

THE MEANING OF CAREGIVER ADAPTATION IN CARING FOR POST-STROKE PATIENTS WITH NEUROLOGICAL DISABILITIES AT HOME

Sri Puguh Kristiyawati^{1*}, Anastasia Hardyati², Kristiyani Herda Rophi³

¹Universitas Telogorejo Semarang, Indonesia

²Universitas MH Thamrin, Jakarta, Indonesia

³Politeknik Kesehatan Kemenkes Jayapura, Indonesia

* Corresponding Author: sripug2008@gmail.com

ARTICLE INFO

Article history:

Received: 20-09-2026

Revised: 08-10-2026

Accepted: 19-10-2026

Available online: 25-10-2026

Kata Kunci:

Adaptasi Caregiver, Disabilitas Neurologis, Keperawatan Pascastroke, Pengasuh Keluarga, Rehabilitasi Stroke

Keywords:

Caregiver Adaptation, Family Caregivers, Neurological Disabilities, Post-Stroke Nursing, Stroke Rehabilitation

ABSTRAK

Perawatan pasien pascastroke dengan disabilitas neurologis di rumah menuntut caregiver keluarga beradaptasi terhadap kebutuhan perawatan jangka panjang. Penelitian terdahulu lebih banyak menguraikan beban, kebutuhan, serta hambatan dan pendukung adaptasi, sedangkan cara caregiver memaknai dan menegosiasikan adaptasi dari waktu ke waktu masih jarang dieksplorasi. Penelitian ini bertujuan mengeksplorasi makna adaptasi pada caregiver keluarga yang merawat pasien pascastroke dengan gangguan neurologis persisten. Penelitian kualitatif dengan pendekatan fenomenologi ini menggali pengalaman hidup 14 caregiver keluarga yang dipilih secara purposif melalui wawancara mendalam semi-terstruktur. Data dianalisis dengan metode Colaizzi.

Analisis menghasilkan empat tema: penataan kembali kehidupan sehari-hari berdasarkan ketergantungan pasien, pembelajaran perawatan melalui pengalaman dan bimbingan profesional, pengelolaan kelelahan emosional dan perubahan peran keluarga, serta berkembangnya penerimaan, kepercayaan diri, dan makna baru dalam merawat. Secara konseptual, adaptasi merupakan proses non-linear yang memadukan penyesuaian praktis, negosiasi relasi keluarga, dan pembentukan makna. Temuan ini mengarah pada tiga implikasi keperawatan: pelatihan keterampilan yang berkelanjutan setelah pasien pulang, pembagian tanggung jawab perawatan di dalam keluarga, dan penilaian kebutuhan caregiver secara berkala.

ABSTRACT

Caring for post-stroke patients with neurological disabilities at home requires family caregivers to adapt to long-term care demands. Previous studies have mostly described caregiver burden, needs, and barriers and facilitators of adaptation, while how caregivers interpret and negotiate adaptation over time remains underexplored. This study aimed to explore the meaning of adaptation among family caregivers of post-stroke patients with persistent neurological impairments. This qualitative study used a phenomenological approach to explore the lived experiences of 14 family caregivers selected purposively and interviewed through in-depth semi-structured interviews. Data were analyzed using Colaizzi's method. Four themes emerged: rebuilding everyday life around patient dependency, learning caregiving through experience and professional guidance, managing emotional exhaustion and changing family roles, and developing acceptance, confidence, and new meaning in caregiving. Conceptually, adaptation is a non-linear process that integrates practical adjustment, negotiation of family relationships, and meaning-making. These findings point to three nursing

implications: continuing skills training after discharge, sharing caregiving responsibilities within the family, and periodic assessment of caregiver needs.

This is an open access article under the [CC BY-NC](#) license.

Copyright © 2026 by Author. Published by Akademi Kebidanan Nusantara 2000



INTRODUCTION

Stroke remains one of the major causes of death and long-term neurological disability worldwide. Approximately 12 million new strokes occur each year, and more than 90 million people are living with the consequences of stroke (Prust *et al.*, 2024). Beyond the acute phase, many survivors live with persistent motor impairment, communication difficulties, cognitive changes, swallowing problems, and limitations in activities of daily living that continue after hospital discharge and affect the physical, psychological, social, and economic well-being of survivors and their families (Feigin *et al.*, 2025; Wang *et al.*, 2025). For this reason, recovery often continues at home, and a substantial part of everyday care shifts from health professionals to family members, who become the primary caregivers for daily activities and ongoing treatment (Damaiyanti *et al.*, 2023). The transition from hospital to home is a particularly vulnerable period because family members may feel insufficiently prepared to manage post-stroke care independently (Raymond *et al.*, 2025; Veronese *et al.*, 2025).

For caregivers, this responsibility combines practical skills, changes in roles, and psychosocial adjustment. In practical terms, they assist with mobility and personal hygiene, prepare food, administer medication, support rehabilitation exercises, manage communication difficulties, and respond to changes in the patient's condition. Educational interventions, individualized care planning, home visits, and telephone follow-up have been reported to improve caregiver preparedness and self-efficacy after discharge (Marini *et al.*, 2025), and transitional care combining education, home follow-up, and psychosocial support has been tested for older adults with stroke (Markle-Reid *et al.*, 2023). Caregiving also alters family roles, employment, social activities, finances, and personal routines (Wittenberg *et al.*, 2020), and qualitative evidence shows major readjustments in caregivers' roles, identities, relationships, and valued activities (Jammal *et al.*, 2024). In Indonesia, family caregivers providing home-based care for stroke survivors report physical, emotional, social, financial, and spiritual consequences and a need to be heard as individuals rather than as extensions of patient care (Septian *et al.*, 2026). These experiences further differ according to the health condition and the relationship between caregiver and care recipient (Neller *et al.*, 2024).

Previous studies have examined these experiences from different angles, but none of those reviewed here centred on how caregivers give meaning to adaptation itself. Wang *et al.* (2025) used a phenomenological approach guided by the *Timing It Right* framework and showed that the needs of family caregivers of stroke patients with disabilities change across diagnosis, stabilization, discharge preparation, adjustment, and adaptation. That study mapped what caregivers need at each stage rather than how they interpret the process of becoming adapted. In Yogyakarta, Muhrodji *et al.* (2022) described the multiple roles of stroke caregivers and their problems, including limited caregiving knowledge, insufficient family support, physical limitations, and burnout, which clarifies what caregivers do and what difficulties arise but not how those difficulties are integrated into a sustained caregiving role. Koosha *et al.* (2026) addressed adaptation directly, identifying barriers and facilitators such as cumulative physical and emotional burden, acquisition of caregiving knowledge, family support, active coping, and reconstruction of identity, and described adaptation as dynamic rather than linear. Because their focus was on factors that hinder or support adaptation, it remains unclear how caregivers themselves connect practical adjustment, changing family relationships, and personal meaning during long-term home care for survivors with persistent neurological disabilities.

Therefore, this study aimed to explore how family caregivers interpret and negotiate adaptation while providing long-term home care for post-stroke survivors with persistent neurological disabilities, with particular attention to changes in daily routines, caregiving competence, family relationships, and personal meaning. The research question was: how do family caregivers experience and give meaning to adaptation while caring at home for post-stroke survivors with persistent neurological disabilities? By clarifying how the practical, relational, and meaning-making dimensions of adaptation are connected, the study is expected to inform nursing care that supports caregivers throughout long-term home care, not only in the period before discharge.

RESEARCH METHODS

Study Design

This study employed a qualitative phenomenological design to explore the meaning of adaptation among family caregivers caring for post-stroke patients with persistent neurological disabilities at home. A phenomenological approach was selected because the study focused on caregivers' lived experiences and how they interpreted changes in daily routines, family roles, emotional responses, and long-term caregiving responsibilities

(Neubauer et al., 2019). The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

Study Setting and Participants

The study was conducted in Semarang, Central Java, Indonesia, between August and November 2025. Participants were recruited through a neurology and rehabilitation outpatient service at a referral hospital and three community health centers (Puskesmas) that provided follow-up care for stroke survivors living in the community.

A purposive sampling technique was used to recruit family caregivers with direct and sustained experience of caring for post-stroke patients at home. Eligible participants were family members, namely spouses, adult children, or siblings, who were directly involved in the daily home care of a post-stroke patient with persistent neurological disability receiving follow-up at the participating services, and who were able to describe their experiences in an in-depth interview conducted in Indonesian. Fourteen caregivers took part. They were aged 30–66 years and had provided care for between 6 months and 4 years.

Data adequacy was judged on the depth and richness of participants' accounts rather than on the number of participants alone. The participants differed in their relationship with the patient, duration of caregiving, and the type of neurological impairment they managed, and the interviews, lasting approximately 45–70 minutes, produced detailed descriptions of everyday caregiving. Because data collection and preliminary analysis were conducted concurrently, meanings identified in earlier transcripts could be compared with those emerging from subsequent interviews. Recruitment was discontinued after the fourteenth interview because no substantially new meanings related to caregiver adaptation emerged.

Data Collection

Data were collected through 14 individual semi-structured in-depth interviews. Ten interviews were conducted in participants' homes and four in private consultation rooms at participating health facilities. Each interview lasted approximately 45–70 minutes, with an average duration of approximately 58 minutes.

The interviews explored participants' experiences of becoming caregivers, changes in everyday life, difficulties in managing neurological disability, sources of caregiving knowledge, emotional responses, family role changes, and the meaning they attributed to adaptation. Follow-up questions were used to clarify and deepen participants' responses.

All interviews were conducted in Indonesian, audio-recorded with participants' permission, and transcribed verbatim within 24–48 hours. Field notes were prepared

immediately after each interview to document non-verbal expressions, emotional responses, contextual conditions, and the researcher's preliminary reflections. Data collection and preliminary analysis were conducted concurrently.

Data Analysis

Data were analyzed using Colaizzi's phenomenological method. Each transcript was read repeatedly to gain an overall understanding of the participants' experiences. Significant statements related to caregiving and adaptation were identified, followed by the formulation of meanings and grouping of similar meanings into thematic clusters.

A total of 172 significant statements were identified and condensed into 29 formulated meanings. These meanings were subsequently organized into eight thematic clusters and synthesized into four major themes: rebuilding everyday life around patient dependency, learning caregiving through experience and professional guidance, managing emotional exhaustion and changing family roles, and developing acceptance, confidence, and new meaning in caregiving.

The themes were continuously compared with the original transcripts to ensure that the interpretation remained grounded in participants' experiences. Member checking was conducted with five participants, all of whom confirmed that the synthesized findings accurately reflected their caregiving experiences.

Trustworthiness

Trustworthiness was addressed through credibility, dependability, confirmability, and transferability. Credibility was strengthened through prolonged engagement with the data, member checking, comparison between interview transcripts and field notes, and peer discussion. Dependability was supported by maintaining an audit trail documenting recruitment, interview procedures, coding decisions, and theme development.

Confirmability was enhanced through reflexive journaling throughout the research process. Two researchers with experience in qualitative nursing research reviewed the thematic structure and discussed alternative interpretations. Transferability was supported by providing sufficient descriptions of participant characteristics, caregiving duration, patient disabilities, and home-care contexts.

Ethical Considerations

Ethical approval was obtained from the institutional research ethics committee before data collection. All participants received clear verbal and written explanations regarding the study objectives, procedures, confidentiality, voluntary participation, and their right to withdraw from the study at any time without consequences. Written informed consent was obtained from each participant before the interview. To protect participants' privacy,

pseudonymous codes were used throughout the study, and identifying information was removed from interview transcripts and research reports. Audio recordings and transcripts were securely stored in password-protected files and were accessible only to the research team. Participants were also informed that they could pause or discontinue the interview if they experienced emotional discomfort or distress. Appropriate support and referral were provided when necessary.

RESULTS AND DISCUSSION

Participant Characteristics

Fourteen family caregivers of post-stroke patients with persistent neurological disabilities participated in the study. Their ages ranged from 30 to 66 years, with a median age of 48 years. Ten participants were women and four were men. Six participants were spouses of the patients, six were adult children, and two were siblings. The duration of caregiving ranged from 6 to 48 months, with a median duration of 18 months.

Most participants lived in the same household as the patient and were responsible for daily care, including assisting with bathing, dressing, feeding, toileting, medication, mobility, and rehabilitation exercises. Twelve caregivers cared for patients with mobility limitations, seven cared for patients with communication difficulties, five reported cognitive or behavioral changes, and four cared for patients with swallowing difficulties. Several patients experienced more than one neurological impairment.

Analysis of the 14 interviews identified 172 significant statements, which were condensed into 29 formulated meanings and eight thematic clusters. These were synthesized into four interconnected aspects of caregiver adaptation involving the reorganization of everyday life, development of caregiving competence, management of emotional and family changes, and reconstruction of meaning within the caregiving role.

Table 1. Characteristics of participants and caregiving context

Participant characteristics	n (%) / Range
Total participants	14
Age	30–66 years
Median age	48 years
Female	10 (71.4%)
Male	4 (28.6%)
Spouse	6 (42.9%)
Adult child	6 (42.9%)
Sibling	2 (14.3%)
Caregiving duration	6–48 months
Median caregiving duration	18 months
Patient with mobility impairment	12 (85.7%)
Patient with communication impairment	7 (50.0%)

Patient with cognitive/behavioral changes	5 (35.7%)
Patient with swallowing difficulties	4 (28.6%)
Neurological impairments were not mutually exclusive.	

Rebuilding Everyday Life Around Patient Dependency

Returning home after hospitalization marked a major transition for both patients and caregivers. Participants described the first weeks and months as a period in which their previous routines were disrupted by the patient's dependence on assistance. Activities that had previously been taken for granted, such as working, sleeping, shopping, attending social activities, or visiting relatives, had to be reorganized according to the patient's needs. For participants caring for patients with severe mobility impairment, caregiving often began early in the morning and continued throughout the day. Bathing, toileting, transferring, preparing meals, administering medication, and accompanying rehabilitation became part of a new daily routine.

One participant described how caregiving gradually became the center of everyday life: *"After my husband came home, my schedule changed completely. I wake up earlier because I have to prepare his medicine, help him bathe, and prepare breakfast. Before doing my own activities, I make sure everything for him is ready first."* (P03, wife, 52 years).

Another participant explained that personal activities became increasingly difficult to plan: *"Before my mother had a stroke, I could go out whenever I needed to. Now, if I want to leave the house, I have to make sure someone can stay with her. I cannot just go because she still needs help to stand and go to the toilet."* (P09, daughter, 37 years)

Some caregivers initially viewed these changes as a loss of independence. However, over time, they began to develop routines that made caregiving more predictable. Participants created medication schedules, arranged household duties among family members, modified rooms to make movement safer, and adjusted working hours where possible.

"At first everything felt chaotic because we did not know what should be done first. After several months, we made a routine. My brother helps in the evening, and I take care of my father during the day. It is still tiring, but now it is more organized." (P12, daughter, 41 years)

These experiences showed that adaptation did not involve returning to life as it had been before the stroke. Instead, caregivers gradually reconstructed daily life around the patient's level of dependency while attempting to maintain their own responsibilities.

Learning to Provide Care Through Experience and Professional Guidance

Most caregivers described feeling insufficiently prepared when the patient first returned home. Although some had received basic instructions before discharge, they

reported that actual caregiving situations were more complex than anticipated. Difficulties commonly involved transferring patients from bed to chair, assisting with walking, preparing appropriate food, managing swallowing problems, preventing falls, and recognizing signs of deterioration.

A spouse who cared for a patient with hemiparesis described the uncertainty experienced during the early period of home care: *"The first time I had to move him from the bed to the chair, I was very afraid. I thought I might drop him or hurt his affected arm. At the hospital there were nurses, but at home I had to do it myself."* (P02, wife, 55 years).

Knowledge acquired from nurses, physiotherapists, doctors, and rehabilitation staff was considered particularly valuable when it addressed practical problems encountered at home.

"The physiotherapist showed me how to support his body when standing and how to exercise his weak leg. After I practiced several times, I became less afraid. I realized there was a correct way to help him." (P06, son, 34 years).

Not all caregiving knowledge came from health professionals. Participants also learned through repeated practice and by observing changes in the patient's responses.

"At first I followed everything exactly as I was told, but later I learned what worked better for my mother. For example, when she is tired, forcing her to exercise makes her frustrated. Now I know when she is ready and when she needs to rest." (P08, daughter, 39 years)

Participants caring for patients with communication difficulties reported that they also developed new ways of understanding patients' needs.

"He cannot speak clearly, so in the beginning we often misunderstood each other. Now I can understand from his gestures or expression what he wants. It took time. We learned together." (P10, wife, 61 years).

As caregiving skills increased, participants described becoming more confident and less dependent on immediate professional assistance. Nevertheless, confidence did not eliminate uncertainty. When the patient's condition changed, caregivers again sought advice from healthcare professionals or adjusted their caregiving strategies. Adaptation was therefore experienced as an ongoing process of learning rather than a single period of preparation after discharge.

Managing Emotional Exhaustion and Changes in Family Roles

Caregiving was accompanied by considerable emotional and physical demands. Participants described fatigue, anxiety, frustration, sadness, sleep disruption, and fear of sudden deterioration. These feelings were particularly intense among caregivers who provided most care without regular assistance from other family members.

One participant described the psychological burden of constant vigilance: *"Even when I sleep, I do not really feel relaxed. If I hear him cough or move, I wake up immediately because I am afraid something has happened."* (P05, wife, 58 years).

Another participant described feeling physically exhausted but reluctant to express it: *"Sometimes my body is very tired, especially after helping him bathe and move several times. But when he sees me tired, he feels guilty. So usually I keep it to myself."* (P01, husband, 60 years).

Emotional exhaustion was often accompanied by uncertainty about recovery. Several participants initially expected that the patient would rapidly regain previous abilities. When improvement occurred more slowly, they experienced disappointment and frustration.

"In the beginning I thought after therapy for a few months my father would walk normally again. When that did not happen, I felt disappointed. Later I understood that recovery is different for every person." (P07, son, 32 years)

Stroke also changed relationships within the family. Spouses described taking over household and financial responsibilities that had previously been shared with the patient. Adult children frequently experienced role reversal as they became responsible for intimate care of a parent.

"She used to take care of everything for us. Now I am the one helping her eat, bathe, and take medicine. At first it felt strange and sad because our roles had completely changed." (P13, daughter, 35 years)

Differences in family involvement occasionally created tension. Some participants felt that caregiving responsibilities were concentrated on one person even when several family members were available.

"My siblings care about him, but because I live here, most things become my responsibility. Sometimes I feel angry because everyone asks about his condition, but not everyone understands what it is like to take care of him every day." (P04, daughter, 44 years)

In contrast, caregivers who received regular assistance from family members reported having more opportunities to rest and maintain personal activities. Sharing caregiving responsibilities reduced feelings of isolation and was perceived as an important factor in sustaining long-term care.

Developing Acceptance, Confidence, and New Meaning in Caregiving

Over time, most participants described a gradual change in how they perceived the patient's disability and their own caregiving role. Early expectations of complete or rapid recovery were increasingly replaced by a more realistic understanding of the patient's condition.

Acceptance was not described as resignation. Rather, it involved recognizing persistent limitations while continuing to support achievable improvements.

"Before, I kept asking when he would become normal again. Now I do not think like that anymore. If today he can sit longer or take a few steps, I am already grateful. We focus on what he can do." (P11, wife, 49 years)

Caregiving experience also strengthened participants' confidence. Situations that had initially caused fear became manageable after months of repeated practice.

"In the first months, every small change made me panic. Now I am calmer. I know what I can manage at home and when I really need to take him to the hospital." (P14, sister, 46 years)

Several participants described finding personal meaning in caregiving through responsibility, affection, reciprocity, and family commitment. Caring for the patient was no longer interpreted solely as an obligation but also as an opportunity to remain present for a family member during a period of dependency.

"It is tiring, of course, but she is my mother. She took care of me when I was young. Now I feel this is my turn to take care of her." (P08, daughter, 39 years)

For some spouses, caregiving also changed the meaning of their relationship.

"Our relationship is different now because I have to help him with almost everything. But I also feel we understand each other more. I learned to be more patient, and he learned to accept help." (P03, wife, 52 years)

Importantly, acceptance and confidence did not eliminate difficult emotions. Participants continued to experience fatigue, worry, and frustration, particularly when the patient's health deteriorated or new problems emerged.

"There are days when I feel I can handle everything, and there are also days when I feel very tired and want to cry. I think adapting does not mean that everything becomes easy. It means I know how to continue even when it is difficult." (P10, wife, 61 years)

This statement captured the central meaning emerging from participants' experiences. Adaptation was not perceived as a final state in which caregiving became effortless. Instead, caregivers learned to live with uncertainty while gradually developing practical competence, emotional endurance, and a more realistic understanding of the patient's condition.

The Meaning of Caregiver Adaptation

Across participants' experiences, caregiver adaptation emerged as a continuous and non-linear process of reconstructing everyday life in response to persistent neurological disability. Caregivers moved repeatedly between uncertainty and confidence, exhaustion and resilience, frustration and acceptance. Adaptation developed through accumulated

caregiving experience, professional guidance, family support, and gradual recognition of both the patient's limitations and the caregiver's own capabilities.

The findings indicate that adaptation involved four closely connected processes: reorganizing everyday routines around patient dependency, developing practical caregiving competence, negotiating emotional and relational changes, and reconstructing personal meaning in caregiving. These processes did not occur sequentially. Participants could experience increased confidence while remaining emotionally exhausted or achieve acceptance while continuing to struggle with practical caregiving demands.

Accordingly, the meaning of adaptation extended beyond the caregiver's ability to perform physical care. It represented an ongoing effort to integrate caregiving into everyday life without completely losing personal identity, family relationships, and emotional well-being. For the participants, becoming adapted did not mean that caregiving was no longer difficult; rather, it meant becoming increasingly capable of living with and responding to the changing realities of long-term post-stroke care.

Table 2. Structure of the findings

Main findings	Related experiences	Meaning of adaptation
Rebuilding everyday life around patient dependency	Changes in routines, work, sleep, household responsibilities, and personal activities	Restructuring daily life to accommodate continuing dependency
Learning to provide care through experience and professional guidance	Initial uncertainty, practical learning, professional guidance, repeated practice	Developing competence through continuous learning and adjustment
Managing emotional exhaustion and changes in family roles	Fatigue, anxiety, uncertainty, role reversal, unequal family responsibilities	Negotiating emotional burden and altered family relationships
Developing acceptance, confidence, and new meaning	Realistic expectations, increased confidence, family commitment, personal meaning	Reconstructing caregiving as a manageable and meaningful life experience

This study explored how family caregivers interpret and negotiate adaptation while caring at home for post-stroke survivors with persistent neurological disabilities. Across the four themes, adaptation appeared as a non-linear process in which caregivers reorganized daily life, built competence, negotiated emotional and family changes, and reconstructed meaning. The following paragraphs discuss each theme in relation to previous studies before setting out the conceptual contribution of the findings.

The first theme showed that caregivers rebuilt everyday life around the patient's dependency. This process can be read as practical adjustment: caregivers did not return to their previous routines but created a new structure, such as medication schedules, shifts

shared among siblings, and safer room arrangements, which made care more predictable (P12). Jammal *et al.* (2024) similarly reported that stroke caregiving disrupts carers' roles and valued activities, and Lilleheie *et al.* (2021) described how the period after discharge shifts responsibilities from health professionals to family members. Those studies emphasized disruption, whereas participants in the present study also described how a workable routine emerged after several months. A likely reason is the stage at which they were interviewed: participants had been caring for 6–48 months, with a median of 18 months, so many could look back on the early disruption from a later point. Khomarun *et al.* (2025) found that Indonesian stroke caregivers faced limited personal time, physical exhaustion, and disrupted family routines and identified devotion to family as a coping strategy. In the present study, the willingness of other family members to share tasks was what made new routines possible, suggesting that practical adjustment depends on how caregiving is distributed within the family.

The second theme concerned caregiving competence. Caregivers felt unprepared when the patient first came home, for example when transferring the patient for the first time (P02), and competence developed through professional demonstration, repeated practice, and learning to read the patient's responses (P06, P08, P10). Competence in home care therefore appears to be partly experiential knowledge that grows through daily contact with the patient's changing condition. Lin *et al.* (2022), in a longitudinal qualitative study of hospital-to-home transitional care, and Wang *et al.* (2025) both showed that caregiver needs change across phases of recovery. The present findings differ in that learning continued long after discharge, and confidence could give way to uncertainty again when the patient's condition changed. This extends reports that caregivers feel insufficiently prepared at discharge (Damaiyanti *et al.*, 2023; Raymond *et al.*, 2025) by showing that preparedness is not achieved once and for all. The longer caregiving period and the persistent impairments of the patients in this study may explain why learning was described as ongoing.

The third theme showed that emotional exhaustion was closely tied to changing family relationships. Constant vigilance (P05), role reversal between adult children and parents (P13), and unequal distribution of tasks among siblings (P04) made caregiving a relational as well as a physical burden. Muhrodji *et al.* (2022) also identified insufficient family support and burnout among caregivers in Yogyakarta, and Koosha *et al.* (2026) listed family support among the facilitators of adaptation. The present study adds how this support was experienced: caregivers who shared responsibilities had time to rest and maintain personal activities, while those who carried most of the care felt isolated and

misunderstood by other relatives. A husband who hid his fatigue because the patient felt guilty (P01) illustrates the tension between carrying a burden and feeling like a burden described by Lilleheie *et al.* (2021), indicating that caregivers manage not only their own emotions but also those of the person they care for. The feeling that daily caregiving was not understood by others echoes the need to be heard reported by Septian *et al.* (2026). Experiences also differed by relationship, as spouses took over shared household and financial roles whereas adult children faced role reversal, in line with evidence that caregiver experiences vary across relationships (Neller *et al.*, 2024).

The fourth theme showed that acceptance, confidence, and meaning developed gradually without removing difficult emotions. Acceptance involved moving from expectations of full recovery to valuing small gains (P11), and meaning was framed through reciprocity, such as caring for a mother who had once cared for the participant (P08), and through a changed but closer spousal relationship (P03). Koosha *et al.* (2026) described reconstruction of identity as part of adaptation, and Jammal *et al.* (2024) reported changes in caregivers' identities and relationships. The present study adds that meaning-making coexisted with continuing fatigue and worry, as one participant described adaptation as knowing how to continue even when it is difficult (P10). Adaptation in this sense is not the absence of burden but the capacity to sustain care alongside it.

Taken together, the findings integrate three dimensions of adaptation that are often examined separately: practical adjustment, negotiation of family relationships, and meaning-making. The data suggest that these dimensions are linked. Sharing tasks among family members made workable routines possible (P12), repeated practice built the confidence that allowed caregivers to remain calm and judge when hospital care was needed (P14), and meanings such as reciprocity and family commitment helped caregivers continue despite fatigue (P08, P10). Conversely, a change in the patient's condition could return caregivers to uncertainty even after they had become confident. Adaptation is therefore better understood as a continuous negotiation across these dimensions than as a sequence of stages or a final state of adjustment. This view complements stage-based accounts of caregiver needs (Wang *et al.*, 2025) and factor-based accounts of barriers and facilitators (Koosha *et al.*, 2026) by describing how caregivers themselves connect these elements over time.

The findings point to three implications for post-stroke nursing care. First, because competence developed through repeated practice and had to be renewed when the patient's condition changed, skills training for caregivers should continue after discharge through outpatient or home-based follow-up, covering mobility assistance, medication

management, nutrition and swallowing safety, and recognition of warning signs. Second, because unequal distribution of care intensified exhaustion while shared care allowed rest, nurses should involve other family members in planning how caregiving tasks are divided. Third, because caregiver needs re-emerged as the patient's condition changed, caregiver needs, fatigue, and emotional distress should be assessed periodically, treating caregivers as individuals who require support rather than only as members of the health team (Sherman, 2019). Transitional care approaches combining education, home follow-up, and psychosocial support (Marini *et al.*, 2025; Markle-Reid *et al.*, 2023; Veronese *et al.*, 2025) offer possible frameworks, although the present study did not evaluate any intervention.

This study has several limitations. Participants were caregivers in Semarang recruited through one referral hospital and three community health centers, so the findings may not reflect caregiving in other cultural or service settings, including caregivers who have little contact with health services. Most participants were women, and the patients' level of dependency was described by type of impairment rather than measured with a standardized instrument, so differences in adaptation by level of dependency could not be examined systematically. Each participant was interviewed once, which means that changes over time were reconstructed from retrospective accounts. Future studies may use longitudinal designs and include caregivers in different service contexts and with patients at different levels of dependency.

CONCLUSIONS

This study shows how family caregivers interpret and negotiate adaptation while caring at home for post-stroke survivors with persistent neurological disabilities. Caregivers experienced adaptation through four interconnected processes: rebuilding daily life around the patient's dependency, learning to provide care through experience and professional guidance, managing emotional exhaustion and changing family roles, and developing acceptance, confidence, and new meaning. The core meaning of adaptation was not that caregiving became easy, but that caregivers became able to continue caring amid ongoing uncertainty and fatigue by linking practical adjustment, family relationships, and personal meaning. Based on these findings, nursing services are recommended to provide continuing skills training after discharge, involve family members in sharing caregiving responsibilities, and assess caregiver needs and well-being periodically. Future research should use longitudinal designs and include caregivers in different service contexts and with patients at different levels of dependency.

REFERENCES

- Damaiyanti, M., Amir, H., Cahyani, D. D., Alhidayat, N. S., Afrianti, N., Rahmiati, C., Hastuti, H., Sari, A. S., & Hidayat, R. (2023). Improving caregiver preparedness in the care transition of stroke patients: A scoping review. *Journal of Medicine and Life*, 16(12), 1723–1731. <https://doi.org/10.25122/jml-2023-0142>
- Feigin, V. L., Brainin, M., Norrving, B., Martins, S. O., Pandian, J., Lindsay, P., Grupper, M. F., & Rautalin, I. (2025). World Stroke Organization: Global stroke fact sheet 2025. *International Journal of Stroke*, 20(2), 132–144. <https://doi.org/10.1177/17474930241308142>
- Jammal, M., Kolt, G. S., Liu, K. P. Y., Dennaoui, N., & George, E. S. (2024). The impact of caregiving on the roles and valued activities of stroke carers: A systematic review of qualitative studies. *PLOS ONE*, 19(5), e0304501. <https://doi.org/10.1371/journal.pone.0304501>
- Khomarun, K., Subijanto, A. A., Nurhidayah, N., & Probandari, A. (2025). Devotion to family: Coping strategy to reduce burden of caregiving stroke patients. *Occupational Therapy International*, 2025(1), 5517436. <https://doi.org/10.1155/oti/5517436>
- Koosha, M. M., Azizi, A., Torabi, A., Khodaveisi, M., & Sadeghian, E. (2026). Exploring barriers to and facilitators of adaptation in family caregivers of stroke survivors: A qualitative study. *BMC Health Services Research*, 26, Article 1101. <https://doi.org/10.1186/s12913-026-14883-7>
- Lilleheie, I., Debesay, J., Bye, A., & Bergland, A. (2021). The tension between carrying a burden and feeling like a burden: A qualitative study of informal caregivers' and care recipients' experiences after patient discharge from hospital. *International Journal of Qualitative Studies on Health and Well-Being*, 16(1), 1855751. <https://doi.org/10.1080/17482631.2020.1855751>
- Lin, S., Wang, C., Wang, Q., Xie, S., Tu, Q., Zhang, H., Peng, M., Zhou, J., & Redfern, J. (2022). The experience of stroke survivors and caregivers during hospital-to-home transitional care: A qualitative longitudinal study. *International Journal of Nursing Studies*, 130, 104213. <https://doi.org/10.1016/j.ijnurstu.2022.104213>
- Marini, G., Longhini, J., Ambrosi, E., Canzan, F., Konradsen, H., & Kabir, Z. N. (2025). Transitional care interventions in improving patient and caregiver outcomes after discharge: A scoping review. *Healthcare*, 13(3), 312. <https://doi.org/10.3390/healthcare13030312>
- Markle-Reid, M., Fisher, K., Walker, K. M., Beauchamp, M., Cameron, J. I., Dayler, D., Fleck, R., Gafni, A., Ganann, R., Hajas, K., Koetsier, B., Mahony, R., Pollard, C., Prescott, J., Rooke, T., & Whitmore, C. (2023). The stroke transitional care intervention for older adults with stroke and multimorbidity: A multisite pragmatic randomized controlled trial. *BMC Geriatrics*, 23(1), 687. <https://doi.org/10.1186/s12877-023-04403-1>
- Muhrodji, P., Wicaksono, H. D. A., Satiti, S., Trisnantoro, L., Setyopranoto, I., & Vidyanti, A. N. (2022). Roles and problems of stroke caregivers: A qualitative study in Yogyakarta, Indonesia. *F1000Research*, 10, 380. <https://doi.org/10.12688/f1000research.52135.2>
- Neller, S. A., Hebdon, M. T., Wickens, E., Scammon, D. L., Utz, R. L., Dassel, K. B., Terrill, A. L., Ellington, L., & Kirby, A. V. (2024). Family caregiver experiences and needs across health conditions, relationships, and the lifespan: A qualitative analysis. *International Journal of Qualitative Studies on Health and Well-Being*, 19(1), 2296694. <https://doi.org/10.1080/17482631.2023.2296694>

- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8, 90–97. <https://doi.org/10.1007/s40037-019-0509-2>
- Prust, M. L., Forman, R., & Ovbiagele, B. (2024). Addressing disparities in the global epidemiology of stroke. *Nature Reviews Neurology*, 20(4), 207–221. <https://doi.org/10.1038/s41582-023-00921-z>
- Raymond, J., Williamson-Link, K., Byrne, M., Spence, A., Hockings, S., Wilemon, L., Lahey, L., Hubling, A., & Brady, S. (2025). Impact of inpatient stroke rehabilitation on caregivers' perceived readiness for patient discharge. *Rehabilitation Nursing*, 50(2), 57–65. <https://doi.org/10.1097/RNJ.0000000000000494>
- Septian, R. B., Pangastuti, H. S., & Nisman, W. A. (2026). “As caregivers, we also need someone who listens”: Family perspectives on providing palliative care for stroke patients. *Journal of Palliative Care*, 41(2), 223–230. <https://doi.org/10.1177/08258597251407761>
- Sherman, D. W. (2019). A review of the complex role of family caregivers as health team members and second-order patients. *Healthcare*, 7(2), 63. <https://doi.org/10.3390/healthcare7020063>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Veronese, M., Vellone, E., Alvaro, R., & Pucciarelli, G. (2025). The transitional care from hospital to home for stroke survivors and their caregivers: A systematic review. *Journal of Vascular Nursing*, 43(2), 86–98. <https://doi.org/10.1016/j.jvn.2025.03.002>
- Wang, M., Wang, K., Xie, B., Liu, D., Song, L., Cao, X., Tong, Y., Liu, C., Fu, H., Zhou, Y., Chen, Q., Zhu, Y., Zhu, L., & Cheng, F. (2025). Understanding the needs of family caregivers of stroke patients with disabilities: A phenomenological study using the Timing It Right theory. *PLOS ONE*, 20(6), e0325671. <https://doi.org/10.1371/journal.pone.0325671>
- Wittenberg, E., Goldsmith, J., Ragan, S. L., & Parnell, T. A. (2020). *Caring for the family caregiver*. Oxford University Press. <https://doi.org/10.1093/med/9780190055233.001.0001>