

EMOTIONAL AND PHYSICAL DISTURBANCES DURING THE PARENTING PROCESS BETWEEN FAMILY CAREGIVERS AND STROKE SURVIVORS

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Abstrak

Background: Paralysis and long-term nerve damage may result from a stroke, which is characterized by an abrupt cutoff of blood supply to the brain. As well as causing physical and mental pain, it restricts the everyday activities that stroke patients may participate in. Despite their important role in satisfying the patient's requirements, family caregivers endure financial, social, psychological, and physical stresses. An efficient plan is required to lessen this load. Caregivers, including family members, friends, or professionals, help with daily tasks and provide emotional support. Proper care improves the patient's health, reduces disability, and reduces dependence on others. **Objective:** This literature review aimed to identify the emotional and physical distress faced by family caregivers during the parenting process of stroke survivors. **Methods:** The research involved the selection of articles based on the year of publication and the availability of the full text. Relevant studies were selected from Google Scholar using keywords such as "psychosocial support" and "caregiver burden of stroke patients' families from 2020-2025. This review focuses on peer-reviewed articles from the last five years to gather the best evidence on psychosocial interventions that ease the burden on caregivers. **Results:** The synthesis of the article revealed three main interventions to reduce caregiver burden: active rehabilitation through social support, the Information-Motivation-Behavior (IMB) model, and family stress resilience-based support programs. **Conclusion:** Family caregivers significantly improve the quality of life of stroke patients by helping to meet their daily needs, highlighting the importance of effective care in stroke recovery.

Keywords: Burden, Family Caregiver, Psychosocial Support, Stroke

Introduction

Disruption of blood flow to the brain causes a persistent neurological illness known as a stroke. It happens abruptly, gradually, and swiftly, and it may cause brain damage or even death. According to research (Rasyida et al., 2023), the number of fatalities and disabilities

caused by stroke is expected to surpass all other causes by 2020, with seventeen million lives lost annually. Worldwide, stroke ranks first in terms of disability and second in terms of mortality in 2019, according to WHO statistics (Koto & Hidayatullah, 2025). One in four individuals will have a stroke at some point in their lives, and the chance of getting one has grown by 50% in the last 17 years, according to Global Stroke Facts released in 2022. There was a 70% rise in the incidence of stroke from 1990 to 2019, nevertheless, stroke associated fatalities surged by 43%, the incidence of strokes by 102%, and the number of years of life lost due to disability (DALY) by 143%. Unexpectedly, poor and middle-income nations account for the vast majority of stroke fatalities (86%, or 89% each year), which places an undue strain on low-income families.

Stroke accounts for 15.4% of all fatalities in Indonesia, particularly among those over the age of fifty. The mortality rate for both sexes is 99 per 100,000 people, and 685 per 100,000 people lose a year of life owing to disability as a result of stroke. Stroke incidence is around 0.0017% in rural areas, 0.022% in urban areas, 0.5% in adults, and 0.8% nationally. Rates varied among provinces, but the most recent RISKESDAS survey indicated a national frequency of 10.9 per 1,000,000 (Sari, 2022). Given the continued high rate of stroke in the province of West Nusa Tenggara, the disease's prevalence has risen to the ranks of the top ten most common illnesses in the world.

Not only does a stroke affect the patient, but it also affects the caregivers who are crucial to the patient's rehabilitation. Even though they are crucial in helping stroke patients, caregivers' mental health might take a hit, particularly in the first year after a patient's hospital release. Over forty percent of stroke caregivers report suffering from post-stroke sadness and emotional distress, which may have a detrimental effect on their own well-being. There is a two-way street of influence between stroke patients' quality of life and depression on their caregivers' relationships with them. Few studies have examined the relationship between these two factors together. It is evident that caregivers' quality of life is related to sustained quality of life for stroke patients, and there is a substantial correlation between depression and the physical and emotional quality of life for both stroke patients and their caregivers (Pucciarelli et al., 2022).

The main objective of post-stroke therapy is to enhance the patient's quality of life. Stroke patients need the assistance of medical experts and certified caretakers in order to enhance their quality of life after a stroke (Shewangizaw et al., 2023). During the rehabilitation and adaption phases, health staff and families work together according to the caregiver's readiness plan, which details the illness progression, treatment options, and continuity of care. Although caring for stroke victims is stressful, caregivers also report positive outcomes and growth as a result of their work. Ultimately, taking care of a loved one has both practical and psychological advantages. On the one hand, it improves one's knowledge and abilities as a caretaker. On the other hand, it helps one become more self-aware, which in turn makes them better at dealing with stress and developing empathy. Caregivers may also learn to accept their patients' conditions, be grateful for what they have, and celebrate their lives after a stroke (Moura et al., 2022).

Caregivers also develop qualities such as humility, sensitivity to the needs of others, and patience. When they begin therapy, they begin to experience the positive effects of caring for stroke victims. There are two types of values: intrinsic (the desire to make a positive contribution to society) and extrinsic (the desire to get praise and appreciation from those closest to you). Gaining these values brings joy and fulfillment to caregivers, as they face the constant challenge of learning new techniques to overcome the difficulties of caring for stroke victims. Caregivers can feel accomplished and fulfilled when stroke victims make improvement. Hence, preparing caregivers to fulfill their parental responsibilities while also

assisting them in feeling. It not only enhances the quality of rehabilitation for stroke patients but also boosts the advantages they obtain (Mei et al., 2020).

Method

As the name implies, this piece is a literature review, and its purpose is to provide a synopsis of the relevant prior research. While this deluge of data is a great opportunity, it also need a systematic review approach to guarantee that researchers make the most of the material while conducting the study. To make sure that only relevant and suitable papers were included in the study, another researcher independently assessed the retrieved documents once the researcher had completed the literature search. The Google Scholar database was queried with terms like "disorder," "emotional," "physical," "caregiving process," "family caregiver," and "stroke survivor." The article search was carried out using the predefined keywords from July 20, 2024, to July 30, 2024. In the end, the author was able to gather 10 publications and papers, which she then examined in order to glean the essential arguments and conclusions. Finalizing the process included penning the article (Nursalam, 2020).

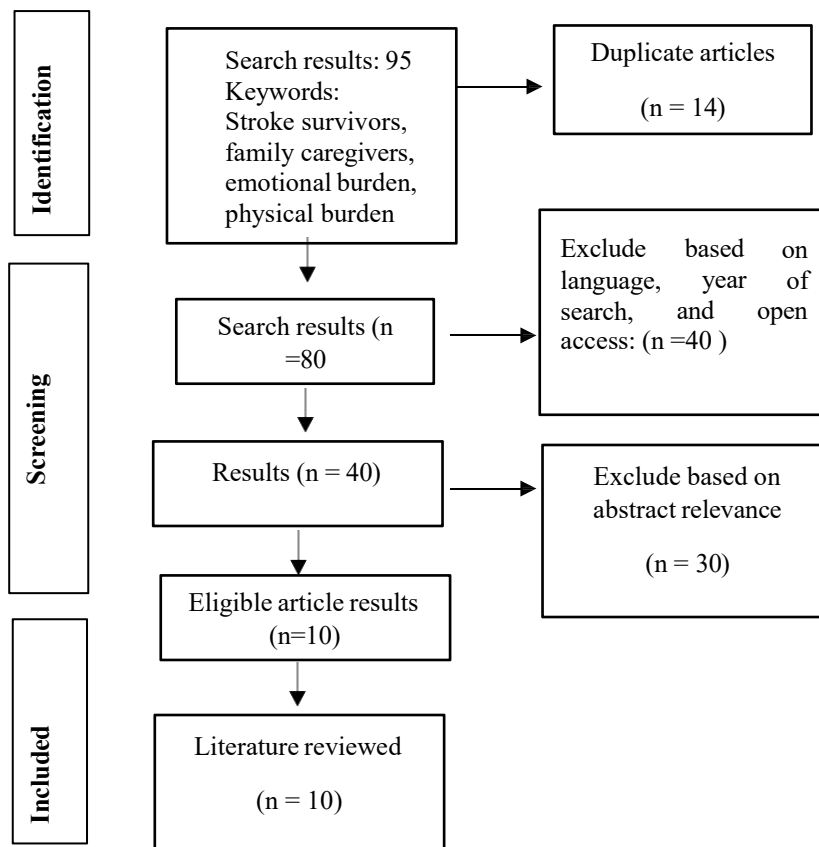


Figure 1: PRISMA

Result

Literature searches were identified and filtered according to the variables used in the study. Next, a feasibility test was carried out, and 10 journals were selected based on predetermined criteria, so that the final selection of 10 journals was made. The journal search engine used in this study is Google Scholar.

Table 1. Details of the Major Journals Selected for Literature Review

Not	Article Title	Writer	Year	Method	Result
1	Effectiveness of dyadic interventions to improve stroke patient-caregiver dyad outcomes after discharge: A systematic review and meta-analysis study	Gianluca Pucciarelli, Marzia Lommi, Gayenell S. Magwood, Silvio Simeone, Sofia Colaceci, Ercole Vellone, Rosaria Alvaro	2020	Systematic Review & Meta-Analysis	Dyadic interventions are effective in improving physical and psychological outcomes for stroke patients and caregivers after discharge from the hospital.
2	A scoping review of studies on the quality of life of informal caregivers of stroke survivors	Ana Moura, Filipa Teixeira, Mariana Amorim, Ana Henriques, Conceição Nogueira, Elisabete Alves	2021	Scoping Review	Caregivers' quality of life is influenced by a variety of factors, including social support, caregiver burden, and patient conditions.
3	Family caregivers' experiences caring for stroke survivors: A phenomenological study	San et al.	2024	Phenomenological Studies	Caregivers experience emotional and physical stress but also find meaning and resilience in their caregiver roles.
4	Exploring the social and psychological consequences of stroke survivors and their caregivers	Seble Shewangizaw, Wubalem Fekadu, Catherine Sackley, Atalay Alem	2023	Qualitative Exploratory Studies	Stroke has a significant impact on the social and psychological well-being of survivors and caregivers; Social and mental support interventions are needed.

5	Effect of a tailored multidimensional intervention on care burden among caregivers of stroke survivors' families: a randomized controlled trial	Mahmoud A. Elsheikh et al.	2022	Randomized controlled (RCTs) trials	Tailored multidimensional interventions significantly reduce the burden on caregivers in caring for stroke patients.
6	Telerehabilitation for Family Caregivers of Stroke Survivors: A Systematic Review and Meta-Analysis	Wen-Jing Sun, Yuan-Yuan Song, Cong Wang, Yan Jiang, Wen-Yao Cui, Wen-Jie Liu, Yan Liu	2023	Systematic Review & Meta-Analysis	Telerehabilitation is effective in improving caregivers' skills and confidence, while reducing stress and fatigue.
7	The Influence of Patient and Caregiver Characteristics on the Burden of Families Caring for Stroke Survivors	Anna Fight et al.	2021	Cross-Sectional Studies	Factors such as the patient's age, stroke severity, and socioeconomic status affect the level of burden experienced by family caregivers.
8	The relationship between care burden, resilience, and depressive symptoms among primary family caregivers of stroke patients	Fang L, Dong M, Fang W, Zheng J	2022	Cross-Sectional Studies	Resilience serves as a protective factor against depressive symptoms due to the burden of parenting among family members.
9	A People-Centered Approach: Understanding the Emotional Health of Stroke Survivors and Family Caregivers	Tina Varughese, Tahani C. Montiel, Joan Engebretson, Sean I. Savitz, Anjail Sharrief, Jennifer E. S. Beauchamp	2022	Qualitative (People-Centered Approach)	A person-centered approach helps understand the emotional dynamics between stroke survivors and caregivers, highlighting the need for emotional support and two-way communication between patients, families, and providers.

10	Correlation Between Caregiver Burden and Quality of Life Among Family Caregivers of Stroke Survivors: The Mediating Role of Resilience	Fitria Handayani, Niken S. D. Kusumaningrum, Meidiana Dwidiyanti	2024	Quantitative (Cross-Sectional Study)	There is a negative correlation between the burden of parenting and quality of life. Resilience significantly mediates the impact of burden on caregivers' quality of life.
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Discussion

Caregivers' active participation is essential in the treatment of stroke victims. Because rehabilitation programs have traditionally prioritized stabilizing stroke patients, caregivers have often been left out. Despite the presence of severe depressive symptoms following hospital release, caregiver preparedness is a changeable feature that, when combined with focused treatments, may enhance care outcomes and the quality of life for survivors and caregivers alike.

Caregivers may learn to better communicate with survivors and comprehend their emotional and physical needs via training. Stroke survivors may have lower rates of depression and caregiver stress as a result of this improved preparedness, which may lead to a better comprehension of patient problems.

According to Pucciarelli et al. (2021), stroke patients and their caregivers may improve their physical and psychological results after discharge via dyadic therapies. Emphasized that this method enhances patient compliance with rehabilitation, reduces caregiver load, and fortifies collaborative care.

Factors such as social support, caregiver load, and the patient's condition impact caregivers' quality of life. A scoping review by (Moura et al., 2022). identified a lack of specific measurement tools for caregiver quality of life within this population. Factors such as patient prognosis, positive family relationships, and a participatory social context are important for improving caregiver well-being. This is further supported by a cross-sectional (Kavga et al., 2021). which linked caregiver burden to patient characteristics e.g., age, stroke severity and socioeconomic status.

Psychologically, caregivers face emotional challenges such as anxiety, frustration, and social isolation. While a phenomenological (San et al., 2024) revealed that caregivers find meaning and develop psychological resilience despite physical and financial exhaustion, limited participation in social activities can exacerbate emotional stress for both survivors and caregivers, (Shewangizaw et al., 2023).

Tailored multidimensional interventions have significantly reduced caregiver burden. An RCT found that a combination of psychoeducation, skills training, and peer support led to a 32% reduction in caregiver burden. This aligns recommendations for structured interventions of 5-9 sessions for optimal impact (Elsheikh et al., 2022; Pucciarelli et al., 2021).

Digital technologies like telerehabilitation offer innovative solutions, showing improvements in caregiver competence and reductions in burnout through various online programs. However, their effectiveness on symptoms of depression and anxiety remains limited, suggesting the need to integrate digital methods with conventional approaches. When it comes to the connection between carer load and quality of life, resilience is a crucial

mediator. Tested the hypothesis that caregivers' quality of life might be up to 40% improved when they are resilient and less affected by stress. Therefore, resilience training through adaptive coping techniques and group support is recommended as a crucial intervention component (Fang et al., 2022).

In low-income countries, socioeconomic support is a vital factor. Qualitative research in Ethiopia highlighted financial crises due to treatment costs and income loss, which exacerbated psychological burden (Shewangizaw et al., 2023). Community-based interventions and financial assistance are necessary to address this gap. The person-centered approach proposed emphasizes caregiver involvement in clinical decision-making, which increases caregiver satisfaction and ensures more personalized patient rehabilitation.

Overall, recent literature confirms that effective interventions for caregivers should be holistic, combining psychological support, skills training, digital technology, and socioeconomic assistance. Future research should focus on large-scale controlled trials with long-term follow-up to evaluate the sustainability of intervention effects.

Conclusion

The quality of life for family caregivers of stroke survivors is negatively impacted by the substantial mental and physical pain they endure. While challenges like anxiety, frustration, and physical exhaustion are common, caregivers often demonstrate remarkable resilience and find meaning in their roles. To mitigate these burdens, comprehensive interventions are crucial (Shewangizaw et al., 2023). Dyadic approaches and tailored multidimensional strategies combining psychoeducation, skills training, and peer support effectively reduce caregiver burden (Elsheikh et al., 2022). Digital health technologies also show promise in enhancing caregiver competence (Sun et al., 2023). Crucially, fostering caregiver resilience through adaptive coping and support groups is vital for their well-being (Fang et al., 2022). Ultimately, healthcare systems must implement holistic interventions that provide robust psychological, physical, and socioeconomic support, recognizing the indispensable contribution of family caregivers to stroke recovery.

Reference

- Ana Moura¹, Z. . (2022). A review of the scope of the study on the quality of life of informal caregivers of stroke survivors. *Research Quality of Life*, 1-20.
- Anna Kavga¹, I. K. (2021). The Effect of Patient and Caregiver Characteristics on the Burden of Families Caring for Stroke Survivors. *Int. J. Environ. Res. Public Health* 2021, 1-11.
- Fitria Handayani, NS (2024). "Correlation Between Caregiver Burden and Quality of Life Among Family Caregivers of Stroke Survivors: The Mediating Role of Resilience". *Nursing: Research and Reviews*, 1-12.
- Gianluca Pucciarelli¹, ML (2020). The effectiveness of dyadic interventions to improve the dyad outcomes of caregivers of stroke patients after discharge. *cardiovascular nursing*, 1-22.
- Elsheikh, M. A., Moriyama, M., Rahman, M. M., Kako, M., El-Monshed, A. H., Zoromba, M., Zehry, H., Khalil, M. H., El-Gilany, A. H., & Amr, M. (2022). Effect of a tailored multidimensional intervention on the care burden among family caregivers of stroke survivors: A randomised controlled trial. *BMJ Open*, 12(2). <https://doi.org/10.1136/bmjopen-2021-049741>
- Fang, L., Dong, M., Fang, W., & Zheng, J. (2022). Relationships between care burden, resilience, and depressive symptoms among the main family caregivers of stroke patients: A cross-sectional study. *Frontiers in Psychiatry*, 13(3).

<https://doi.org/10.3389/fpsy.2022.960830>

- Kavga, A., Kalemikerakis, I., Faros, A., Milaka, M., Tsekoura, D., Skoulatou, M., Tsatsou, I., & Govina, O. (2021). The effects of patients' and caregivers' characteristics on the burden of families caring for stroke survivors. *International Journal of Environmental Research and Public Health*, 18(14). <https://doi.org/10.3390/ijerph18147298>
- Koto, Y., & Hidayatullah, A. (2025). *Effectiveness Of " Aiueo " Speech Therapy And Therapy Intonation Melodie*. April, 7717–7731.
- Mei, Y. X., Lin, B., Zhang, W., Yang, D. Bin, Wang, S. S., Zhang, Z. X., & Cheung, D. S. K. (2020). Benefits finding among Chinese family caregivers of stroke survivors: A qualitative descriptive study. *BMJ Open*, 10(10), 1–8. <https://doi.org/10.1136/bmjopen-2020-038344>
- Moura, A., Teixeira, F., Amorim, M., Henriques, A., Nogueira, C., & Alves, E. (2022). A scoping review on studies about the quality of life of informal caregivers of stroke survivors. *Quality of Life Research*, 31(4), 1013–1032. <https://doi.org/10.1007/s11136-021-02988-x>
- Pucciarelli, G., Lommi, M., Magwood, G. S., Simeone, S., Colaceci, S., Vellone, E., & Alvaro, R. (2021). Effectiveness of dyadic interventions to improve stroke patient-caregiver dyads' outcomes after discharge: A systematic review and meta-analysis study. *European Journal of Cardiovascular Nursing*, 20(1), 14–33. <https://doi.org/10.1177/1474515120926069>
- Rasyida, Z. M., Silviani, N. E., Mildawati, R., & Puspitosari, D. R. (2023). Psychosocial Support for the Burden of Families Caring for Stroke Patients. *JURNAL PIKES: Journal of Health Science Research*, 4(1), 26–34.
- San, K., Pratama, I. H., Mukhtar, Z., & Nasution, C. R. (2024). *Family caregivers' experiences caring for stroke survivors : A phenomenological study*. 6(2), 136–144.
- Sari, I. (2022). *Ecological Analysis: The Relationship Between Risk Factors and Stroke Prevalence in Indonesia in 2018*. *ARTERI: Journal of Health Sciences*, 3(4), 132–138. <https://doi.org/10.37148/arteri.v3i4.236>
- Shewangizaw, S., Fekadu, W., Sackley, C., & Alem, A. (2023). Life after stroke: exploring social and psychological consequences of stroke survivors and their caregivers. *Ethiopian Medical Journal*, 61(4), 315–325. <https://doi.org/10.4314/emj.v61i4.3>
- Sun, W. J., Song, Y. Y., Wang, C., Jiang, Y., Cui, W. Y., Liu, W. J., & Liu, Y. (2023). Telerehabilitation for Family Caregivers of Stroke Survivors: A Systematic Review and Meta- Analysis. *Journal of Nursing Management*, 2023. <https://doi.org/10.1155/2023/3450312>
- S. I. (2024). Family caregivers' experiences caring for stroke survivors: A phenomenological study. *Journal of Prima Medika Sains Vol.6 No.2*, 136-144.
- Linlin Fang1, MD (2022). The relationship between care burden, resilience, and depressive symptoms among the main families of stroke patients A:. *Joanna Fox, Anglia Ruskin University*, 1-10.
- Mahmoud Ahmed Elsheikh, I. M.-M. (2022). Effect of a tailored multidimensional intervention on care burden among caregivers of stroke survivors' families: a randomized controlled trial. *Elsheikh MA, et al.*, 1-12.
- Mei, Y.-X., Lin, B., Zhang, W., Yang, D.-B., Wang, W., Zhang, Z., & Cheung, D. (2020). Benefits found among Chinese family caregivers of stroke survivors: A qualitative descriptive study. *BMJ Open*, 10(10), e038344. <https://doi.org/10.1136/bmjopen->

- Seble, W. F. (2023). Life after stroke: exploring the social and psychological consequences of stroke survivors and their caregivers. *Ethiopian Medical Journal* 2023, 61(4), 315-325.
- Tina Varughese, T.C. (2022). A People-Centered Approach: Understanding the Emotional Health of Stroke Survivors and Family Caregivers. *Journal of Neuroscience Nursing*, 1-73.
- Wen-Jing Sun, I. Y.-Y.-Y.-J. (2023). Telerehabilitation for Family Caregivers of Stroke Survivors: An ASsystematic Review and Meta-Analysis. *Journal of Nursing Management Volume* 2023, 1- 13.