



# Family Caregivers' Lived Experiences for Post-Stroke Patients: A Qualitative Study

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## ABSTRACT

Stroke survivors in Indonesia depend on their families to meet their daily needs. Therefore, the function of family caregivers in stroke patients is essential in helping to meet their needs. This study aims to determine family caregivers' lived experiences for post-stroke patients. The study design was a qualitative descriptive phenomenology with a sample of 6 participants recruited by purposive sampling. Instruments include semi-structured questions, field notes, and a voice recorder. Data was analysed using the thematic content analysis method. This study was conducted from October 2021 to February 2022 at the Gisting Health Center, Tanggamus Regency, Lampung Province, Indonesia. The study found three main themes and seven sub-themes. The themes were knowledge of stroke (sub-themes: stroke disease and stroke management), seeking treatment (sub-themes: following community habits, drug therapy according to what is felt useful, alternative therapies produced by factories), and Difficulty in taking care (sub-themes: difficulties caring for patients at home and efforts to solve the difficulties). In conclusion, caregivers have Difficulty taking care of post-stroke patients at home and in the community. Nurses can participate as nurses in community health centres and family health nurses in providing comprehensive care and educating caregivers on how to take care of post-stroke patients properly.

**Keywords:** Caregivers, Experience, Family, Post-stroke, Qualitative study

## 1. Introduction

An attack on the brain is the term used to describe a stroke. A stroke results from a blockage or rupture in the bloodstream, leading to a deficiency of oxygen and nutrients (Susanti, Baeda, & Saputri, 2022). Stroke is the most common cause of death and disability worldwide, particularly in low and middle-income countries, and it is a growing burden (Lin et al., 2021). Stroke is the second-most common cause of death and a significant health issue in both developed and developing countries. An estimated fifteen million individuals experience a stroke annually, with one-third enduring permanent physical, cognitive, and emotional disorders (Lu, Mårtensson, Zhao, & Johansson, 2019), and about 5.9 million end in death (Nursiswati, Halfens, & Lohrmann, 2022).

The incidence of stroke in Indonesia has increased from 7% in 2013 to 10.9% in 2018 (Nursiswati et al., 2022). The prevalence of stroke in Indonesia is also increasing, in tandem with an increasing life expectancy (Sari, Nofrel, & Lukman, 2023). In general, stroke survivors in Indonesia rely on their families to provide for

their daily necessities. After six months of discharge from the hospital, the dependency rate of stroke patients has not even decreased (Nursiswati et al., 2022). For stroke patients who have returned home and are experiencing physical and psychosocial disorders, family support is essential. In Indonesia, it is also the responsibility of family members to provide care for sick family members (Nursiswati et al., 2022).

The role of family caregivers for stroke patients is crucial, as they assist in providing necessities, serve as mentors during the adaptation process at home, and offer psychological and social support. Consequently, to ensure that the assistance provided to stroke patients is of the highest quality, caregivers must be physically and psychologically prepared to fulfil their responsibilities. The quality of the assistance provided is enhanced, and the recovery process of stroke patients is positively impacted when caregivers are not burdened by their role (Dharma, Damhudi, Yarden, & Haeriyanto, 2021).

Paralysis is the consequence of stroke, and approximately 45% of those who survive are cognitively and functionally impaired, necessitating assistance from others to maintain their independence at home (Carolina B. Day et al., 2021). The initial year is the most difficult for caregivers to provide care for stroke patients at home, which can have a detrimental effect on their health. They encounter a diverse array of emotional, social, and physical challenges, including financial difficulties, anxiety, stress, social isolation, and relationship issues (Bierhals, Low, & Paskulin, 2019). Caring for stroke patients adversely affects these caregivers' quality of life, causing them to undergo negative physical and mental experiences (Bierhals et al., 2019). Unexpected events frequently permanently disrupt the stroke victim's life, leading to cognitive, behavioural, psychological, and physical challenges (Pallesen et al., 2018).

Stroke has harmful physical effects and long-term social challenges. Stroke survivors and their caregivers must adjust to the novel, unpleasant circumstances and evolving intimacy. Stroke patients and their caregivers must exert effort to adapt to new routines and responsibilities (Abendschein, Basinger, & Wehrman, 2021). The family plays a critical role in the optimal recovery of motor disorders that stroke patients experience. The family is the fundamental foundation that enables the direct provision of services to each family member, regardless of their health status. The family's capacity to provide adequate care for stroke patients is contingent upon their knowledge, attitudes, and actions by behavioural health theory (Sari et al., 2023).

In Indonesia, providing care for sick family members is mandatory due to cultural and religious traditions. Providing care for stroke patients in their homes is a new responsibility for families who have previously encountered this challenge. The challenges that families encounter include a need for knowledge regarding the proper care of their loved ones, financial constraints that prevent them from meeting their long-term needs, and inadequate facilities that hinder the completion of daily activities at home (Fauziah, Kato, Shongenji, Tsujiguchi, & Taniguchi, 2022).

Spouses and children primarily bear the burden of meeting stroke patients' needs, including personal hygiene, comfort, eating, rehabilitation activities, and health service treatment, accounting for approximately 80% of the care. Caregivers must make coping adjustments to accommodate stroke patients' needs. Many caregivers experience mental disorders, including anxiety and depression, as they fulfil their responsibilities. They also experience a decline in physical health and a lack of energy, including the risk of developing chronic diseases, fatigue, weight loss, and disturbed sleep (Lu et al., 2019). Approximately 88% of stroke patients who reside in the community and return home from the hospital have a disability, necessitating the assistance of family caregivers (Torregosa, Sada, & Perez, 2018). Researchers have never thoroughly investigated the effects of stroke on survivors and their families in Tanggamus Regency, Lampung Province, Indonesia. As a result, this investigation aims to ascertain the lived experiences of family caregivers responsible for the care of post-stroke patients in the community.

## **2. Methods**

Descriptive phenomenology served as the foundation for this study's qualitative design. The researchers implemented purposive sampling to recruit a group of six participants. This study's data collection by the six participants has resulted in saturated data. The inclusion criteria for this study were that the participants were willing to participate, had been stroke caregivers for at least two years, and were proficient in Indonesian. In this study, the caregiver is one of the family members responsible for caring for stroke patients. This study used a semi-structured list of questions to guide in-depth interviews, field notes, and a voice recorder to record the content of conversations during interviews. The research aimed to provide the basis for developing the interview question guides. To analyse the data, the researchers employed the thematic content analysis method. This method involves the generation of initial codes, the search for themes, the review of themes, the definition and naming of themes, and the production of the report. The Gisting Health Centre in Tanggamus Regency, Lampung Province, Indonesia, conducted a study from October 2021 to February 2022.

Lincoln and Guba (1985) attained trustworthiness by satisfying the criteria of dependability, credibility, confirmability, and transferability. The researchers established credibility by conducting member checks and allowing participants to modify emerging themes. To ensure dependability, the researchers employed external audit techniques, specifically soliciting evaluations of the study's process and results from colleagues at the University of Sumatra, who are experts in qualitative research and stroke. The researchers maintained a complete record of all research steps. The researchers achieved transferability by fully storing all data in a file. This study was approved by the Faculty of Nursing, the University of Indonesia's research ethics committee, under the following number: Ket-229/UUN2. F12. D1.2.1/PPM.00.02/2021. The participant executed informed consent.

### 3. Results

3 of the 6 participants were male, while 3 were female. The highest age group was 50 and older (83%), with a range of 38–70 years, and the highest level of education was high school (50%). The characteristics of caregivers are presented in Table 1.

**Table 1** Characteristic of participants

No	Age (Years)	Gender	Education Level	Relation to stroke patients
P1	65	Female	Elementary	Husband
P2	68	Female	High School	Husband
P3	38	Female	Bachelor	Father
P4	56	Male	High School	Father
P5	50	Male	High School	Mother
P6	70	Male	Elementary	Wife

**Table 2** The themes and sub-themes

No	Theme	Sub-themes
1.	Knowledge of stroke	Stroke disease Stroke management
2.	Seeking treatment	Following community habits Drug therapy according to what is felt useful Alternative therapies produced by factories
3.	Difficulty in taking care	Difficulties caring for patients at home Efforts to solve the difficulties

The study found 3 themes and 7 sub-themes. The first theme is knowledge about stroke. Participants understood stroke with various opinions, starting from a history of diseases related to stroke, stroke experienced at this time, and stroke comorbidities.

*Stroke caused by the blood is thick so blood vessels are clogged...broken blood vessels...blockage of blood vessels in the head (P3).*

*Cramps all over the body, feeling tingling, feeling sick, feeling dazed, confused, starting to lose memory, talking incoherently (P5).*

*The nerves of the legs and arms do not work, the shoulders are a bit down, cannot even stand, walking is difficult it is climbing the wall, it is hard to spoon, often falls, no one knows fainting (P6).*

Treatments for healing efforts include physiotherapy, alternative therapies, and complementary therapies. Participants explained the stroke management they did, including taking drugs when signs and symptoms of stroke appeared and stopping the drugs if signs and symptoms did not improve.

*...physiotherapy, radiation, therapy every evening, once a month. A therapist come to visit at home, twice a day, the treatment was three times (P1).*

*The leg was told to move as a guideline by a massager. However, there was no improvement after three-times treatment program, and took it off (P3).*

*Eating lots of cucumber and shallots, along with a "sinshe" (traditional Chinese medicine) (P5).*

The second theme is seeking treatment. Efforts to recover from disease are carried out by consuming natural ingredients based on the habits of the community for generations. Medical drugs are only consumed when there is a perceived benefit. In addition, traditional medicines processed and produced by traditional medicine factories are consumed.

*Consuming traditional medicine, "temu lawak," clover, coffee leaves, and "bamboo wulung (P2).  
Consuming palm sugar, herbs, roasted and boiled coconut water, dried moringa leaves in a blender, chased honey, rhizomes, and algae (P3).  
Reflexology massage, cupping, acupuncture (P4).  
Sinshe, "kyai", shaman, smart people, medicine from China, medicine from Japan (P6).*

Following the doctor's recommendations, food processing is adjusted to their needs and situation to maintain their nutritional adequacy.

*Eating soft food, rice, and fruit vegetables in a blender (P2).  
Avoiding eating shrimp, squid, and sea fish, as the doctor advises (P4).  
The food is not salt, do not consume monosodium glutamate (P5)*

The third theme is the difficulty in taking care of patients. Participants stated that they were burdened to fill the patient's self-care due to the patient's physical limitations and inability to swallow, urinate, and move. Other problems are unwillingness to quit smoking and to follow a healthy diet.

*Cannot bathe alone, paralyzed hands, difficulty for sucking, cannot stand even, and must be helped when walking (P2).  
Wake up alone at night, worried about falls...once it fell in front of the room... want to get up... it is hard for me to pick it up (P3).  
Pee a lot but did not want to wear diapers and did not want to use urine pot (P2).*

#### 4. Discussion

This research aims to understand the everyday struggles faced by families caring for their stroke-affected family members. The initial theme that emerged from this investigation was acquiring stroke knowledge. Sari et al. (2023) conducted a study at a community health centre in Bandung, Indonesia, which revealed that post-stroke patients' families had above-average knowledge and skills in performing a range of motion. Knowledge correlates with the skill of performing a range of motion (Sari et al., 2023). Caregivers must possess the necessary knowledge and abilities to care for stroke patients. Caregivers with sufficient knowledge can tailor high-quality care to the patient's requirements. Furthermore, it is crucial to inform caregivers about the dangers and complications associated with stroke. An optimal recovery will be easier if the caregiver is aware of the treatment process and the measures taken to improve the disease's condition. Self-efficacy is critical to the caregiver's role, enabling them to confidently fulfil their responsibilities in the face of adversity and obstacles. High self-efficacy and family support will positively influence stroke patients' recovery (Sari et al., 2023).

Age and education level are factors that influence one's understanding of stroke. As people age, their experience increases, and as a result, their knowledge improves. Similarly, increased education will enhance knowledge of disease and stroke management (Sari et al., 2023). Therefore, to be prepared, caregivers must comprehend stroke and learn how to manage it at home. In order to facilitate the recovery of stroke patients and address their daily requirements, health professionals, including nurses and rehabilitation therapy teams, can facilitate caregiver readiness (Szczepeńska-Gieracha & Mazurek, 2020). In addition to resources and support, knowledge is one of the critical factors in facilitating stroke recovery. Caregivers must be familiar with stroke conditions, risk factors, and recovery. If not, the situation will become a barrier to achieving optimal recovery. The researchers should provide the caregivers with a comprehensive understanding of the healthcare system. Following their discharge from the hospital and transition to the home and community, caregivers and stroke patients often express frustration over the insufficient information they receive about stroke and its treatment (Magwood et al., 2019).

Providing patients and caregivers with the necessary knowledge and support to employ effective coping mechanisms, they can adapt to their new circumstances as individuals with a post-stroke identity (Norlander, Iwarsson, Jönsson, Lindgren, & Månsson Lexell, 2022). In addition to a lack of knowledge and skills regarding the care of stroke patients at home, caregivers encounter various challenges, including instrumental, emotional, and financial support (Carolina Baltar Day et al., 2018). Caregivers whom hospital health workers educate

acquire knowledge about stroke care at home or in the community. Employing a telephone that emphasises technical skills and patient care can further this education (Carolina Baltar Day et al., 2018).

In a planned and structured manner, nurses can provide caregivers with education to enable them to perform their duties. Adequate education positively impacts caregivers' quality of life and burden while reducing hospital readmission probability (Carolina Baltar Day et al., 2018). Often, caregivers must fulfil their responsibilities in unexpected ways at home, leading to the emergence of new challenges. As a result, caregivers must be trained in executing activities related to stroke patients to gain a more comprehensive understanding of safe patient care and managing emotions while providing care at home (Carolina Baltar Day et al., 2018). Caregivers will be less likely to experience burdens if they comprehensively understand stroke and how to care for it at home. In contrast, it will instil confidence in them, ultimately resulting in a positive perception of the responsibility of caring for stroke patients rather than viewing it as a burden (Dharma et al., 2021).

In general, caregivers perceive the responsibility of caring for stroke patients as a perpetual burden, which has a detrimental impact on their physical and psychological well-being. Frequently reported complaints include fatigue, anxiety, and depression. These issues will impede the optimal recovery from stroke by reducing their capacity to care for patients at home. The nurse's duties extend beyond merely imparting knowledge; they also involve empowering caregivers at home to improve their adaptive behaviour and coping mechanisms when faced with these challenges. According to research, comprehensive education empowers caregivers to address challenges that arise during stroke patient care at home, leading to superior outcomes (Dharma et al., 2021).

Nevertheless, it is crucial to emphasize that caregivers must possess the necessary knowledge and skills to care for stroke patients and maintain their health to ensure the continuous continuity of stroke care (Helty, Sitorus, Martha, & Nusdwinuringtyas, 2021). The second theme concerns the pursuit of treatment. Stroke patients and their caregivers frequently express their complaints that they have not received the necessary therapy. They are dissatisfied with the current treatment approach, the prevailing health or socioeconomic system, and the lack of treatment they receive (Stokman-Meiland et al., 2022).

In this regard, stroke patients and their caregivers are seeking alternative treatments to sustain positive attitudes and behaviours. This situation pertains to the socio-cultural practices, customs, and beliefs they uphold daily. They are seeking alternative treatments because they believe that the rehabilitation programme has reached a plateau and is no longer able to have a positive impact on their health. Indeed, in addition to their involvement in alternative medicine, they also seek spiritual support to recover from strokes and feel avoided or burdened (Xu et al., 2019).

Patients and caregivers with a higher self-efficacy level are more likely to adhere to and complete a stroke treatment programme. The study results indicate that individuals who do not experience increased self-efficacy have a lower level of disease acceptance, a poorer quality of life, and a poorer functional status. Furthermore, their self-efficacy was diminished when they were dissatisfied with the outcomes of treatment to improve their health following a stroke (Szczepeńska-Gieracha & Mazurek, 2020). Caregivers must possess sufficient motivational support and self-efficacy to ensure that they behave and act positively when caring for sick family members, such as stroke patients. Research indicates that stroke patients exhibit a positive correlation between their knowledge, self-efficacy, and care skills (Sari et al., 2023). Age, duration of treatment, presence or absence of comorbidities, marital status, and patient acceptance of the disease all influence the holistic treatment of stroke patients (Suprayitno, Kustiningsih, & Ismail, 2023). Financial factors also influence stroke treatment. Some of them experience elevated medical expenses as a consequence of diminished financial resources. Numerous individuals encounter financial challenges when seeking medical treatment (Dharma & Rahayu, 2022).

The third theme pertains to the challenge of patient care. Family caregivers who are not prepared to care for a family member who has suffered a stroke frequently report experiencing health issues such as stress, fatigue, and depression. One of the reasons is the lack of information health workers provide during their hospitalization (Abu, Arafat, & Syahrul, 2020). Stroke patients often perceive their disability as severe because their bodies have deteriorated due to ageing (Carolina B. Day et al., 2021). In addition, patients and caregivers are less cognizant of the potential for fatigue to lead to coping difficulties, exacerbating emotional distress (Bicknell, Said, Haines, & Kuys, 2022).

The availability of support programs for caregivers after discharge from the hospital has been proven to benefit caring for stroke patients at home by reducing the burden and improving their quality of life (Carolina Baltar Day et al., 2018). Therefore, as part of the health workforce, nurses play an essential role in the transition from hospital to home, namely providing education and training on knowledge and skills to care for stroke patients at home to reduce the burden on caregivers (Day et al., 2021).

Stroke patients and caregivers feel a crisis not only at the time of hospitalization but also at the rehabilitation stage. In Indonesia, dependence on the needs of stroke patients' daily living activities is more on mild dependence (70%) and the rest is moderate, severe, and total dependence (Fadilah & Rahariyani, 2020). From the perspective of stroke patients, they state that they do not yet know adequately about rehabilitation goals, both long-term and short-term. In addition, they also lack information on how to proceed with rehabilitation at home (Zawawi, Aziz, Fisher, Ahmad, & Walker, 2020). Therefore, currently, the use of home-based virtual reality training can also be followed by stroke patients as an alternative option to carry out rehabilitation programs. This program can provide benefits for improving limb function and maintaining balance while standing and is recommended as an ongoing rehabilitation program at home (Sheehy et al., 2019). Post-stroke patient care at home through rehabilitation programs serves as a very important program for optimal recovery of stroke patients (Fadilah & Rahariyani, 2020). This study has limitations because the participants only come from one local ethnicity, therefore it cannot be generalized to the entire population in Indonesia.

Both during hospitalisation and rehabilitation, stroke patients and their caregivers experience a crisis. In Indonesia, the incidence of mild dependence (70%) on the daily living activities of stroke patients is higher than that of moderate, severe, and total dependence (Fadilah & Rahariyani, 2020). They assert that stroke patients are not yet adequately informed about the long-term and short-term rehabilitation objectives. Furthermore, they are also devoid of information regarding the rehabilitation process at home (Zawawi, Aziz, Fisher, Ahmad, & Walker, 2020). As a result, stroke patients may also use home-based virtual reality training as an alternative to current rehabilitation programs. Sheehy et al. (2019) recommend this program as an ongoing rehabilitation program at home, which can improve limb function and maintain balance while standing. The provision of post-stroke patient caregivers at home through rehabilitation programmes significantly influences the optimal recovery of stroke patients (Fadilah & Rahariyani, 2020). The study's limitations stem from the participants' exclusive local ethnicity. Consequently, it is not possible to generalise the findings to the entire Indonesian population.

## 5. Conclusion

Caregivers have difficulty caring for post-stroke patients at home and in the community. Families follow traditional treatments usually carried out by the surrounding community. The treatment has not been scientifically proven to treat stroke cases. As health workers, nurses have a duty to be nursing care providers and consultants for post-stroke patients. Nurses can participate as nurses in community health centres and family health nurses in providing comprehensive care and educating caregivers on how to take care of post-stroke patients properly. Thus, stroke patients still get the fulfilment of their daily needs on an ongoing basis, and caregivers can carry out their roles well and maintain their health and quality of life. As a recommendation, in the following study, it is hoped that participants from various ethnicities can be taken so that the results can be more likely to be generalized to a broader population.

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