especially for "sandwich" caregivers supporting both children and parents. The family caregivers become the "hidden" victims of the disease.
- Gendered basis of care**, with women being forced to take on the caregiver role. Per Hindu values, it is a male child's responsibility to care for aging parents, so the responsibility falls to the son and primarily the daughter-in-law, causing relationship strain.
- The PICA trend (standing for "Parents in India, Children Abroad") to describe how parents remain in India while children **migrate internationally** for professional opportunities. Children abroad provide **financial caregiving**, while family remaining in India provide **emotional caregiving**. This causes unsustainable push-and-pull, as conflicts arise about the best ways to provide care for aging parents.



Healthcare Professionals and Institutional Care

- It is likely for AD to be diagnosed by a physician's suspicion only during a hospital visit for an unrelated bodily concern (e.g. knee pains or teeth problems). By this point, it can be too late to slow the deterioration. As the doctor is not able to fully cure AD or slow the progression, the family can **perceive the doctor as unhelpful**.
- Even if families suspect that an elderly relative's cognitive problems go beyond the threshold of "normal" aging, they may hesitate to seek a formal diagnosis because they believe it would not make a difference. The patient may not have the cognitive capacity to understand the diagnosis themselves, and the **unfamiliar, "western" disease status carries as a stigmatized label**.
- Traditional remedies** (e.g. Ayurveda) may be sought out prior to seeking professional help because of increased familiarity, trust, relative affordability, and access. For example, it is believed that meditation, yoga, and herbal remedies can resolve depression and memory loss. There could potentially be a bridge if biomedical procedures are used to manage the symptoms of the disease while Ayurvedic practices are incorporated into daily routines to support overall well-being.
- Though **government-funded elderly care homes** exist, they have limited funding, staff, and resources; the vast majority will reject caring for AD patients who require specialized care.
- Living in institutional care centers is a taboo as they are viewed as symbols of "social degeneration" with elderly relatives being "dumped" and *seva* being "commercialized."
- With the Indian healthcare system being mostly privatized, **out-of-pocket costs** and travel from rural to urban areas pose a barrier to lower socioeconomic class families seeking professional healthcare.

