

Family caregivers' experiences caring for stroke survivors: A phenomenological study

Kon San¹, Suhartina², Irza Haicha Pratama^{2*}, Zulfikri Mukhtar³, Chairul Radjab Nasution⁴, Todung Donald Aposan Silalahi⁴, Arna Fransisca Millyanti Purba²

Abstract

Families play a crucial role in caring for stroke patients, but they often face various challenges. This study aims to explore the experiences of family members as caregivers for stroke patients. Using a phenomenological approach, this research examines the participants' direct experiences to uncover the phenomenon's essence. Data was collected through in-depth interviews over three months, from May to July 2024. In-depth interviews were used as the main instrument for gathering qualitative data from nine informants. The interview process was conducted in-depth and systematically, with triangulation techniques to enhance data validity. Data analysis was performed using a thematic content analysis approach. Data was continuously analyzed during the collection process, focusing on recurring keywords and phrases. The results were then grouped and organized into relevant subthemes. The findings indicate that caregivers often experience sleep deprivation, physical exhaustion, and social isolation. Additionally, they face financial challenges due to loss of income and increased healthcare costs. Despite these challenges, caregivers derive satisfaction from their role. This study highlights the need for a comprehensive support system, including respite care, financial assistance, and educational resources, to improve caregiver well-being and enhance the quality of care for stroke patients.

Keywords: caregiver, stroke patient, quality of life, psychological burden

Introduction

Stroke is a major global health challenge that continues to rise. Worldwide, stroke is the leading cause of acquired physical disability in adults and the second leading cause of death in high-income countries. In these countries, the incidence of ischemic and hemorrhagic strokes has increased over the past decade to 85–94 per 100,000 people, but it is much higher (1,151–1,216 per 100,000) in individuals over 75 years of age. Furthermore, 85% of all stroke-related deaths occur in low-income countries, which also account for 87% of the disability caused by stroke. In the UK, the cost of stroke treatment and lost productivity amounts to £8.9 billion annually, with healthcare costs representing about 5% of the total NHS expenditure. Cerebrovascular disease is also the leading cause of epilepsy in the elderly and the second most common cause of dementia in older adults.¹

Acute stroke can be categorized as either ischemic or hemorrhagic, with some overlap in risk factors and clinical presentation; however, the treatment approaches differ significantly. Ischemic stroke occurs when a blood vessel is blocked, limiting blood flow to the brain, while hemorrhagic stroke results from a ruptured blood vessel, causing blood to spill into the intracranial space. Interprofessional and multidisciplinary teamwork is essential to quickly identify, treat, and provide adequate care for acute stroke patients during their recovery and rehabilitation.² Regardless of the type, strokes often lead to long-term

Affiliation

¹Master's Programme in Clinical Medicine, Universitas Prima Indonesia, Medan, Indonesia

²Department of Public Health and Community Medicine, Universitas Prima Indonesia, Medan, Indonesia

³Department of Cardiology and Vascular Medicine, Universitas Prima Indonesia, Medan, Indonesia

⁴Department of Internal Medicine, Universitas Prima Indonesia, Medan, Indonesia

Correspondence

irzahp12@gmail.com

disability, with most stroke patients returning home after hospitalization.^{3,4} Although advances in medical technology and public health can help reduce stroke mortality, stroke survivors are usually still disabled. Therefore, early recovery among stroke patients is essential, especially during the first 3-6 months (the "golden period"), which aims to improve the patient's physical, mental, and performance abilities in daily activities, reduce disability, and prevent complications.⁵ Current clinical practice guidelines support stroke patients and their families across the care continuum by recommending shared decision-making concerning treatment goals and planning.^{6,7}

Family function is an integral part of post-stroke protection because the family plays an essential role in the recovery of stroke patients.⁸ Family members are the first to adopt the role of caregiver immediately after a stroke.⁹ Family members, especially immediate family members, can support primary caregivers through direct or indirect supervision in other activities by assisting them with medical appointments, providing caregiving, assisting them with household chores, and offering transportation.^{9,10} A family caregiver is an unpaid family member, spouse, child, friend, or neighbor who cares for people with chronic illnesses who need help managing tasks, including bathing, dressing, and taking medication.¹¹ However, family caregivers often have to take on their new roles suddenly, resulting in a change in the pattern of family functioning.^{12,13}

During this period, caregivers may face new challenges in providing post-stroke care due to a lack of knowledge and skills, such as managing medications, preparing meals, preventing complications, handling stroke recurrence, and accessing community resources.¹⁴ Furthermore, long-term caregiving can lead to social isolation, a lack of personal life, and less time for the caregiver's health (e.g., managing back pain from lifting the stroke patient). Families may also face financial uncertainties and loss of income, which can increase stress for both the caregiver and the family.¹⁵

A study in Germany found that many caregivers expressed a strong desire to care for their family members but also faced significant health risks and caregiving burdens. Addressing financial issues through long-term care benefits and improving daily care services for stroke patients can help alleviate some of this burden. It is also essential to consider the patient's and caregiver's perspectives when evaluating care needs.¹⁶ A study in Malaysia identified two primary needs for caregivers: comprehensive information on home stroke care and psychological support for themselves. The level of motivation in stroke patients and community support, along with access to comprehensive stroke care, were identified as key internal and external factors driving caregiving.¹⁷

Qualitative research methods are essential for understanding stroke care's social dynamics and challenges.¹⁸ This study aims to explore the experiences of family members caring for stroke patients in Medan. It focuses on the unique difficulties they face and the coping strategies they use.

Method

This study adopts a phenomenological approach, a qualitative method to explore the deep meaning behind human experiences. By suspending preconceived assumptions, the research seeks to understand how individuals give meaning to the phenomena they experience. The study was conducted at Royal Prima Hospital in Medan over three months, from May to July 2024.

The focus is on the experiences of families caring for stroke patients during their recovery at home. The study population includes families of stroke patients treated at Royal Prima Hospital. Purposive sampling was used to gather in-depth and representative data. Participants were selected based on characteristics such as age, gender, relationship with the patient, education level, and duration of care, aiming to capture diverse family perspectives. Specifically, the participants were primary caregivers in stroke patients' home care. Participation was voluntary, and those unable to commit to the study were excluded. The researcher contacted potential participants by phone to explain the study's purpose and obtain their consent, then scheduled interviews based on availability.

In-depth interviews were the primary tool for data collection. The interview process was conducted carefully, ensuring participants understood the research's objectives and consented. Triangulation techniques, including data and researcher triangulation, were applied to ensure data quality. Additionally, the researcher periodically reviewed the findings to ensure accuracy and reliability. This approach aims to yield valid and reliable results applicable to similar research contexts.

Data were analyzed using thematic content analysis. This approach involved analyzing data alongside its collection.¹⁹ Initially, frequently occurring words were coded line by line across the data set, with each code representing a key datum. Similar codes were grouped and refined, forming subthemes aligned with the socio-ecological model.

Results

This study aims to explore the experiences of family members caring for stroke patients during their recovery. The participants selected for interviews are those who voluntarily agreed to share their stories and have a family member currently undergoing recovery after a stroke. The informants in this study have diverse backgrounds. Their ages range from 40 to 62 years, with the last level of education ranging from high school to undergraduate. Some work as housewives, self-employed, and retiree. Their relationships with stroke sufferers also vary, some as wives, husbands, or children.

Table 1. Characteristics of research informants

Code	Age	Relationship with stroke patients	Education	Occupation
KL01	52 years	Wife	High School	Housewife
KL02	50 years	Wife	High School	Housewife
KL03	57 years	Husband	Bachelor's Degree	Self-employed
KL04	51 years	Wife	Diploma	Self-employed
KL05	52 years	Wife	Bachelor's Degree	Housewife
KL06	60 years	Husband	Diploma	Retired
KL07	40 years	Child	Bachelor's Degree	Housewife
KL08	62 years	Wife	High School	Retired
KL09	38 years	Child	Bachelor's Degree	Self-employed

Lifestyle changes

The results of this study show that the role of caregivers significantly impacts the physical and mental health of family members who take on the caregiving role. Stroke patients often require assistance with daily activities, including at night. As a result, caregivers frequently wake up and struggle to get a restful sleep.

"I often don't get enough sleep, so my body feels sore and dizzy. Although I don't feel anything is wrong, it might just be from a cold." (KL02, 50 years)

Caregivers often prioritize the needs of the patient over their own, leading to neglect of their physical and mental health. One participant shared that caring for a stroke patient also limited their time and opportunities for social interaction.

"I'm so busy. Sometimes I eat late, but what else can I do? Dad needs constant attention." (KL05, 52 years)

"I feel lonely. All my friends have families, children. I'm still here, at home, taking care of Dad. Sometimes I feel envious seeing them go wherever they want." (KL09, 38 years)

Additionally, managing the care of both a young child and a stroke patient at the same time leads to high emotional stress and exhaustion for the caregiver.

"My husband works, my child is still young and needs extra care, while Dad also needs constant attention." (KL07, 40 years)

The interviews also revealed that caring for a sick family member often exceeds the family's ability to cope. As a result, many caregivers need external support to meet financial and care needs.

"I'm just a housewife, so for daily expenses or hospital visits, we rely on my husband's pension, which isn't much. Thankfully, my children who work overseas often send money." (KL03, 57 years)

This study reveals that the role of the caregiver for a stroke patient has a profound impact on the caregiver's physical and mental health. Drastic lifestyle changes, such as sleep deprivation and lack of time

for oneself, often add extra burdens. Overall, caring for a family member recovering from a stroke is a challenging and demanding task. In addition to providing physical care, caregivers must also cope with various emotional and financial pressures.

Resource limitations

Various shortcomings pose significant barriers for caregivers in providing optimal care. The lack of adequate facilities at home, along with limited knowledge of how to care for stroke patients, further complicates the situation.

"There are many, Sir. But if I may be honest, the thing that overwhelms me the most is the facilities issue. So many tools are needed, but not everything is available at home. And we also don't know where to seek help in an emergency." (KL01, 52 years)

"Every day, I have to carry my father back and forth to move him from the bed to the wheelchair. There's no adequate assistive device at home, so I must do it myself. My body often aches from all that lifting." (KL04, 51 years)

"I'm confused about what to do. The doctor already explained, but I forget parts of it when we're at home. Then, my wife gets fussy when I move her. I'm afraid I might do something wrong and cause her more pain." (KL06, 60 years)

Loss of income

For both stroke patients and caregivers, loss of income becomes a dominant factor in financial issues. The added burden of transportation costs and ongoing care, especially physical therapy, further strains the caregiver's economic situation.

"Medication, assistive devices, and home care are quite costly. If there's a doctor's visit, I also need to pay for transportation. Honestly, I've been overwhelmed dealing with all of this." (KL05, 52 years)

"...for outpatient care at the hospital, we can still use BPJS (health insurance). But for home care, it's a problem too, Sir. Especially since I can't sell at the market like I used to because I have to care for my father." (KL08, 62 years)

Interviews with stroke patient caregivers revealed significant barriers that hinder optimal care at home. The lack of adequate healthcare facilities at home is a primary issue. The absence of assistive devices such as wheelchairs, walking aids, or specialized beds for stroke patients makes it difficult for caregivers to perform daily tasks, such as transferring the patient or maintaining their body position. Furthermore, limited knowledge about stroke care poses a significant problem. Many caregivers feel confused and uncertain about their actions, particularly in emergencies. This is exacerbated by the psychological burdens caregivers face, such as anxiety, stress, and fatigue.

Financial problems also serve as a dominant factor that worsens the situation. The loss of income for the stroke patient and the caregiver leads to difficulties in meeting daily needs, including care costs. Additional burdens, such as transportation fees, medications, and assistive devices, further strain the family's financial condition.

Strategies for overcoming challenges

The role of the caregiver in caring for a stroke patient is a heavy and challenging task. One of the keys to their success is the ability to self-motivate, maintain a positive mindset, and have a strong determination to see the patient recover. The informants also expressed that seeing the patient's progress gives the family a profound sense of satisfaction from their efforts.

"Every time I see my husband making progress, I feel so happy and proud. That's what keeps me going." (KL02, 50 years)

"... sometimes, Sir, I feel exhausted, hopeless, even angry. But seeing my father-in-law working so hard to get better makes me keep fighting. I always tell myself that all of this is for his recovery." (KL07, 40 years)

Caring for a stroke patient at home teaches many valuable lessons. Caregivers become more patient, families grow more substantial, and patients find inner peace. This recovery is about physical improvement and restoring social and emotional relationships within the family.

"Sometimes I think, why is this trial so heavy for us? But I remember the pastor's sermon, so I learn always to be grateful and see each trial as a sign of God's love for me." (KL03, 57 years)

"Over time, I realized that caring for my father is a way of repaying my parents. I'm always grateful for the opportunity to care for and accompany my father through his trials in life. My husband also helps when he comes home from work, which makes me very happy." (KL07, 40 years)

The informants stated that support from other family members and their closest social environment has a significant impact on the well-being of caregivers. The support offered varies, from help with daily activities, financial assistance, and recommendations for alternative care to spiritual support through prayer.

"Sometimes the neighbors visit, bring food, or just chat. All of that gives me incredible motivation." (KL05, 52 years)

"... there was an old colleague of my husband who suggested we try alternative medicine for my father-in-law. Like acupuncture or massage." (KL03, 57 years)

"... once a week, my children and their spouses call me to check on my father's condition. They also do video calls with the grandchildren. They work in Jakarta and can only help by sending money." (KL06, 60 years)

It can be concluded that caregivers face physical challenges in providing care and confront various emotions, such as exhaustion, hopelessness, gratitude, and pride. Intrinsic motivation, such as seeing the patient's progress and the family's sense of responsibility, is the main driving force for caregivers to continue providing the best care.

Social support from family, friends, and the surrounding community is crucial in maintaining caregivers' well-being. Practical, emotional, and spiritual assistance from those closest to them can alleviate caregivers' burdens and improve their quality of life. The experience of caring for a stroke patient not only impacts the patient's physical condition but also triggers a transformation in family dynamics. Caregivers become more patient, families grow closer, and patients find inner peace.

Discussion

This study highlights the complexity of the caregiver's role in caring for post-stroke patients. It reveals that caregiving requires not only significant time and physical commitment but also has a profound impact on the caregiver's own physical and mental health. One key finding is the strong correlation between the caregiver's role and sleep disturbances. Chronic sleep deprivation is a common complaint among caregivers, significantly affecting their quality of life—insufficient sleep results from physical exhaustion, muscle pain, and reduced concentration. Additionally, social isolation is a frequent issue, as limited time and energy for socializing lead to feelings of loneliness and seclusion.

One study reported that about 76% of caregivers reported poor sleep quality, with female caregivers being more affected than men.²⁰ Caregivers experienced a reduction in total sleep time, with some experiencing a reduction of up to 44% compared to the recommended eight hours.²¹ Sleep disturbances in

caregivers are associated with negative physical and mental health outcomes, including depression, anxiety, fatigue, and high levels of inflammation.^{22,23} Factors contributing to sleep problems include the health status of the caregiver, the *caregiver's* health, and psychological distress.^{20,22} The interaction between sleep deprivation and parenting stress increases susceptibility to chronic disease.²³s

The burden of caring for a post-stroke patient, especially when combined with other responsibilities like raising young children, can trigger significant emotional stress and fatigue. Caregivers often feel overwhelmed by the continuous demands of caregiving. To address these challenges, healthcare professionals must assess caregiver needs and provide tailored interventions and support systems.²⁴ Clinical practice guidelines recommend identifying vulnerable caregivers, monitoring the patient and caregiver after discharge, and implementing evidence-based interventions to alleviate the caregiver's burden.²⁵ These steps are crucial for improving the well-being of both caregivers and stroke patients.

Financial challenges also pose a significant obstacle for many caregivers. High healthcare costs and reduced household income from an ill family member can create considerable financial strain. This often forces caregivers to seek support from other family members. Previous research consistently highlights the financial pressure experienced by stroke caregivers, who face substantial costs related to stroke care, often resulting in a financial burden.²⁴ These challenges are exacerbated by employment and household income changes due to caregiving responsibilities. Economic pressure is especially pronounced among socio-economically disadvantaged groups in rural areas.²⁶

In-depth interviews with caregivers in this study identify several significant barriers to providing optimal care for stroke patients at home. These findings align with prior research that underscores the complexity of post-stroke care, particularly in the home context. One major issue is the lack of adequate healthcare facilities at home. The absence of assistive devices like wheelchairs, walkers, or specialized beds presents a significant challenge for caregivers in providing safe and comfortable patient care. This forces caregivers to engage in physically demanding tasks, such as lifting and transferring patients, which can lead to self-injury.

Previous studies highlight significant challenges in providing adequate in-home care for stroke patients. A systematic review found that caregivers face safety risks due to awkward working positions, physical workload, and inadequate equipment.²⁷ The lack of assistive devices and proper home modifications becomes a barrier to providing safe care, increasing the risk of injury to the caregiver.²⁸ Caregivers often experience physical strain, which can negatively affect their health and potentially lead to institutionalizing the stroke patient.²⁹ To address these issues, research emphasizes the need to assess caregiver needs, provide relevant information, and offer support during the caregiving transition.³⁰

A lack of knowledge about how to care for stroke patients is another significant barrier. Despite receiving explanations from healthcare professionals, caregivers often feel confused and unsure of the steps to take, especially during emergencies. This indicates a gap between the information provided by healthcare professionals and the real needs of caregivers in the field. Recent literature has highlighted the ongoing challenges arising from insufficient knowledge about stroke care among caregivers. Even with medical guidance, caregivers often feel unprepared and uncertain, particularly during crises.^{31,32} The mismatch between the information given and the practical needs of caregivers is evident, as their diverse and often unmet educational needs range from clinical aspects of stroke to functional recovery and psychological changes.³³ Lack of preparedness can lead to feeling overwhelmed, anxious, and fatigued.³² To address this, research emphasizes the need for tailored and comprehensive information delivery at the right time throughout the caregiving period.^{32,33}

Loss of income for both the stroke patient and the caregiver is a major factor exacerbating the situation. Healthcare costs, including medication, assistive devices, and transportation, add a financial burden many families struggle to bear. This forces families to sacrifice other living needs to meet the demands of stroke patient care. Previous research reports that direct medical costs, including rehabilitation and ongoing care, significantly contribute to this financial strain. High costs often lead to severe economic crises for families, reducing their overall well-being.^{34,35} Caregivers, usually elderly, face various challenges, including declining physical health, emotional pressure, and financial strain due to medical expenses and changes in employment.^{24,29}

A central theme emerging from the data is the dual nature of caregiving. On one hand, caregivers describe experiencing a range of negative emotions, such as exhaustion, frustration, and even anger. These feelings are understandable, given the physical and emotional demands of the role. Constant vigilance and the potential for setbacks in the patient's recovery can be emotionally draining. Literature reviews reveal the dual nature of caregiving for stroke patients and older adults with chronic conditions. Caregivers experience various negative emotions, including fatigue, frustration, anxiety, and uncertainty.³⁶ The impact of caregiving varies, influenced by the intensity of care required and the patient's condition.³⁷

However, these narratives also reveal deep satisfaction and a sense of purpose among caregivers. Witnessing even minor improvements in the health of their loved ones provides a strong source of motivation. This intrinsic reward and a strong sense of family responsibility drive caregivers to persevere through difficult times. Previous literature highlights the complex experience of stroke caregivers. Caregiving is often seen as a moral obligation and a choice driven by love and reciprocity, but it can also result in physical, psychological, and social suffering.³⁸

Social support emerges as a crucial factor in reducing the challenges of caregiving. Narratives indicate that caregivers who receive support from family, friends, and their community are better equipped to handle the demands of their role. This support can take various forms, including practical help, emotional encouragement, and spiritual guidance. Recent research supports the importance of diverse support systems for caregivers. Family members, particularly spouses, provide comprehensive emotional, informational, and practical support.³⁹ Community services play a key role, although barriers such as time constraints and cultural factors can limit access.⁴⁰

The broader role of the community is also emphasized. Neighbors, colleagues, and even strangers can offer invaluable support through acts of kindness, such as providing meals or companionship. These actions can significantly enhance comfort and reduce feelings of isolation. Professional networks and healthcare providers also have opportunities to improve caregiver support and preparedness.⁴¹ The National Family Caregiver Support Program, established under the Older Americans Act, funds various services for families caring for older adults.⁴² Spiritual and religious contexts often offer valuable assessment support, while fellow survivors provide valuable informational guidance.³⁹

The experience of being a caregiver is not just a burden; it can also be a catalyst for personal growth and transformation. Many caregivers report developing new skills such as patience, empathy, and resilience. Furthermore, shared experiences caring for a loved one can strengthen family bonds and foster a deeper connection. Some studies challenge the assumption that caregiving is solely a burden, highlighting its potential for personal growth and transformation. Caregivers report developing new skills such as patience, empathy, and resilience; many experience personal growth, better relationships, and spiritual benefits.^{43,44} A positive perspective on caregiving can lead to a more balanced view of the experience, focusing on both hedonic and eudaimonic well-being.⁴⁴ Caregivers of dialysis patients, despite facing numerous challenges, also report personal growth that helps them build resilience.⁴⁵

Conclusion

This study reveals the complexity of the caregiver's role in post-stroke care. The dual physical and psychological burdens and resource constraints create a highly demanding situation. However, strong intrinsic motivation and social support are significant buffering factors for the caregiver's well-being. These findings underscore the importance of improving systemic support for caregivers, including easier access to healthcare services, education, and financial assistance.

References

1. Murphy SJ, Werring DJ. Stroke: causes and clinical features. *Medicine (Baltimore)*. 2020 Sep;48(9):561–6.
2. Tadi P, Lui F. *Acute Stroke*. StatPearls. Treasure Island (FL): StatPearls Publishing; 2024.
3. Clery A, Bhalla A, Bisquera A, Skolarus LE, Marshall I, McKevitt C, et al. Long-Term Trends in Stroke Survivors Discharged to Care Homes. *Stroke*. 2020 Jan;51(1):179–85.
4. Reeves MJ, Fritz MC, Woodward AT, Hughes AK, Coursaris CK, Swierenga SJ, et al. Michigan Stroke Transitions Trial. *Circ Cardiovasc Qual Outcomes*. 2019 Jul;12(7).
5. Hirunkhro B. Effectiveness of home based rehabilitation nursing program on functional status health perceptions and health-

- related quality of life among Ischemic stroke survivors. International Graduate Studies Human Resource Development Center, Burapha ...; 2016.
6. Lindsay P, Bayley M, Hellings C, Hill M, Woodbury E, Phillips S. Canadian best practice recommendations for stroke care (updated 2012). *Can Med Assoc J*. 2012 Dec 2;179(12):S1–25.
 7. Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P, et al. Comprehensive Overview of Nursing and Interdisciplinary Rehabilitation Care of the Stroke Patient. *Stroke*. 2010 Oct;41(10):2402–48.
 8. Creasy KR, Lutz BJ, Young ME, Stacciarini JMR. Clinical Implications of Family-Centered Care in Stroke Rehabilitation. *Rehabil Nurs*. 2015 Nov;40(6):349–59.
 9. Thongthawee B, Matchim Y, Kaewsriwong S. Family members' experience in providing care for persons with stroke: a phenomenological study. *J Res Nursing-Midwifery Heal Sci*. 2018;38(3):179–91.
 10. Lai DWL. Effect of Financial Costs on Caregiving Burden of Family Caregivers of Older Adults. *SAGE Open*. 2012 Oct 1;2(4).
 11. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting Family Caregivers in Providing Care. In: *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville: Agency for Healthcare Research and Quality; 2008.
 12. Ckumdee S, Arpanantikul M, Sirapo-ngam Y. Family caregivers' adjustment problems in caring for stroke patients. *J Thai Nurs Midwifery Counc [Internet]*. 2014 Nov 17;29(4):45–63. Available from: <https://he02.tci-thaijo.org/index.php/TJONC/article/view/27638>
 13. Kumar R. Family Needs of Caregivers of Stroke Survivors. *Adv Pract Nurs*. 2016;1(3).
 14. Hayashi Y, Hai HH, Tai NA. Assessment of the Needs of Caregivers of Stroke Patients at State-Owned Acute-Care Hospitals in Southern Vietnam, 2011. *Prev Chronic Dis*. 2013 Aug 22;10:130023.
 15. Gillespie D, Campbell F. Effect of stroke on family carers and family relationships. *Nurs Stand*. 2011 Sep 14;26(2):39–46.
 16. Jirů-Hillmann S, Gabriel KMA, Schuler M, Wiedmann S, Mühler J, Dötter K, et al. Experiences of family caregivers 3-months after stroke: results of the prospective trans-regional network for stroke intervention with telemedicine registry (TRANSIT-Stroke). *BMC Geriatr*. 2022 Mar 19;22(1):228.
 17. Sidek NN, Kamalakannan S, Tengku Ismail TA, Musa KI, Ibrahim KA, Abdul Aziz Z, et al. Experiences and needs of the caregivers of stroke survivors in Malaysia—A phenomenological exploration. *Front Neurol*. 2022 Sep 23;13.
 18. O'Hara J, Thompson M, Deen G, Leather AJM, Youkee D, Wall J, et al. Exploring the experiences of stroke survivors, informal caregivers and healthcare providers in Sierra Leone: a qualitative study protocol. *BMJ Open*. 2021 Dec 30;11(12):e051276.
 19. Creswell JW, Poth CN. *Qualitative inquiry and research design: Choosing among five approaches*. 4th ed. SAGE Publications; 2016.
 20. Byun E, Lerdal A, Gay CL, Lee KA. How Adult Caregiving Impacts Sleep: a Systematic Review. *Curr Sleep Med Reports*. 2016;2(4):191–205.
 21. Maltby KF, Sanderson CR, Lobb EA, Phillips JL. Sleep disturbances in caregivers of patients with advanced cancer: A systematic review. *Palliat Support Care*. 2017 Feb;15(1):125–40.
 22. Peng HL, Chang YP. Sleep disturbance in family caregivers of individuals with dementia: a review of the literature. *Perspect Psychiatr Care*. 2013 Apr;49(2):135–46.
 23. McCurry SM, Song Y, Martin JL. Sleep in caregivers: what we know and what we need to learn. *Curr Opin Psychiatry*. 2015 Nov;28(6):497–503.
 24. Tziaka E, Tsiakiri A, Vlotinou P, Christidi F, Tsiptsios D, Aggelousis N, et al. A Holistic Approach to Expressing the Burden of Caregivers for Stroke Survivors: A Systematic Review. *Healthcare*. 2024 Feb 29;12(5).
 25. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. *J Rehabil Med*. 2006 May;38(3):153–8.
 26. Mishra AK, Mishra N, Gajjar K. Financial burden of stroke on family and caregiver in India: a literature review. *Int J Res Med Sci [Internet]*. 2016 Dec 18;4(9):3675–8. Available from: <https://www.msjonline.org/index.php/ijrms/article/view/44>
 27. Hignett S, Edmunds Otter M, Keen C. Safety risks associated with physical interactions between patients and caregivers during treatment and care delivery in Home Care settings: A systematic review. *Int J Nurs Stud*. 2016 Jul;59:1–14.
 28. Marcheschi E, Von Koch L, Pessah-Rasmussen H, Elf M. Home setting after stroke, facilitators and barriers: A systematic literature review. *Health Soc Care Community*. 2018 Jul;26(4):451–9.
 29. Camak DJ. Addressing the burden of stroke caregivers: a literature review. *J Clin Nurs*. 2015 Sep;24(17–18):2376–82.
 30. Damaiyanti M, Amir H, Cahyani DD, Alhidayat NS, Afrianti N, Rahmiati C, et al. Improving caregiver preparedness in the care transition of stroke patients: a scoping review. *J Med Life*. 2023 Dec;16(12):1723–31.
 31. Oliveira BC de, Garanhani ML, Garanhani MR. Caregivers of people with stroke: needs, feelings and guidelines provided. *Acta Paul Enferm [Internet]*. 2011 Jan 1;24(1):43–9. Available from: <https://acta-ape.org/article/cuidador-de-pessoa-com-acidente-vascular-encefalico-necessidades-sentimentos-e-orientacoes-recebidas/>
 32. Lobo EH, Frølich A, Abdelrazek M, Rasmussen LJ, Grundy J, Livingston PM, et al. Information, involvement, self-care and support-The needs of caregivers of people with stroke: A grounded theory approach. *PLoS One*. 2023;18(1):e0281198.
 33. Hafsteinsdóttir TB, Vergunst M, Lindeman E, Schuurmans M. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Educ Couns*. 2011 Oct;85(1):14–25.
 34. Fadhilah H, Permanasari VY. Beban ekonomi yang ditanggung pasien dan keluarga akibat penyakit stroke: Studi literatur. *Ber Kedokt Masy*. 2019 Jun 25;35(6).
 35. Fadhilah H, Permanasari VY. Economic Burden Bore by Patients and Families because of stroke: Policy Assessment. *J Indones Heal Policy Adm*. 2020;5(3).
 36. Wang L, Liu J, Wu L, Zhang J, Fang H. Caregiving experiences of stroke caregivers: A systematic review and meta-synthesis of qualitative studies. *Medicine (Baltimore)*. 2023 Mar 31;102(13):e33392.

37. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family Caregiving for Older Adults. *Annu Rev Psychol*. 2020 Jan 4;71:635–59.
38. Zhang J, Lee DTF. Meaning in stroke family caregiving: A literature review. *Geriatr Nurs (Minneap)*. 2017;38(1):48–56.
39. Kelly EP, Meara A, Hyer M, Payne N, Pawlik TM. Understanding the Type of Support Offered Within the Caregiver, Family, and Spiritual/Religious Contexts of Cancer Patients. *J Pain Symptom Manage* [Internet]. 2019 Jul 1;58(1):56–64. Available from: <https://doi.org/10.1016/j.jpainsymman.2019.03.003>
40. Choi H, Reblin M, Litzelman K. Conceptualizing Family Caregivers' Use of Community Support Services: A Scoping Review. *Gerontologist* [Internet]. 2024 May 1;64(5):gnad039. Available from: <https://doi.org/10.1093/geront/gnad039>
41. Young H. Harnessing the power of networks: Partnerships to promote health and well-being for family caregivers. *Innov Aging*. 2019 Nov 8;3(Supplement_1):S539–S539.
42. Bangerter LR, Fadel M, Riffin C, Splaine M. The Older Americans Act and Family Caregiving: Perspectives from Federal and State Levels. *Public Policy Aging Rep* [Internet]. 2019 Jun 5;29(2):62–6. Available from: <https://doi.org/10.1093/ppar/prz006>
43. Netto NR, Jenny GYN, Philip YLK. Growing and gaining through caring for a loved one with dementia [Internet]. Vol. 8, *Dementia: The International Journal of Social Research and Practice*. 2009. p. 245–61. Available from: <https://www.deepdyve.com/lp/sage/growing-and-gaining-through-caring-for-a-loved-one-with-dementia-kW9BccCr0l>
44. Marino VR, Haley WE, Roth DL. Beyond hedonia: A theoretical reframing of caregiver well-being. Vol. 3, *Translational Issues in Psychological Science*. US: Educational Publishing Foundation; 2017. p. 400–9.
45. Hoang VL, Green T, Bonner A. Informal caregivers' experiences of caring for people receiving dialysis: A mixed-methods systematic review. *J Ren Care* [Internet]. 2018 Jun 1;44(2):82–95. Available from: <https://doi.org/10.1111/jorc.12235>