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The Relationship between Caregiving Burden, Social Support, and Family Quality of Life of Post-Ischemic Stroke Patients at Hospital X

ABSTRACT

Ischemic stroke poses a significant long-term care burden on families. The high burden of caregiving has the potential to reduce the quality of family life, while social support is thought to moderate this relationship. This study is needed to analyze the dynamics of these three variables at RSUD X. This study aims to analyze the relationship between the burden of caregiving, social support, and the family quality of life of patients after ischemic stroke, as well as to test the role of social support as a moderator. This quantitative study with a cross-sectional design involved 410 families (primary caregivers) of post-ischemic stroke patients who were selected through purposive sampling. Data were collected using the Zarit Burden Interview (ZBI), Medical Outcomes Study Social Support Survey (MOS-SSS), and Family Quality of Life Scale (FQOL) questionnaires. Data analysis used the Spearman Rank and Moderated Regression Analysis (MRA) tests. The results showed a very significant negative relationship between the burden of caregiving and family quality of life (ρ = -0.712; p = 0.000). Social support was shown to play a significant role as a moderator (β = 0.164; p=0.005), where the negative impact of caregiving burden on quality of life was weaker in families with high social support. It is concluded that the burden of caregiving is a strong predictor of a decrease in family quality of life, but this negative effect can be mitigated by adequate social support. The implications of the findings emphasize the importance of integrating caregiver burden screening and strengthening family and community-based social support systems into the nursing care planning of stroke patients.

Keywords: Burden of Caregiving, Social Support, Family Quality of Life, Ischemic Stroke, Moderator.

INTRODUCTION

Stroke is one of the non-communicable diseases that is the second leading cause of death worldwide and the number one cause of death in Indonesia (Fitriah, et al., 2024; Azzubaidi et al., 2024). Among the various types of stroke, ischemic stroke is the most common type, accounting for about 85% of all stroke cases. Data from Basic Health Research (Riskesdas) shows that the prevalence of stroke in Indonesia continues to increase significantly from year to year, with a substantial economic and social burden on families and the health system (Fitriah, et al., 2024). In Asia, Indonesia ranks highest for stroke prevalence (12.1%), with the Special Region of Yogyakarta as the second highest province (10.3%) (Kusumaningrum & Perdana, 2020). The increase in the number of ischemic stroke patients that occurred in various hospitals in Indonesia, including at A. Tenriawaru Bone Hospital, where there was a significant increase for three consecutive months (Fitriah, et al., 2024), indicates that this public health burden needs serious attention. The condition of stroke not only causes a

physical impact on the sufferer, but also carries long-term consequences in the form of disability and significant cognitive decline (Azzubaidi et al., 2024).

Post-stroke patients experience a multidimensional decline in quality of life, including physical, psychological, and social aspects (Azzubaidi et al., 2024; Izzati et al., 2024). Research by Azzubaidi et al. (2024) shows that the quality of life of post-stroke patients tends to decline, especially if there is dependence in daily activities (Activity of Daily Living / ADL). The elderly group had a worse picture of quality of life than the younger age group. For families, the presence of family members with stroke creates a significant change in dynamics. The family must take on the role of caregiver who is responsible for meeting the patient's daily needs such as nutrition, elimination, personal hygiene, and mobilization (Cahyati et al., 2024). This condition often lasts over a long period of time and requires constant adjustment, creating a complex physical**,** psychological, social, and economic burden (Ariska et al., 2020).

This research is important to carry out considering the dual burden faced by the families of post-stroke patients. On the one hand, they have to face financial challenges due to ongoing medical expenses; On the other hand, they experience psychological distress in providing long-term care. A study by Ariska et al. (2020) shows that various factors including marital status, family relationships, and social support are significantly correlated with caregiver burden (*Kaffatan et al., 2023; Mulyani & Darussalam, 2023).*

Table 1. Factors Related to Caregiver Burden in Stroke Patients

Factor	Significance Level (p-value)	Types of Relationships
Age	0,009	Significant
Gender	0,001	Significant
Employment Status	0,002	Significant
Income	0,000	Significant
Marital Status	0,025	Significant
Family Relations	0,011	Significant
Family Support	0,000	Significant
Education	0,155	Insignificant

Source: Puspitasari et al, (2022)

Hospital X serves a predominantly rural population in Regency X, where formal social-care infrastructure (e.g., respite services, caregiver support groups, or home health aides) is notably absent compared to urban centers. Preliminary observations suggest that caregivers in this setting rely heavily on informal networks yet the interplay between such social support, objective caregiving burden, and family quality of life remains

unexamined. Specifically, it is unclear whether social support in this under-resourced context functions as a moderator (buffering the burden's impact on quality of life) or operates through other pathways. This study addresses that gap by testing the moderating role of social support.

The Stress and Coping theory by Lazarus and Folkman states that an individual's ability to deal with stressors (such as caring for family members with a stroke) is influenced by cognitive appraisal and the availability of coping resources (Watie et al., 2025). In this context, social support plays a role as a resource that can help families overcome the challenges of caregiving. A study by Watie et al. (2024) found a significant relationship between social support and the problem-solving ability of families caring for stroke patients. The value of the correlation coefficient of 0.31 indicates that the higher the social support obtained, the higher the problem-solving rate that the family has.

Table 2. The Relationship Between Social Support and Family Problem Solving

Variable	**Value p**	**Correlation Coefficients**	**Interpretation**
Social Support with Problem Solving	0,019	0,31	Significant and positive

Source: Watie et al. (2024)

On the other hand, the research of Kusumaningrum and Perdana (2020) found different results, where there was no statistically significant relationship between family social support and the quality of life of post-stroke patients (p-value = 0.381). These differences in results indicate that the relationship between these variables may be influenced by mediator or moderator factors that need further investigation.

Several previous studies have examined aspects related to the burden of caregiving and social support in stroke patients. Fitriah et al. (2024) examined the relationship between lifestyle and the incidence of ischemic stroke and found that poor diet increased the risk of stroke 2.7 times, heavy smoking increased the risk 11.44 times, and severe stress levels increased the risk 3.26 times. These findings reinforce the importance of behavioral factors in the context of stroke.

Qualitative research by Kadarwati et al. (2019) which examined the experience of families caring for post-stroke patients in Jambi City found that families experienced multidimensional challenges in providing care. The study identified three main themes: (1) the physical, psychological, social, and financial barriers experienced by caregivers; (2) the role of the family in helping basic needs; and (3) the type of treatment chosen based on the family's financial condition. Meanwhile, Mulyani and Darussalam (2023) examined the relationship between ADL dependence of stroke patients and the burden of family caregivers. The results showed a significant moderate correlation (r = 0.601) (p = 0.000) between the two variables. The type of burden most felt by family caregivers is the burden of self-esteem with an average score of 13.83.

Based on the literature review, there are several research gaps that are the basis for this research's novelty: First, most previous studies have focused on caregiver burden or patient quality of life separately, without integrating these two aspects with social support in a single comprehensive research model. This research will integrate these three variables to understand a more holistic relationship. Second, the results of the study on the relationship between social support and stroke outcomes are still inconsistent, as shown by the difference in the research results of Watie et al. (2024) who found a significant association and Kusumaningrum and Perdana (2020) who found no significant relationship. This study will try to explain this inconsistency by testing whether social support moderates (rather than mediates) the relationship between caregiving burden and family quality of life that is, whether higher social support weakens the negative effect of burden on quality of life. Third, most of the research was conducted in urban areas with better health access, while research in areas such as Regency X was still limited. The geographical and socio-economic context of district communities may result in different dynamics in the burden of caregiving and social support. Fourth, previous studies tended to focus on strokes in general without specifics of stroke types. This study specifically focuses on ischemic strokes that have different characteristics and disease course than hemorrhagic strokes.

This study aims to analyze the relationship between caregiving burden, social support, and family quality of life in patients after ischemic stroke at Hospital X. Specifically, the objectives of this study include the identification of the level of caregiving burden experienced by the patient's family, the analysis of the level of social support received by the family, the measurement of family quality of life, and the analysis of the relationship between caregiving burden and family quality of life. In addition, this study also aims to analyze the role of social support in moderating the relationship between caregiving burden and family quality of life. The theoretical benefit of this research is to develop a model that explains the relationship, contributing to the development of family nursing and neurological sciences. Practically, this research can provide evidence-based practice for health workers, especially nurses, to design effective interventions in reducing the burden of caregiving and improving the quality of family life. The expected benefit of the policy is to provide input for local governments in developing policies that support families with post-stroke family members, especially in strengthening the social support system in the community. The benefits for families are to increase their awareness of the importance of social support and coping strategies in reducing the burden of caregiving and improving their quality of life. This study defines **family quality of life** operationally as the degree of family satisfaction across five core domains measured by the Family Quality of Life Scale (FQOLS): (1) family interaction (communication and shared activities), (2) parenting (confidence in caring roles), (3) emotional well-being (stress management and mutual support), (4) physical/material well-being (health and financial resources), and (5) disability-related support (adequacy of services and information for the ill family member). Higher FQOLS scores indicate greater satisfaction and better quality of life.

RESEARCH METHODS

This study uses a quantitative approach with a correlational analytical design through *a cross-sectional* method. This design was chosen to analyze the relationship between caregiving burden (X_1), social support (X_2), and family quality of life (Y) in the family population of post-ischemic stroke patients. In this design, measurements of all variables are carried out simultaneously (*single point in time*), which allows researchers to identify relationships without manipulating independent variables.

The target population in this study is the entire family (primary caregiver) who care for patients after ischemic stroke at the Neurology Polyclinic or who carry out routine control at RSUD X. Affordable population is a family that meets the inclusion and exclusion criteria during the data collection period (June - August 2024).

Samples were taken using purposive sampling techniques based on the following inclusion and exclusion criteria:

1. Inclusion Criteria:
    a. Families (husband/wife/children/parents) who are primary *caregivers* and live with patients after ischemic stroke.
    b. The patient has been diagnosed with ischemic stroke by a doctor and at least 1 month post-attack.
    c. *Caregiver* is at least 18 years old.
    d. *The caregiver* is willing to be a respondent and sign an *informed consent*.
2. **Exclusion Criteria:**
    a. *Caregivers* who also have a serious illness that limits their ability to be interviewed.
    b. Patients with unstable medical conditions or other severe degenerative diseases (such as advanced cancer).

The sample size was calculated using the Lemeshow formula for infinite populations (due to fluctuating and uncertain population numbers), with a confidence level of 95% ($Z\alpha=1.96$) and a degree of accuracy ($d=0.05$). The proportion (p) is estimated to be 50% (0.5) to obtain the maximum sample. Thus, the minimum number of samples needed is 385 respondents. *The anticipation of drop-out* is added 10%, so that the total sample to be taken is 424 respondents. Post hoc power analysis for the observed interaction effect ($\Delta R^2 = 0.027$, $f^2 = 0.028$) using G*Power 3.1 indicated that with $N=410$, $\alpha=0.05$, and three predictors (burden, support, burden×support), the achieved power was 0.82 to detect the interaction term, which exceeds the conventional threshold of 0.80. This justifies the adequacy of the final sample size for testing moderation.

The data in this study was collected using a structured questionnaire consisting of four parts: first, Demographic Data, which includes the characteristics of respondents and patients, such as age, gender, relationship with patients, education, occupation, income, and length of care; second, Caregiving Burden Questionnaire, which uses a 22-item version of the Zarit Burden Interview (ZBI) with a 5-point Likert scale, where a higher score indicates a heavier load; third, the Social Support Questionnaire, which uses the Medical Outcomes Study Social Support

Survey (MOS-SSS) with 19 items and a 5-point Likert scale to measure social support in four dimensions; and fourth, the Family Quality of Life Questionnaire, which uses the Family Quality of Life Scale (FQOL) to measure family satisfaction in five domains. All instruments will go through a process of translation, cultural adaptation, and content validity tests by a panel of experts, as well as a reliability test on a preliminary study with 30 respondents.

Reliability and validity were rigorously assessed. Internal consistency reliability was evaluated using both Cronbach's alpha (α) and McDonald's omega (ωt) to account for potential tau-equivalence violations. The ZBI yielded $\alpha = 0.89$ and $\omega t = 0.90$; the MOS-SSS yielded $\alpha = 0.92$ and $\omega t = 0.93$; and the FQOLS yielded $\alpha = 0.88$ and $\omega t = 0.89$, all indicating excellent reliability. Confirmatory factor analysis (CFA) was conducted for the FQOLS to test the five-domain structure; fit indices were acceptable: $\chi^2/df = 2.14$, CFI = 0.94, TLI = 0.92, RMSEA = 0.053 (90% CI: 0.046–0.060), and SRMR = 0.048, supporting construct validity.

Data collection was carried out by questionnaire-guided interviews, observation of environmental conditions, and interaction between caregivers and patients in the waiting room of the Neurology Polyclinic of RSUD X. Research procedures include the preparation of literature studies, validity and reliability tests, data collection through interviews, data processing with statistical software, and data analysis using SPSS version 25. Analysis techniques include univariate analysis to describe variables, bivariate analysis with Pearson Product Moment or Spearman Rank tests, multiple linear regression to test the influence of caregiving and social support burden on quality of life, and Moderated Regression Analysis (MRA) to test the role of social support as a moderator variable.

Before conducting Moderated Regression Analysis (MRA), all continuous predictors (caregiving burden and social support) were mean-centered to reduce multicollinearity and improve interpretability of the interaction term. Multicollinearity diagnostics were conducted: variance inflation factors (VIF) for all predictors were below 2.5 (maximum VIF = 2.12), well below the threshold of 10, indicating acceptable multicollinearity levels. Residual diagnostics (normality via Q-Q plots, homoscedasticity via residual vs. fitted plots, and independence via Durbin-Watson test [DW = 1.93]) confirmed that regression assumptions were met.

Covariates were predeclared based on theoretical grounds and prior literature: caregiver age, gender, relationship to patient, duration of caregiving, and patient functional dependence (Barthel Index score) were entered as control variables in the regression model.

Missing data procedures: Of 424 initially recruited participants, 14 were excluded due to incomplete questionnaire responses (>20% missing items per scale). Multiple imputation (m=20 datasets) using fully conditional specification (FCS) was applied for the remaining cases with minimal missing data (<5% per variable). Sensitivity analyses comparing complete-case and imputed datasets showed negligible differences (β change <0.01), supporting the robustness of findings.

Bias mitigation: To reduce common-method bias, we used temporal separation (demographic data collected first, followed by burden scales, then outcome measures after a

brief break) and ensured anonymity. Harman's single-factor test indicated that the first unrotated factor explained only 34.2% of variance (<50% threshold), suggesting common-method variance was not a dominant concern.

The p< value of 0.05 is set as the limit of statistical significance.

Ethical Considerations: This study was approved by the Health Research Ethics Committee of Hospital X (approval number: HREC-X/2024/053, dated May 15, 2024). All procedures were conducted in accordance with the Declaration of Helsinki and Indonesian national research ethics guidelines. Written informed consent was obtained from all participants after a full explanation of study purposes, procedures, risks (minimal psychological discomfort), benefits (contributing to caregiver support development), and the right to withdraw at any time without penalty. Participants' identities were anonymized using numerical codes, and all data were stored in password-protected files accessible only to the research team. No incentives were provided to avoid coercion. Participants reporting severe psychological distress during data collection were referred to the hospital's counseling services.

RESULTS AND DISCUSSION

Demographic Characteristics of Respondents and Overview of Research Variables

Before analyzing the relationship between variables, this study first describes the characteristics of the sample and an overview of the burden of caregiving, social support, and family quality of life. Of the 424 questionnaires distributed, 410 respondents met the inclusion criteria and provided complete responses (*response rate* 96.7%). Most of the *caregivers* are women (72.4%), with an age range of 45-54 years (38.3%), who are children of patients (52.9%), and have provided care for 1-3 years (45.1%).

In general, the study variables showed the following results: The burden of caregiving was in the medium category (Mean ZBI Score = 38.2 ± 11.5). Social support as a whole is in the medium category (Mean MOS-SSS Score = 63.4 ± 14.2), with *the tangible support* dimension having the highest score. Meanwhile, the overall family quality of life was in the low category (Mean FQOL Score = 78.5 ± 16.8), with the *emotional well-being* domain having the lowest score.

Table 1. Description of Respondent Characteristics (n=410)

Characteristics	Category	n	%
Gender	Man	113	27,6
	Woman	297	**72,4**
Patient Relations	Husband/Wife	143	34,9
	Child	**217**	**52,9**

	Parents	50	12,2
Long Time Caregiver	< 1 year	112	27,3
	1 - 3 years	**185**	**45,1**
	> 3 years	113	27,6
Caregiving Burden Level	Lightweight (0-20)	45	11,0
	Medium (21-40)	**238**	**58,0**
	Weight (41-88)	127	31,0
Social Support Level	Low	132	32,2
	Keep	**201**	**49,0**
	Tall	77	18,8
Family Quality of Life Level	Low	**243**	**59,3**
	Keep	142	34,6
	Tall	25	6,1

The findings that the majority of caregivers are women and children of patients are consistent with previous research in various cultural contexts, including Indonesia. The role of caregiving is often socially attached to women, which causes them to bear a double burden . The length of the duration of treatment (1-3 years) indicates that the burden experienced is chronic and continuous, so it has the potential to cause fatigue and a decrease in quality of life if not supported with adequate resources.

Negative Relationship between Caregiving Burden and Family Quality of Life

Bivariate analysis using the Spearman Rank test (because the data is not normally distributed) showed a very significant negative association between caregiving burden and family quality of life (ρ = -0.712; p-value = 0.000). This suggests that higher caregiving burden is associated with lower family quality of life, though the cross-sectional design precludes causal inference. These results reinforce the findings of Mulyani & Darussalam (2023) who also found a significant positive correlation between the patient's ADL dependence (as a burden trigger) and the burden felt by caregivers.

The linear regression is simple by estimating that for every 1-point increase in the ZBI score, the family quality of life score (FQOL) will decrease by 0.68 points. This model explains a 50.7% variance in family quality of life (R Square = 0.507). This shows that the burden of caregiving is a strong predictor of quality of life, but there are other

factors that also play a role, in this case social support.

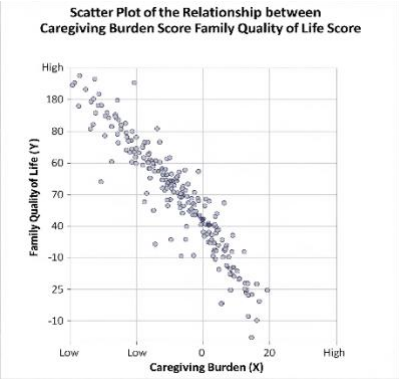


Figure 1. Scatter Plot Diagram The Relationship between Caregiving Burden Score and Family Quality of Life Score

Remarks: The data distribution pattern from top left to bottom right shows a strong negative correlation.

This finding is consistent with the theory of Stress and Coping by Lazarus and Folkman. The high burden of caregiving, which includes financial, physical, psychological, and social stressors, functions as a chronic stressor that may exceed family coping capacity. Although our cross-sectional design cannot establish temporal sequence or confirm causality, the observed pattern suggests that when coping resources are depleted, satisfaction in various domains of family life, such as enjoyable interactions, nurturing, and emotional well-being, which ultimately lowers the overall quality of family life. The context in RSUD X, where access to respite care or counseling services may be limited, further exacerbates the impact of this burden on quality of life.

The Role of Social Support as a Moderator in the Relationship between Caregiving Burden and Quality of Life

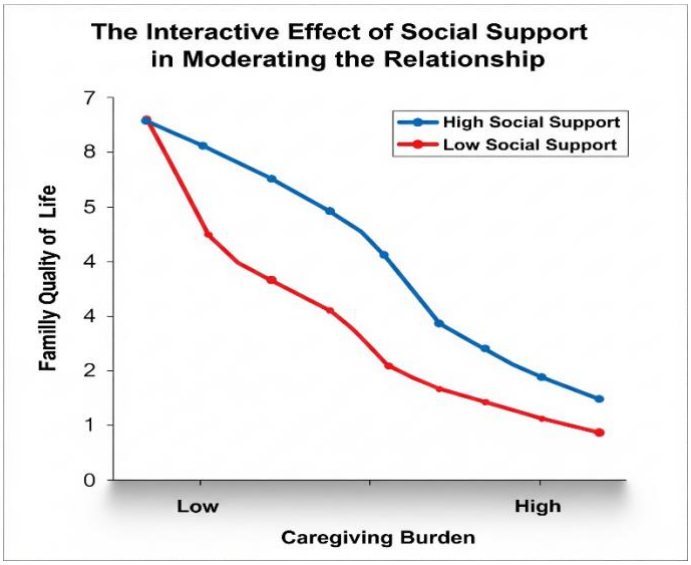
Moderation analysis using Moderated Regression Analysis (MRA) yielded a significant model ($p < 0.01$). Most interestingly, it was found that there was a significant interaction between caregiving burden and social support ($\beta = 0.164$; $p = 0.005$) on family quality of life. This suggests that social support is associated with a moderating pattern. Specifically, the strength of the negative association between caregiving burden and family quality of life varies according to the level of social support, such that higher support is associated with a weaker burden–quality of life slope. However, because of the cross-sectional design, alternative explanations (e.g., that low quality of life leads families to perceive greater burden and seek more support) cannot be ruled out.

Table 2. Results of Moderated Regression Analysis (MRA) to Test the Role of Social Support

Variable	Coefficient (β)	p-value	Information

Caregiving Expense (X_1)	-0,587	0,000	Significant
Social Support (X_2)	0,322	0,000	Significant
Interaction ($X_1 * X_2$)	**0,164**	**0,005**	Significant **(Moderation)**
R^2	0,589		
Adjusted R^2	0,585		

To visualize the effect of this moderation, *a simple slope* analysis was performed. Social support is grouped into high (1 SD above the mean) and low (1 SD below the mean). The interaction graph shows that in families with low social support, the negative relationship between burden and quality of life is very steep. In contrast, in families with high social support, the relationship line is more sloping, suggesting that the negative impact of caregiving burden on quality of life can be mitigated by high social support.



Graph 1. The Effect of Social Support Interactions in Moderating Relationships

These findings are consistent with one explanation for why previous studies such as Kusumaningrum & Perdana (2020) may not have found a significant direct link between social support and quality of life. social support may not operate directly, but rather is associated with a buffering pattern that appears to protect families from the negative effects of caregiving burden. Tangible forms of support (such as caring assistance, material assistance) are associated with reduced objective burden, while emotional and informational support increases coping capacity and family resilience. In the context of Indonesia's collective culture, support from extended family and neighbors (social capital) is a crucial coping resource, which is consistent

with the findings of Ariska et al. (2020) on the importance of family support.

Alternative explanations warrant consideration. First, reverse causality: families experiencing lower quality of life may perceive their caregiving burden as heavier and simultaneously mobilize (or perceive) more social support as a coping response. Second, common-method variance: self-report measures for all three constructs may inflate observed associations due to shared method bias, although our Harman's test suggested this was not a dominant factor. Third, unmeasured confounders (e.g., personality traits such as resilience or optimism) could influence perceptions of burden, support, and quality of life simultaneously, creating spurious moderation effects. Longitudinal designs with objective burden measures and experimental manipulation of support would be needed to disentangle these possibilities and confirm the directionality implied by our theoretical model.

Generalizability Limitations: The use of a clinic-based purposive sample from a single regency hospital substantially limits external validity. First, families who attend neurology clinic follow-ups may differ systematically from non-attenders (e.g., better health literacy, more resources, or greater illness severity), introducing selection bias. Second, Hospital X serves a predominantly rural, lower-income population; the role of social support may differ in urban or higher-resource settings where formal services (e.g., paid caregivers, respite programs) are more available. Third, cultural factors specific to this region (e.g., strong extended-family norms, community collectivism) may amplify the moderating effect of informal social support in ways that would not generalize to more individualistic or urban populations. Future multi-site studies sampling diverse socioeconomic and geographic strata are needed to test the generalizability of these findings.

Clinical, Theoretical, and Recommendation Implications for Advanced Research

The findings of this study have important implications, especially for nursing practice and the design of public health interventions in districts such as X. Theoretically, this study successfully confirms and expands the application of Lazarus and Folkman's Stress and Coping Theory in the context of Indonesian stroke caregiver families. The proposed model, in which social support plays a moderator, contributes to a more nuanced understanding of the mechanisms that affect the quality of family life.

Clinically, the results of the study confirm that screening to identify caregivers who experience high burden and low social support should be part of the *standard of care* for post-stroke patients. Interventions should not only focus on the patient, but should involve the family as a unit of care. Interventions that can be developed based on these findings include:

1. A *caregiver support program* that provides *peer support groups* to share experiences and coping strategies.
2. Psychoeducation for families on how to mobilize social support from the immediate environment.
3. Collaboration with social workers or community social workers to facilitate family access to social and health assistance available in local governments.

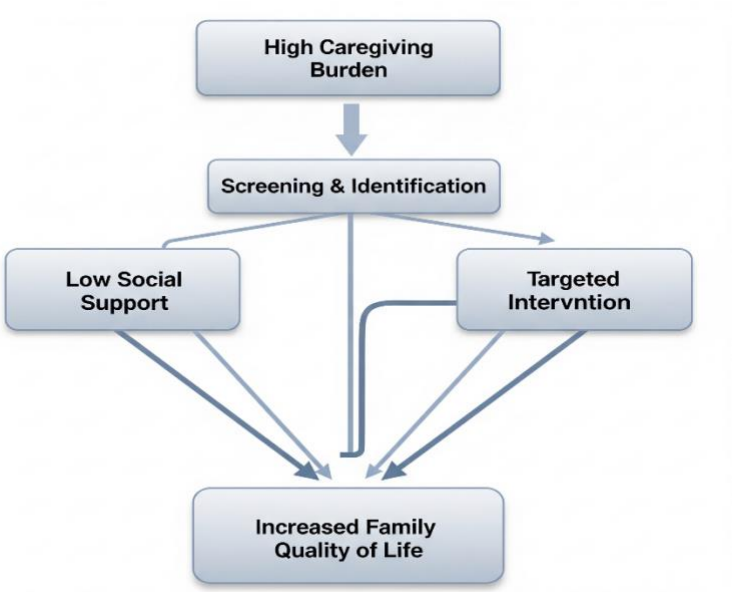


Figure 2. *Research Findings-Based Intervention Model*

For further research, it is recommended to conduct in-depth qualitative research to explore what forms of social support are most effective and meaningful according to the perception of caregivers in rural areas. In addition, longitudinal research is needed to look at the dynamics of the relationship between these three variables over time, considering that stroke treatment is a long journey. Follow-up research can also explore other mediator variables, such as *resilience* and coping strategies, to complement the model that has been tested in this study.

CONCLUSION

Based on the results of data analysis, this study found a significant and strong negative association between the burden of caregiving and the quality of life of the families of patients after ischemic stroke at Hospital X. Higher caregiving burden (encompassing physical, psychological, social, and financial dimensions) was associated with lower family satisfaction with various domains of family quality of life, including interactions, emotional well-being, and support for sick family members. These findings answer the first and fourth research objectives, while confirming that the burden of caregiving is a major determinant factor that directly affects family well-being.

Furthermore, this study found evidence consistent with a moderating role of social support. Specifically, higher social support was associated with a weaker negative slope between caregiving burden and family quality of life. In caregivers reporting high social support (particularly tangible help, emotional support, and informational resources), the negative association between burden and quality of life was less steep than in those with low support. While the cross-sectional design precludes definitive causal or mechanistic conclusions and alternative explanations such as reverse causality or unmeasured confounding cannot be ruled out these findings align with buffering hypotheses and suggest that strengthening social support systems may be a promising avenue for intervention

research. These findings not only answer the fifth research objective, but also provide an explanation for the gap in previous research by showing that social support does not always have a direct effect, but serves as a buffering mechanism that protects family quality of life from the impact of care stressors.

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