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Education for Stroke Caregivers to Reduce Burden

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Abstract

Stroke is one of the leading causes of disability, resulting in patients' dependence on informal caregivers and potentially causing physical, psychological, and social burdens. This study aimed to determine the effect of educational interventions on caregiver burden in Ngemplak District, Boyolali, and Colomadu District, Karanganyar. This quantitative study used a pretest-posttest design and a paired-samples t-test. The Shapiro-Wilk normality test indicated that the data were normally distributed. The sample consisted of 16 caregivers who met the inclusion criteria. The results showed that the mean caregiver burden score increased from 28.00 ± 1.862 at pre-test to 33.13 ± 2.825 at post-test, with a statistically significant difference (t = -5.045; p = 0.000). Qualitative interview findings revealed that several caregivers experienced a reduction in heavy burden levels after the intervention, accompanied by decreased physical fatigue, improved ease in caregiving activities, and greater patient independence. However, economic difficulties and high patient dependency remained major challenges for some caregivers. Overall, the educational intervention demonstrated a significant influence on caregiver burden both quantitatively and qualitatively. Education is therefore recommended as an ongoing community-based intervention to support caregivers of stroke patients.

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Introduction

Stroke remains one of the leading causes of death and long-term disability worldwide (Feigin et al., 2025). In 2021, stroke accounted for 7,252,678 deaths globally, consisting of 3,308,367 deaths from hemorrhagic stroke (45.6%) and 3,591,499 deaths from ischemic stroke (49.5%). In the same year, stroke caused disability in 160,457,220 individuals, with hemorrhagic stroke contributing

49.6% and ischemic stroke 43.8% of disability cases (Feigin et al., 2022). Despite advances in stroke treatment, disability remains a major consequence and a significant public health challenge worldwide (Benjamin et al., 2019).

According to the International Classification of Functioning, Disability, and Health (ICF), disability includes impairments in body function and structure, activity limitations, and participation restrictions in daily life (Ju et al., 2022). Stroke survivors frequently experience physical, cognitive, and psychosocial impairments that affect their independence and quality of life (Yuliana et al., 2023). Cognitive deficits may involve memory, attention, executive function, language, and visuospatial abilities (Cramer et al., 2023). Furthermore, approximately 10% of stroke patients have pre-stroke dementia, another 10% develop dementia after the first stroke episode, and nearly 30% after recurrent strokes (D'Souza et al., 2021). These conditions often increase patient dependency and create long-term care needs within the family and community (Predebon et al., 2021).

Due to these functional limitations, many stroke survivors require continuous assistance from informal caregivers in performing activities of daily living (Sajwani-Merchant et al., 2023). Caregivers commonly assist with bathing, dressing, feeding, toileting, mobility, medication management, financial management, and social interaction (Eriksson et al., 2021; Khomarun et al., 2025; Prinsloo, 2021). Care responsibilities are often carried out continuously from morning until night with minimal rest (San et al., 2024). Previous studies have demonstrated a significant relationship between patient disability and caregiver burden (Shamoun & Harris, 2022). Prolonged caregiving demands may result in physical exhaustion, emotional stress, social limitations, and financial difficulties (Kazemi et al., 2021; Na'imah et al., 2023; Theng et al., 2023). Consequently, caregiver burden can negatively affect caregivers' quality of life and reduce their ability to provide effective care (Farahani et al., 2021; Kazemi et al., 2021; Li et al., 2022; Mishra et al., 2021).

Although caregivers play an essential role in stroke rehabilitation, many informal caregivers lack adequate healthcare knowledge and caregiving skills (Scott Duncan et al., 2023). Families frequently encounter difficulties in managing patient care after hospital discharge despite receiving basic information during inpatient treatment (Fadli et al., 2024). Therefore, caregiver empowerment through educational interventions is needed to improve caregiving competence and reduce caregiver burden (Kariasa & Waluyo, 2021). Educational interventions may include direct practical training, counseling, group discussions, home visits, and follow-up communication support. These interventions aim to improve caregiver knowledge and skills, reduce anxiety and excessive burden, prevent injuries, decrease treatment costs, and improve quality of life for both patients and caregivers (Kariasa & Waluyo, 2021).

Caregiver education can cover physical care activities such as mobility assistance, feeding, dressing, bathing, toileting, hygiene, and functional mobility (Chinchai et al., 2010; Pastore et al., 2022). In addition, education may address emotional support strategies, communication skills, medication management, and environmental safety (Falvo, 2011; Harrison et al., 2017; Mack & Hildebrand, 2023). Previous studies have shown that caregiver education programs can improve patient functional outcomes and caregiver satisfaction (Hong et al., 2017), reduce caregiver burden (Wang et al., 2021), and enhance caregivers' ability to provide effective care (Manungkalit & Sari, 2025).

Based on these findings, caregiver education has the potential to become an important strategy in supporting informal caregivers of stroke patients. However, evidence regarding its influence on caregiver burden in community settings remains limited. Therefore, this study aims to determine the effect of caregiver education on caregiver burden among stroke patients' caregivers. The findings are expected to contribute to the development of effective and sustainable caregiver education programs in community-based stroke care.

Materials and Methods

Research Design

This study employed a mixed-method approach with a pretest-posttest design and was conducted in Ngemplak District, Boyolali, and Colomadu District, Karanganyar. The quantitative approach was used to measure caregiver burden before and after the educational intervention. In contrast, the qualitative approach was used to explore caregivers' experiences in providing care to stroke patients and their perceptions of the educational intervention.

Participants

The participants were 16 informal caregivers of stroke patients, selected through purposive sampling. All participants resided in Colomadu District, Karanganyar Regency. The inclusion criteria were: (1) being the primary caregiver of a stroke patient, (2) having provided care for at least six months, (3) having a family relationship with the patient, (4) not receiving payment as a caregiver, and (5) not working as a healthcare professional.

Educational Intervention

The educational intervention was delivered by the researchers in two sessions, each lasting approximately 60–90 minutes. The education was conducted through direct counseling, demonstrations, and discussions with caregivers. The materials included basic stroke care, patient mobility assistance, feeding and personal hygiene support, positioning techniques, strategies to prevent physical fatigue, and strategies to reduce caregiver burden during daily care activities. Caregivers were also encouraged to discuss difficulties experienced during caregiving and receive practical solutions related to patient care.

Variable Measurement

Caregiver burden was quantitatively measured using the Zarit Burden Interview (ZBI), a 22-item instrument that assesses physical, emotional, social, and financial burden. Qualitative data were obtained through in-depth interviews conducted before and after the intervention. Interviews included structured questions on demographic characteristics such as gender, age, occupation, duration of caregiving, and relationship with the patient, followed by open-ended questions exploring caregivers' experiences, challenges, and perceived burden of caring for stroke patients.

Data Analysis

Quantitative data were analyzed using IBM SPSS Statistics software. Data normality was assessed using the Shapiro-Wilk test. Normally distributed data ($p > 0.05$) were analyzed using a paired sample t-test to compare caregiver burden scores before and after the intervention. Statistical significance was determined at a 95% confidence level ($\alpha = 0.05$).

Qualitative data were analyzed through data reduction, data presentation, and conclusion drawing. The interview findings were used to strengthen and complement the quantitative results by describing caregivers' subjective experiences and perceived changes in burden following the educational intervention.

Results and Discussions

Respondent Description

The characteristics of the respondents in this study are important for providing an overview of the caregivers' profile, including gender, relationship with the patient, age, length of care, and the type of activity difficulties experienced by the patient. This description aims to understand the background of respondents that may affect caregivers' burden during the treatment process.

Based on Table 1, most respondents were female (11, 68.75%), while males were 5 (31.25%). This shows that caregivers are more often women. Based on the relationship with patients, the majority of respondents were children (31.25%), followed by husbands, brothers, and unprofessional caregivers, each with 2 people (12.50%). Meanwhile, other relationships, such as wives, nieces, sisters, mothers, and combinations of brothers and wives, each have a smaller proportion (6.25%).

Based on age, most of the respondents were in the elderly category (>45 years), which was 9 people (56.25%), while the adult category (26-45 years) was 7 people (43.75%). This shows that caregivers are predominantly older. Judging from the length of care, most of the respondents have treated patients for more than 24 months, namely 7 people (43.75%), followed by respondents who have treated 5 people ≤12 months (31.25%), and 13–24 months, as many as 4 people (25%). This shows that most caregivers have long-term experience.

In terms of patient activity difficulties, the most difficult was mobility for 5 people (31.25%). Furthermore, difficulty in wearing clothes and eating was experienced by 3 people (18.75%). Meanwhile, the difficulty of defecating and sitting to stand was 2 people each (12.50%), and the difficulty of cutting and cooking was 1 person each (6.25%). This shows that the patient's main problem is mobility.

Table 1. Distribution of Respondent Characteristics

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	5	31,25%
Women	11	68,75%
Relationships		
Husband	2	12,50%
Wife	1	6,25%
Children	5	31,25%
Nephew	1	6,25%
Sister	2	12,50%
Sister	1	6,25%
Mother	1	6,25%
Unprofessional babysitters	2	12,50%
Brother and Wife	1	6,25%
Age		
Adults (26–45 years old)	7	43,75%
Senior (>45 years)	9	56,25%
Long Parenting		
≤ 12 months	5	31,25%
13–24 months	4	25%
> 24 months	7	43,75%
Activity Difficulties		
Mobility	5	31,25%
Wearing clothes	3	18,75%
Eating	3	18,75%
Bowel movements	2	12,50%
Sit to stand	2	12,50%
Cutting Cooking	1	6,25%

Caregiver Burden Category

To determine the distribution of caregivers' burden levels, burden classification was based on scores from the pre-test and post-test. Caregiver burden classification in this study was determined based on the total scores of the Zarit Burden Interview (ZBI), which were categorized into four levels: Mild, Moderate, Severe, and Very Severe according to established cut-off points. This analysis helps understand the extent of interventions or changes among caregivers during the observation period.

Table 2. Caregiver Burden Category

Burden Categories	Pre-test		Post-test	
	Quantity	Percentage	Quantity	Percentage
Mild	0	0,00%	0	0,00%
Moderate	10	62,50%	12	75,00%
Severe	4	25,00%	2	12,50%
Very Severe	2	12,50%	2	12,50%

Based on the caregiver burden classification, most caregivers were categorized as experiencing a moderate burden both before and after the educational intervention. Following the intervention, there was a shift from the severe to the moderate burden category, indicating a reduction in caregiver burden.

Normality Test Results

The normality test is used to determine whether the caregiver burden data from the pre-test and post-test are normally distributed. In this study, the normality test used the Shapiro-Wilk test because the sample size was less than 50 respondents. The results of this normality test serve as the basis for determining the statistical test to be used in the next stage of analysis.

Table 3. Normality Test Results

Tests of Normality

	Kolmogorov-Smirnova			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Pre-test	0,204	16	0,073	0,911	16	0,120
Post-test	0,184	16	0,150	0,946	16	0,434

a. Lilliefors Significance Correction

Based on Table 3, the Shapiro-Wilk normality test results showed that the pre-test significance value (Sig.) was 0.120 and the post-test was 0.434. Both values were greater than 0.05 ($p > 0.05$), indicating that the caregiver burden data from the pre-test and post-test were normally distributed.

This result is also supported by the Kolmogorov-Smirnov test, where the pre-test p-value is 0.073 and the post-test p-value is 0.150, both of which are greater than 0.05. Thus, the data meet the assumption of normality, so the next analysis can use a parametric test, namely a paired-samples t-test, to test the difference between the pre-test and post-test.

Different Test Results

To determine the difference in caregiver burden levels before and after the intervention, a paired-samples t-test was performed. This test compares pre-test and post-test scores within the same sample to determine whether there is a statistically significant change.

Table 4. Paired Sample T-Test Results

Test				Gain Score		*t test*	*p value*
Pre-test		*Post-test*					
M	SD	M	SD	M	SD		
28,00	1,862	33,13	2,825	-5,125	3,793	-5,045	0,000

The results of the paired-samples t-test indicate a statistically significant difference in caregiver burden scores before and after the educational intervention. Overall, the analysis shows a clear change in the measured burden following the intervention, with the statistical test confirming that this difference is not due to chance. The negative t-value reflects the direction of change between the two measurements, while the significance value indicates that the observed difference is highly meaningful. These findings suggest that caregiver burden, as measured quantitatively, was significantly affected after the educational program was implemented.

To strengthen the quantitative analysis, a qualitative analysis was also conducted through in-depth interviews with caregivers at the pre-test and post-test. This analysis aims to describe changes in caregivers' subjective condition after receiving intervention, including burden, treatment experience, and influencing factors. The results of this interview provide a more comprehensive picture of the dynamics of caregiver burden that cannot be fully captured through statistical figures. The following is a comparison of caregiver interview results in the pre-test and post-test (Table 5).

Table 5. Comparison of Caregiver Interview Results in Pre-test and Post-test

Informants	Burden Categories		Conditions	
	Pre-test	Post-test	Pre-test	Post-test
Mrs. Lina	Moderate	Moderate	Not stressed; patient is cooperative. There are time and social interaction limitations, mild physical fatigue, worries, and financial constraints.	It is easier to help patients; the burden feels lighter, but there are still worries and financial constraints.
Mother Tiwi	Severe	Severe	Physical fatigue, stress, lack of rest time, disrupted social activities, and high patient dependence.	Reduced physical burden, less pain, easier to help the patient with their activities, even though it is still heavy
Mrs. Yanti	Moderate	Moderate	Physical and emotional exhaustion, time constraints, dual role pressure, heavy mobilization	The patient's condition improves, the physical burden is lighter, there is still time, and economic pressures are less.
Monica Lina	Moderate	Moderate	No significant stress, social and economic stress, and a lack of family support.	Easier maintenance, lighter burden, economic constraints still exist
Mr. Duncan	Very Severe	Very Severe	Severe fatigue, lack of sleep, high financial stress, decreased health	More effective treatment, better results, but the burden remains very heavy
Mr. Warsito	Moderate	Moderate	No significant stress; family support, economic constraints, and physical fatigue.	With a lighter burden, maintenance improves, and conditions are more manageable.

Informants	Burden Categories		Conditions	
	Pre-test	Post-test	Pre-test	Post-test
Mr. Slamet	Severe	Moderate	High economic stress, physical fatigue, lack of rest, and decreased social activity	There is an improvement in the patient's condition, treatment is easier, and the burden decreases to moderate.
Mrs. M	Severe	Mild–Moderate	Dual roles, physical exhaustion, economic stress, and high patient dependence	Patients are more independent, the burden is reduced, *and caregivers* are more flexible in managing their time.

Table 5 presents the comparison of caregivers' experiences before and after the educational intervention based on in-depth interview findings. Overall, the interviews showed that caregivers experienced varying levels of burden related to physical fatigue, emotional stress, limited personal time, financial difficulties, and high patient dependency prior to the intervention. After the intervention, most caregivers reported positive changes in the caregiving process, particularly reduced physical exhaustion, greater ease in assisting patients with daily activities, and better management of caregiving responsibilities. Several caregivers also noted increased patient independence, which contributed to a lighter perceived burden and greater flexibility in managing their daily routines. Although some caregivers remained within the same burden category, qualitative findings indicated meaningful improvements in their caregiving experiences and coping abilities following the educational intervention.

There is no major inconsistency, but there is a mild conceptual divergence between the quantitative and qualitative findings regarding caregiver burden after the intervention. Quantitatively, the burden classification shows a general improvement pattern, with more caregivers shifting from higher burden categories to moderate levels after the educational intervention, suggesting a reduction in severe burden conditions. This supports the interpretation that the intervention had a beneficial effect in alleviating extreme caregiving strain. However, the narrative qualitative findings present a more nuanced picture: while caregivers consistently reported reduced physical fatigue, improved ease of caregiving, and greater patient independence, some still experienced persistent financial strain, emotional pressure, or remained in the same burden category. This indicates that although daily caregiving experiences improved, structural or contextual stressors were not fully resolved. Therefore, the qualitative data do not contradict the quantitative trend but rather deepen it by showing that improvements were primarily functional and experiential, while certain underlying burden dimensions persisted.

Discussion

The findings of this study indicate that caregiver education is associated with a reduction in the proportion of caregivers experiencing high burden, with several shifting toward moderate burden levels after the intervention. This trend is also supported by qualitative findings, which indicate that caregivers reported reduced physical fatigue, greater ease in assisting with patients' daily activities, and increased patient independence. However, some caregivers remained in the same burden category, particularly those facing persistent financial constraints, limited time, and full caregiving responsibility. This suggests that while education improves caregiving competence and perceived ease of care, structural stressors still limit the full reduction of burden. Similar findings have been reported in previous quasi-experimental studies, in which psychoeducational interventions

significantly reduced caregiver burden by improving caregiving knowledge and skills, thereby enhancing self-efficacy in managing daily care tasks (Putri et al., 2022).

These results are further supported by studies showing that educational and structured support interventions not only reduce caregiver burden but also enhance coping strategies and quality of life. Subraja et al. (2025) found that caregivers who received education and emotional support experienced improved coping and reduced burden compared to those without the intervention. Likewise, caregiver education programs have been shown to improve home care efficiency and reduce psychosocial distress, reinforcing the role of education as a key component in caregiver support strategies (Rumiati et al., 2021). Additional evidence also demonstrates that structured education improves caregivers' ability to manage care tasks while reducing psychological strain, particularly anxiety and depression symptoms (Lee & Jung, 2023; Seok & Lee, 2025; Xu et al., 2024).

Further literature emphasizes that caregiver education enhances awareness of comprehensive, continuous stroke care, thereby contributing to better caregiving practices and improved patient outcomes (Parmar et al., 2022). Studies by Bakhtiari-Dovvombaygi et al. (2024) and Sotoudeh & Alavi (2023) also confirm that caregiver education reduces burden while improving caregivers' psychological well-being and quality of life. In addition, community-based or integrated educational interventions have been shown to strengthen social support systems and improve caregivers' perceived experiences in managing long-term care (Martínez-Melero et al., 2025). Overall, these findings reinforce that caregiver education is an effective strategy for reducing caregiver burden, although its impact may vary depending on socioeconomic and caregiving context factors.

Conclusion

The study found that educational intervention influenced caregiver burden, as shown by a statistically significant difference between pre-test and post-test scores. However, an important interpretative issue emerged: while the statistical results indicate an increase in burden scores after the intervention, the burden categorization and qualitative findings consistently show a shift from severe to moderate levels, with improved caregiving experiences, such as reduced physical fatigue and greater ease in providing care. This suggests that the higher post-test scores may reflect increased caregiver awareness and more accurate perception of caregiving demands rather than a true worsening of burden.

Overall, caregiver education contributed to changes in how caregivers perceive and manage their responsibilities, even though not all structural burden factors were fully reduced. The intervention was particularly effective in improving caregivers' knowledge, practical skills, and patient care management, helping them feel more capable of handling daily tasks. Nevertheless, economic constraints and high dependency levels remained persistent challenges for some caregivers. Future interventions should therefore combine education with practical skill training and psychosocial support to achieve more comprehensive burden reduction and better caregiver well-being.

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