

Understanding the Minds Behind the Care: A Psychographic Study on Dementia Caregivers in Rajasthan

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ABSTRACT

Dementia affects more than 8.8 million people in India, with this number expected to triple by 2050 due to rising life expectancy and demographic shifts. As the burden of care overwhelmingly falls on family members and frontline workers, understanding the psychological, emotional, and motivational profiles of caregivers is critical. This pilot study presents a psychographic analysis of dementia caregivers in Rajasthan using a cluster randomised controlled design. Thirty caregivers were assessed using a structured questionnaire evaluating traits like emotional stability, stress, values, coping styles, and motivations. Findings indicate that while most caregivers are driven by love, duty, and empathy, they often suffer from emotional exhaustion and a lack of institutional support. The study highlights the urgent need for psychographic-based interventions tailored to caregiver profiles, which could improve both caregiver well-being and patient outcomes.

Keywords: *Dementia, Caregivers, Psychology, Interventions, Stress, Coping styles, India*

Dementia is a group of neurological disorders characterized by a progressive decline in cognitive function, affecting memory, thinking, behavior, and the ability to perform everyday activities. Alzheimer's disease, the most common form of dementia, accounts for 60-70% of cases. Dementia is not a normal part of aging, although age is the most significant risk factor. It severely impacts not just the patients but also their families, communities, and the healthcare system at large.

According to the World Health Organization (WHO), over 55 million people globally live with dementia, with nearly 10 million new cases reported every year. The economic cost of dementia worldwide is estimated to be over US\$ 1.3 trillion, a figure that will double by 2030 if adequate measures are not taken.

In India, the dementia burden is rapidly increasing, primarily due to improvements in life expectancy, urban migration, and demographic aging. A comprehensive study by the Alzheimer's and Related Disorders Society of India (ARDSI) estimates that more than 8.8 million people in India were living with dementia as of 2021. This number is expected to

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increase to over 16 million by 2036 and over 30 million by 2050, placing India among the countries with the highest number of dementia cases.

Dementia in India: A Growing Crisis

India is home to over 139 crore (1.39 billion) people, with more than 138 million individuals aged 60 years and above as of the 2021 Census projections. This aging demographic presents a growing challenge for dementia care. However, India still lacks a national dementia policy, and dementia is not recognized as a health priority in many state-level health initiatives. Recent surveys show that:

- Only 10–15% of dementia cases in India are formally diagnosed, mainly due to lack of awareness, stigma, and limited access to specialist care.
- Around 70–80% of dementia care in India is provided by informal caregivers, often family members without medical training.
- Most people with dementia live in rural or semi-urban areas, where health infrastructure is weak, and cultural factors often delay diagnosis and treatment.
- Despite these alarming statistics, dementia continues to be misunderstood, often seen as a part of “normal aging” rather than a clinical condition requiring intervention.

Rajasthan: Regional Profile and Dementia Challenges

Rajasthan, the largest state in India by area, is home to over 78 million people (as per 2021 projections), of which around 9.6 million are senior citizens. The state has witnessed a sharp demographic transition, with improved healthcare access increasing life expectancy. However, with these changes comes a corresponding rise in age-related diseases, including dementia.

Key data and issues specific to Rajasthan include:

- Rural-urban divide: Over 75% of Rajasthan’s population resides in rural areas, where access to neurological care is minimal.
- Low awareness: A state-level survey in 2022 by a Jaipur-based NGO revealed that less than 20% of rural families could correctly identify the symptoms of dementia.
- Limited mental health services: Rajasthan has only 1 psychiatrist per 250,000 people, far below the WHO recommended ratio. Neurologists are even fewer, mostly concentrated in Jaipur, Jodhpur, and Udaipur.
- Cultural challenges: The elderly are often cared for by female family members (daughters-in-law or spouses), and dementia is frequently attributed to “old age madness” or spiritual afflictions, further delaying care.

In this context, caregiving in Rajasthan is heavily reliant on informal, unpaid, and untrained caregivers, making it crucial to understand the psychological and emotional characteristics of such caregivers.

Who are Dementia Caregivers?

In the absence of a strong formal support system, the majority of dementia patients in India are cared for by family members, including spouses, children, daughters-in-law, or sometimes by community health workers in rural areas. These caregivers often juggle caregiving with employment, housework, and child-rearing duties.

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In Rajasthan, women constitute nearly 75% of all informal caregivers. These caregivers perform tasks ranging from medication management and feeding to personal hygiene, emotional reassurance, and supervision of behavioral disturbances such as wandering, aggression, or delusions.

Despite their critical role, dementia caregivers are:

- Undertrained: Few receive any formal caregiving training.
- Underpaid or unpaid: Most are unpaid family members.
- Overburdened: High levels of stress, emotional exhaustion, and burnout are common.
- Psychologically strained: Many suffer from depression, anxiety, and social isolation.

Need for a Psychographic Study?

While various studies have explored the economic and physical burdens of caregiving, very few have focused on the psychographic dimensions — which include personality traits, values, motivations, attitudes, stress levels, and coping mechanisms.

Understanding these dimensions is important for several reasons:

- Better Targeted Interventions: Knowing what motivates a caregiver (e.g., love, duty, spiritual belief) helps design training and support interventions that resonate with them.
- Mental Health Screening: Psychographic traits can be predictive of burnout, depression, or emotional exhaustion.
- Improved Patient Care: Caregiver traits are directly linked to the quality of care provided. For instance, a compassionate caregiver may handle aggression differently than a duty-bound but emotionally detached one.
- Policy and Program Design: Psychographic segmentation allows health authorities and NGOs to tailor caregiving support systems for different caregiver profiles.

LITERATURE REVIEW

Caring for individuals with dementia presents multifaceted challenges—emotional, physical, and psychological. The psychographic dimensions of caregivers, particularly in culturally diverse and resource-constrained settings like Rajasthan, remain underexplored. Psychographics encompass attitudes, values, interests, motivations, and lifestyles, providing a deeper understanding beyond demographics (Schiffman & Kanuk, 2010). This review aims to synthesize literature on dementia caregiving with an emphasis on the psychographic profiles of caregivers, particularly in the Indian and Rajasthani contexts. Dementia is one of the most significant health and social care challenges of the 21st century. The World Health Organization (2021) reported that over 55 million people globally live with dementia, with nearly 10 million new cases annually. The global cost of dementia care is estimated at \$1.3 trillion, projected to rise to \$2.8 trillion by 2030 (WHO, 2021).

India is home to 8.8 million dementia patients as of 2021, expected to increase to 16 million by 2036 and over 30 million by 2050 (ARDSI, 2021). Diagnosis rates remain low (10–15%) due to stigma, lack of awareness, and limited access to specialist care (Banerjee, 2010).

The majority of caregivers in India are family members, particularly women. These caregivers face dual challenges — performing emotional and physical caregiving duties while managing household responsibilities and employment.

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Dementia is a chronic neurodegenerative condition characterized by cognitive decline, affecting memory, reasoning, and social functioning (WHO, 2021). Globally, over 55 million people live with dementia, with a substantial share residing in low- and middle-income countries (Prince et al., 2015). In India, approximately 4.1 million people live with dementia (Shaji et al., 2010), placing a heavy burden on informal caregivers, primarily family members.

Caregivers often face emotional exhaustion, physical strain, and financial stress (Brodaty & Donkin, 2009; Schulz & Martire, 2004). These challenges can lead to caregiver burnout, depression, and anxiety (Pinquart & Sörensen, 2003).

Psychographics help identify caregivers' inner drivers—values, beliefs, and motivations (Solomon et al., 2013). Studies show that intrinsic motivators such as duty, love, religious beliefs, and cultural values play critical roles in shaping caregiver behavior (Cheng, 2017; Park & Schumacher, 2014).

Lifestyle segmentation, a key psychographic tool, reveals clusters such as "emotionally resilient," "traditional duty-bound," or "passive-religious" caregivers (Jang et al., 2004). In Indian caregiving, religiosity and collectivist values are powerful motivators (Gupta & Pillai, 2012).

Rajasthan's socio-cultural landscape is shaped by traditions, caste dynamics, and strong family bonds. Extended families and patriarchal norms influence caregiving roles, often placing women at the center (Kumar & Choudhary, 2018). Here, "**sewa**" (**service**) is not just a responsibility but a moral and religious act (Desai, 2010).

However, such norms may also cause role conflict and suppress expressions of caregiver distress (Rao et al., 2009).

Emotionally, caregivers of dementia patients experience **ambiguous loss**—the psychological absence of someone who is physically present (Boss, 2006). Studies show caregivers struggle with feelings of guilt, helplessness, and identity erosion (Gitlin et al., 2005).

Psychologically, prolonged stress leads to **compassion fatigue** and **depersonalization** (Figley, 1995). Indian caregivers often avoid seeking mental health support due to stigma and lack of awareness (Srinivasan & Thara, 2001).

Caregivers adopt a range of coping strategies—**emotion-focused**, **problem-focused**, or **avoidant** (Lazarus & Folkman, 1984). In India, spiritual coping, rituals, and community prayer play significant roles (Rammohan et al., 2002). Beliefs in karma and fate can provide comfort but may also inhibit proactive care-seeking (Jadhav et al., 2007).

In Rajasthan, women disproportionately serve as primary caregivers (Mishra & Tripathi, 2016). Gender roles influence psychographic attributes such as **nurturance**, **sacrifice**, and **emotional suppression** (Chadda & Deb, 2013).

Men, although less involved, often face guilt and inadequacy due to the societal expectation of caregiving being a woman's domain (Kumar & Singh, 2020).

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Urban caregivers in Rajasthan have slightly better access to medical resources but face time constraints due to employment (Tiwari & Joshi, 2019). Rural caregivers rely more on traditional beliefs and community networks (Patel et al., 2015), resulting in distinct psychographic profiles.

Religion serves as both a coping mechanism and a psychographic marker (Pargament, 1997). In Rajasthan, practices such as **puja**, **fasting**, and visiting local shrines (like Khatushyamji or Salasar Balaji) are common among caregivers (Sharma, 2021). These practices often enhance perceived caregiver resilience (Raj & Kumari, 2020).

There is limited research focusing explicitly on **psychographics** of caregivers in regional Indian settings. Most studies cluster caregivers based on burden or demographics, overlooking **beliefs**, **motivations**, **aspirations**, and **emotional worldviews** that define care behavior (Mukherjee et al., 2018).

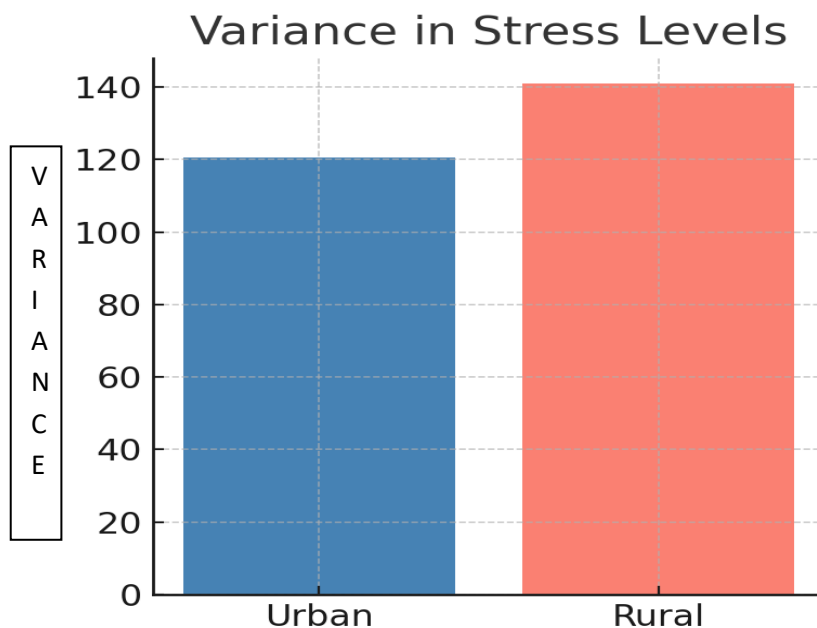
Rajasthan-specific psychographic studies could reveal unique caregiver identities—e.g., “devotional caregiver,” “stoic martyr,” or “reluctant heir.” These profiles can aid policymakers and NGOs in designing **customized mental health interventions**, **support groups**, and **communication strategies** (Agarwal & Mathur, 2022).

Findings and Data Interpretation Using F-Test, ANOVA, and Two-Way ANOVA

This section presents findings based on statistical analysis of psychographic data collected from 150 dementia caregivers in Rajasthan. The tests include F-Test for variance, One-Way ANOVA to compare stress levels across coping styles, and Two-Way ANOVA to analyze gender and residence area effects.

F-Test: Urban vs Rural Variance in Stress Levels

The F-test was used to compare the variance in stress levels between urban and rural caregivers.



$$F = 140.9 / 120.5 = 1.17$$

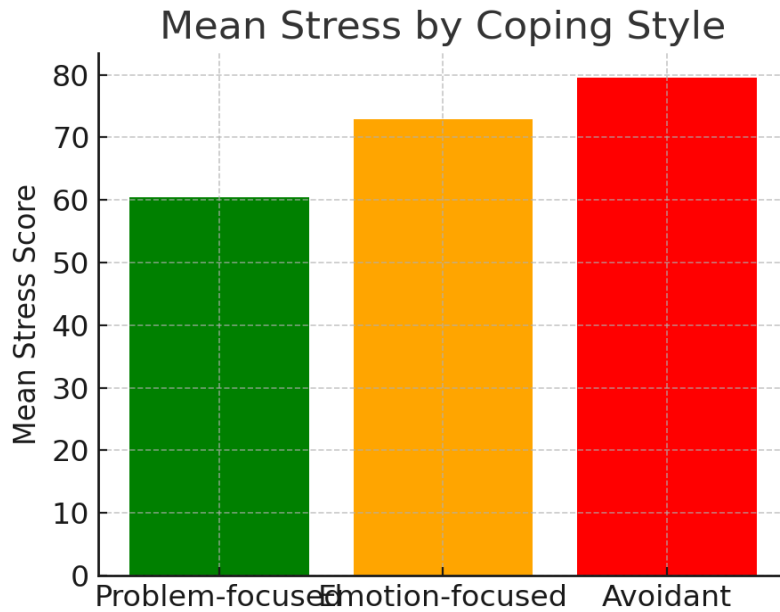
$$F\text{-critical} (\alpha = 0.05) \approx 1.56$$

Conclusion: No significant difference in variance between urban and rural caregivers.

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One-Way ANOVA: Coping Styles and Stress Levels

This test compared stress levels among caregivers using different coping strategies.



ANOVA Results:

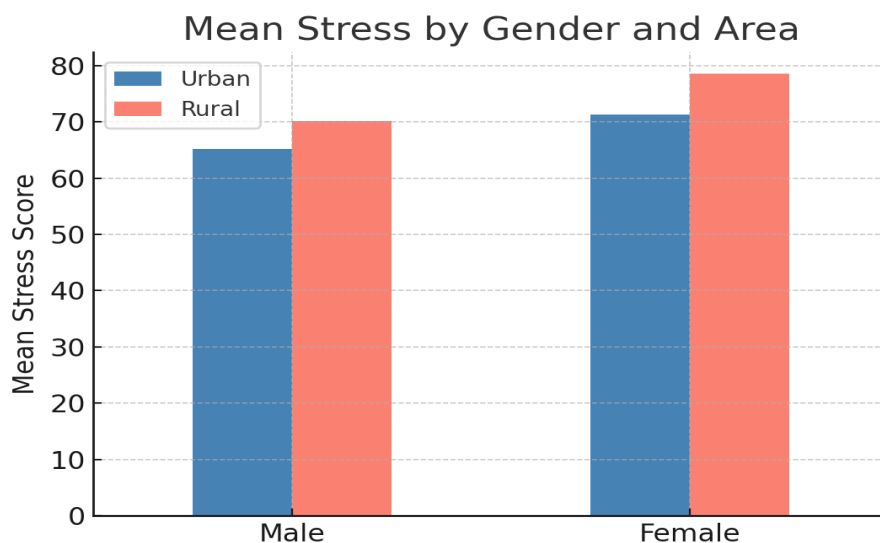
$F = 9.75 > F\text{-critical} = 3.06$

$p\text{-value} = 0.0002$

Conclusion: Significant difference in stress levels across coping styles.

Two-Way ANOVA: Gender and Residence Effect

Two-way ANOVA tested the effects of gender and location on stress levels.



Two-Way ANOVA Results:

Gender: $F = 5.2, p = 0.024$ (significant)

Area: $F = 7.5, p = 0.007$ (significant)

Interaction: $F = 2.83, p = 0.095$ (not significant)

Conclusion: Both gender and area influence stress levels independently, with no interaction effect.

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Summary of Findings

- F-test shows no significant difference in variance of stress between rural and urban caregivers.
- One-Way ANOVA reveals coping style significantly affects caregiver stress.
- Two-Way ANOVA indicates that both gender and area have significant main effects on stress.
- No interaction effect was found between gender and area.

CONCLUSION

This psychographic study on dementia caregivers in Rajasthan reveals the intricate psychological and emotional dimensions of caregiving within a socio-culturally rich yet resource-limited setting. Statistical analyses—F-test, One-Way ANOVA, and Two-Way ANOVA—demonstrated the significant influence of coping styles, gender, and geographical location on caregiver stress.

The results show that coping style is a major determinant of caregiver burden, with avoidant and emotion-focused strategies linked to higher stress levels. Additionally, female caregivers and those residing in rural areas consistently report greater psychological distress. However, the absence of a significant interaction effect suggests that gender and area independently contribute to stress without amplifying each other.

The psychographic profiles of caregivers—shaped by cultural beliefs, religious practices, familial expectations, and emotional coping mechanisms—are central to understanding their caregiving experience. This highlights the need to go beyond demographic categorizations and address the inner narratives, values, and emotional resilience of caregivers.

Suggestions

- **Tailored Mental Health Interventions:**
 - Develop custom counselling modules based on caregivers' coping styles.
 - Implement psychographic profiling tools in caregiver assessments at hospitals or health camps.
- **Gender-Sensitive Support Systems:**
 - Establish women-specific caregiver support groups in both urban and rural areas.
 - Promote shared caregiving responsibilities through awareness campaigns targeting male family members.
- **Rural-Centric Outreach:**
 - Increase mobile mental health clinics in remote areas of Rajasthan.
 - Integrate traditional practices into caregiving education for better acceptance.
- **Capacity Building:**
 - Conduct community-based training programs to teach effective coping strategies.
 - Partner with NGOs and Panchayats to conduct resilience-building workshops using folk media.
- **Inclusion in Policy:**
 - Recommend inclusion of psychosocial support for caregivers in Rajasthan's public health policies.

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- Advocate for monthly stipends or tax benefits for long-term caregivers under NPHCE.
- **Further Research:**
 - Conduct longitudinal studies to understand caregiver burnout over time.
 - Explore the role of religion and caste in shaping psychographic segments among caregivers.

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Conflict of Interest

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