

CURRENT STATUS OF CAREGIVER BURDEN AMONG STROKE PATIENT CAREGIVERS IN THE EMERGENCY AND STROKE DEPARTMENT, NATIONAL GERIATRIC HOSPITAL, 2025

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ABSTRACT

Objective: To investigate the characteristics of caregivers and the level of caregiver burden in Vietnam, and to identify associated factors.

Subjects and Methods: A cross-sectional study was conducted on 137 caregivers. Demographic and clinical information was collected, and caregiver burden was assessed using the Zarit Burden Interview. Sleep quality was measured using the PSQI, and patient dependence was evaluated using the ADL/IADL scales.

Results: The majority of caregivers were aged 40–60 years (69.3%), 55.5% were female, 94.9% were married, 76.6% had a university degree or higher, and 74.5% lived in urban areas. Most caregivers experienced low to moderate burden (88%), while only 11.2% had moderate to high burden. Comparing caregiver burden levels, PSQI scores were significantly higher in the high-burden group than in the low-burden group (6.5 vs. 3; $p = 0.001$), whereas age, gender, marital status, and ADL/IADL scores showed no significant differences.

Conclusions: Most caregivers adapt well to their caregiving role. The low burden may be related to higher educational levels, better health literacy, and East Asian cultural values, where caring for relatives is considered a responsibility and duty. Sleep quality was strongly associated with caregiver burden, while the patient's physical dependency was not a determining factor. Caregivers with high burden should be screened and provided with psychological support and opportunities for rest.

Keywords: Caregiver burden, Zarit, sleep quality, ADL/IADL, caregiver.

1. INTRODUCTION

Stroke is the second leading cause of death worldwide and remains the primary cause of long-term disability, particularly in low- and middle-income countries, including Vietnam (1). In 2020, there were an estimated 7.08 million deaths caused by cerebrovascular diseases globally, with Southeast Asia being among the regions with the highest stroke-related mortality rates[2]. In Vietnam, the incidence of stroke is approximately 250 per 100,000 population per year, and stroke accounts for 21.7% of all deaths recorded in 2012. The burden of stroke is increasing rapidly, not only resulting in severe consequences for patients themselves but also creating substantial impacts on families and society.

Caregiver burden is a complex and broad concept, generally associated with negative connotations. It is understood as “the stress that individuals may

experience when providing care for another person, often a family member suffering from an illness.” Objective burden refers to direct caregiving activities such as feeding, bathing, and administering medications. In contrast, subjective burden reflects the caregiver's perception and emotional response to these responsibilities.

Among the various tools used to measure caregiver burden, the Zarit Burden Inventory (ZBI) is considered one of the most effective and widely applied instruments. Initially developed in 1980, the scale has undergone several modifications, including a shortened version introduced in 2001. Since then, ZBI has been used extensively in many countries, including Brazil, Iran, China, India, and South Korea. In Vietnam, the ZBI was first applied in evaluating caregiver burden in dementia

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and cancer patients.

International studies indicate that the majority of stroke survivors require caregivers to support their daily activities. Traditional Vietnamese family culture emphasizes the family as the core social unit, in which older adults or individuals with chronic illnesses are primarily cared for by family members. Therefore, caregivers play a pivotal role in the rehabilitation and recovery process of stroke patients. A study conducted in Vietnam in 2021 reported that 54.39% of caregivers of stroke patients experienced a moderate level of caregiver burden[3].

Caregivers not only assist with daily care tasks but also face emotional and psychological challenges related to the patient's condition, which may lead to significant stress and burden. Factors associated with caregiver burden include age, gender, educational level, perceived personal health, and the patient's degree of functional dependence. However, research on caregiver burden among caregivers of stroke patients in Vietnam remains limited.

The National Geriatric Hospital is a tertiary-level healthcare facility for older adults and admits thousands of stroke cases each year, particularly at the Emergency and Stroke Department, where patients often present in acute and complex conditions. Despite the critical role of caregivers, a comprehensive assessment of caregiver burden in this setting has not been thoroughly conducted. Previous studies have tended to focus on specific aspects of care rather than providing an overall evaluation of caregiver burden—an essential indicator of care effectiveness and the need for targeted interventions.

Based on this context, we conducted the study entitled "Caregiver Burden Among Primary Caregivers of Stroke Patients at the Emergency and Stroke Department, National Geriatric Hospital, 2025" with two main objectives:

- To assess the caregiver burden among primary caregivers of stroke patients using the Zarit Burden Inventory.
- To identify factors associated with caregiver burden among these caregivers.

2. SUBJECTS AND METHODS

2.1. Study Subjects

The study included primary caregivers of older adults diagnosed with stroke who were receiving treatment at the Emergency and Stroke Department, National Geriatric Hospital, from March 2025 to November 2025. A primary caregiver was defined as the individual who spent the most time providing care for the patient and did not receive payment for caregiving services. All caregivers were aged ≥ 18 years.

- Exclusion criteria:

- + Caregivers who were unable to answer interview

questions or had psychiatric or cognitive impairments.

+ Patients with progressive comorbid diseases (e.g., cancer, Alzheimer's disease, Parkinson's disease, schizophrenia).

+ Caregivers who declined participation.

2.2. Study Design

This research employed a cross-sectional descriptive design.

- Sample size:

A total of 137 caregivers were included. The sample size was determined based on the proportion of caregivers experiencing moderate to high caregiver burden reported in a study by Pham Thi Ngoc (2021), with $p = 54.39\%$ (3). The sample size for a cross-sectional study was calculated using the formula:

$$n = Z^2_{1-\alpha/2} \frac{p(1-p)}{d^2}$$

With $Z = 1.96$ at a 95% confidence level and an acceptable absolute error of $d \approx 8.6\%$, the minimum required sample size was 130. In this study, 137 caregivers were recruited, ensuring an adequate sample with an actual margin of error of approximately $\pm 8.3\%$.

2.3. Data Collection

- Caregiver burden was assessed using the Zarit Burden Interview (ZBI), administered through face-to-face interviews. The ZBI includes 22 self-rated items on a 5-point Likert scale: 0 = never, 1 = rarely, 2 = sometimes, 3 = fairly often, and 4 = always. Total scores range from 0 to 88, with higher scores indicating greater caregiver burden:

- + 0 - 20: No or minimal burden
- + 21 - 40: Moderate burden
- + 41 - 60: Severe burden
- + 61 - 88: Very severe burden

The instrument has been validated and widely applied in Vietnam[4]:

- Additional information collected included demographics, clinical characteristics, medical history, lifestyle factors

- The PSQI assesses sleep quality over 1 month. The questionnaire consists of 19 self-rated questions and five questions to be answered by bedmates or roommates. The 19 questions are categorized into seven components and graded on a scale of 0 to 3. The PSQI components are as follows: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The sum of scores for these seven components yields a single global score that ranges from 0 to 21, with the highest score indicating the worst sleep quality. A global PSQI score greater than 5 indicates significant difficulties in at least two components or moderate challenges in more than three components. Sleep quality according to the PSQI (The Pittsburgh Sleep Quality Index

PITTSBURGH).

- Self-control in daily activities according to the ADL (Activities of daily living). The questionnaire includes six items (bathing, dressing, toilet use, transferring in and out of bed or chair, urine and bowel continence, and eating). Support needs for each activity (no support, some support, complete dependence) were assessed.

- The Instrumental Activities of Daily Living (IADL) questionnaire includes eight items (using the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances) and is used to evaluate the capabilities of performing daily activities with tools. Each IADL item is scored as impaired (score = 0) or not (score = 1); hence, the summary score ranges from 0 to 8. Functional disability based on the summary score was dichotomized as ≥ 3 IADL disability (1 = Yes, 0 = No).

- The 15-item Geriatric Depression Scale, Vietnamese version, was used to screen for depression in the older patients. The total scores range from 0 to 15, in which scores of 0–5 are considered normal and 6–15 indicate having depressive symptoms.

- Alcohol abuse according to the Alcohol Use Disorders Identification Test-Concise (AUDIT-C). The Vietnamese version of this tool was validated. There are three questions, and patients receive a total score from 0 to 12. Higher scores suggest a higher risk of alcohol dependence. A score of > 4 for males and > 3 for females was used to classify those individuals at risk of hazardous drinking.

- Level of nicotine dependence according to the Fagerström test for nicotine dependence (FTND) scale. It consists of six items: the age of first tobacco use, the number of cigarettes smoked daily, the most difficult time patients had when trying to give up smoking, whether they smoked in smoke-free areas, whether they smoked in the morning, and whether they suffered illness. We classified FTND scores into five groups regarding the levels of nicotine dependence: very low, low, moderate, high, and very high. The higher scores suggested higher nicotine dependence. In addition, water-pipe smoking is prevalent in Vietnam. Three water pipes were set to equal one cigarette to calculate the number of cigarettes used.

- We used the International Physical Activity Questionnaire (IPAQ) to assess physical activity, which included moderate and vigorous activity and walking in the past 7 days. Physical activity levels were categorized as low, moderate, or high based on the total score.

2.4. Study Procedure

- A list of patients aged ≥ 60 years admitted to the Emergency and Stroke Department was obtained.
- Patients with clinically and radiologically confirmed acute stroke (CT/MRI) were identified.
- Caregivers were interviewed directly to collect data, which were recorded in standardized questionnaires, coded, and entered for analysis.

2.5. Data Management and Analysis

- Descriptive statistics: frequencies, percentages, means, standard deviations, and min–max values.
- Distribution assessment: histogram and Shapiro–Wilk test.
- Group comparisons: t-test or Mann–Whitney U test; ANOVA or Kruskal–Wallis test, as appropriate.
- Factors associated with caregiver burden were examined using multivariable linear regression.

Statistical significance was set at $p < 0.05$.

2.6. Ethical Considerations

The study adhered to the Declaration of Helsinki on ethical principles for medical research. Written informed consent was obtained from all participants before data collection.

3. RESULTS

Table 1. General characteristics of caregivers (N = 137)

Characteristics	Frequency (n)	Percentage (%)
Age		
< 40 years	25	18.2
40–60 years	95	69.3
> 60 years	17	12.4
Gender		
Male	61	44.5
Female	76	55.5
Marital status		
Married/living with partner	130	94.9
Widowed/divorced/single	7	5.1
Educational level		
Primary school	9	6.6
Intermediate/College	23	16.8
University or higher	105	76.6
Occupation before retirement		
Government/office worker	42	30.7
Factory worker	30	21.9
Farmer	13	9.5
Freelance/household/other	52	38.0
Place of residence		
Urban	102	74.5
Rural	35	25.5

*: $p < 0.05$ was considered statistically significant

Most caregivers were aged 40–60 years (69.3%), with a slightly higher proportion of females (55.5%). The majority were married (94.9%), and educational

attainment was relatively high, with 76.6% having completed university or higher. Over 74% lived in urban areas, which may provide greater access to healthcare and long-term care services. Occupational backgrounds were mainly government employees and freelance/household workers.

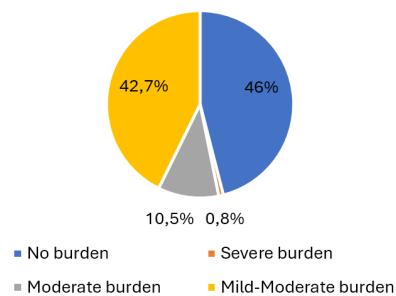


Figure 1. Distribution of caregiver burden levels based on the Zarit Burden Inventory

Results show that most caregivers experienced low to moderate burden, accounting for 88.0% of the sample (45.6% no burden and 42.4% mild to moderate burden). Only 11.2% of caregivers had moderate or severe burden.

Table 2. Comparison of demographic and clinical characteristics according to caregiver burden level

Characteristics	Low burden (Zarit < 41)	High burden (Zarit ≥ 41)	p-value
Age, median (IQR)	51 (43–57)	52 (45–54)	0.788
ADL score	6 (6–6)	6 (6–6)	0.330
IADL score	8 (8–8)	8 (8–8)	0.946
PSQI score	3 (0–5)	6.5 (3.8–8)	0.001
Gender, n (%)			
Male	47 (43.9%)	6 (42.9%)	1.000
Female	60 (56.1%)	8 (57.1%)	
Hypertension, n (%)			
Yes	8 (7.5%)	2 (14.3%)	0.326
No	99 (92.5%)	12 (85.7%)	
Diabetes, n (%)			
Yes	1 (0.9%)	1 (7.7%)	0.204
No	107 (99.1%)	12 (92.3%)	
Marital status, n (%)			
Widowed/Divorced/Single	5 (4.6%)	1 (7.1%)	0.523
Married/living with partner	104 (95.4%)	13 (92.9%)	

*: $p < 0.05$ was considered statistically significant

There were no significant differences in caregiver burden by age, gender, marital status, hypertension, diabetes, ADL score, or IADL score ($p > 0.05$), suggesting that basic demographic characteristics and functional dependency levels of the patients did not markedly influence caregiver burden.

The most prominent associated factor was sleep quality (PSQI): Caregivers in the high-burden group had significantly poorer sleep quality (median PSQI = 6.5; IQR 3.8–8) compared to those in the low-burden group (median PSQI = 3; IQR 0–5), with $p = 0.001$.

4. DISCUSSION

This study, conducted among 137 caregivers of stroke patients at the National Geriatric Hospital, revealed that the majority of caregivers experienced low-to-moderate burden (88%). In contrast, only approximately 12% fell into the moderate-to-high burden group. These findings are consistent with previous studies in Vietnam, such as Pham Thi Ngoc (2021)[3], which also reported that most caregivers can adapt effectively to their caregiving roles, particularly when supported by social networks, medical knowledge, and financial resources. However, the proportion of caregivers experiencing high burden in our study was lower than that reported in many international studies. This difference may reflect the specific characteristics of our study population, who were predominantly urban residents with higher educational attainment, strong family support networks, and better access to health information. These factors likely enable caregivers to manage caregiving responsibilities more effectively, reducing perceived stress and feelings of being overwhelmed.

Detailed analysis according to burden levels showed that demographic factors such as age, gender, marital status, and the basic dependency level of patients (ADL, IADL) did not significantly affect caregiver burden. This suggests that the patient's physical needs do not solely determine caregiver burden but are closely related to caregivers' psychological, physiological, and adaptive capacities. In other words, two caregivers attending to patients with similar dependency levels may experience different levels of burden depending on their mental health, experience, stress management skills, and available support networks. This aligns with the concept of "perceived burden" in international literature, highlighting that subjective perceptions of difficulty play a more crucial role than objective caregiving demands [5].

A notable finding in our study is the strong association between caregiver burden and sleep quality. Caregivers with high burden had a median PSQI score of 6.5 compared to 3 in the low-burden group ($p = 0.001$). This is an important observation consistent with numerous global studies. A 2023 systematic review of 27 caregiver burden studies found that sleep disturbances among caregivers were associated with higher caregiver burden and increased risk of psychological and physical health

problems[6]. Furthermore, analysis of 58 studies assessing caregiver and patient burden indicated that both patient and caregiver health and quality of life declined when caregivers experienced poor sleep quality [7].

The underlying mechanism may be that poor sleep impairs emotional regulation, cognitive function, decision-making ability, and motivation, thereby increasing perceived caregiving burden. Many caregivers may enter a negative cycle: stress leads to poor sleep, which in turn exacerbates stress and reduces caregiving effectiveness, further heightening perceived burden[8].

This finding underscores the importance of screening for sleep disturbances and implementing interventions to improve sleep, such as relaxation techniques, time management strategies, shared caregiving responsibilities, and psychological support, to alleviate burden and enhance caregivers' overall well-being.

International studies also emphasize the critical role of psychological support, caregiving guidance, and intervention programs in reducing caregiver burden. In Vietnam, East Asian cultural norms consider caregiving for family members a moral and familial responsibility[9, 10], which may help caregivers adapt well to their roles. Nonetheless, even well-adapted caregivers may face adverse physiological and psychological consequences such as sleep disruption, prolonged stress, and insufficient rest, highlighting the need for comprehensive support programs that provide knowledge, psychological assistance, stress management training, and opportunities for rest.

Several limitations should be noted. First, the cross-sectional design precludes establishing causal relationships between burden and associated factors. Second, participants were primarily caregivers in urban tertiary hospitals, limiting generalizability to rural or remote populations, where caregiving conditions and access to healthcare may differ. Nevertheless, the study provides valuable insights into caregiver burden in Vietnam, emphasizing the importance of addressing sleep quality, providing psychological support, and enhancing caregivers' awareness and access to resources.

Moreover, our findings suggest several practical implications for policy and clinical interventions. First, support programs should target high-burden caregivers, including regular screening for sleep quality and stress, as well as provision of psychological support and opportunities for rest. Second, caregiver training programs should be expanded to include home-care skills, responsibility sharing among family members, and community-based support groups to alleviate individual stress. Third, the development of online health information networks and caregiver experience-sharing platforms may facilitate timely access to information, thereby improving adaptive capacity and reducing perceived burden.

Finally, this study highlights the importance of a

comprehensive assessment of caregiver burden, considering not only objective patient care needs but also caregivers' physiological, psychological, and adaptive capacities. Understanding these factors provides a foundation for effective multi-component interventions that improve caregivers' mental health, caregiving quality, and patient outcomes. The findings also open avenues for future longitudinal research on multifactorial interventions aimed at reducing caregiver burden, particularly in Vietnam, where family-centered caregiving is deeply rooted in cultural norms.

5. CONCLUSION

The majority of caregivers of stroke patients at the National Geriatric Hospital experienced low to moderate burden, with only a small proportion falling into the moderate to high burden group. Sleep quality was significantly associated with caregiver burden, whereas demographic factors and the basic dependency levels of patients (ADL/IADL) did not show a significant impact. Caregivers with high burden require timely screening and additional support focusing on psychological well-being, sleep, and rest to improve caregiving effectiveness and mental health. This study emphasizes the importance of comprehensive assessment of caregiver burden, providing a basis for designing interventions that enhance sleep quality and overall caregiving quality for stroke patients.

RECOMMENDATIONS

High-burden caregivers should be identified early and provided with interventions focused on psychological support, stress management, adequate rest, and improved sleep quality. Caregiver programs should offer practical training on caregiving skills, coping strategies, and stress management to enhance competence and confidence. Encouraging shared caregiving responsibilities within families and developing community support groups can provide both emotional and practical assistance. Improving caregivers' access to reliable health information through digital platforms, printed materials, and professional guidance is essential to enhance adaptive capacity and reduce perceived burden. Health policies should recognize the critical role of family caregivers and integrate caregiver support services into routine healthcare delivery, including both hospital-based and community-based interventions. Implementing these measures can improve the quality of care for stroke patients while safeguarding caregivers' physical and mental health, ultimately contributing to better patient outcomes and sustainable caregiving.

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