

A Phenomenological Study of Javanese Family Caregivers' Perspectives on Caring for Stroke Survivors

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Abstract: Stroke is a major cause of long-term disability in Indonesia, where family members often become primary caregivers with minimal formal support. In culturally rooted communities like East Java, caregiving is deeply influenced by local values, yet limited research has examined how these values shape caregiver resilience. This study aimed to explore how Javanese cultural beliefs influence the experiences and resilience of family caregivers providing home-based care for stroke survivors. Using a qualitative design, in-depth interviews were conducted with ten caregivers in East Java, employing interpretative phenomenological analysis.

Thematic analysis identified four key themes: caregiving as a devotion and cultural duty; the family's understanding of illness as a foundation for meaning; home-based continued care with love, hope, and spirituality; and emotional dynamics in the early stages of caregiving. Caregiving was seen not only as a responsibility, but as a moral and spiritual calling rooted in values such as *Ngabekti* (devotion), *Nrimo* (acceptance), and *Pasrah* (surrender). Participants employed both biomedical and traditional practices, showing creativity in overcoming limited resources. These findings highlight the importance of culturally responsive nursing care that addresses the emotional, spiritual, and informational needs of caregivers. Supporting caregiver resilience through culturally informed nursing and medical interventions may enhance stroke rehabilitation outcomes and promote caregiver well-being in similar community settings.

Keywords: Culture, Family caregivers, Interpretative phenomenology, Java, Non-communicable disease, Resilience, Stroke rehabilitation

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Introduction

Stroke remains the leading cause of long-term disability worldwide, with over 12 million new cases annually and approximately 6.5 million deaths reported each year.^{1,2} Globally, more than 100 million people have experienced a stroke at some point in their lives.³ In Indonesia, stroke prevalence reaches 10.9 per 1,000 population, and in East Java Province, it is even higher, at 12.4%.⁴ This epidemiological burden has significant implications for families, as stroke survivors frequently rely on assistance with activities of daily living (ADL) and long-term care.⁵

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In many low- and middle-income countries, including Indonesia, family members often become informal caregivers responsible for the 24-hour care of stroke survivors.⁶ This caregiving role can result in considerable physical, psychological, and financial strain.^{3,7} In addition, cultural values in regions like East Java frame caregiving as a moral duty, which, while strengthening familial commitment, may also increase emotional expectations and caregiving pressure.⁸ A caregiver's perspective, whether positive or burdensome, can significantly influence their resilience and the quality of care they deliver.^{6,9,10}

While previous studies have explored the experiences of family caregivers for stroke patients, including their perspectives, burdens, and coping strategies,^{11,12} limited attention has been given to the role of culture and gender in shaping caregiving practices, particularly in low- and middle-income countries. In Indonesia, most research remains quantitative, with limited exploration of caregivers' emotional and cultural contexts. Emerging qualitative studies, such as those by Tarigan et al.⁶ and Na'imah et al.,¹³ highlight the influence of spiritual beliefs, gender roles, and family expectations, though often without deep cultural framing.^{6,13} In many Asian contexts, caregiving is not merely a health responsibility but a culturally embedded obligation grounded in spiritual beliefs, intergenerational duty, and social expectations.¹⁴⁻¹⁶

In East Java, caregiving is deeply influenced by local philosophical values, such as *Ngabekti* (devotion), *Nrimo* (acceptance), and *Trah* (lineage responsibility), which compel family members, especially women, to endure emotional and physical burdens due to cultural and moral commitments.^{6,13} These values often reinforce traditional gender roles and lead caregivers to sacrifice personal well-being. Research further indicates that female caregivers are more likely to experience elevated stress, reduced autonomy, and reduced quality of life.¹⁷

Despite the centrality of these cultural and gendered dimensions, little is known about how they

operate within specific subcultural contexts such as East Java, where caregiving is intimately tied to Javanese philosophical values and patriarchal norms. A clearer understanding of these dynamics is essential to guide culturally attuned nursing interventions that can bolster caregiver resilience and improve stroke care outcomes. Therefore, this study aimed to explore how cultural values shape the resilience of Javanese family caregivers in caring for stroke survivors.

Methods

Study Design: This study employed a qualitative design using an interpretative phenomenological analysis (IPA) approach to explore the lived experiences of Javanese family caregivers providing care for stroke survivors. IPA was selected for its suitability in examining personal, emotional, and culturally embedded experiences, particularly within complex and ambiguous caregiving contexts.¹⁸ This approach emphasizes the active role of researchers in interpreting participants' meaning-making processes through a reflective and empathetic lens. The aim was to gain an in-depth understanding of how caregivers perceive and assign meaning to their caregiving roles, particularly within the context of Javanese culture. This study is reported based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Setting: Data were collected from August to September 2024 at a referral teaching hospital in Surabaya, Indonesia. The hospital was selected due to its high volume of patients affected by stroke and comprehensive stroke care services, including acute treatment and rehabilitation. As a regional referral center, the hospital provided access to a diverse range of caregiving experiences, making it an ideal setting to explore family caregiving in a culturally and clinically rich environment.

Participants and Sampling: A total of ten participants were recruited using purposive sampling, with the goal of achieving maximum variation in age, gender, caregiving duration, and caregiving relationships

(e.g., spouse, sibling, in-law). Inclusion criteria included being of Javanese ethnicity, aged 18 years or older, and having provided daily home-based care for a stroke survivor for a minimum of three months. All participants received oral and written explanations of the study and signed informed consent forms before participation. There were no prior relationships between the researchers and the participants. Data saturation was reached after ten interviews.

Data Collection: Data were collected through face-to-face, semi-structured, in-depth interviews using an interview guide developed by the research

team. The guide included open-ended questions, which were revised after two pilot interviews to improve clarity and relevance. Interviews were conducted by the first author and lasted approximately 45–60 minutes. Interviews began with questions such as, “Can you tell me about your experience as a caregiver?” and were followed by probes like, “What were you thinking or feeling at the time?” or “How did this situation affect you?” These prompts encouraged participants to reflect on emotional, spiritual, and cultural aspects of their caregiving journey (see **Table 1**).

Table 1. Interview questions

Interview Questions

1. Can you share your experience and feelings about being a caregiver for a family member with a stroke, including your responsibilities and what motivates you to continue?”
 2. “How has being a caregiver impacted your life, and how do you balance your roles within the family and community?”
 3. “How do you manage your emotions and address the challenges that arise while caring for your family member with a stroke?”
 4. “How do those around you respond when you share your feelings about being a caregiver?”
 5. “What are your hopes for yourself and your family in meeting the care needs of your family member with a stroke?”
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Eight interviews were conducted at the participants’ homes and two at the hospital, based on the participants’ preference. All interviews were audio-recorded with the participants’ consent, and nonverbal cues and contextual observations were documented in field notes. This comprehensive approach aimed to capture both verbal and non-verbal expressions of meaning.

Data Analysis: All audio-recorded interviews were transcribed verbatim in Bahasa Indonesia. Transcripts were returned to participants for member checking before being translated into English. Thematic analysis followed the six-phase process by Braun and Clarke:¹⁹ 1) familiarization with the data, 2) generation of initial codes, 3) identification of themes, 4) reviewing and grouping themes, 5) defining and naming themes, and 6) writing the final analytical

narrative. Analysis was conducted using NVivo software to systematically organize codes and themes.

Trustworthiness: The principles of credibility, dependability, confirmability, and transferability, as outlined by Guba and Lincoln,²⁰ were systematically applied to ensure trustworthiness throughout this study. Credibility is maintained through member checking, where the researcher provided interpretive summaries and thematic excerpts from in-depth interviews to participants for review and verification. This aimed to ensure that the researcher’s interpretation aligned with the participant’s intended meaning. During this process, participants were able to proofread, clarify, and add interpretation results. Dependability is strengthened through researcher triangulation. The data analysis process was carried out independently by each researcher; then the research findings were discussed together to

reach a consensus on the development of the themes. This aims to reduce subjectivity and increase consistency in data analysis. Confirmability was ensured by compiling a detailed trail audit, which includes interview process records, transcripts, initial coding, theme development, and interpretive decisions. Reflexivity was maintained through reflective journals during the data collection and analysis process to help researchers critically reflect on their interpretation. The transferability was supported by the presentation of a complete description of the cultural context, spiritual values, and background of participants in caring for stroke survivors in the Javanese family environment. Thick descriptions of participants' backgrounds and caregiving contexts were provided to enable readers to assess the applicability of findings to similar cultural settings.

Preunderstanding: As qualitative researchers, our positionality inevitably shapes the interpretation of participants' narratives. All authors in this study were registered nurses with professional and academic backgrounds in family and mental health nursing. The first (SCR, male), second (YS, female), and sixth authors (AY, male) have specific experience in stroke rehabilitation care, while the third, fourth, and fifth authors (RN, NMH, AF, all female) bring qualitative research expertise rooted in cultural and psychosocial perspectives. Being culturally embedded in Javanese society allowed us to approach participants with cultural sensitivity, but we remained reflexively aware of our assumptions through the use of reflective journals and team debriefings. Our insider-outsider dynamic facilitated deep rapport while also maintaining critical distance during thematic interpretation. This reflexive stance ensured that the findings accurately reflected the lived experiences of caregivers, rather than merely the researchers' prior knowledge or expectations.

Ethical Considerations: Ethical approval was obtained from the Ethics Committee of Nursing and Health Research at Universitas Airlangga Hospital, Surabaya (No.113/KEP/2024/NA-02). All participants were informed about the study's purpose,

procedures, risks, and their rights, including the right to withdraw at any time. Written informed consent was obtained for participation and audio recording. To protect confidentiality, pseudonyms were used, and all data were securely stored. Participants' identities were not disclosed in any reports or publications.

Findings

Participant's characteristics

A total of ten participants were included (Table 2). All were Javanese family caregivers living in East Java, Indonesia, a region rich in cultural values that deeply shape social roles, health practices, and family obligations. Participants consisted of spouses, children, and extended family members (e.g., nieces/nephews) who had provided care for a stroke survivor at home for at least three months. Their ages ranged from 28 to 62 years, with most being middle-aged or older. Culturally, all participants identified themselves as Javanese Muslims, and caregiving was strongly influenced by local philosophical values such as *Ngabekti* (devotion to elders), *Nrimo* (acceptance of fate), and *Trah* (lineage responsibility). These beliefs framed caregiving not merely as a duty but as a spiritual and moral obligation. The participants' gender distribution reflected traditional roles, where female caregivers were dominant, consistent with Javanese patriarchal family systems in which caregiving is often seen as a woman's responsibility.

Participants came from varied socio-economic and occupational backgrounds, including housewives, private employees, and informal workers. Regardless of profession, their shared cultural orientation shaped a caregiving approach marked by sacrifice, humility, and spiritual endurance. These values provided both a source of strength and an emotional burden in managing the long-term demands of stroke care at home.

This overarching theme captures the way family caregivers view their role and responsibilities in caring for stroke patients (Figure 1). The thematic analysis had four themes described below:

Table 2. Sociodemographic characteristics of participants (N = 10)

Characteristics	Category	N	%
Age	< 30 years	2	20
	31–50 years	3	30
	51–60 years	4	40
	> 60 years	1	10
Gender	Male	3	30
	Female	7	70
Religion	Islam	10	100
Occupations	Housewife/not working	4	40
	Private employee	4	40
	Freelance	1	10
	Retired	1	10
Familial relationship with stroke survivor	Husband/wife	4	40
	Daughter	3	30
	Son	2	20
	Sibling	1	10
Durations of care (months)	< 6 months	1	10
	7–24 months	2	20
	25–60 months	4	50
	> 60 months	3	30

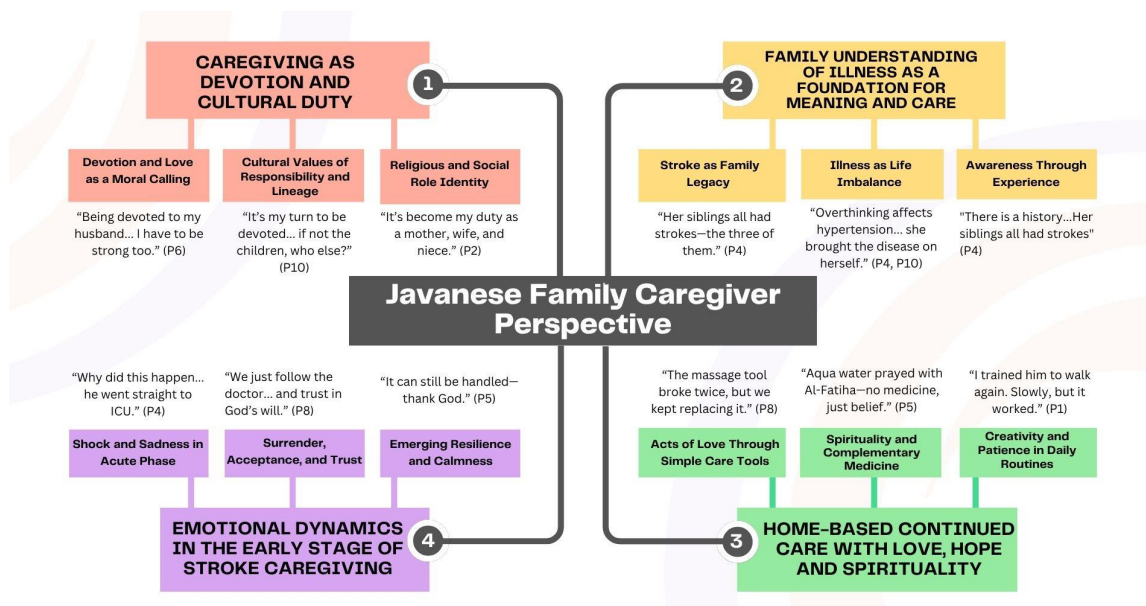


Figure 1. Thematic map illustrating Javanese family caregivers' resilience during stroke care

Theme 1: Caregiving as devotion and cultural duty

Participants viewed caregiving as a sacred obligation rooted in Javanese values such as *Ngabekti* (devotion), *Nrimo* (acceptance), and *Trah* (lineage responsibility). Caring for a stroke survivor was not perceived as merely a practical task, but a spiritual calling.

“Yes, being devoted to my husband, I encourage him like this. You have to be healthy, you have to be strong; I also have to be strong like that.” (P6)

Caregiving is not perceived merely as a task but as a *Tindakan luhur* (noble act) rooted in the Javanese concept of *Ngabekti* (devotion to parents and elders) and *Trah*. Unlike previous studies that frame caregiving as a psychological or physical burden, this study highlights how spiritual merit (*Pahala*) and the belief in karma motivated caregivers to endure prolonged hardship with dignity and grace.

“I can’t really explain the calculation. Yeah, it’s just the only treasure. If not the children, then who else? Besides, it was you who took care of Mom before; now it’s my turn to be devoted.” (P10)

“I endure caring for my mother because of one wife, and two, that is my vow. I will take care of you wherever you are.” (P1)

Realization of karma and spiritual values also strengthens the motivation to care, where suffering is regarded as part of the journey of life that must be accepted gracefully and overcome together:

“I correct myself like this, Uncle is sick and can’t do anything, everyone just raises their hands. If Allah brings karma upon us, and then the pain is inflicted upon us, what can we do? Well, that’s what makes me take care of it. Whatever happens in the future, I will take care of Uncle.” (P2)

Caregiving responsibilities are primarily assigned to women, consistent with the patriarchal structure of many Javanese families. Female participants, in particular, emphasized the cultural obligations tied to their gender roles.

“It has become my responsibility as a mother, wife, and niece to take care of my uncle.” (P2)

“This is a typical answer, right... it’s a responsibility, yes, a child’s responsibility to take care of him until he gets better.” (P4)

Caring for stroke survivors for Javanese families is not just a medical act or physical routine, but a form of love, devotion, and spiritual responsibility based on cultural values, religion, and family relationships. The act of caring becomes a reflection of loyalty, respect for parents, and achieving meaning in life through shared suffering.

Theme 2: Family understanding of illness as a foundation for meaning and caregiving

Participants linked their experience of caring for a family member with stroke to an understanding of family health history, lifestyle, and genetic inheritance. The experience of caring for a loved one with a stroke led to an understanding that this disease does not occur suddenly, but rather is an accumulation of hereditary factors, lifestyle, and poor stress management over the years. Some participants revealed that family history has the most contribution to the incidence of stroke experienced by family members, such as heredity, hypertension, and diabetes mellitus.

“There is a history, uh, a history of high blood pressure and stroke. Her siblings all had strokes, the three of them. The two who had strokes.” (P4)

“That issue has a history with kidney failure and diabetes, which is causing the current illness.” (P1)

"My father had diabetes and high blood pressure before, and now he has a stroke." (P9)

In Javanese culture, disease is seen not only as a biological condition but also as a hereditary legacy and the result of imbalance in *Rasa-Pikir-Laku* (feeling, thought, and action). Witnessing a family member's death from stroke further reinforces its perceived severity if left untreated.

"Umm, it seems like his father, what was it, exactly like that [pointing at the patient], but maybe he wasn't treated, didn't take medication or anything, until he passed away, just like that." (P7)

In addition to genetic factors, diet, mindset, and lifestyle are also risk factors that can worsen stroke conditions.

"First of all, it's because of genetics, eating habits, lifestyle, and mindset. If you overthink, it affects your hypertension, right? My mother has hypertension too, and in the end..." (P4)

"If it's not a stroke, it's a tumor." (P4) showed awareness of other signs that worsen a family member's stroke condition.

Javanese culture also upholds the principle of *Eling Lan Waspada* (always remember and be vigilant), which encourages individuals to observe other symptoms that worsen the stroke condition. However, not all participants associated stroke with a hereditary disease. Participants also saw that risk factors, such as diabetes mellitus, could arise from an unhealthy diet.

"If it's my mother, there's no hereditary diabetes; it's a disease she made herself. None of her parents were sick like that. Maybe it's from her eating habits." (P10)

Thus, there were two complementary perspectives: one side views disease as inherited, and the other views disease as a consequence of poor health behaviors.

Theme 3: Home-based continued care with love, hope, and spirituality

For family caregivers, simple assistive devices such as massagers, air mattresses, and oxygen cylinders are not just functional objects, but symbols of deep love and care. The provision of such devices demonstrates a process of adaptation to a chronic condition and a willingness to ease the burden and suffering of a stroke family member, albeit a simple but meaningful one.

"There's a cheap massage device my youngest child bought. I don't remember how much, maybe thirty thousand or so. He repurchased it then because after my husband was hospitalized, he often had body aches. The child got tired of massaging him, so he bought that device, and it worked like a charm until it broke twice. They don't buy it anymore." (P8)

The participants indicated that purchasing a simple massage tool often set a minimal standard to meet the child's expectations of easing the burden of physical care for their parents. This reflects their support and affection.

"Tell them to buy a ball like a durian, the one for grip therapy, the one that looks like a rambutan, you know, a small one." (P5)

Other participants also expressed gratitude for what seemed to be small acts of kindness from their families, such as the purchase of an inflatable mattress to prevent pressure sores. Such acts were viewed not just as a practical supply but regarded as affection and care from family members.

"At home, when he had a decubitus ulcer, his child immediately bought this inflatable mattress. Thank God the children are doing well, so they don't mind spending money on it, as long as they care for me." (P7)

In several cases, equipment such as oxygen tanks and infrared lamps used to alleviate suffering

was viewed as devices employed thoughtlessly, but with a caring intention. Each of these devices alleviated pain and discomfort, thereby supporting the claim that caregivers play a significant role in patients' health and well-being.

"Yeah, when it flares up, he can't do anything. I just give him oxygen and that thing, oh, there's one more, an infrared lamp for muscle relaxation. It can also be used for muscle relaxation, you know, it's applied to specific parts of the body that are stiff." (P6, P10)

Additionally, the younger caregivers illustrated a willingness to invest in medical technology by renting suction machines and nebulizers. This demonstrates the increasing skill and growing responsibility of younger family members in the complex and challenging tasks of caregiving.

"Yes, so I rented a suction machine because I was told to suction twice or thrice a day, and I bought the hose myself. Taught how to use a nebulizer to thin the phlegm. If I buy the nebulizer myself. Taught how to use a nebulizer to thin the phlegm." (P4)

Caregivers approached stroke survivors' eating and drinking tasks meticulously and systematically to ensure success, step by step. The story of the participant teaching the patient to eat and drink reflects the Javanese philosophy of *Alon-Alon Asal Kelakon* (slowly but surely), which embodies perseverance, patience, and appreciation for the long-term recovery process following a stroke.

"Told to learn to eat using rice porridge to practice chewing. Could do it little by little, even though there were some coughs, kept trying, and eventually succeeded. Then he was taught to drink using the bottle cap little by little." (P4)

As described in the participants' experiences, the activity of bathing patients is done with full awareness

of comfort, dignity, and warmth. The warm water prepared every morning, evening, and early morning symbolizes *Welas Asih* (compassion) and *Tresna* (affection), and *Pasrah Sumarah* (sincere acceptance).

"When it comes to bathing, I do the bathing. Let's bathe in the tub; it's never cold water, always warm water, morning, evening, and in the early morning, we bathe then. He sits in the bathroom, right? It's high for him compared to me. Sitting on the toilet is a bit high like a chair, so I bathe him there." (P6)

The creativity of caregivers was challenged by patients' dignity and comfort, particularly during toileting. Participants' answers about altering a plastic chair by adding a water container are often where caregivers try to bridge the gap between what is medically possible and what can be done at home. This action is also included in *Prihatin* (mindful sacrifice), which involves being aware of and acting in a simple way to meet the needs of stroke survivors.

"Make a chair with holes, a plastic chair, you know, with holes, and underneath it, put a container, put a container, put water, and then he can defecate." (P3)

When administering medication, it is necessary to assess the patient's ability. Attempts to swallow pills often require modification through crushing of tablets or division into smaller portions. In Javanese tradition, simple yet meaningful actions are known as forms of *Ngabekti* and *Ngopeni*.

"If before it was hard for him to swallow the medicine, I would crush it, but now, he can take it directly." (P2)

There's nothing big; there may be something big later. I'll divide it into two, but the drink will still be one pill, not just into small pieces." (P8)

The participants described the provision of home-based therapy to their relative as a form of self-acceptance, patience, and maximum care efforts provided. Participants showed an attitude of *Sabar Lan Nerimo Ing Pandum* which is patient and accepting whatever fate is given, and without stopping trying.

"Told to lift hands and legs like that, then lift weights using a half-kilo barbell, I can still do it." (P10)

"When I couldn't walk from here, I had already trained for it. I trained him to stand and walk. I bought him a cane to walk on his own. I bought him a device that can help him walk in place. I trained him like that." (P1)

"Well, in the morning I bathe him and then let him sunbathe. Then I moved his hand, I moved his stiff body." (P2)

Speaking exercises, as advised by the doctor, are one of the efforts to improve communication skills after a stroke. This process also serves as a means of connection, fostering inner connection between participants and stroke survivors, which can strengthen family ties.

"Just regular conversations, practicing his speech. He should be taught the basics like A I U or counting from front to back, if the doctor suggests that." (P4)

Participants' narratives reveal that the use of complementary and alternative treatments in stroke care is not merely a pragmatic choice, but is deeply rooted in personal beliefs, cultural traditions, and spiritual meaning. The use of honey, date, olive oil, and prayer showcase the deeply religious aspect of caregiving and devotion among caregivers.

"I once gave this drink, it's like medicine from religion, with honey for healing. I also gave green apples, dates, and olive oil. Those are good, right? I gave those." (P4)

The use of complementary and alternative medicine (CAM) in Javanese caregiving reflects a blend of ancestral wisdom and Islamic spirituality, where healing is viewed as a journey that encompasses both medical and spiritual aspects. CAM practices also serve a psychosocial function, with belief and faith helping caregivers cope emotionally and sustain resilience.

"Needles first, my mom called everyone, mas. Acupuncture three times a week, I called them to the house, massage therapy like this, acupuncture, called everyone, mas." (P5)

"Wanting to get better, mas, so someone told me, oh over there if someone has a stroke..., I've been around, mas, there's Dayak oil treatment, I've taken him there." (P6)

"If it comes to alternatives, most of the time, it's just Aqua. Aqua is just regular water, and it's only prayed for like that. Prayed with Al-Fatiha or whatever, their beliefs, our beliefs. But all the ones we visit are always Muslim, like grandfathers and fathers. There's no special herbal medicine, just a potion, nothing but water, but we buy the 1.5-liter one. I told him to buy a big bottle of water, then I didn't give it to the priest. Just asked him to pray and drink it and didn't give him anything else." (P5)

The above quote indicates the relationship between religion and caregiving. The relationship demonstrates that the caregiver's efforts transcend beyond the physical actions and include prayer and spiritual support for the journey ahead.

Theme 4: Emotional dynamics in the early stage of stroke caregiving

The sudden onset of stroke evoked intense emotional shock among caregivers, marked by fear, confusion, and grief over the uncertain future. The abrupt decline, ICU admission, and threat of long-term disability heightened this distress. Yet, amid emotional turbulence, some caregivers began to anchor themselves

in trust toward healthcare providers, signaling early resilience shaped by hope and belief in recovery.

“The first time, of course, it was sad, like why did it have to be like this, the first time, and they went straight to the ICU, sad. But it’s okay, just follow the doctor’s advice.” (P4)

“I fainted. I don’t remember anything until now, when I was taken to the hospital. I’m afraid that all of it will be thought of as difficult, sad, everything is there.” (P6)

Despite experiencing emotional turmoil, some caregivers demonstrated early acceptance and adjustment by choosing to trust medical professionals and remain calm. This shows that although the experience was initially shocking, it also triggered a process of psychological adjustment as families began to adapt and prepare for their new caregiving responsibilities.

“Yes, for sure, shocked, afraid that it might be like this, you know, directly getting a total permanent stroke. Luckily, it can still be handled. Thanks God.” (P5)

“Yeah, shocked, man, surprised about what will happen next, later about my child not working because of the father being sick with a stroke and surgery until he comes back home, it took several months without working.... I surrender to God’s will.” (P8)

Caregivers experienced a profound emotional and destabilizing experience during the suddenness of a stroke, which was characterized by sadness, fear, and uncertainty, but also marked the beginning of a process of acceptance and resilience.

Discussion

This study examined the spiritual, emotional, and cultural dimensions of caregiving within Javanese families. Four key themes emerged: 1) caregiving as devotion and cultural duty, 2) family understanding

of illness, 3) home-based continued care, and (4) emotional dynamics in the early stage of caregiving. These findings deepen our understanding of family resilience in stroke care within a culturally embedded context.

Caregiving was described as a spiritual and moral calling, framed within the cultural values of *Balas Budi* (reciprocity) and *Trah* (lineage responsibility). Cultural beliefs, like karma, also influence caregiving decisions.^{9,21} Thus, families become the main source of support for stroke survivors, which can lead to substantial physical, emotional, and financial burdens. Emotional, cultural, and spiritual factors shape the family’s motivation to continue caregiving.²² In Javanese and Islamic belief systems, caring for ill family members is both an act of love and a form of worship (*Ibadah*), reinforcing long-term commitment despite burdens. These motivations align with collectivist cultural norms, where caregiving is viewed as a moral obligation and a source of spiritual merit.

This study highlighted that caregiving in Javanese families is primarily performed by women, reflecting entrenched gender norms within a patriarchal structure. Roles such as *Ngayomi* (to nurture), *Ngopeni* (to care), and *Ngabekti* (to be devoted) are culturally assigned to women, positioning caregiving as both duty and identity. These gendered expectations contribute to emotional strain and limited autonomy, consistent with findings from other collectivist societies.²³ Culturally sensitive interventions should not only support female caregivers’ emotional and spiritual strengths but also promote gender equity in caregiving roles to improve outcomes for both caregivers and stroke survivors.

The second theme shows that Javanese caregivers understand stroke through both biomedical and cultural-spiritual lenses. Stroke was seen as resulting from genetic factors, lifestyle,²⁴ and also an imbalance in *Rasa, Pikir, Lan Laku* (feeling, thought, and behavior).²⁵ This meaning-making aligns with the Health Belief Model (HBM),²⁶ particularly the constructs of perceived

susceptibility and perceived cause. Caregivers with prior knowledge or family history of stroke expressed heightened awareness of risk and showed greater involvement in preventive or supportive actions.¹⁵ Narratives of inherited illness (*Keturunan*), divine will (*Kawula-Gusti*), and overthinking (*Kakehan Mikir*) illustrate a hybrid model of understanding. Fatalism, or the belief that illness is predetermined by divine will or karma, emerged as a common coping mechanism. Caregivers invoked *Nrimo Ing Pandum* (acceptance of fate), not as passive surrender, but as a source of strength—blending spiritual acceptance with active caregiving and hope, reflecting a culturally empowered form of resilience.

In parallel, local wisdom (*Kearifan Lokal*) guided caregivers' interpretations and responses. Concepts such as *Ngabekti* (devotion),¹³ *Eling Lan Waspada* (awareness and vigilance),²⁵ and *Tresna* (affection)²⁷ reinforced caregiving as a spiritual and moral duty. Such values informed how caregivers interpreted illness as both a consequence of lifestyle and a sacred opportunity to fulfill familial and religious responsibilities.

These insights suggest that Javanese caregivers engage in a hybrid model of health interpretation—one that integrates modern health knowledge with ancestral belief systems. This synthesis highlights the importance of healthcare providers adopting culturally tailored communication strategies that respect diverse spiritual frameworks while promoting effective stroke education.²⁸ Enhancing health literacy must go hand-in-hand with acknowledging local explanatory models to improve engagement and health outcomes in community-based stroke care.

Caregiving was not limited to clinical routines but extended into symbolic and spiritual practices. Devices such as oxygen tanks, infrared lamps, or modified household items were used creatively, often imbued with emotional meaning.^{29,30} However, while these devices play a role in rehabilitation, they are not enough on their own; psychological support, motivation,

and active family participation are crucial for optimal recovery. Emotional and mental encouragement from family members significantly influences the effectiveness of medical devices and the patient's recovery.³¹ The act of providing tools and support is an experience that blends emotional intention and practical action. These are acts of profound compassion intending to relieve suffering, improve comfort, and maintain the dignity of the surviving partner of a stroke. For caregivers, especially family members, the tools of care are more than just inanimate objects; they are symbols of autonomy, hope yet to be fulfilled, and tangible evidence of steadfast devotion and enduring loyalty.

Creativity in adapting household appliances, such as modifying a plastic chair with holes for toileting, reflects the local genius of the Javanese community. Instead of succumbing to the limitations of medical equipment, they demonstrate the value of *Prihatin*, the awareness to act in a simple, calculated way, and without compromising respect for those being treated.²⁵ The maintenance tools are also a sign of hope that has not been extinguished. They are a symbol of *Pangarep-arep* (optimism) and *Urip Iku Urup* (life is lit)³² meaning that with good intentions, inner and outer effort, and constant prayer, healing will come, or at least suffering will be reduced.

Families often help with daily activities (ADLs) such as eating, bathing, and toileting, as 25–74% of patients post-stroke require assistance with these tasks.³³ The shared experiences of caregivers regarding the assistance they provide with daily self-care activities reveal a profound journey of patience, creativity, and an enduring emotional connection. Personal hygiene activities and medication management are not just a fulfillment of physical needs but also a form of *Ngopeni*, a form of loving attention, sincerity, and respect for others. Javanese tradition also upholds the value of *Ajining Diri Saka Lathi, Ajining Raga Saka Busana* (individual self-esteem is seen from speech and physical appearance).³² Keeping a clean, neat and comfortable appearance is not trivial, but a form

of respect for the dignity of stroke survivors. The activity of bathing using warm water shows an attitude of *Welas Asih* (compassion), *Tresna* (love), and *Ngabekti* (devotion). The practice of care in activities of daily living is not only a functional action, but also a concrete form of *Tandha Katresnan* (love signs), as well as a form of presence and involvement. In Javanese culture, presence, both physical and presence in a broad sense, is highly emphasized and considered important. Presence is not just physical presence, but also includes involvement, attention, and active participation in a situation or relationship.

Supporting patients after stroke with daily living activities conveys a deeper caregiving experience characterized by adaptability, patience, and emotional intimacy.³⁴ This is in line with Javanese tradition, where norms and values encourage family members to help each other, especially those who are less fortunate. Javanese families are known for *Tepo Seliro* for their spirit of cooperation and concern for fellow family members.³⁵ Javanese families also still believe in karma, which is understood as a concept related to a person's good and bad deeds and their impact in the future, both in this world and the hereafter.³² The Javanese family caregivers reinterpret small changes as milestones, which makes the mundane routines deeply moving acts of devotion. They transform the perception of caregiving from a burden to an act of infinite love, steadfast resilience, and profound humanity. Each act—however small—emerges not just as a caregiving task but as a deeply human experience filled with resilience, empathy, and love.

The Javanese approach to health is often a combination of traditional and modern healthcare practices. Individuals may initially use traditional remedies and self-treatment, such as herbal medicines or consulting traditional healers, before seeking help from formal healthcare facilities, including community health centers or private clinics.²⁸ Javanese health-seeking behavior is often influenced by cultural beliefs, accessibility, and perceived effectiveness of treatments.³⁶

Central to Javanese healing philosophy is the belief that divine intervention plays a pivotal role, positioning God as the ultimate and most essential element in the therapeutic process.³⁷ Everything the Javanese do always leads to the axis of *Manunggaling Kawula-Gusti*, which means having an attachment (relationship) between humans and God, often referred to as spirituality. In the context of Javanese traditional healing, suggestion (*Suggesti*) emerges as a significant psychosocial element that shapes the patient's healing experience. Suggestion originates from both the healer and the patient, creating a reciprocal dynamic of trust and belief.³⁸

Research has shown that the use of CAM in stroke rehabilitation is common in many Asian countries, particularly among caregivers who prioritize holistic and spiritual dimensions of healing.^{39,40} Complementary treatments, such as herbal medicine and acupuncture, are also sought by many individuals who are influenced by local wisdom and traditional practices.^{28,41} These treatments are not a replacement for conventional stroke treatment, but they can assist in managing stroke risk factors, including hypertension and diabetes mellitus. In the Javanese caregiving experience, CAM serves multiple roles: as a practical support to physical recovery, a cultural expression of familial devotion, and a spiritual channel of hope. These findings suggest that healthcare providers should recognize and engage with caregivers' use of CAM with cultural humility. Rather than dismissing traditional practices, nurses and clinicians should foster open dialogue that validates caregivers' beliefs, while also guiding them toward evidence-based use of CAM. This approach not only strengthens trust but also promotes integrative care strategies that align with caregivers' values and enhance stroke recovery outcomes.

The fourth theme highlights the emotional turmoil caregivers faced during the early phase of stroke, including shock, sadness, and fear. Participants described initial reactions of shock, sadness, fear, and confusion following the sudden onset of their family member's

stroke.^{3,30} These emotional dynamics align closely with the Transactional Model of Stress and Coping proposed by Lazarus and Folkman,⁴² which emphasizes the interplay between individual appraisal of stress and the strategies used to manage it. In this model, caregivers' responses to the stroke event can be understood through two primary processes: primary appraisal (evaluating the stroke as a threat or loss) and secondary appraisal (assessing one's ability and resources to cope with it).⁴³ Many caregivers initially viewed a stroke as a catastrophic loss—both of physical function in the survivor and of normalcy in their own lives. However, this transition reflects a dynamic process of emotional adjustment and coping.

Participants' narratives also illustrate the emergence of emotion-focused coping strategies, such as *Pasrah Sumarah* (sincere surrender),²⁵ spiritual acceptance, and internal dialogue to reduce distress. These culturally grounded coping responses are consistent with what Lazarus and Folkman describe as attempts to regulate emotional reactions to stressors that are not immediately changeable.⁴² This is particularly relevant in the early phase of caregiving, where uncertainty and lack of control are dominant features.

This process of emotional adaptation also reflects the development of resilience, or the capacity to recover and grow through adversity. In the Javanese cultural context, resilience is often nurtured through spiritual meaning-making (*Nrimo Ing Pandum, Ikhlas*),¹⁰ family solidarity (*Tepo-Seliro*),³⁵ and the belief that caregiving is part of one's *Takdir* (destiny).⁴⁴ Rather than resisting the caregiving role, families integrate it into their identity, drawing strength from cultural values and relational bonds. The attitude of surrender, or *Pasrah Sumarah*, in the Javanese view of life is a manifestation of a sincere soul and a spiritual reflection of the relationship between humans and God. This mindset of surrender does not mean a complete lack of effort, but rather, with full awareness, Javanese people believe that all efforts ultimately depend on

God's will. *Manungsa Mung Isa Gawe Pestha, Nanging Gusti Kang Gawe Pesthi*—humans can only make plans, but it is God who decides.²⁵

These findings reinforce the view that resilience is not a fixed trait but a dynamic, evolving process influenced by cultural, emotional, and relational factors. Supporting caregivers in the early emotional phase is therefore critical. Healthcare providers must be equipped to offer psychological first aid, empathetic communication, and culturally sensitive reassurance, particularly during the initial diagnosis and hospitalization period. By acknowledging both the emotional vulnerability and adaptive strength of caregivers, nurses and health teams can better design interventions that facilitate not only coping but thriving through the caregiving journey.

Conclusions

Through in-depth phenomenological analysis, this study reveals that caregiving is a profoundly human, cultural, and spiritual journey, marked by emotional sacrifice, enduring love, and adaptive resilience. Caregiving in the Javanese context is not merely a functional or medical obligation—it is a deep moral and spiritual commitment. Families provide comprehensive physical, emotional, and spiritual care despite the significant burden it places on their well-being. Their motivations are rooted in cultural norms such as filial piety, karma, and religious devotion, which are often reflected in values like *Nrimo* (acceptance), *Pasrah* (surrender), and belief in divine will. This worldview not only sustains caregivers through the uncertainty and exhaustion of long-term care but also shapes their interpretation of recovery and resilience. This study emphasizes that supporting stroke caregivers requires an integrated approach, one that values not only the clinical aspects of stroke rehabilitation but also the emotional, cultural, and spiritual realities that shape the caregiving experience.

Limitations and Recommendations

This study was limited by its culturally homogeneous sample, as all participants were Javanese Muslims with similar socio-cultural backgrounds in East Java. This study highlights how culturally embedded parenting practices can resonate in situations where parenting is also influenced by intergenerational responsibilities, spiritual beliefs, and gender norms. Future research should include more diverse populations to explore cross-cultural differences in caregiving values, strategies and support needs. To improve the resilience and well-being of family caregivers, policymakers and healthcare providers are encouraged to develop culturally responsive support systems. This can include targeted training, accessible information technology, and integrated psychological and spiritual support services that reflect the realities of caregivers' lives. Integrating traditional beliefs with modern healthcare frameworks can increase trust, engagement and adherence to stroke rehabilitation, especially in communities where cultural identity is strongly associated with caregiving roles. Additionally, community and hospital-based nursing practitioners are encouraged to recognize and incorporate the cultural aspects of stroke rehabilitation. Nurses play a key role in providing culturally sensitive education, emotional support, and meaningful spiritual dialogue with families. To strengthen caregiver resilience, health systems should institutionalize support programs—such as counseling, skills training, and peer groups—that respect caregivers' cultural identities. Recognizing the often-invisible emotional labor of caregiving is crucial for enhancing stroke outcomes and promoting the well-being of caregivers across diverse cultural contexts.

Author Contributions

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Analysis and interpretation: S.C.R., Y.S., R., N.M.H., A.F.

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การศึกษาเชิงปรากฏการณ์วิทยาตามมุมมองของผู้ดูแลในครอบครัวชาวชวาต่อการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมอง

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บทคัดย่อ : โรคหลอดเลือดสมองเป็นสาเหตุสำคัญของภาวะทุพพลภาพระยะยาวในประเทศอินโดนีเซีย ซึ่งสมาชิกในครอบครัวมักต้องรับบทบาทเป็นผู้ดูแลหลักโดยได้รับการสนับสนุนอย่างเป็นทางการแค่เพียงเล็กน้อย ในชุมชนที่มีรากฐานทางวัฒนธรรมที่เข้มแข็งดังเช่น ชาวตะวันออก การดูแลผู้ป่วยได้รับอิทธิพลจากค่านิยมท้องถิ่นอย่างมาก ทว่ายังมีการศึกษาที่จำกัดโดยเฉพาะการศึกษาค่านิยมเหล่านี้หล่อหลอมความเข้มแข็งทางจิตใจของครอบครัวผู้ดูแลอย่างไร การวิจัยครั้งนี้จึงมีวัตถุประสงค์เพื่อศึกษาความเชื่อทางวัฒนธรรมของชาวชวาส่งผลต่อประสบการณ์และความเข้มแข็งทางจิตใจของครอบครัวผู้ดูแลซึ่งให้การดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมองที่บ้านอย่างไร โดยใช้ระเบียบวิธีวิจัยเชิงคุณภาพด้วยการสัมภาษณ์เชิงลึกกับผู้ดูแลจำนวน 10 ราย ในพื้นที่ชาวตะวันออก และทำการวิเคราะห์ปรากฏการณ์วิทยาเชิงตีความ

ผลการวิเคราะห์ข้อมูลเชิงเนื้อหาพบประเด็นหลัก 4 ประการ ได้แก่ 1) การดูแลในฐานะการอุทิศตนและหน้าที่ทางวัฒนธรรม 2) ความเข้าใจของครอบครัวต่อความเจ็บป่วยเป็นฐานะรากฐานของการให้ความหมาย 3) การดูแลอย่างต่อเนื่องที่บ้านด้วยความรัก ความหวัง และจิตวิญญาณ และ 4) พลวัตทางอารมณ์ในช่วงแรกของการดูแล โดยผู้ดูแลมองว่าการดูแลผู้ป่วยไม่ใช่แค่เพียงความรับผิดชอบแต่เป็นพันธกิจทางศีลธรรมและจิตวิญญาณซึ่งมีรากฐานมาจากค่านิยม เช่น การอุทิศตน (*Ngabekti*) การยอมรับ (*Nrimo*) และ การปล่อยวาง (*Pasrah*) ผู้ดูแลในการศึกษานี้ ได้ทำการปรับใช้ทั้งแนวปฏิบัติทางการแพทย์สมัยใหม่และการรักษาแบบดั้งเดิมร่วมกัน ซึ่งการดูแลดังกล่าวสะท้อนให้เห็นถึงความคิดสร้างสรรค์ในการก้าวข้ามข้อจำกัดด้านทรัพยากร ผลการศึกษาในครั้งนี้ชี้ให้เห็นถึงความสำคัญของการพยาบาลที่ตอบสนองต่อบริบททางวัฒนธรรม ซึ่งสามารถตอบสนองต่อความต้องการทั้งในด้านอารมณ์ จิตวิญญาณ และข้อมูลที่สำคัญของผู้ดูแลได้ การสนับสนุนความเข้มแข็งทางจิตใจของผู้ดูแลผ่านการช่วยเหลือทางการแพทย์และการแพทย์ที่ใช้ความเข้าใจในวัฒนธรรมเป็นพื้นฐาน อาจช่วยปรับปรุงผลลัพธ์ของการฟื้นฟูผู้ป่วยโรคหลอดเลือดสมองให้ดีขึ้น และส่งเสริมสุขภาพที่ดีของผู้ดูแลในบริบทชุมชนอื่น ๆ ที่มีลักษณะคล้ายคลึงกัน

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