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Assessment of Level of Burden Among Caregivers of Stroke Patients

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ABSTRACT

Background: Stroke is a leading cause of long-term disability, often requiring sustained caregiving by family members. Caregivers frequently experience physical, psychological, and social burden.

Objectives: 1) To assess the level of burden among caregivers of stroke patients at selected hospitals; 2) To explore the association of burden level with selected demographic variables.

Methods: A prospective observational study was conducted among 100 primary caregivers of stroke survivors in Pune, India. Socio-demographic and caregiving-related data were collected using a structured questionnaire from caregivers of patients admitted to the neurology wards of four selected hospitals. Caregiver burden was measured using the Zarit Burden Interview (ZBI-22), a validated tool assessing multidimensional caregiving impact. Assessments were performed at four timepoints: baseline, 2, 4, and 8 weeks. Data were analysed using descriptive statistics (frequency, percentage, mean, SD) and inferential tests (Chi-square/Fisher's exact test). A p-value <0.05 was considered statistically significant.

Results: Caregivers were predominantly female (67%) and aged 41–50 years (30%). Most were married (82%) and from urban areas (47%). The majority provided 8–10 hours of daily care (40%). Caregiver burden increased progressively across the four timepoints, with moderate burden reported by 58–80% and severe burden by 15% at 8 weeks. No significant association was observed between caregiver burden and demographic variables, indicating that burden was independent of age, gender, education, occupation, marital status, family type, or region (p>0.05).

Conclusion: Stroke caregivers experience substantial and progressively increasing burden, irrespective of demographic characteristics. These findings underscore the need for universal interventions, including structured caregiver education, psychological support, and respite services, to mitigate burden and enhance caregivers' quality of life.

Keywords: *stroke, caregiver burden, caregiving, demographic variables*

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1. INTRODUCTION

Stroke is a leading non-communicable disease and a major cause of death and disability worldwide. In 2021, there were about 11.8 million new cases and over 7 million deaths, with more than 93 million survivors living with its consequences.[1,2] In India, new cases rose to 1.25 million in 2021, a 51% increase since 1990, highlighting its growing public health impact.[3] Despite advances in care, many survivors continue to face long-term physical, cognitive, and psychosocial challenges, requiring sustained caregiving support.[4]

The responsibility of providing this care primarily falls on informal caregivers, usually family members. These caregivers not only assist with physical care and rehabilitation but also provide emotional, social, and financial support.[5] While caregiving is crucial for recovery, it often imposes a substantial burden, manifested as physical exhaustion, psychological distress, financial strain, and disruption of social roles.[6,7] Studies have shown that between 30–60% of stroke caregivers experience moderate to severe burden, and nearly half report symptoms of depression or anxiety related to caregiving demands.[8,9]

Caregiver burden is influenced by multiple factors, including patient dependency, duration of caregiving, caregiver's age, gender, education, socioeconomic status, and availability of social support. Understanding these associations is critical in identifying high-risk groups and tailoring interventions that can alleviate burden, enhance caregiver resilience, and ultimately improve patient outcomes. Despite the global evidence, research in the Indian context remains limited, particularly regarding the role of demographic and socio-economic variables in shaping caregiver burden.

Given this gap, the present study aims to assess the level of caregiver burden among stroke caregivers and to examine its association with selected demographic characteristics. Findings are expected to generate evidence for developing targeted interventions and informing health policies that strengthen caregiver support systems in stroke care.

2. MATERIALS AND METHODS

2.1 Study Design and Setting

A prospective observational study was conducted to assess caregiver burden among caregivers of stroke survivors at four timepoints. Data were collected between August 2024 and March 2025 at the selected hospitals in Pune, Maharashtra, India.

2.2 Sample Size and Sampling Method

A total of **100 primary caregivers** of stroke patients were included. Participants were recruited using **non-probability purposive sampling** based on eligibility criteria.

Sample size was calculated using the formula $n = (Z^2 * p *(1-p))/ d^2$ with 95% confidence, p=0.5p=0.5p=0.5, and 10% precision, yielding 96. To account for non-response, 100 caregivers were enrolled.

Inclusion Criteria

- Age ≥ 18 years
- Primary caregiver of a stroke survivor
- Providing ≥ 6 hours of care per day
- Able to read and complete the questionnaire in English or Marathi

Exclusion Criteria

- Caregivers of critically ill or terminal patients
- Caregivers currently participating in other intervention programs

2.3 Tools for Data Collection

Demographic Data

Section A: A structured demographic tool (14 variables):

Age, gender, education, occupation, marital status, family type, monthly income, residence (urban/semiurban/rural), relation to patient, caregiving hours/day, personal habits (smoking/tobacco/alcohol/caffeine/none/other), type of exercises (yoga/meditation/walking/weight-bearing/none/other), history of chronic illness, and type of chronic illness.

Section B: Caregiver Burden

Caregiver burden was measured using the Zarit Burden Interview (ZBI-22), a standardized, validated 22-item instrument scored on a 5-point Likert scale (0 = never to 4 = nearly always). Total scores range from 0–88, with higher scores indicating greater burden. Burden categories were applied:

- 0–20: little or no burden
- 21–40: mild to moderate burden
- 41–60: moderate to severe burden
- 61–88: severe burden

2.4 Reliability and Validity

Face and content validity were confirmed by nursing, neurology, and psychology experts. In the present study, ZBI demonstrated excellent reliability: Cronbach's $\alpha = 0.98$; test–retest correlation $(r) = 0.89$.

2.5 Data Collection Procedure

Informed written consent was obtained from all participants after explaining the study objectives and procedures. Caregivers were provided with the structured questionnaire, including socio-demographic details and the Zarit Burden Interview (ZBI-22), and were asked to complete it independently. Research staff offered clarification when needed but did not influence responses, and forms were reviewed for completeness before analysis. Data was collected at following timelines.

1. Timepoint 1 : Baseline
2. Timepoint 2 : (2 weeks after baseline)
3. Timepoint 3 : (4 weeks after baseline)
4. Timepoint 4 : (8 weeks after baseline)

2.6 Ethical Considerations

The study received ethical clearance from the Institutional Ethics Committee of Dr. D.Y. Patil Vidyapeeth, Pune (Approval No: DYPV/CON/954/2021). Participants were assured of confidentiality, the right to withdraw at any time, and voluntary participation in compliance with ICMR 2019 and the Declaration of Helsinki.

2.7 Data Analysis

Data was entered in Microsoft Excel 2019 and analysed using Python. Normality was checked using the Shapiro–Wilk test. As data were normally distributed, parametric tests were used:

Descriptive statistics (frequency, percentage, mean, standard deviation) were used to summarize demographic variables and caregiver burden scores.

Associations between caregiver burden and selected demographic variables were examined using **Chi-square test or Fisher's exact test**, as appropriate.

A p-value < 0.05 was considered statistically significant.

3. RESULTS

Table 3.1 Demographic Characteristics of study participants

Variable	Frequency	Percentage (%)
Age		
18–30 years	17	17
31–40 years	22	22
41–50 years	30	30
51–60 years	21	21
61 years and above	10	10
Gender		
Female	67	67
Male	33	33
Education		
Primary	13	13
Secondary	16	16
Higher Secondary	32	32
Diploma	21	21
Graduation & above	18	18

Occupation		
Government employee	7	7
Private employee	29	29
Self-employed/business	24	24
Retired	6	6
Housewife/Homemaker	34	34
Marital Status		
Married	82	82
Unmarried	5	5
Separated	3	3
Widow	10	10
Family Type		
Nuclear	31	31
Joint	62	62
Extended	7	7
Monthly Income		
Below ₹10,000	22	22
₹10,001–20,000	31	31
₹20,001–30,000	34	34
Above ₹30,000	13	13
Region		
Rural	26	26
Semiurban	27	27
Urban	47	47
Relation with Patient		
Daughter	14	14
Daughter-in-law	21	21
Son	21	21
Spouse	7	7
Other	37	37
Care Hours/Day		
6–8 hours	26	26
8–10 hours	40	40
10–12 hours	24	24
12+ hours	10	10
Caregiving Experience		

No	85	85
Yes	15	15
Personal Habits		
None	53	53
Smoking	11	11
Tobacco chewing	6	6
Alcohol	3	3
Excess caffeine	15	15
Other	12	12
Exercise Type		
None	59	59
Yoga	14	14
Meditation	3	3
Walking	17	17
Weight-bearing	1	1
Other	6	6
History of Chronic Illness		
Yes	27	27
No	73	73
Type of Chronic Illness		
Hypertension	4	4
Diabetes	6	6
Asthma	1	1
Arthritis	5	5
COPD	0	0
Hypertension/Diabetes	6	6
Others	5	5

The study included 100 primary caregivers of stroke patients. The majority were female (67%) and aged 41–50 years (30%). Most caregivers were married (82%), had completed higher secondary education (32%), and were primarily employed as private employees (29%) or homemakers (34%). Urban residents represented 47% of participants, while 26% were from rural areas and 27% from semiurban areas.

Caregivers were mostly family members, with daughters-in-law (21%) and sons (21%) being the largest groups, followed by others (37%). The majority (40%) provided 8–10 hours of daily care, and 85% were new to caregiving.

Regarding personal habits, 53% of caregivers reported no habits, while 11% smoked, 6% chewed tobacco, 3% consumed alcohol, and 15% reported excess caffeine intake. Most caregivers (59%) did not engage in regular exercise, while walking (17%), yoga (14%), and meditation (3%) were practiced by others. Approximately 27% reported a history of chronic illness, with diabetes (6%), hypertension/diabetes (6%), and arthritis (5%) being the most common conditions.

Graph 1: Distribution of Caregiver Burden Among Stroke Caregivers at Different Timepoints (N = 100)

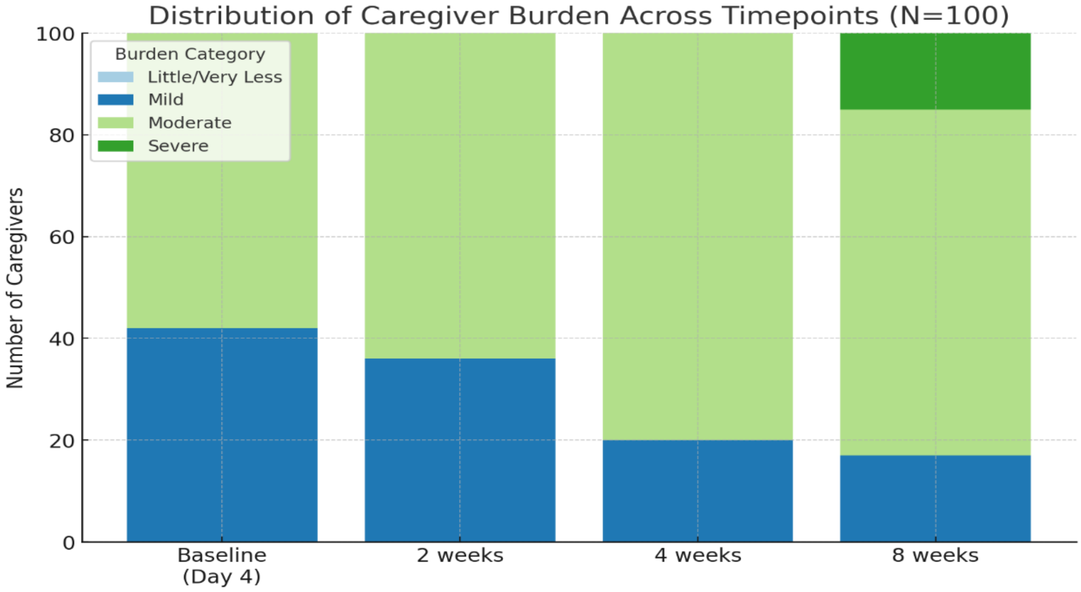

Table 3.2: Mean Caregiver Burden Scores Across Four Timepoints (N = 100)

Timepoint	**Mean ZBI Score ± SD**	**Burden Category Summary**
Timepoint 1 (Baseline, ~Day 4 of care)	34.5 ± 5.2	Mild: 42%, Moderate: 58%
Timepoint 2 (2 weeks after baseline)	36.2 ± 5.4	Mild: 36%, Moderate: 64%
Timepoint 3 (4 weeks after baseline)	40.5 ± 5.8	Mild: 20%, Moderate: 80%
Timepoint 4 (8 weeks after baseline)	44.1 ± 6.0	Mild: 17%, Moderate: 68%, Severe: 15%

- At **Timepoint 1 (Baseline)**, the mean burden score was 34.5 ± 5.2, with 58% of caregivers experiencing moderate burden.
- At **Timepoint 2 (2 weeks)**, the mean score increased slightly to 36.2 ± 5.4, with moderate burden reported by 64% of caregivers.
- At **Timepoint 3 (4 weeks)**, caregiver burden rose further, with a mean score of 40.5 ± 5.8; 80% of caregivers experienced moderate burden.
- By **Timepoint 4 (8 weeks)**, the mean burden increased to 44.1 ± 6.0, with 68% reporting moderate burden, 17% mild burden, and 15% experiencing severe burden.

These findings indicate that caregiver burden progressively increased over the 8-week period, with a subset of caregivers experiencing severe burden by 8 weeks, highlighting the ongoing physical, emotional, and social challenges faced by stroke caregivers.

Associations between caregiver burden at 8 weeks (Timepoint 4) and selected demographic variables—including age, gender, education, occupation, marital status, family type, and region—were analyzed using the Chi-square test when cell frequencies were ≥5. For variables with small sample sizes or frequencies <5, Fisher's exact test was applied. A p-value <0.05 was considered statistically significant.

No significant associations were found between caregiver burden and any of the demographic variables (all p-values > 0.05). This indicates that caregiver burden among stroke caregivers in this study was independent of the demographic characteristics assessed.

4. DISCUSSION

The present study demonstrated a progressive increase in caregiver burden among stroke caregivers over the 8-week period, with the majority experiencing moderate burden and a notable proportion reporting severe burden at the final assessment.

These findings are consistent with prior studies indicating that caregiving for stroke survivors imposes a significant and increasing burden over time.

Lee et al. (2018) conducted a community-based caregiver training program and reported that caregivers of stroke patients faced escalating burden without structured support, highlighting the cumulative physical, emotional, and social challenges inherent in caregiving.[10] Similarly, Akosile et al. (2018) in Nigeria found that stroke caregivers experienced progressively higher burden across time, particularly in domains of role strain and emotional distress.[11] Nationally, Kumar et al. (2015) reported that family caregivers of patients with chronic illnesses in India experienced moderate to severe burden, emphasizing the ongoing challenges faced by informal caregivers.[12]

In contrast, several studies have reported **no significant association** between caregiver burden and demographic characteristics, aligning with the findings of the present study. Bhattacharjee et al. (2012) found that caregiver burden was independent of age, gender, or education among stroke caregivers in Mumbai.[13] Kumar et al. (2022) similarly reported that demographic variables did not significantly predict caregiver burden, suggesting that caregiving demands themselves are the primary determinants of stress.[14]

The absence of significant associations in our study may be due to the relative homogeneity of the sample, predominantly female caregivers aged 41–50 years, providing 8–10 hours of care daily. Furthermore, the self-reported nature of the ZBI may have limited the detection of subtle differences across demographic subgroups.

Overall, the findings underscore the universal nature of caregiver burden, highlighting the need for interventions that target all caregivers, rather than specific demographic groups. Strategies such as structured caregiver education, psychological support, and respite services are essential to mitigate the cumulative burden experienced by caregivers over time.

5. LIMITATIONS

- Short follow-up period of 8 weeks may not capture long-term trends in caregiver burden.
- Homogeneity in the sample (e.g., predominantly female caregivers) may limit the generalizability of findings.
- Use of self-reported data may introduce response bias.

6. RECOMMENDATIONS

- Implement longitudinal studies to assess long-term caregiver burden.
- Develop and evaluate interventions targeting caregivers to reduce burden.
- Incorporate caregiver support programs into stroke rehabilitation services.
- Promote awareness and training for caregivers to enhance coping strategies.
- Advocate for policy changes to provide financial and social support to caregivers.

7. CONCLUSION

The study found that a structured family intervention package significantly improved self-efficacy among stroke caregivers. The combination of education, caregiver support, and follow-up proved effective in enhancing caregiving confidence. These findings highlight the need to incorporate such interventions into routine stroke care. Further research with larger samples and longer follow-up is recommended.

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