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The lived experience and caregiver burden of family members supporting chronic stroke survivors

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ABSTRACT

Background: Stroke is a debilitating neurological condition and a leading cause of long-term disability worldwide; effective management of chronic stroke survivors requires continuous family support for rehabilitation and recovery. This study aimed to examine the lived experiences and caregiving burden of family members of chronic stroke survivors.
Methods: This descriptive qualitative study was conducted in Yogyakarta, Indonesia (March - April 2025), using purposive sampling to recruit eleven primary family caregivers of chronic stroke survivors attending outpatient rehabilitation. Data were collected through semi-structured, face-to-face interviews, audio-recorded, transcribed verbatim, and analyzed using Braun and Clarke's thematic analysis. Data collection and analysis proceeded concurrently until thematic saturation was reached. Ethical approval and informed consent were obtained.
Results: Three themes emerged: health-seeking behavior, access to rehabilitation, and caregiving experiences. Caregivers faced significant physical, psychological, and financial burdens due to continuous care demands, limited access to physiotherapy, and inadequate rehabilitation guidance despite having health insurance.
Conclusion: The findings highlight the urgent need for financial support and policy action to advance digital innovation in rehabilitation and reduce the chronic burden caused by systemic gaps.

Keywords: Caregiver burden, chronic stroke, family support, lived experience, rehabilitation access.
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INTRODUCTION

Stroke is a neurological disease that affects the blood vessels of the brain.[1] It remains a leading cause of long-term morbidity and disability worldwide and is the primary cause of long-term disability globally, affecting approximately 13.7 million people and resulting in about 5.5 million deaths each year.[2,3] Stroke fundamentally alters the life trajectories of affected individuals and their families.[4] Globally, the prevalence of stroke is projected to continue increasing, placing substantial strain on healthcare systems and community resources. In Indonesia, although stroke prevalence decreased in 2023 after rising from 2007 to 2018, it remains high at 8.3 per 1,000 population.[5]

Stroke recovery is typically divided into three phases: acute, subacute, and chronic.[6,7] The acute phase occurs in the hospital, the subacute phase represents the transition from hospital to home, and the chronic phase involves long-term care at home.[8] After the acute phase, many stroke survivors experience persistent functional limitations that require ongoing assistance, ranging from basic activities of daily living (ADLs) to more complex instrumental tasks.[9] As a result, caregiving responsibilities often shift to family members, who become the primary informal caregivers.[10]

Family members serve as the primary caregivers in post-stroke care, particularly during the chronic phase (months to years after onset), when survivors require intensive rehabilitation and assistance with daily activities.[10] Caregivers are responsible for supporting therapy, mobility, and nutritional needs.[11] This role is demanding and long-term.[10] The literature describes these challenges as caregiver burden, a multidimensional construct encompassing physical, psychological, emotional, social, and financial strain. High caregiver burden has been associated with depression, social isolation, reduced quality of life, and adverse physical health outcomes among stroke caregivers.[12]

Although family caregivers are central to supporting chronic stroke survivors, existing research largely emphasizes physical and clinical outcomes and relies on quantitative measures such as patient disability.[13,14] As a result, the subjective and contextual dimensions of caregiver burden remain underexplored. There is a critical need for qualitative research to examine caregivers lived experiences, including their emotional and psychological responses to daily caregiving demands. Furthermore, non-clinical challenges such as logistical, financial, and interpersonal or culturally driven burdens are insufficiently addressed in the current literature, despite their substantial impact on caregiver well-being.

Stroke remains a leading cause of long-term disability worldwide; however, the lived experiences and multidimensional burden of family caregivers in Indonesia remain underexplored. Although international literature has extensively documented caregiver strain, limited evidence exists on how these challenges manifest within Indonesia's distinct socio-economic and cultural context. Notably, no prior studies have examined this issue within the specific healthcare and social framework of Yogyakarta. Therefore, this study aimed to examine the lived experiences and caregiving burden of family members of chronic stroke survivors.

METHODS

This study employed a descriptive qualitative research design to obtain an in-depth understanding of caregiver burden and the lived experiences of family members caring for chronic stroke survivors, as expressed from their own perspectives. This approach was appropriate for exploring complex and subjective phenomena that are difficult to quantify.The study was conducted in the Special Region of Yogyakarta, Indonesia, between March and April 2025. Participants were family caregivers of chronic stroke survivors who were undergoing or seeking outpatient rehabilitation at a private hospital in Yogyakarta.

Purposive sampling was used to recruit participants who met the following inclusion criteria: (1) identified as the primary family caregiver responsible for daily care; (2) caring for a stroke survivor who had experienced a first-ever stroke at least three months prior to the interview; (3) the stroke survivor was actively attending outpatient rehabilitation or follow-up clinics; (4) had provided primary care for more than three months; (5) resided in Yogyakarta; and (6) were able and willing to participate in an in-depth, face-to-face interview. Caregivers who were not the primary care providers or were unable to communicate clearly during the interview were excluded. A total of eleven family caregivers participated. Recruitment ceased when data saturation was achieved and no new themes emerged.

Data were collected through semi-structured, face-to-face interviews guided by an interview protocol addressing lived experiences, dimensions of caregiver burden, logistical barriers, and interactions with the health system. Interviews were conducted in private, comfortable settings (e.g., hospital waiting areas during therapy sessions or participants' homes), lasted approximately 45-90 minutes, and were audio-recorded with participants' consent. Field notes were taken to complement the recordings. All interviews were transcribed verbatim in Indonesian and subsequently translated into English, with careful attention to maintaining semantic equivalence.

Data were analyzed using thematic analysis following the six phases proposed by Braun and Clarke: familiarization with the data, coding, theme development, theme review, theme definition and naming, and reporting. Analysis was conducted iteratively and concurrently with data collection to support theme saturation. Ethical approval was obtained from the Institutional Ethics Committee of Sekolah Tinggi Ilmu Kesehatan Bethesda Yakkum, Yogyakarta, Indonesia (registration number: 20/KEPK-RSB/III/25), and written informed consent was obtained from all participants prior to data collection.

RESULTS

Based on the in-depth interview transcripts, the sociodemographic characteristics of informants who served as primary family caregivers for stroke patients are summarized in Tables 1 and 2, as well as in the narrative below. The thematic analysis of eleven in-depth interviews revealed that caregiver burden among families of chronic stroke survivors is complex and multidimensional, encompassing three central themes. The table below outlines these themes and provides examples of the key questions posed to participants.

The qualitative findings were organized into three main themes derived from in-depth interviews: health-seeking behavior, access to physiotherapy services, and family experiences in patient care.

A. Health seeking behaviour

This sub-theme examines the caregiver's role, the types of services utilized, and the chronic economic burden.

1. Intensive role and crucial economic burden

Family caregivers often provide near–round-the-clock care, resulting in significant physical exhaustion.

"…. saya merawat bapak full seharian, mbak. kalau pas bapak tidur baru saya bisa sambi bersih-bersih - (PS - XI)

In English: "I am a full-time caregiver for my father; therefore, I can only perform cleaning tasks when he is asleep." - (PS - XI)

".....Semua apa-apanya saya, bahkan sampai saya sempat masuk rumah sakit karena sakit lutut dan pinggang kecapean mengurus suami" - (PS - X)

In English: "I handled everything and was even hospitalized due to knee and back pain caused by exhaustion while caring for my husband." - (PS - X)

".....Saya bergantian dengan adik saya kalo nunggu Ibu, kalau pas saya masuk siang saya jaga pagi, tapi kalo saya masuk pagi ya saya jadi Ibu malam, Mbak" - (PS - V)

In English: "My younger sibling and I alternate caregiving duties for our mother. When my work requires afternoon availability, I handle her care in the morning; when I work mornings, I provide care at night, Ma'am." - (PS - V)

"saya biasanya memberikan latihan sebisanya saya aja mbak takut salah otot" -(PS - 7)

In English: "I usually provide exercises to the best of my ability, ma'am, because I'm afraid of making a mistake."

While major medical expenses are covered by the national health insurance (BPJS), the primary financial burden arises from non-medical and logistical costs. The household income, which is approximately at the minimum wage (UMR), is insufficient to meet these additional needs. The primary caregiver stated regarding income:

"......gaji masing-masing anak kan paling sekitar UMR. Terus Bapak ini terapinya

kan juga pakai BPJS, mungkin lebih ringan ya, mungkin kalau untuk biaya cuma transportnya aja sih Mbak.” - (PS - I).

In English: “The children earn approximately the regional minimum wage. However, since the father’s therapy is covered by BPJS, the financial burden is likely minimal, with transportation costs being the main expense.” - (PS I).

“....dulu awal-awal saya cari pengasuh untuk istri saya, tapi begitu mulai bisa sendiri, saya rawat sendiri, lah bayarannya pengasuh ya mahal Mbak, gaji saya nda cukup”- (PS - IX)

In English: “... Initially, I looked for a caregiver for my wife, but as she became more independent, I took over her care myself. The caregiver’s wages were expensive, and my salary was not sufficient.” - (PS - IX)

These expenses, combined with limited income (UMR-level earnings) and the inability to afford professional respite care, forced families to provide round-the-clock care, thereby increasing both instrumental and financial burdens. Families also reported substantial financial strain when patients were not yet able to use the bathroom independently. “Spending on diapers is relatively high.”

“............pengeluaran di awal cukup berat mbak terutama saat belum bisa ke kamar mandi sendiri, harus menyiapkan uang lebih untuk membeli pampers” - (PS - VI)

In English: “The initial expenses were substantial, particularly when the patient lacked independent mobility for toileting, necessitating additional costs for adult diapers.” - (PS - VI)

Families also reported that food was a significant expense, as post-stroke diets must be carefully managed to prevent recurrence.

“...... banyak belanja makanan khusus buat Bapak makan, Mbak” - (PS - IV)

In English: “We spend a significant amount on purchasing special dietary items for Father’s meals.”- (PS - IV)

“......masih suka makan gorengan kan to Mbak, jadi saya belikan minyak kelapa atau olive oil itu juga mahal to mbak” - (PS - VIII)

In English: “...He still likes fried food, ma’am, so I buy coconut oil or olive oil, which is quite expensive.” - (PS - VIII)

“.....jadi harus sering nyetok buah buat Bapak makan” - (PS - II)

In English: “...Therefore, I regularly purchase and maintain a supply of fruit for my father.” - (PS - II)

Other patients’ families reported facing many expenses, such as buying special puréed foods when the patient initially could not swallow.

“........dulu pas belum bisa nelan makanannya kan khusus ya mbak, lumayan juga itu harga susu khususnya” - (PS - III)

In English: “...When he first had difficulty swallowing, his diet required specialized nutritional milk, which was quite costly.” - (PS - III)

2. Obstacles of distance, cost, and system failure

This burden is worsened by the home’s distance from the referral hospital, which makes routine transportation costly. Families acknowledge the importance of intensive training for recovery.

“Nah di otak ini bisa pulih karena ada simulasi atau ada latihan.” - (PS - I)

In English: “Well, the brain can recover through stimulation or training.” - (PS - I)

However, the cost of private physiotherapy, ranging from Rp150,000 to Rp200,000 per session, makes it unaffordable.

“Enggak ada, Mbak. Enggak kuat bayarnya,” - (PS - II).

In English: “We don’t have it, Ma’am, and can’t afford it.” - (PS - II).

This hidden logistical and non-medical financial burden underscores the national social security system’s failure to cover essential costs for ongoing home therapy.

“.....padahal awal-awal dulu kan Bapak belum bisa duduk sendiri apalagi jalan to mbak, tapi kalo mau datangin terapi gak kuat bayarnya” - (PS - III)

In English: “Even though Father couldn’t sit up on his own at first, let alone walk, Ma’am, we couldn’t afford to bring a therapist here.” - (PS - III)

“….kalo datangkan Fisio ke rumah perdatang Rp200.000,00 kalo seminggu tiga kali kan udah Rp 600.000,00 ya Mbak, sebulan udah Rp 1.800.000,00, saya bisa nggak makan Mbak” - (PS - X)

In English: “...If we have a physiotherapist come to the house, it costs Rp200,000 per visit. Three times a week, that’s Rp600,000, and in a month, Rp1,800,000. I might not even afford food, Ma’am.” - (PS - X)

“…. Dulu awal-awal bawa istri saya nyewa ambulance mbak, karena nyonya kan belum bisa duduk kan itu sekali sewa ambulance 300 ribu mbak. Dan kan ke RS seminggu bisa sampai 3 kali, dan itu berbulan-bulan” - (PS - VIII)

“...At first, I rented an ambulance to take my wife because she couldn’t sit yet. Each ride cost 300,000 Rupiah, and we went to the hospital up to three times a week for several months.” - (PS - VIII)

Caregivers often reported that the high cost of routine transportation, such as Grab, was a major financial burden, especially for those living in peripheral areas like Bantul or Sampanan, when traveling to specialized centers in Yogyakarta.

“.....berat diongkos. Mbak karena tidak ada kendaraan sendiri akhirnya naik grab, padahal rumah kami di Sampangan yang jaraknya belasan kilometer dari sini.” - (PS - IV)

In English: “...It’s costly, Ma’am, because we don’t have our own vehicle and have to take Grab, even though our house in Sampangan is tens of kilometers away.” -(PS - IV)

“….PP RS ke rumah udah 150 an ribu Mbak. 2 kali ke RS aja dalam seminggu udah 300 ribu Mbak. Gimana kalo sebulan udah sejuta lebih Mbak” - (PS - XI)

In English: “...Ma’am, a round trip from the hospital to home costs around 150,000 Rupiah. Two trips per week would be 300,000 Rupiah, and in a month, that’s over one million Rupiah.” - (PS - XI)

Some patients' families reported that, lacking money for transportation, they had to ride a motorcycle to the hospital, which caused the patient's legs to swell by the time they returned home after traveling approximately 15 km.

"......pernah nekat mbak, lah jadwalnya kontrol tapi nda ada uang buat nge-grab jadi bawa Bapak naik motor, eh sampai rumah kaki Bapak bengkak semua" - (PS V)

In English: "...We were desperate, Ma'am. It was time for Father's check-up, but we couldn't afford a Grab, so we took him on a motorcycle. By the time we got home, his feet were swollen." - (PS - V)

The patient's family reported that monthly expenses exceed Jogja's regional minimum wage due to transportation to the hospital, diapers, food, and medications not covered by insurance.

"Ya kalau dihitung perbulan bisa 3 jutaan Mbak untuk Bapak" - (PS - VI)

In English: "Ma'am, that would be about 3 million Rupiah per month for Father." - (PS - VII)

"......biaya buat beli pampers sekarang mahal mbak, satu piece nya aja paling rendah empat ribu, padahal sehari seenggaknya butuh 3" - (PS - VII)

In English: "...Ma'am, diapers are expensive now. The lowest price for a single piece is 4,000 Rupiah, and we need at least three per day." - (PS - VII)

"Saya awal-awal dulu gak pakai BPJS ini obatnya udah jutaan loh Mbak, belum untuk biaya beli pampers ataupun makanan khusus buat istri saya." - (PS - IX)

In English: "At first, I didn't use BPJS, and the medication alone already cost millions of Rupiah, Ma'am, not to mention the expenses for diapers and special food for my wife." - (PS - IX)

B. Access to physiotherapy services

This sub-theme examines the structural, logistical, and educational challenges of formal rehabilitation services.

1. Structural gaps and long waiting times

Families struggled to access specialist services physiotherapy, speech therapy, and occupational therapy, due to the limited number of therapists in hospitals.

"Harus antre lebih dari sejam baru dipanggil"- (PS - I)

In English: "We had to wait in line for over an hour before being called." - (PS - I)

"Antrenya lama sekali" - (PS - III)

In English: "The line is long." - (PS - III)

"Harus datang pagi-pagi untuk dapat nomer antrean" - (PS - IV)

In English: "Arrive early in the morning to get a queue number." - (PS - IV)

Caregivers reported a structural barrier, particularly in accessing Speech Therapy, where they faced long queues and could not secure confirmed appointments.

"Sama ini TW-nya yang perlu banget karena kita juga belum masih... Jadi, nggak dapat, nggak tahu nggak dapat atau memang belum dijadwalkan..." - (PS - II).

In English: "Additionally, this speech therapy is essential because we haven't received it yet, we don't know whether it's unavailable or simply hasn't been scheduled." - (PS - II)

"..... sering enggak kebagian OT" - (PS - V)

In English: "... often do not receive a share of OT." - (PS - V)

"......sering tidak kebagian TW" - (PS - VI)

In English: "... often do not receive a share of speech therapy" - (PS-VI)

"...... nah baru hari ini dapat lengkap" - (PS - VII)

In English: "Today was the first time they successfully received all scheduled therapies and services." - (PS - VII)

"....pernah terapi di double sama pasien lain, ya saya maklum mungkin lagi ramai pasiennya ya" - (PS - X)

In English: "...I once had my therapy doubled because of another patient. I understand, perhaps there were many patients." (PS - X)

"....harusnya ditambahi si pegawainya kadang di tinggal-tinggal pas lagi di terapi" - (PS - IX)

In English: "... it should be added that the staff sometimes leave the patient during therapy." - (PS IX)

" Antrenya sama terapinya, lamaan antre nya" - (PS-VIII)

In English: "The time spent waiting in line is significantly longer than the therapy session itself." - (PS-VIII)

Families heavily rely on BPJS to ease the burden of medical expenses, yet they receive therapy only once a week.

"Untuk pembiayaan bapak berobat lumayan terbantu oleh BPJS, Mbak. Hanya saja jadwal terapinya hanya kadang dapatnya 1 kali seminggu" - (PS-XI)

In English: "For my father's treatment costs, we received considerable support from BPJS, Ma'am. However, the therapy sessions are sometimes available only once a week." - (PS-XI)

2. Need for educational innovation and self-learning

This structural condition is compounded by the fact that caregivers are often not properly taught or given adequate education on how to train the patient at home.

"Pernah melihat atau pernah diajari di mana? Enggak." - (PS-III).

In English: "Have you ever seen or been taught this anywhere? No." - (PS-III)

Caregivers also found static media, such as a book, to be ineffective:

"Kalau cuma buku, saya enggak bisa." - (PS - I).

In English: "If it's just a book, I can't handle it." - (PS - I)

Consequently, they sought external resources to learn how to train the patients: "Well, I just watched videos on YouTube on my phone. There are educational materials about stroke there."

"Ya ini aja saya baca-baca di YouTube pada lewat HP. Itu kan ada bahan edukasi tentang stroke." - (PS - II).

In English: "Well, I just watched them on YouTube on my phone. There are educational materials about stroke there." (PS - II)

"Sebenernya saya nyontoh yang lewat di tiktok aja. Tapi gak tau bener apa enggak gerakan untuk latih orang yang kena stroke" - (PS - XI)
In English: "Actually, I just imitate what I see on TikTok, but I'm not sure if the movements are correct for training someone who has had a stroke." - (PS - XI)

To address the limitations of verbal education and the time constraints faced by caregivers, they emphasized the urgent need for innovative educational approaches for exercises to be performed at home. This underscores the untapped potential of digital resources to bridge the gap between hospital care and community-based rehabilitation.

"Iya kami membutuhkan video atau buku panduan agar bisa kami praktekkan di rumah langsung saat tidak pas jadwalnya ke rumah sakit." - (PS - IV)
In English: "Yes, we need videos or guidebooks so we can practice at home right away when it's not our scheduled hospital time." - (PS - IV)

".......Pengin ngevideo saat Bapak di terapi tapi kan gak boleh video ya waktu di rumah sakit" - (PS - V)
In English: "….We want to record when Father is receiving treatment, but video recording is not allowed in the hospital." - (PS - V)

"Pengin bisa melakukan di rumah apa yang dicontohkan tapi sering lupanya" - (PS - VI)
In English: "We want to be able to do at home what was demonstrated, but we often forget how." - (PS - VI)

"Penginnya ada video panduan untuk gerak-gerakin lengan dan tungkai Bapak saat di rumah" (PS - VII)
In English: "We wish there were a guidance video on how to move Father's arms and legs at home." - (PS - VII)

"Jane pingin ada buku panduannya biar nda salah gerakin" - (PS - VIII)
In English: "Actually, we want a manual so that we don't move the patient incorrectly."

"Kalo di rumah Saya nyoba gerakkan bahu istri saya, dia marah-marah, katanya sakit, nah jadi butuh pedomannya biar dia mau gerak kayak pas di RS ini" - (PS - IX)
In English: "If I try to move my wife's shoulder at home, she gets angry and says it hurts. We need guidance so that she will be willing to move it, just like she does at the hospital." - (PS - IX)

"… bukan gak mau ya cuman lupa aja kalo lisan aja" - (PS - X)
In English: "... It's not that we don't want to; we just forget if it's only told verbally." - (PS - X)

C. Family feelings in patient care

This sub-theme explores the emotional burden, conflicts, and coping strategies of caregivers.

1. Physical and mental exhaustion, and time constraints

The demands of intensive care induce stress and feelings of exhaustion, which are key indicators of sleep deprivation.

"Capek? Ya pasti pernah lah" - (PS - IV)
In English: "Tired? Yes, of course." - (PS - IV)

"Ya nda di rasa aja" - (PS - V)
In English: "We just try to ignore it."- (PS - V)

"Kalo di tanya capek ya capek tapi ya dinikmati" - (PS - III)
In English: "If I'm asked whether I'm tired, yes, I am, but I actually enjoy it." - (PS - III)

"Kerasanya kalo pas udah mau tidur capek banget" - (PS - II)
In English: "I really feel exhausted right before I go to sleep." - (PS - II)

"Kalo adik saya nda datang gantiin itu bisa kayak digebukin" - (PS - I)
In English: "If my sibling doesn't come to cover for me, it feels like I've been beaten up." - (PS - I)

"Iya capeknya secara fisik saja... karena kurang tidur aja." - (PS - VII)
In English: "Yes, the fatigue is purely physical, due to insufficient sleep." - (PS - VII)

"Kalau capek ya manusiawi. Yang penting saya berdoa." - (PS - VI)
In English: "If you're tired, it's only human. What's important is that I pray." - (PS - VI)

These time constraints and fatigue made it difficult to maintain consistency in home rehabilitation exercises. Even a short, focused session of 15 minutes was challenging to perform regularly, as caregivers had to balance work and other household responsibilities. This difficulty was further compounded by the patient's non-compliance, for example, when the patient was supposed to change position but continued sleeping instead.

"24 jam itu sudah kanan terus, terus ngeyel." - (PS - VIII)
In English: "For 24 hours, they have remained continuously on the right, persistent and stubborn." - (PS - VIII)

"Sebenernya yang bikin sebel kalo pasien tidak nurut, terus kitanya maksa jadinya kita capek sendiri" - (PS - IX)
In English: "Actually, what frustrates us is when the patient doesn't cooperate, and we have to force them, which ends up exhausting us."

"Kalau Bapak tidak semangat, saya juga jadi tidak semangat kan ya Mbak" - (PS - X)
In English: "If Father isn't enthusiastic, I also lose motivation, right, Ma'am?" - (PS - X)

"Kalo dah capek banget ya nda sempet ngajak Bapak latihan gerak-gerak mbak" - (PS - XI)
In English: "If I'm really tired, I don't have time to invite Father to do his exercises, Ma'am." - (PS - XI)

2. Patient conflict and emotional coping

One of the caregivers, who worked as a civil servant (PNS - Pegawai Negeri Sipil, a civil servant of the Indonesian government), described the role conflict and exhaustion: "Only when conditions are like this do I have to… do the work, clean the house, and tidy up."

"Cuma kalau pas kondisi-kondisi tertentu yang kayak riweh, saya harus...

> *Mengerjain kerjaan, harus mbersih-bersih rumah, beres-beres rumah." - (PS - I)*
>
> In English: "Only under certain complex or busy circumstances do I have to work, clean, and tidy the house." - (PS - I)

> *Kalau siang tidur itu Bapak, kalo malam yampun manggil-manggil terus, akhirnya saya kan nda bisa tidur to mbak padahal besok paginya saya harus kerja - (PS - IV)*
>
> In English: "During the day, Father sleeps, but at night, oh my, he keeps calling, so in the end, I can't sleep, even though I have to work the next day." - (PS - IV)

The caregiving task is very burdensome and can cause frustration when patients have high demands or display stubborn non-compliance with the rehabilitation program, as illustrated here:

> *"Hanya untuk kesehatan, jangan ngeyel… Makan ko lak kan ya tombo pengen ya sehari dua kali minta lagi." - (PS - VII).*
>
> In English: "For the sake of health, don't be stubborn… When it comes to eating, he often gives in to cravings, asking for food twice a day." - (PS - VII).

Despite carrying this emotional burden, most caregivers cope through spiritual practices, emphasizing their sincerity in providing care. Additionally, caregivers reported feeling intense irritation when patients displayed learned helplessness, seeking help with tasks they could perform independently, highlighting the experience of role conflict.

> *"Terus kayak apa-apa manggil, apa-apa manggil ya mesti ada jengkelnya juga." - (PS - III)*
>
> In English: "Always calling for everything-there must be some annoyance too." - (PS - III)

> *"Yampun Mbak, semenjak sakit kayak manja sekali kayak anak kecil lagi dia" - (PS - VI)*
>
> In English: "Oh my goodness, Ma'am, ever since the illness, he/she has become so spoiled, like a little child again." - (PS - VI)
>
> "
>
> *Sering ngigau sambil manggil yang udah meninggal itu loh ganggu sekali waktu istirahat saya" - (PS - IX)*
>
> "He often mumbles or talks in his sleep, calling out the names of those who have passed away, which really disrupts my rest." - (PS - IX)

Internal family conflicts also emerged regarding treatment decisions, with some members favoring alternative medicine over the primary caregiver's preference for conventional medical treatment, causing relational strain. To manage these pressures, caregivers mainly relied on emotional coping strategies such as prayer and brief physical breaks (leaving the room), highlighting an urgent need for formal psychological and emotional support.

> *"Kami kadang kala ya merasa terbebani... Jadi memang, memang kalau benar kami secara ikhlas gitu." - (PS - II)*
>
> In English: "We sometimes feel burdened… So indeed, truly, if we do it sincerely." - (PS - II)

> *"Lebih banyak doa aja mbak biar diberikan kekuatan" - (PS - X)*
>
> In English: "We mostly just pray, Ma'am, so that we may be given strength." - (PS - X)

> *"Sebenernya sejak istri saya sakit, saya jadi semakin rajin beribadah Mbak, saya takut kehilangan dia jadi sebisa mungkin saya doa agar terus kuat" - (PS - VIII)*
>
> In English: "Actually, ever since my wife fell ill, I've become more diligent in my prayers, Ma'am. I'm afraid of losing her, so I pray as much as I can to stay strong." - (PS - VIII)
>
> In the early days after hospital discharge, a patient's worsening condition or an emergency could trigger panic, an acute stress response. "Well, the most common time to panic is when there's a fever, low oxygen saturation, or something like that, maybe just a bit of panic."

> *"Ya paling kalau panik tuh kalau pas demam atau saturasinya kurang atau apa gitu mungkin agak panik-panik gitu ya." - (PS - V)*
>
> In English: "Well, mostly, if I panic, it's when there's a fever or low oxygen saturation, or something like that, I might feel a bit panicked." - (PS - V)

> *"Bingung banget pas Bapak itu kejang Mbak dan saya di rumah sendiri" - (PS - XI)*
>
> In English: "I was really scared and confused when Father had a seizure, Ma'am, and I was home alone." - (PS - XI)

DISCUSSION

The findings of this study indicate that caregiver burden among family members of chronic stroke survivors in Yogyakarta is not merely the accumulation of individual stressors but represents a multidimensional crisis rooted in systemic and structural deficiencies. Using a socio-ecological framework, this study demonstrates how individual caregiver resilience is compromised by broader economic and institutional constraints.

The demands of continuous 24-hour caregiving are consistently associated with high levels of physical fatigue[15], psychological stress[16], and sleep deprivation[17] among family caregivers of stroke survivors, reinforcing prior evidence that chronic exhaustion and psychological distress constitute the core of caregiver burden. Similar findings have been reported in studies conducted in India, where caregivers experience comparable levels of stress and sleep disruption.[17] This persistent burden is concerning, as it increases the risk of caregiver burnout syndrome.[18] Importantly, caregiver exhaustion extends beyond physical fatigue to encompass significant emotional strain, driven by sustained anxiety and insufficient opportunities for personal recovery.[19-20] Prolonged work-related exhaustion has been shown to reduce quality of life and is associated with an elevated risk of sleep disorders and chronic health conditions, including mild cognitive impairment, diabetes[21], and cardiovascular disease.[22,17]

Notably, despite these pressures, caregivers predominantly rely on spiritual coping strategies. Consistent with previous studies, effective spiritual coping is essential for caregivers to sustain their

Table 1. Sociodemographic profiles, economic status, and caregiving characteristics of family caregivers

No.	Initials/Name of Informant	Relationship with Patients	Age (Years)	Last Education	Occupation	Estimated Monthly Income	Duration of Caregiving	Domicile/Origin
11	Patient's Family (PS I)	Child	41	High School	Housewife	±2.7 Million IDR	± 3 years	Godean, Sleman
22	Patient's Family (PS II)	Child	39	High School	Civil Servant (PNS)	±4.5 Million IDR	3 years	Yogyakarta
33	Patient's Family (PS III)	Wife	67	High School	Housewife	±2.7 Million IDR	> 6 months	Yogyakarta
44	Patient's Family (PS IV)	Wife	48	High School	Housewife	±2.7 Million IDR	± 6 months	Sleman
55	Patient's Family (PS V)	Child	40	Bachelor's Degree	Kindergarten Teacher	±2.7 Million IDR	±2 years	Sleman
66	Patient's Family (PS VI)	Child	43	High School	Private Employee	±2.7 Million IDR	± 5 months	Bantul
77	Patient's Family (PS VII)	Child	42	High School	Housewife	±2.7 Million IDR	± 3 years	Sleman
88	Patient's Family (PS VIII)	Husband	43	High School	Driver	±4.2 Million IDR	± 6 months	Yogyakarta
99	Patient's Family (PS IX)	Husband	55	High School	Self-employed	±4.5 Million IDR	±2 years	Yogyakarta
110	Patient's Family (PS X)	Wife	68	Bachelor's Degree	Private employees	±2.7 Million IDR	±1.5 years	Yogyakarta
111	Patient's Family (PS XI)	Child	42	High School	Private employees	±2.7 Million IDR	± 3 years	Bantul

daily responsibilities amid persistent fatigue, stress, and psychological distress.[23] Sincere acceptance emerges as a key coping mechanism, contributing to improved quality of life. This reliance on acceptance underscores the important role of spiritual beliefs in fostering psychological resilience and helping caregivers find meaning in their suffering, while also suggesting limited access to formal psychosocial support.[15,24]

Furthermore, the considerable geographical distance between patients' residences and healthcare facilities constitutes an additional challenge for caregivers.[17,25] This distance directly increases the financial burden on families due to higher transportation costs for medical visits, consultations, and ongoing rehabilitation.[26-27] These expenses, combined with the cost of essential care materials such as diapers and specialized post-stroke diets, are the primary contributors to caregivers' financial stress.[28] Similar levels of financial strain have been reported in studies on elderly care.[29] The average monthly expenditure for stroke care is approximately three million Rupiah, which exceeds the regional minimum wage and often equals or surpasses total household income. This disparity between care-related expenses and family income is the principal driver of the severe financial stress experienced by caregivers.[28]

Another challenge is the long distance to the clinic. Although BPJS covers treatment costs, patients who are unable to sit or move cannot afford transportation to the hospital. Home-based care is a potential alternative; however, the associated fees are also unaffordable for many families. Additionally, limited hospital staffing restricts access to essential services such as speech and occupational therapy. When services are available, therapy is often scheduled only once or twice per week, which is insufficient and may delay recovery. Overall, these findings indicate that the burden experienced by family caregivers of chronic stroke patients is multifactorial, arising from financial limitations, interpersonal challenges, and structural constraints within the healthcare system. Previous studies have shown that successful family-based stroke rehabilitation is strongly influenced by health system capacity. Inequities in access to rehabilitation services may therefore exacerbate disability and disproportionately affect stroke survivors.[30]

These conditions collectively increase caregivers' risk of stress and burnout. Interventions should therefore prioritize practical solutions. First, financial assistance or logistical subsidies for non-medical expenses (e.g., transportation, special nutrition, and assistive equipment) should be expanded, considering the distance to referral hospitals, limited household income (minimum wage or civil servant salaries), and the demands of continuous 24-hour caregiving that contribute to fatigue and sleep

Table 2. **Thematic framework and guiding interview questions on health-seeking behaviour and access to rehabilitation services**

Theme	Sub-Theme	Guiding Interview Questions
I. Health Seeking Behaviour	1. Intensive Role and Crucial Economic Burden	What are your roles toward the patient? (Probing: How long do you care for them daily, is it just routine care or do you also provide exercises for the patient?) How much cost is spent per month during the patient's care? (Does cost become an obstacle in seeking healthcare services?)
	2. Obstacles of Distance, Cost, and System Failure	What healthcare services are frequently used? (Probing: Do you only use medical services or have you ever used traditional services?) How do you go about seeking healthcare for the patient? (Probing: Do you search for services yourself? If you need help, who assists? Is it possible to do it alone?) Who decides on the choice of healthcare service? (Probing: Is there influence from others? What form does the influence take?)
II. Access to Rehabilitation eg: Physiotherapy, Ocupational Therapy and Speech Therapy Services	1. Structural Gaps and Long Waiting Times	Does the patient receive physiotherapy services? If the patient has received physiotherapy services, what form was the service provided? (Probing: Do you think what the patient received was sufficient? How long was the physiotherapy service provided?) What constraints are faced in obtaining physiotherapy services? (Probing: Does it require going to the hospital? Does the physiotherapist come to the home? Are there constraints regarding time?)
	2. Need for Educational Innovation and Self-Learning	How do you obtain physiotherapy services for the patient? (Probing: Is physiotherapy service important? Does it have an impact on the patient? Where do you get information about physiotherapy services?)** What are your suggestions for physiotherapy services in the future? (Probing: What about the physiotherapist's professionalism? Access to physiotherapy services? What if BPJS covered homecare physiotherapy services?)** (Note: Questions ** help extract data on the need for education and the solution of video/homecare).
III. Family Feelings in Patient Care	1. Physical and Mental Exhaustion, and Time Constraints	Are you providing care alone? What constraints are frequently faced by you as the person caring for the patient? How do you feel when providing care to the patient? (Probing: Do you feel tired? Dizzy? Confused?)
	2. Patient Conflict and Emotional Coping	How do you overcome the existing problems? (Probing: Is it with the help of others? Who helps?) Have you ever experienced conflict with the patient? (Probing: How do you resolve it?)

deprivation. Second, referral hospitals should invest in clinically validated, easily accessible digital, video-based training modules rather than static manuals, while also addressing long waiting times and limited availability of physiotherapy and other specialist services, which are often provided only once per week. Caregivers should receive structured education on safely guiding effective home-based exercises, such as breathing exercises[31] and static stretching.[32] However, existing evidence indicates that improving balance, walking ability, and quality of life in individuals with chronic stroke requires a minimum training frequency of three sessions per week. Collectively, these strategies are essential to reduce caregiver burden and conflict, ensure continuity of accurate home-based rehabilitation, and optimize long-term recovery outcomes in chronic stroke survivors.[33-35]

This study has several limitations that should be considered when interpreting the findings. First, the use of a descriptive qualitative design and purposive sampling in a single private hospital in Yogyakarta limits the transferability of the results to other regions in Indonesia, particularly rural areas and public healthcare settings with different resource constraints. Second, the small sample size, although adequate for achieving data saturation in qualitative research, may not capture the full heterogeneity of caregiver experiences across diverse cultural, socio-economic, and healthcare contexts. Third, the reliance on self-reported lived experiences introduces the potential for recall and emotional bias, as participants' responses may have been influenced by psychological distress, fatigue, or situational factors at the time of the interview. Additionally, the translation of interview transcripts from Indonesian to English may have led to subtle losses in meaning despite efforts to maintain semantic equivalence.

Future research should build on these findings by employing longitudinal and mixed-methods designs to examine changes in caregiver burden over time and to integrate qualitative insights with quantitative measures of physical, psychological, and social burden. Studies involving larger and more diverse samples across multiple healthcare settings and regions in Indonesia are warranted to enhance generalizability. Furthermore, future investigations should rigorously evaluate the feasibility and effectiveness of structured digital education and home-based rehabilitation interventions for caregivers, particularly across varying socio-economic groups, to inform scalable and equitable stroke rehabilitation strategies.

CONCLUSION

The burden on family caregivers of chronic stroke survivors is a multidimensional crisis shaped by economic strain, emotional exhaustion, and systemic healthcare limitations. Non-medical costs, such as transportation and daily care, restrict access to rehabilitation services for low-income families. Continuous 24-hour caregiving leads to fatigue, role conflict, and sleep deprivation, reducing adherence to home-based exercises. These challenges are compounded by healthcare system deficits, including therapist shortages, long waiting times, and inadequate caregiver education that often relies on ineffective verbal instruction, forcing caregivers to seek guidance independently. To improve patient outcomes and reduce caregiver burnout, urgent measures are needed to subsidize non-medical costs and implement accessible, digital, visual-based training modules through referral hospitals.

ETHICAL CONSIDERATIONS

This study received ethical approval from the Institutional Ethics Committee of Sekolah Tinggi Ilmu Kesehatan Bethesda Yakkum, Yogyakarta, Indonesia (registration number: 20/KEPK-RSB/III/25).

CONFLICT OF INTEREST

The authors declare no financial or non-financial conflicts of interest related to this manuscript.

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AUTHOR CONTRIBUTIONS

GLA contributed to conceptualization, methodology development, supervision, and drafting of the original manuscript; NAK and HN handled data collection and curation, formal analysis, and visualization; EOG contributed to the conceptual framework and provided critical review and editing; NAPS assisted with data collection and resource provision. FW interpreted the data and prepared the final revised manuscript.

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