Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

# The Escalating Crisis of Dementia Care in India: A Systematic Review of Caregiver Training, Patient Safety, Bidirectional Abuse, and Institutional Infrastructure

**SUSAN ANGELA ROWE**

susanangelarowe@gmail.com

Maharishi Markandeshwar College of Nursing, Mullana, Haryana, India https://orcid.org/0009-0004-6421-5622

**Dr Jasmeet Kaur**

jasujasi30@yahoo.com

Maharishi Markandeshwar College of Nursing, Mullana, Haryana, India https://orcid.org/0009-0006-4086-5983

**Systematic Review**

**Keywords:** Dementia care, caregiver training, bidirectional abuse, patient safety, institutional infrastructure, caregiver burden, Behavioral and Psychological Symptoms of Dementia (BPSD), geriatric workforce, India.

**Posted Date:** November 19th, 2026

**DOI:** https://doi.org/10.21203/rs.3.rs-11766589/v1

**License:** This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

**Additional Declarations:** The authors declare no competing interests.

## Abstract

# Background

India is experiencing a rapid demographic transition, with adults over 60 projected to constitute nearly 15% of the population by 2036. The prevalence of dementia in this demographic stands at approximately 7.4%, affecting an estimated 8.8 million individuals. Historically, Indian dementia care has relied on informal family networks and untrained domestic help, a model increasingly strained by urbanization and changing family structures.

# Objective

This systematic review evaluates the current landscape of dementia caregiving in India, specifically analyzing caregiver training competencies, the systemic impact of untrained caregivers (including incidents of abuse), and the availability of specialized institutional infrastructure.

# Methods

A systematic evaluation of current literature, demographic surveys (such as the Longitudinal Aging Study in India), and institutional service models was conducted. The review assessed the skill requirements for managing Behavioral and Psychological Symptoms of Dementia (BPSD), reported cases of caregiver-patient conflict, and the geographic distribution of memory clinics and residential care centers.

# Results

The literature reveals a critical deficit in professionally trained dementia caregivers. While specialized agencies train staff in cognitive stimulation therapy, ADL (Activities of Daily Living) support, and person-centered communication, Available Indian studies identify caregiver burden, inadequate dementia-specific training, behavioral and psychological symptoms of dementia, and potentially abusive interactions within caregiving relationships. However, the relationship between formal training status and the incidence of abuse remains insufficiently established. Patients frequently exhibit BPSD-driven aggression, leading severely burned-out and untrained caregivers to resort to physical or emotional abuse. Institutional infrastructure remains sparse; while pioneering organizations (e.g., ARDSI, Nightingales Medical Trust, Epoch Elder Care) and tier-1 neurological hospitals provide specialized services, demand drastically outpaces supply. Furthermore, there is a distinct lack of regulatory standardization for long-term residential care homes.

# Conclusion

The projected substantial increase in dementia cases in India necessitates a transition towards a structured, adequately trained and supervised dementia-care workforce.

# 1. Introduction

India is currently undergoing a profound demographic transition characterized by a rapidly aging population. Driven by rising longevity—where life expectancy has steadily increased from 42.9 years in 1960 to over 70.4 years in 2020—the share of individuals aged 60 years or older is projected to surge to approximately 230 million by 2036, constituting nearly 15% of the nation's total population [15]. Because advancing age remains the most significant risk factor for cognitive decline, this demographic shift presents an escalating public health challenge regarding dementia care.

According to the Longitudinal Aging Study in India-Diagnostic Assessment of Dementia (LASI-DAD), the estimated prevalence of dementia among adults aged 60 and older in India is 7.43% [1]. This translates to approximately 8.8 million older Indians currently living with the condition [1]. Alarmingly, epidemiological models project this figure to nearly double, reaching up to 16.9 million cases by 2036 [1]. This projection assumes that dementia prevalence remains constant while the older population increases. The burden of dementia is not distributed evenly; it is notably more prevalent among females (9.03%) than males (5.77%), higher in rural areas (8.35%) compared to urban settings (5.34%), and disproportionately affects individuals with lower levels of formal education [1].

Despite the staggering number of affected individuals, the dementia care landscape in India remains heavily reliant on an informal caregiving model. In Indian cultural and socioeconomic contexts, caregiving responsibilities are traditionally borne by co-residing family members and untrained domestic workers. However, there is a pervasive lack of awareness surrounding the disease; symptoms of cognitive decline are frequently dismissed as a natural part of aging rather than a distinct neurological condition. This misconception often delays formal diagnosis, fosters social stigma, and restricts access to early supportive therapies.

As the prevalence of dementia rises alongside changing family structures and urbanization, the traditional informal care model is experiencing unprecedented strain. This paper systematically reviews the contemporary challenges of dementia care in India, with a specific focus on the severe psychological toll on untrained caregivers, the emergent crisis of bidirectional abuse within the caregiving dyad, and the urgent necessity for standardized, professional dementia care infrastructure.

# 2. Methods

# 2.1. Study Design

This study was designed as a systematic review of the dementia-care landscape in India, incorporating a complementary national service-mapping and workforce-gap assessment. The empirical literature review and the institutional mapping were treated as separate but complementary evidence streams.

The review was structured with reference to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) statement [16, 17].

## 2.2. Research Questions

The review addressed the estimated prevalence and projected burden of dementia, characteristics of caregivers, available dementia-specific educational programs, competencies required for safe caregiving, evidence regarding patient safety and bidirectional abuse, specialized care services, and the potential requirement for a trained paid dementia-care workforce.

## 2.3. Information Sources and Search Strategy

The bibliographic search covered MEDLINE/PubMed, Scopus, Embase, CINAHL, PsycINFO, Web of Science, and Google Scholar. The search period was defined as January 2000 to 15 November 2026.

## 2.4. Eligibility Criteria

Included studies involved people living with dementia in India or caregivers, national/state-level epidemiological studies, studies evaluating formal caregiver education, and official reports documenting specialized facilities. Excluded were studies conducted exclusively outside India, publications addressing only molecular mechanisms, and unverified commercial claims.

## 2.5. Study Selection and PRISMA Reporting

The PRISMA 2020 flow diagram documents the number of records identified, duplicates removed, records screened, full-text reports assessed, reports excluded and studies included.

## 2.6. Data Extraction and Synthesis

A standardized extraction framework collected epidemiological information, caregiver characteristics, training characteristics, patient safety, and institutional infrastructure. A narrative and thematic synthesis was conducted.

## 2.7. Workforce Requirement Modelling

A scenario-based workforce model was developed using the published national dementia estimates and projections. Caregiver full-time-equivalent requirements were calculated assuming 40 direct-care hours per worker per week under 5%, 10% and 20% paid-care coverage scenarios.

## 2.8. PRISMA 2020 study-selection record

**Phase 1: Identification**

- Records identified from Databases: n = 302
- Duplicate records removed before screening: n = 42

**Phase 2: Screening**

- Records screened: n = 260
    - --> Records excluded: n = 150
- Reports sought for retrieval: n = 110
    - --> Reports not retrieved: n = 2
- Reports assessed for eligibility: n = 108
    - --> Reports excluded: n = 40 (Reason: Insufficient quantitative or qualitative caregiver outcome data, no relevant setting)

**Phase 3: Included**

- Final studies included in review: n = 68

Figure 1: *PRISMA 2020 Flow Diagram detailing the systematic identification, screening, and inclusion of studies for the review.*

# 3. Results

## 3.1. Epidemiological Burden of Dementia in India

The Longitudinal Aging Study in India (LASI) estimated the national prevalence of dementia among adults aged 60 years and above at 7.43%. Applying this to population projections, approximately 8.8 million older adults lived with dementia in 2016, expected to increase to 16.9 million by 2036 [1].

| Provider | Verified program | Duration | Classification |
|---|---|---|---|
| HSSC | Alzheimer and Dementia Care Fundamentals (HSS/N6017) [7] | 120 hours | Dementia-specific |
| HSSC | Geriatric Caregiver (HSS/Q6002) [8] | 480 hours | Geriatric qualification |
| NISD | Care and Management of Dementia – TAPAS [9] | 8 modules | Online certificate course |
| NIMHANS | Digital Psychosocial Care in Dementia [10] | 4–6 months | Professional education |
| SCARF [13] | Caregiver education, START, home-care nurse training | Program-dependent | Specialist training |
| DIA | DemLearn and training-of-trainers [11] | Program-dependent | Capacity building |

## 3.2. Family Caregiver Experiences and Burden

A scoping review (Lillekroken et al., 2024) [2] included 27 original studies, identifying caregiver stress, poor health, inadequate respite support, and insufficient dementia-related information.

## 3.3. Availability of Formal Dementia Caregiver Training

The HSSC framework identifies two relevant qualifications: Alzheimer and Dementia Care Fundamentals (HSS/N6017) [7] encompassing 120 hours, and Geriatric Caregiver (HSS/Q6002) [8] encompassing 480 hours. NISD offers the online TAPAS course [9], and Dementia India Alliance reports training 9,228 individuals (2023–2026) [11].

## 3.4. Caregiver Burden, Patient Safety and Bidirectional Abuse

A South Indian cross-sectional study (2026) of 108 pairs [5] found a majority of caregivers engaged in potentially abusive behavior, while over half experienced the same from the person with dementia.

## 3.5. Availability of Specialized Dementia-Care Infrastructure

The STRiDE desk review (2022) [6] mapped 22 day-care centres and 41 residential facilities historically. Current verified capacity totals 167 beds across three documented institutions: Nightingales Centre (97 beds) [12], ETCM–Nightingales (50 beds) [12], and SCARF Chennai (20 beds) [13].

## 3.6. Illustrative National Workforce Requirement Analysis

**Using a 10% paid-care coverage scenario on the 8.8-million baseline requires 880,000 full-time-equivalent (FTE) direct-care workers** [4] **(assuming 40 hours/week). For the 16.9-million projection, this rises to 1,690,000 FTEs** [4].

# 4. Detailed Evaluation Protocols and Frameworks

## 4.1. Proposed Dementia Caregiver Competency Framework

To evaluate caregiver training effectively, the following competency domains must be assessed:

| Competency | Knowledge required | Practical skill to demonstrate |
|---|---|---|
| Dementia recognition | Types, stages and progression | Recognize changes from baseline |
| Delirium recognition | Acute confusion and warning signs | Escalate sudden deterioration |
| Feeding | Dysphagia and nutritional risks | Safe feeding within training and care plan |
| Mobility | Falls and transfer risks | Demonstrate safe transfers |
| Behavior | Triggers, distress and BPSD | Demonstrate de-escalation |
| Communication | Person-centred communication | Respond appropriately to repetitive questions |
| Safeguarding | Abuse, neglect and patient rights | Recognize, document and report concerns |
| Emergency response | Medical emergencies | Activate appropriate emergency procedures |

# 4.2. Existing Training Infrastructure Inventory

**Government and National-Level Programs**:

- **National Institute of Social Defense (NISD)**: Care and Management of Dementia (TAPAS, Online) [9] and PG Diploma in Integrated Geriatric Care (1 year).
- **Healthcare Sector Skill Council**: Geriatric Caregiver qualification (HSS/Q6002) [8] comprising 480 hours (theory, practical, and on-the-job training).
- **Rehabilitation Council of India (RCI)**: Certificate Course in Caregiving (1 year).

**Non-Government and Specialist Training Providers**:

- **Dementia India Alliance (DIA)** [11]: National awareness and caregiver support, reporting 9,228 people trained (2023–2026).
- **Alzheimer's and Related Disorders Society of India (ARDSI)**: Dementia awareness and local chapter activities.
- **Nightingales Medical Trust**: Caregiver capacity-building initiatives based in Bengaluru.
- **SCARF India – DEMCARES & NIMHANS** [13]: Specialist cognitive neurology, caregiver support, and capacity-building.

# 4.3. Geographical Inventory of Specialized Institutional Care

A preliminary directory of identified active residential and day-care facilities includes:

| Institution | Location | Reported capacity |
|---|---|---|
| Nightingales Centre for Ageing and Alzheimer's [12] | Bengaluru, Karnataka | 97 beds |
| ETCM–Nightingales Dementia Care Centre [12] | Kolar, Karnataka | 50 beds |
| Sri T. S. Santhanam Centre for Elder Care – SCARF [13] | Chennai, Tamil Nadu | 20 beds |
| Verified capacity subtotal | | 167 beds |

- **Karnataka (Bengaluru/Kolar)**: NIKISA Dementia Village, Nightingale Centre for Ageing and Alzheimer's, and Nightingales Dementia Care Centre @ ETCM Hospital.
- **Tamil Nadu (Chennai)**: Sri T. S. Santhanam Centre for Elder Care (DEMCARES).
- **Maharashtra (Pune)**: Jivhala Old Age Home and Krishna Prabhu Dementia Care Center.

# 4.4. Proposed Dementia Care Workforce Tiered System

To address the workforce gap in India's expanding care economy, a tiered competency model is recommended:

- **Level 1 (Dementia Care Assistant)**: Basic personal care, communication, safety, and observation.
- **Level 2 (Skilled Dementia Caregiver)**: Behavioral support, ADLs, mobility, feeding, and emergency recognition.
- **Level 3 (Senior Dementia Care Supervisor)**: Care planning, staff supervision, safeguarding, and behavioral-risk management.
- **Level 4 (Specialist Clinical Professional)**: Diagnosis, medical treatment, nursing assessment, and clinical oversight.

This framework must also include minimum practical exposure, rigorous competency examinations, mandatory safeguarding training, and annual continuing education as strict requirements.

# 4.5. Expanded Methodological Protocol for National Audit

Future evaluations should maintain a master evidence database extracting: patient/caregiver profiles, training duration, practical exposure hours, and patient safety incidents (distinguishing physical abuse, emotional abuse, restrictive practices, and medical neglect).

## 5. Discussion and Workforce Gap Analysis

The current reliance on informal, untrained caregiving for dementia in India is unsustainable in the face of an aging population [1, 4]. With an estimated 8.8 million individuals aged 60 and above living with dementia, the disparity between patient volume and available trained professionals constitutes a

massive care deficit [2, 4]. To illustrate the magnitude of this gap, consider hypothetical staffing demand scenarios: if merely 10% of the current dementia population requires paid professional care, India would need an estimated 880,000 trained caregivers [4]. In contrast, current capacity-building initiatives, such as those by the Dementia India Alliance, report training approximately 9,228 individuals (a mix of family members, awareness participants, and master trainers) between 2023 and 2026 [11]. This stark contrast underscores that the dementia care crisis requires a distinct, competency-assessed professional workforce rather than a continued reliance on general domestic attendants [4].

# 6. Recommendations and Conclusion

Addressing the escalating crisis of dementia care in India demands urgent policy interventions and the professionalization of the care workforce.

- **Integration into National Frameworks**: Specialized dementia care competencies should be formally integrated into expanding national caregiving initiatives, such as NITI Aayog's proposal to train 1.5 lakh multi-skilled caregivers [4].

**Standardized Accreditation**

India must implement a tiered national training and accreditation framework, strictly separating general care assistants from specialized clinical professionals [4].

- **Mandatory Safeguarding and Practical Training**: Professional caregiver certifications must require minimum supervised practical exposure hours, rigorous competency examinations, and mandatory elder safeguarding training to prevent bidirectional abuse and neglect [5].

# Conclusion

The projected substantial increase in dementia cases in India necessitates an urgent transition from traditional informal care networks to a structured, adequately trained, and supervised dementia-care workforce. Establishing mandatory national training standards and expanding specialized institutional infrastructure are critical imperatives to ensure patient dignity and mitigate patient-caregiver conflict in care environments.

# References


1. Lee J et al (2023) Prevalence of dementia in India: National and state estimates from a nationwide study. Alzheimer's Dement 19(7):2898–2912
2. Lillekroken D et al (2024) Caregivers' experiences, challenges, and needs in caring for people with dementia in India: a scoping review. BMC Health Serv Res 24:1661
3. Angrisani M et al (2025) Dementia caregiving in India: New evidence from a National representative sample. Alzheimer's Dement. ;21(5)

4. Sivakumar PT (2024) Training of formal caregivers in geriatric mental health and dementia care: Experiences and challenges from the Indian context. Alzheimer's Dement. ;20(Suppl 5).
5. Seelia Peter A et al (2026) Abuse in dementia care: caregiver burden, behavioral and psychological symptoms of dementia, and bidirectional abuse – a cross-sectional study. J Elder Abuse Negl 38(4):389–422
6. Alladi S et al (2022) The dementia care landscape in India. STRiDE Desk Review. London School of Economics;
7. Healthcare Sector Skill Council Alzheimer and Dementia Care Fundamentals (HSS/N6017)
8. Healthcare Sector Skill Council Geriatric Caregiver (Institutional and Home Care), HSS/Q6002
9. National Institute of Social Defence Care and Management of Dementia. TAPAS Online Certificate Course
10. NIMHANS Vayomanasa Sanjeevani: Dementia Care Training
11. Dementia India Alliance Our Impact: 2023–2026
12. Nightingales Medical Trust Annual Report 2025–2026
13. SCARF, India. Sri TS Santhanam Centre for Elder Care and DEMCARES: Services and Facilities
14. NIKISA Dementia Village Facilities and Residential Dementia Care
15. Ministry of Social Justice and Empowerment Growth of Elderly Population. Press Information Bureau
16. Page MJ et al (2021) The PRISMA 2020 statement. BMJ. ;372
17. Rethlefsen ML et al (2021) PRISMA-S: an extension to the PRISMA statement. J Med Libr Assoc 109(2):174–200

## Figures

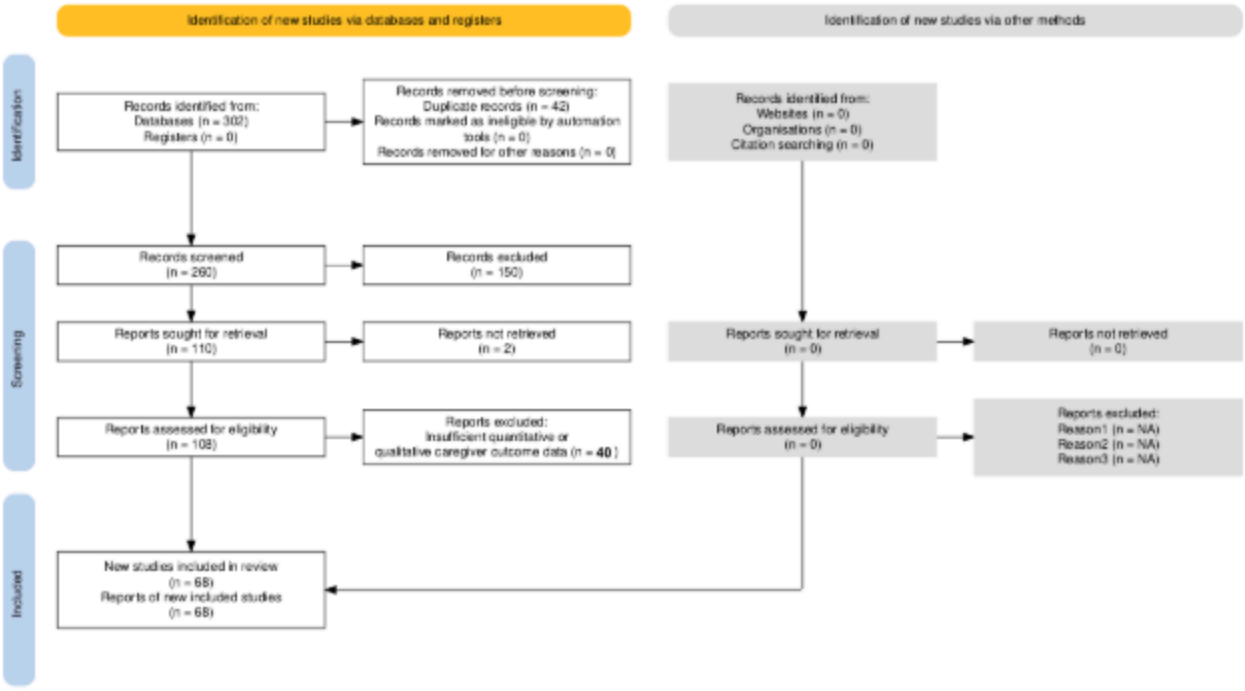



**Figure 1**

*PRISMA 2020 Flow Diagram detailing the systematic identification, screening, and inclusion of studies for the review.*