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Neuropsychiatric Symptoms and Caregiver Burden Across Different Stages of Dementia: A Cross-Sectional Observational Study.

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Abstract

Background: Neuropsychiatric symptoms are frequent in dementia and can intensify the emotional and practical demands placed on family caregivers. Their relationship with burden across clinically defined stages requires evaluation. ***Objectives:*** To compare neuropsychiatric symptoms and caregiver burden across mild, moderate, and severe dementia and identify factors independently associated with caregiver burden. ***Methods:*** This hospital-based cross-sectional observational study included 100 patient–caregiver dyads at Mamata Academy of Medical Sciences, Hyderabad, India, from April 2025 to March 2026. Dementia was categorized as mild, moderate, or severe. Cognition, neuropsychiatric symptoms, caregiver distress, and burden were assessed using the Mini-Mental State Examination, Neuropsychiatric Inventory Questionnaire, and Zarit Burden Interview. Group comparisons, correlations, and multiple linear regression were performed. ***Results:*** The sample comprised 35 mild, 35 moderate, and 30 severe dementia cases. At least one neuropsychiatric symptom occurred in 91.0%; apathy was most frequent (59.0%). Mean neuropsychiatric severity scores increased from 6.8 ± 4.1 in mild dementia to 12.9 ± 5.2 in moderate and 19.1 ± 6.0 in severe dementia. Corresponding caregiver burden scores were 24.6 ± 10.2, 39.8 ± 11.7, and 55.7 ± 12.4. Burden correlated with neuropsychiatric severity ($r=0.71$), caregiver distress ($r=0.78$), caregiving hours ($r=0.49$), and cognitive scores ($r=-0.62$); all $P<0.001$. Caregiver distress, severe dementia, and caregiving duration independently predicted burden. The model explained 64.0% of variance. ***Conclusion:*** Neuropsychiatric symptoms and caregiver burden increased with dementia severity. Caregiver distress was the strongest independent correlate, supporting structured behavioural assessment and stage-sensitive caregiver interventions.

Keywords: caregiver burden; dementia; disease severity; neuropsychiatric symptoms; Neuropsychiatric Inventory Questionnaire; Zarit Burden Interview.

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INTRODUCTION

Dementia is a chronic neurocognitive syndrome characterized by progressive impairment in cognition, function, and independent living. Alzheimer's disease is its most common cause, while vascular, Lewy body, frontotemporal, and mixed pathologies account for a substantial proportion of cases. Clinical care often focuses on cognitive decline, yet behavioural and psychological manifestations frequently determine the everyday complexity of management. These manifestations, commonly described as neuropsychiatric symptoms, include apathy, depression, anxiety, agitation, aggression, delusions, hallucinations, disinhibition, irritability, sleep disturbance, aberrant motor behaviour, and altered eating patterns. They can occur at any stage, fluctuate over time, and become increasingly disruptive as dementia advances [1-3].

Neuropsychiatric symptoms affect patients beyond their direct behavioural expression. They are associated with functional deterioration, impaired quality of life, accelerated institutional placement, greater healthcare use, and clinical risk. The Neuropsychiatric Inventory and its brief questionnaire version provide structured measurement of symptom occurrence, severity, and the distress experienced by caregivers [2-4]. Cognitive screening and staging instruments, including the Mini-Mental State Examination and Clinical Dementia Rating, complement behavioural assessment by locating symptoms within the broader course of cognitive and functional decline [5,6]. Stage-specific analysis is important because the type and impact of symptoms can change as communication, insight, mobility, and dependence deteriorate.

Most persons with dementia receive substantial support from relatives. Family caregivers coordinate medication, supervise safety, assist with activities of daily living, manage behavioural disturbances, and navigate healthcare services. This sustained responsibility can produce physical exhaustion, emotional distress, social restriction, financial strain, and deterioration in caregivers' own health. Caregiver burden is multidimensional and is commonly quantified using the Zarit Burden Interview [7]. Evidence indicates that neuropsychiatric symptoms, particularly disruptive behaviours, psychosis, and nighttime disturbances, often contribute more strongly to burden than cognitive impairment alone [8-11]. The duration and intensity of daily care, caregiver relationship, co-residence, coping resources, and access to formal support also shape this experience [12].

Indian families frequently deliver dementia care at home, where cultural expectations, limited respite services, and variable awareness of behavioural symptoms can intensify caregiving demands. Indian evidence has demonstrated close associations between neuropsychiatric symptoms and burden, but stage-stratified clinical data remain limited [13]. Clarifying these relationships can help clinicians identify high-risk dyads early and align psychoeducation, behavioural management, caregiver counselling, and referral with disease severity. Therefore, the present study aimed to describe neuropsychiatric symptoms across mild, moderate, and severe dementia; compare caregiver distress and burden between these stages; examine correlations among symptom severity, cognition, caregiving intensity, and burden; and determine the independent factors associated with higher caregiver burden.

METHODOLOGY

Study design and setting

A hospital-based cross-sectional observational study was conducted in the Department of Psychiatry, Mamata Academy of Medical Sciences, Bachupally, Hyderabad, Telangana, India, from April 2025 to March 2026. Consecutive patient–caregiver dyads attending psychiatric outpatient and inpatient services were screened. Dementia stage was the principal grouping variable and caregiver burden was the main outcome.

Participants and eligibility

Patients were eligible when they had a clinically established diagnosis of dementia, were accompanied by an adult primary informal caregiver, and could be categorized into a defined severity stage. A primary caregiver was a relative aged 18 years or older who provided regular unpaid care and knew the patient's behaviour sufficiently to complete informant assessments. Dyads were excluded for patient delirium, unstable medical illness, a major psychiatric disorder predating dementia, inadequate caregiver contact, or caregiver illness or communication difficulty preventing reliable participation. One hundred eligible dyads were enrolled: 35 mild, 35 moderate, and 30 severe cases.

Clinical assessment and study instruments

Sociodemographic and clinical information included patient age, sex, dementia subtype, illness duration, caregiver age, sex, relationship to the patient, duration of caregiving, and average daily caregiving hours. Cognitive status was assessed using the Mini-Mental State Examination, a 30-point screening instrument [5]. Dementia stage was assigned through clinical assessment supported by cognitive and functional information and categorized as mild, moderate, or severe, consistent with established staging principles [6]. Neuropsychiatric symptoms were evaluated using the Neuropsychiatric Inventory Questionnaire, which records 12 symptom domains. For each present symptom, severity is rated from 1 to 3 and caregiver distress from 0 to 5; domain ratings are summed to obtain total severity and distress scores [2,4]. Caregiver burden was measured with the 22-item Zarit Burden Interview, with higher scores indicating greater perceived burden [7]. Scores of 41 or above were classified as moderate-to-severe or severe burden for categorical comparisons.

Data collection and ethics

Written informed consent was obtained from caregivers and from patients whenever decisional capacity permitted; an authorized representative provided consent when appropriate. Trained personnel conducted private interviews, cross-checked available records, and removed identifiers from the analytic dataset. Necessary Permissions were obtained before starting the study. Applicable ethical standards for human-participant research were followed.

Statistical analysis

Continuous variables were summarized as mean ± standard deviation or median with interquartile range; categorical variables were expressed as frequency and percentage. Groups were compared using one-way analysis of variance with adjusted post-hoc comparisons, the Kruskal–Wallis test, and chi-square or exact tests, as appropriate. Pearson or Spearman correlations were selected according to data characteristics. Multiple linear regression identified independent associations with Zarit Burden Interview score, with standardized coefficients reported. Tests were two-sided, and $P<0.05$ indicated statistical significance.

RESULTS

A total of 100 patient–caregiver dyads were analysed. Thirty-five patients had mild dementia, 35 had moderate dementia, and 30 had severe dementia. The overall mean patient age was 72.6 ± 7.8 years, and 58.0% were female. Alzheimer's disease was the most frequent diagnosis (62.0%), followed by vascular dementia (25.0%) and other dementia subtypes (13.0%). Age, sex, and dementia subtype distributions were comparable across the three groups. Illness duration increased with advancing dementia stage, while the mean Mini-Mental State Examination score declined from 22.1 ± 2.3 in mild dementia to 7.8 ± 2.9 in severe dementia (Table 1).

Table 1. Sociodemographic and clinical characteristics according to dementia stage (N=100)

Characteristic	Mild (n=35)	Moderate (n=35)	Severe (n=30)	Total (N=100)	P value
Age, years, mean ± SD	70.8 ± 7.2	72.9 ± 7.6	74.3 ± 8.3	72.6 ± 7.8	0.184
Female sex, n (%)	19 (54.3)	20 (57.1)	19 (63.3)	58 (58.0)	0.758
Alzheimer's disease, n (%)	23 (65.7)	22 (62.9)	17 (56.7)	62 (62.0)	0.869*
Vascular dementia, n (%)	8 (22.9)	9 (25.7)	8 (26.7)	25 (25.0)	
Other dementias, n (%)	4 (11.4)	4 (11.4)	5 (16.7)	13 (13.0)	
Illness duration, years, median (IQR)	2.0 (1.0–3.0)	4.0 (3.0–5.0)	6.0 (4.0–8.0)	4.0 (2.0–6.0)	<0.001
MMSE score, mean ± SD	22.1 ± 2.3	15.4 ± 2.6	7.8 ± 2.9	15.5 ± 6.4	<0.001

MMSE: Mini-Mental State Examination; IQR: interquartile range; SD: standard deviation. *P value compares the overall distribution of dementia subtypes.

At least one neuropsychiatric symptom was identified in 91 patients (91.0%). Apathy or indifference was most frequent (59.0%), followed by irritability or emotional lability (52.0%), nighttime behavioural disturbance (48.0%), depression or dysphoria (46.0%), agitation or aggression (43.0%), and anxiety (41.0%).

Delusions, hallucinations, agitation or aggression, apathy, aberrant motor behaviour, and nighttime behavioural disturbance differed significantly across stages and were most frequent in severe dementia. Differences in depression, anxiety, euphoria, disinhibition, irritability, and appetite disturbance did not reach statistical significance (Table 2).

Table 2. Distribution of neuropsychiatric symptoms across dementia stages

Neuropsychiatric symptom	Mild (n=35)	Moderate (n=35)	Severe (n=30)	Total n (%)	P value
Delusions	3 (8.6)	10 (28.6)	15 (50.0)	28 (28.0)	0.001
Hallucinations	2 (5.7)	7 (20.0)	12 (40.0)	21 (21.0)	0.003
Agitation/aggression	8 (22.9)	16 (45.7)	19 (63.3)	43 (43.0)	0.004
Depression/dysphoria	13 (37.1)	17 (48.6)	16 (53.3)	46 (46.0)	0.397
Anxiety	11 (31.4)	15 (42.9)	15 (50.0)	41 (41.0)	0.304
Euphoria/elation	2 (5.7)	4 (11.4)	5 (16.7)	11 (11.0)	0.370
Apathy/indifference	13 (37.1)	23 (65.7)	23 (76.7)	59 (59.0)	0.003
Disinhibition	5 (14.3)	10 (28.6)	12 (40.0)	27 (27.0)	0.064
Irritability/lability	14 (40.0)	19 (54.3)	19 (63.3)	52 (52.0)	0.162
Aberrant motor behaviour	4 (11.4)	11 (31.4)	15 (50.0)	30 (30.0)	0.003
Nighttime behavioural disturbance	10 (28.6)	18 (51.4)	20 (66.7)	48 (48.0)	0.008
Appetite/eating disturbance	8 (22.9)	13 (37.1)	15 (50.0)	36 (36.0)	0.074

Values are n (%). P values were obtained from overall comparisons across the three dementia stages.

The number and severity of neuropsychiatric symptoms rose progressively across dementia stages. The mean Neuropsychiatric Inventory Questionnaire severity score increased from 6.8 ± 4.1 in mild dementia to 12.9 ± 5.2 in moderate dementia and 19.1 ± 6.0 in severe dementia (P<0.001). Caregiver distress showed a parallel gradient. Mean Zarit Burden Interview scores were 24.6 ± 10.2, 39.8 ± 11.7, and 55.7 ± 12.4, respectively (P<0.001).

Adjusted post-hoc comparisons showed significant differences between every pair of stages for symptom severity, caregiver distress, and caregiver burden (all adjusted P<0.01). Moderate-to-severe burden was present in 54.0% of caregivers and increased from 20.0% in mild dementia to 86.7% in severe dementia (Table 3).

Table 3. Neuropsychiatric symptoms and caregiver burden according to dementia stage

Outcome measure	Mild (n=35)	Moderate (n=35)	Severe (n=30)	Total	P value
Number of neuropsychiatric symptoms	3.1 ± 2.0	5.2 ± 2.3	7.0 ± 2.5	5.0 ± 2.7	<0.001
NPI-Q severity score	6.8 ± 4.1	12.9 ± 5.2	19.1 ± 6.0	12.6 ± 7.1	<0.001
NPI-Q caregiver distress score	7.4 ± 4.8	14.8 ± 6.1	22.6 ± 7.3	14.6 ± 8.5	<0.001
ZBI score	24.6 ± 10.2	39.8 ± 11.7	55.7 ± 12.4	39.3 ± 16.6	<0.001
Moderate-to-severe caregiver burden, n (%)	7 (20.0)	21 (60.0)	26 (86.7)	54 (54.0)	<0.001

Values are mean ± SD unless otherwise indicated. NPI-Q: Neuropsychiatric Inventory Questionnaire; ZBI: Zarit Burden Interview.

The mean caregiver age was 47.8 ± 11.6 years; 66.0% were female, and 52.0% were the patient's son or daughter. Median caregiving duration was 3.5 years (IQR: 2.0–5.0 years), and caregivers provided a mean of 8.7 ± 4.3 hours of care daily. Zarit Burden Interview scores correlated strongly with neuropsychiatric severity (r=0.71, P<0.001) and caregiver distress (r=0.78, P<0.001). Burden also correlated positively with daily caregiving hours and illness duration, whereas cognitive score showed an inverse correlation (Table 4).

Table 4. Correlates of caregiver burden measured using the Zarit Burden Interview

Variable	Correlation coefficient	P value
NPI-Q severity score	r=0.71	<0.001
NPI-Q caregiver distress score	r=0.78	<0.001
Daily caregiving hours	r=0.49	<0.001
Duration of illness	r=0.36	<0.001
MMSE score	r=−0.62	<0.001

MMSE: Mini-Mental State Examination; NPI-Q: Neuropsychiatric Inventory Questionnaire.

In multiple linear regression, Neuropsychiatric Inventory Questionnaire caregiver distress score (standardized β=0.49, P<0.001), severe dementia stage (β=0.28, P=0.002), and daily caregiving duration (β=0.19, P=0.018) were independently associated with higher caregiver burden. Caregiver age, caregiver sex, patient age, and dementia subtype were not independently associated with the Zarit score. The final model explained 64.0% of variance in caregiver burden (adjusted R^2=0.64) (Table 5).

Table 5. Multiple linear regression analysis of factors associated with caregiver burden

Predictor	Standardized β	P value
NPI-Q caregiver distress score	0.49	<0.001
Severe dementia stage	0.28	0.002
Daily caregiving hours	0.19	0.018
Caregiver age	0.08	0.284
Caregiver sex	0.06	0.391
Patient age	0.05	0.467
Dementia subtype	0.04	0.529

Dependent variable: Zarit Burden Interview score. Adjusted R^2=0.64. NPI-Q: Neuropsychiatric Inventory Questionnaire.

DISCUSSION

This study demonstrated a clear stage-related escalation in neuropsychiatric symptoms and caregiver burden among 100 dementia dyads. More than nine in ten patients had at least one neuropsychiatric symptom, and apathy was the most frequent manifestation. Symptom number, overall severity, caregiver distress, and Zarit burden scores increased consistently from mild through severe dementia. The strong correlation between caregiver distress and burden, together with its independent contribution in regression analysis, indicates that caregivers' responses to behavioural symptoms are central to the experience of burden rather than a secondary consequence of cognitive impairment alone.

The predominance of apathy is clinically plausible and agrees with work showing that reduced initiative and motivation are common across dementia syndromes. Irritability, nighttime behavioural disturbance, depression, agitation, and anxiety were also frequent. Indian research by Basu and Mukhopadhyay identified widespread neuropsychiatric morbidity and a strong relationship between symptom severity and caregiver burden [13]. Broader reviews similarly show that disruptive behaviours, delusions, mood symptoms, and sleep-related problems exert substantial effects on caregiver well-being [9-11]. In the present analysis, delusions, hallucinations, agitation, apathy, aberrant motor behaviour, and nighttime

disturbance became more prevalent as dementia advanced. These symptoms demand supervision, interrupt sleep, complicate personal care, and can weaken the emotional reciprocity that sustains long-term caregiving.

The steep gradient in Zarit scores is another important finding. Only one fifth of caregivers in the mild group had at least moderate-to-severe burden, compared with nearly nine tenths in the severe group. Declining cognitive scores were inversely related to burden, although severe stage remained independently associated after adjustment. Previous longitudinal evidence indicates that burden evolves through interacting patient, caregiver, and contextual factors rather than through cognition alone [12,14]. The positive association with daily caregiving hours reinforces the role of exposure intensity. Greater dependence expands the caregiver's workload, reduces time for employment and rest, and limits opportunities for social recovery.

Caregiver distress had a stronger statistical association with burden than patient age, caregiver age, sex, or dementia subtype. This finding supports routine use of an informant-based behavioural inventory because it identifies both the patient's symptom profile and the caregiver's distress. Screening should be followed by assessment for pain, infection, medication effects, sensory impairment, sleep disruption, environmental triggers, and unmet needs. Non-pharmacological behavioural strategies, structured routines, sleep hygiene, caregiver communication training, and respite planning should be prioritized, while pharmacotherapy should be individualized to symptom severity, risk, and underlying diagnosis.

The findings have practical relevance for stage-sensitive dementia services in India. Mild-stage care can emphasize anticipatory guidance and coping skills; moderate-stage care requires active behavioural planning and shared caregiving; severe-stage care should add intensive support, safety planning, respite, and caregiver mental-health assessment. A dyadic model that evaluates the patient and caregiver together is more informative than cognition-focused follow-up. Prospective multicentre studies should examine symptom trajectories and determine whether targeted caregiver interventions reduce burden, delay institutionalization, and improve outcomes for both members of the dyad.

LIMITATIONS

The cross-sectional design prevents temporal or causal interpretation. Recruitment from a single tertiary-care department limits representativeness, and consecutive clinical sampling can overrepresent symptomatic dyads. Neuropsychiatric symptoms and burden were caregiver-reported and therefore susceptible to recall and reporting bias. Functional dependence, caregiver depression, socioeconomic status, coping style, and formal support were not fully modelled. The modest sample also restricted subtype-specific analysis and external validation of the regression model.

CONCLUSION

Neuropsychiatric symptoms were highly prevalent and increased markedly across mild, moderate, and severe dementia. Apathy, irritability, nighttime behavioural disturbance, depression, agitation, and anxiety formed the dominant symptom profile. Caregiver burden showed a parallel stage-related rise, with moderate-to-severe burden affecting most caregivers of patients with severe dementia. Caregiver distress, severe dementia, and longer daily caregiving hours independently predicted higher burden, while cognitive performance was inversely correlated with burden. Routine dementia care should therefore combine cognitive staging with structured behavioural assessment and direct evaluation of caregiver distress. Early psychoeducation, behavioural management, respite planning, and caregiver mental-health support should be integrated and intensified as dementia progresses to improve outcomes for the entire patient–caregiver dyad.

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