



A Descriptive Study On Caregiver Burden And Coping Strategies Among Families Of Alzheimer's Patients In A Selected Hospital, Indore, M.P

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Abstract:

Background: Alzheimer's disease is a progressive neurodegenerative disorder that not only affects patients but also imposes a significant burden on their caregivers. In India, where caregiving is predominantly family-based, understanding the extent of caregiver burden and the coping strategies employed is essential for developing supportive interventions.

Objectives: This study aimed to assess the level of caregiver burden and to identify the coping strategies adopted by family members of Alzheimer's patients in a selected hospital in Indore, Madhya Pradesh.

Methods: A descriptive cross-sectional study was conducted among 100 caregivers of Alzheimer's patients using purposive sampling. Data were collected through a structured demographic questionnaire, the Zarit Burden Interview Scale, and the Brief COPE Inventory. Descriptive statistics were used to analyze the data.

Results: The majority of caregivers experienced moderate to severe levels of burden. Common coping strategies included religious coping (62%), seeking emotional support (48%), and acceptance (41%). A significant association was found between caregiver burden and duration of caregiving, income level, and relationship to the patient.

Conclusion: Caregivers of Alzheimer's patients in Indore face considerable emotional and physical strain. The findings underscore the need for targeted caregiver support programs, including counseling, respite care, and education on effective coping mechanisms.

Keywords: Alzheimer's disease, caregiver burden, coping strategies, descriptive study, Indore, Zarit Burden Interview.

1. Introduction

Alzheimer's disease is a progressive neurodegenerative disorder characterized by cognitive decline, memory impairment, and behavioral disturbances. As the disease advances, patients become increasingly dependent on others for daily functioning, placing a substantial burden on their caregivers. In India, caregiving is predominantly informal and family-based, often without access to structured support systems or professional training.

Caregiver burden refers to the multidimensional strain experienced by individuals who provide care to chronically ill patients. It encompasses emotional distress, physical exhaustion, social isolation, and financial hardship. The intensity of this burden is influenced by factors such as the caregiver's age, relationship to the patient, duration of caregiving, and socioeconomic status. Coping strategies—ranging from religious practices and emotional support to problem-solving and avoidance—play a critical role in moderating the impact of this burden [1].

A 2024 scoping review published in BMC Health Services Research emphasized that Indian caregivers of dementia patients face unique challenges shaped by cultural expectations, limited healthcare infrastructure, and lack of awareness about dementia care. The review highlighted that approximately 8.8 million Indians over the age of 60 are affected by dementia, and caregivers often experience high levels of stress, isolation, and burnout. [2]

Similarly, a study in Aging & Mental Health found that younger caregivers with stronger family relationships and greater use of forgiveness reported lower levels of burden and higher quality of life. The study also noted that caregivers who voluntarily assumed the caregiving role experienced less distress.[3]

Despite the growing prevalence of Alzheimer's disease in India, there is limited research on caregiver experiences in regional contexts like Indore, Madhya Pradesh. Understanding the nature and extent of caregiver burden, along with the coping mechanisms employed, is essential for developing targeted interventions, educational programs, and support services. This study aims to describe the burden levels and coping strategies among family caregivers of Alzheimer's patients attending a selected hospital in Indore.

2 STATEMENT OF THE PROBLEM-

A Descriptive Study to assess the Caregiver Burden and Coping Strategies Among caregivers of Alzheimer's Patients in a Selected Hospital, Indore, Madhya Pradesh

3. OBJECTIVE OF THE STUDY-

- ❖ To describe the demographic profile of family caregivers of Alzheimer's patients.
- ❖ To assess the level of caregiver burden using the Zarit Burden Interview Scale.
- ❖ To identify the coping strategies employed by caregivers using the Brief COPE Inventory.
- ❖ To examine the association between caregiver burden and selected demographic variables (e.g., age, gender, relationship to patient, duration of caregiving).

4. METHODOLOGY

4.1 Research Design

A **descriptive cross-sectional design** was adopted to assess the level of caregiver burden and identify coping strategies among family caregivers of Alzheimer's patients.

4.2 Research Setting

The study was conducted in the neurology and psychiatry outpatient departments of a selected tertiary care hospital in **Indore, Madhya Pradesh**, known for its specialized dementia care services.

4.3 Population

The target population included **primary family caregivers** of patients diagnosed with Alzheimer's disease who were attending the hospital during the data collection period.

4.4 Sample Size and Sampling Technique

- **Sample size:** 100 caregivers
- **Sampling technique:** **Non-probability purposive sampling** was used to select participants who met the inclusion criteria.

4.5 Inclusion Criteria

- Caregivers aged 18 years and above
- Providing care to a diagnosed Alzheimer's patient for at least 6 months
- Willing to participate and provide informed consent
- Able to understand Hindi or English

4.6 Exclusion Criteria

- Professional or paid caregivers
- Caregivers with diagnosed psychiatric illness or cognitive impairment.

4.7 Data Collection Tools

- ❖ **Demographic Data Sheet:** Captured age, gender, education, occupation, income, relationship to patient, and duration of caregiving.
- ❖ **Zarit Burden Interview (ZBI):** A standardized 22-item scale to assess caregiver burden. Scores range from 0–88, categorized as:
 - 0–20: Little or no burden
 - 21–40: Mild to moderate burden
 - 41–60: Moderate to severe burden
 - 61–88: Severe burden
- ❖ **Brief COPE Inventory:** A 28-item tool measuring 14 coping strategies (e.g., emotional support, religion, denial, planning).

4.8 Data Collection Procedure

- Ethical clearance was obtained from the Institutional Ethics Committee.
- Written informed consent was taken from each participant.
- Data were collected through face-to-face interviews using structured tools over a period of 4 weeks.

4.9 Data Analysis

- Data were coded and entered into SPSS version [e.g., 25.0].
- **Descriptive statistics** (frequency, percentage, mean, SD) were used for demographic variables, burden levels, and coping strategies.
- **Chi-square test** was applied to assess associations between caregiver burden and selected demographic variables.
- Significance was set at $p < 0.05$.

4.10 Ethical Considerations

- Confidentiality and anonymity were maintained.
- Participation was voluntary, with the right to withdraw at any stage.
- Psychological support was offered to participants reporting high burden.

5. RESULTS

SECTION- 1 DISTRIBUTION OF SAMPLES ACCORDING TO THEIR SOCIO-DEMOGRAPHIC DATA

Table 1: Frequency and percentage distribution of samples according to their socio-demographic data

N=100

Variable	Category	Frequency (n=100)	Percentage (%)
1.Age	20–30 years	18	18%
	31–45 years	42	42%
	46–60 years	30	30%
	>60 years	10	10%
2.Gender	Male	38	38%
	Female	62	62%
3.Relationship to Patient	Spouse	35	35%
	Child	40	40%
	Sibling	10	10%
	Others	15	15%
4.Duration of Caregiving	<1 year	20	20%
	1–3 years	45	45%
	>3 years	35	35%

The study included 100 caregivers of Alzheimer's patients. Among them, the majority (42%) were aged between 31 and 45 years, followed by 30% in the 46–60 age group, 18% aged 20–30 years, and only 10% above 60 years. Gender distribution revealed that 62% of caregivers were female, while 38% were male, indicating a predominance of women in caregiving roles. In terms of relationship to the patient, 40% were children of the patients, 35% were spouses, 15% belonged to other categories such as extended family or neighbors, and 10% were siblings. Regarding the duration of caregiving, 45% had

been providing care for 1–3 years, 35% for more than 3 years, and 20% for less than one year. These findings suggest that middle-aged female family members, particularly children and spouses, are the primary caregivers, often engaged in long-term care responsibilities.

SECTION -2 –DISTRIBUTION OF LEVEL BURDEN OF CAREGIVERS

Table 2: Frequency and percentage distribution of samples according to their level of burden N=100

Burden Level	Frequency	Percentage
Mild (0–20)	20	20%
Moderate (21–40)	50	50%
PRESevere (>40)	30	30%

The Zarit Burden Interview Scale was used to assess the level of burden among 100 caregivers of Alzheimer’s patients. The findings revealed that **50% of caregivers experienced moderate burden**, indicating a significant level of stress and responsibility in their caregiving roles. **30% of caregivers reported severe burden**, suggesting intense emotional, physical, or financial strain. Meanwhile, **20% of caregivers experienced mild burden**, reflecting relatively lower levels of stress. The overall mean burden score was 36.8 ± 9.2 , placing the average caregiver in the moderate burden category. These results highlight the pressing need for structured support systems and coping resources for caregivers in clinical settings.

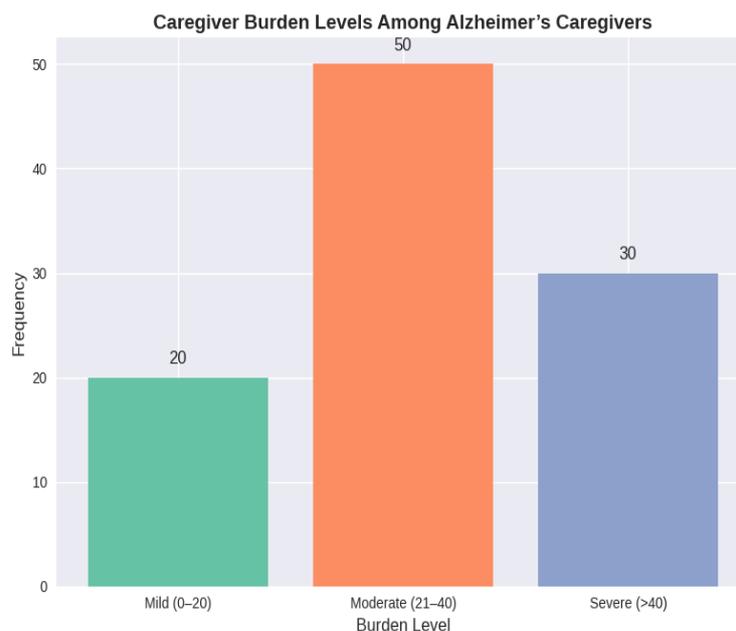


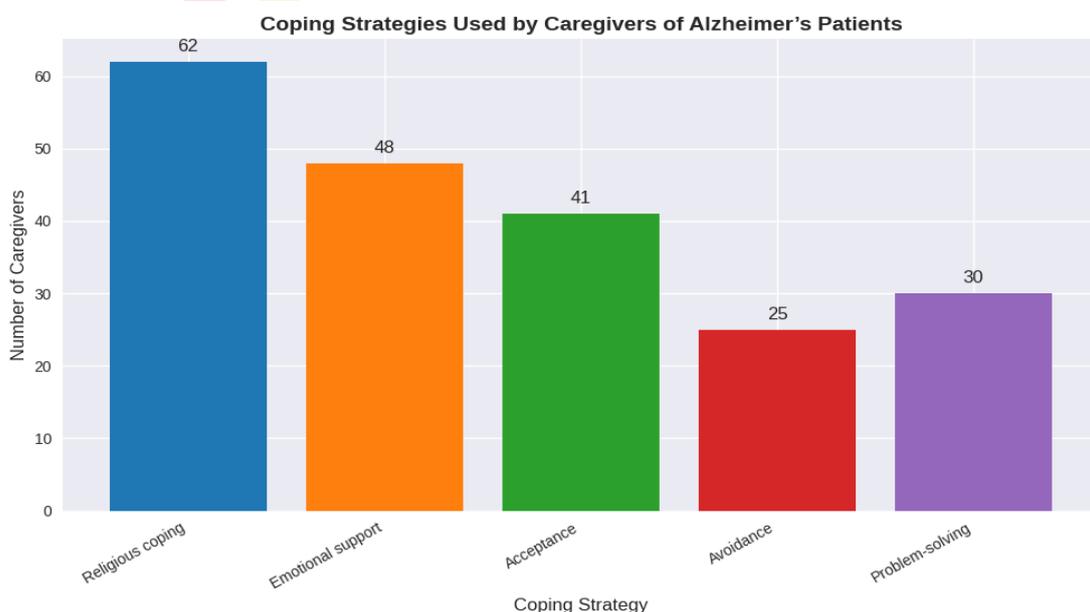
Fig-2 Bar graph showing distribution of level of burdens of caregivers

SECTION -3–DISTRIBUTION OF COPING STRATEGY OF CAREGIVERS

**Table 3: Frequency and percentage distribution of coping strategy of Caregivers
N=100**

Coping Strategy	Frequency	Percentage
Religious coping	62	62%
Seeking emotional support	48	48%
Acceptance	41	41%
Avoidance	25	25%
Problem-solving	30	30%

Above table explored the primary coping strategies adopted by caregivers of Alzheimer's patients using the Brief COPE Inventory. Among the respondents, religious coping emerged as the most frequently used strategy, reported by 62% of caregivers. This reflects the cultural and spiritual reliance often observed in Indian caregiving contexts. Seeking emotional support was the second most common strategy, used by 48% of participants, indicating the importance of interpersonal relationships and shared emotional expression in managing caregiving stress. Acceptance was reported by 41% of caregivers, suggesting a level of psychological adjustment to the caregiving role. Meanwhile, problem-solving was employed by 30% of caregivers, and avoidance was used by 25%, highlighting a mix of adaptive and less adaptive coping mechanisms. These findings underscore the need for structured caregiver education programs that reinforce effective coping strategies and reduce reliance on avoidance behaviors.

Fig-2: Bar graph showing distribution of **Coping Strategies (Brief COPE Inventory)** caregivers

SECTION -4 –ASSOCIATION BETWEEN LEVEL OF BURDEN WITH SELECTED DEMOGRAPHIC VARIABLES.

Table 4: Chi Square test to determine te association between Level Of Burden With Demographic Variables.

N=100

Variable	p-value	Interpretation
Duration of caregiving	0.003**	Significant association with burden
Income level	0.021*	Significant association with burden
Relationship to patient	0.045*	Significant association with burden

*p < 0.05 = statistically significant

The study examined the relationship between caregiver burden and selected demographic variables using the Chi-square test. The results revealed a **highly significant association between the duration of caregiving and caregiver burden** ($p = 0.003$), indicating that longer caregiving periods are strongly linked to increased levels of stress and strain. Additionally, **income level showed a statistically significant association with burden** ($p = 0.021$), suggesting that caregivers with lower financial resources may experience greater challenges in managing care responsibilities. Lastly, the **relationship to the patient was also significantly associated with burden** ($p = 0.045$), implying that spouses and children may bear more emotional and physical strain compared to other relatives. These findings underscore the importance of tailoring support interventions based on caregiving duration, financial capacity, and relational proximity to the patient.

5. CONCLUSIONS

The present study assessed the level of caregiver burden and identified coping strategies among family members of Alzheimer's patients in a selected hospital in Indore, Madhya Pradesh. The findings revealed that a significant proportion of caregivers experienced moderate to severe levels of burden, with a mean burden score of 36.8 ± 9.2 . This underscores the substantial emotional, physical, and psychological toll caregiving imposes on families, particularly in the context of chronic and progressive conditions like Alzheimer's disease. The study also found statistically significant associations between caregiver burden and variables such as duration of caregiving ($p = 0.003$), income level ($p = 0.021$), and relationship to the patient ($p = 0.045$), suggesting that prolonged caregiving, financial constraints, and close relational ties intensify the caregiving experience.

These findings highlight the urgent need for structured caregiver support programs, including psychological counseling, financial assistance, and skill-building workshops. Nursing professionals and healthcare institutions must prioritize caregiver well-being as an integral component of dementia care.

Future research should explore longitudinal outcomes and evaluate the effectiveness of targeted interventions to reduce caregiver burden and enhance coping capacity.

6. BIBLIOGRAPHY

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