

Lived experiences of Informal Caregivers Providing Post-Stroke Care in Rural Ghana: A Qualitative Study

Philemon Adoliwine Amooba

paadoliwine.chs@knust.edu.gh

Kwame Nkrumah University of Science and Technology

Ebenezer Baba Asore

Nursing and Midwifery Training College

William Wilberforce Amoah

Kwame Nkrumah University of Science and Technology

Francis Tibil

Nursing and Midwifery Training College

Francisca Achaliwie

University of Technology and Applied Sciences

Freda Asomlokiya Akampoi

Zanlerigu Health Centre

Victoria Bubunyo Bam

Kwame Nkrumah University of Science and Technology

Article

Keywords: Experiences, Informal Caregivers, Stroke survivors

Posted Date: September 29th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10628121/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Stroke is a major cause of disability, leaving most survivors functionally dependent. Optimal recovery requires expert care from multidisciplinary health professionals. However, limited access to such services in resource-constrained countries places the long-term burden of caring for stroke survivors on family members. However, little is known about the context-specific realities faced by these informal caregivers in Ghana. This study aimed to explore the lived experiences of informal caregivers of stroke survivors in the Upper East Region of Ghana.

Methods

This was a descriptive phenomenological study, involving 12 purposively sampled informal caregivers who accompanied stroke survivors to the physiotherapy unit of the Upper East Regional Hospital. Data was obtained through individual face-to-face interviews, transcribed verbatim, and analyzed using reflexive thematic analysis.

Results

We found that informal stroke caregivers struggle with an overwhelming workload amidst limited opportunities for rest and sleep, culminating in sheer physical exhaustion and chronic fatigue. Emotionally, caregivers experienced profound sadness and worry, fear and anxiety, and sometimes anger and frustration.

Conclusion

Our findings suggest that the burden of stroke transcends the pain and anguish endured by survivors but adversely impacts the physical and emotional wellbeing of informal caregivers. This calls for tailored policies and interventions that address the unique challenges faced by family members caring for stroke survivors in Ghana.

1. Introduction

Stroke is a global health concern, affecting over 101 million people worldwide and responsible for more than 6 million deaths annually [1]. Beyond the high prevalence and fatality, stroke is a leading cause of disability [2], leaving survivors with varied impairments that render them functionally dependent [3, 4]. The complex aftermath of a stroke requires expert care from multidisciplinary health professionals, preferably delivered in dedicated stroke units [5, 6]. However, limited access to such services in Ghana and similar resource-poor countries [7, 8], shifts the long-term burden of care to friends and family

members categorized as informal caregivers [9]. In these countries, informal caregivers provide more than 80% of the support needs of stroke survivors [10]. They assist with activities of daily living while serving as the vital link between survivors and healthcare providers [11, 12].

In Ghana, caring for a sick family member is considered a reciprocal responsibility [13, 14]. But within the context of post-stroke care, this practice is a stressful life-changing experience [10]. Unlike other conditions, the sudden nature of stroke onset leaves families inadequately prepared to assume caregiving roles [7, 15, 16]. This has devastating consequences on the health and well-being of informal caregivers [10, 12, 17]. Yet, the welfare of informal stroke caregivers remains under-prioritized in Ghana. Whereas available evidence recommends a dyadic approach to stroke management [18, 19], post-stroke care remains patient-centered in Ghana, often focused on improving functional independence of survivors, with limited consideration given to the wellbeing of informal caregivers [20].

Consequently, the level of strain experienced by informal stroke caregivers is overwhelmingly high in Ghana [21, 22]. Reports from urban areas of the country indicate that over 76.7% of informal stroke caregivers are severely distressed [21]. The situation even worsens in the Upper East Region, a medically under-served area where stroke ranks among the top five non-communicable diseases recorded each year [23]. The researchers have also noted a worrying trend where informal caregivers in the region are often overlooked during discharge planning for stroke survivors. This does not only negatively impact the quality of informal care rendered to stroke survivors but undermines their safety and well-being [24]. It further leaves caregivers with limited time to care for themselves, resulting in poor outcomes including declining health, restricted social life, and dwindling family income [24, 25]. Thus, given the increasing burden of stroke in Africa [26], Ghana may be headed for a looming health crisis if this situation remains unaddressed.

While a plethora of research exists on the experiences of informal caregivers globally [12, 27, 28], studies on the context-specific realities faced by caregivers in Ghana remain limited. This is detrimental to efforts toward ameliorating the burden of stroke on caregivers. Thus, this study explored the experiences of informal caregivers of stroke survivors in the Upper East Region of Ghana.

2. Materials and Methods

2.1. Study Design

The study utilized the descriptive phenomenological design to explore the experiences of informal stroke caregivers in the Upper East Region of Ghana. This design was appropriate for the study as it allowed for an in-depth exploration of participants' subjective experiences, yielding valuable insights into how people experience an intricate social phenomenon such as caregiving.

2.2. Study Setting

The study was conducted at the physiotherapy unit of Bolgatanga Regional Hospital. This 226-bed capacity hospital was selected because it is the only public health facility with a fully operational physiotherapy unit in the region.

2.3. Study Participants and Sampling Strategy

The study was conducted on 12 purposively sampled individuals who assumed primary responsibility for the care of a stroke survivor. Eligible participants were adults aged 18 years or older, had been caregivers for at least three months, and were willing to share their caregiving experiences. Caregivers were excluded if they had mental health issues affecting communication or were healthcare professionals.

2.4. Data Collection Instrument

Data was collected through individual face-to-face interviews using a semi-structured interview guide. The interview guide had open-ended questions with several probes to facilitate a thorough discussion of the topic. It was piloted on the first two interviews to assess the clarity of questions.

2.5. Data Collection Procedure

Between October and November 2024, caregivers accompanying stroke survivors to the regional hospital's physiotherapy unit were screened by a case manager to determine their eligibility for inclusion. Details of the study was explained to caregivers who met the inclusion criteria, and they were given one week to decide. Fourteen (14) caregivers ultimately consented to participate and were scheduled for interviews. To ensure a quiet and conducive environment, the interviews were conducted in a designated interview room at the reproductive and child health unit of the hospital. Each interview session began with informal conversation to ease participants, before the main questions and several follow-up questions to elicit detailed responses. Field notes were also taken to help capture non-verbal cues. Data saturation was achieved with twelve (12) participants, with no new insights emerging from the data, and this constituted the study's final sample.

2.6. Data Management and Analysis

In preparing for analysis, all audio-recorded interviews were transcribed verbatim and returned to participants for verification. The data was then analyzed using reflexive thematic analysis by Braun & Clarke, 2020, a 'data-driven' approach that identifies patterns within datasets to understand shared and unique experiences [29]. During this six-phased iterative process, we repeatedly read the transcripts to familiarize ourselves with the data (phase 1), then created descriptive labels on relevant segments of each transcript, yielding 152 initial codes (phase 2). In phase 3, patterns were identified and grouped into candidate themes. These candidate themes were then reviewed and refined to ensure coherence with the overall dataset (Phase 4). During phase 5, we defined and named themes, ensuring that each theme was distinct and centered around a core concept. The report was written during the sixth phase, reflecting the experiences shared by informal caregivers.

2.7. Methodological Rigor

Credibility of the study was enhanced through member checking, where transcriptions were shared with participants for their validation. An audit trail of coding processes and theme development was also maintained to enhance dependability. Interviews were conducted using the same interview guide, enhancing consistency in data collection. Confirmability was ensured through peer-debriefing, where the data was scrutinized against codes and themes generated. Transferability was enhanced by providing a detailed description of the research processes.

2.8. Ethical Consideration

The study had ethical approval from the Committee on Human Research and Publication Ethics of KNUST (CHRPE/AP/1135/24). The rights of participants were protected by explaining the study's purpose and all data collection processes before involving them. Participants were further made to understand that their participation was voluntary, and they could withdraw at any stage of the study. It was only after this that participants were made to sign a consent form indicating their approval to take part in the study. To maintain anonymity and confidentiality of participants, they were not required to provide any identifying information, such as name or house address. Also, each transcript was assigned a serial code that could only be identified by the researchers.

3. Results

3.1. Demographic Profile of Participants

A total of twelve caregivers, comprising five males and seven females, aged between 19 -52 years participated in the study. Almost all participants (n=11) had a minimum of Junior High School education, and eight (8) were in active employment. Most participants were non-spousal caregivers and had been in the role for more than three months. Table 3.1 is a summary of the demographic characteristics of participants.

Table 3.1: Demographic Characteristics of Participants

Code	Age	Sex	Educational Level	Employment Status	Marital Status	Caregiving Duration	Caregiver Type
P1	43	Male	Tertiary	Employed	Married	7 months	Filial
P2	19	Male	SHS	Employed	Single	5 months	Filial
P3	22	Male	Tertiary	Unemployed	Single	4 months	Filial
P4	50	Female	Tertiary	Unemployed	Separated	8 Months	Sibling
P5	52	Male	Junior	Employed	Married	11 months	Sibling
P6	34	Female	SHS	Employed	Married	5 months	Sibling
P7	22	Female	SHS	Employed	Married	6 months	Filial
P8	35	Female	JHS	Employed	Married	7 months	Sibling
P9	23	Male	JHS	Unemployed	Single	5 months	Filial
P10	37	Female	Tertiary	Employed	Married	2 years	Spousal
P11	40	Female	Primary	Employed	Married	10 months	Spousal
P12	25	Female	Tertiary	Unemployed	Single	3 years	Filial

NB: JHS= Junior High School, SHS = Senior High School

3.2. Themes and Sub-themes Identified

As shown in table 3.2. below, analysis of the data yielded two main themes, with several sub-themes that detailed the realities faced by informal stroke caregivers in Ghana.

Table 3.2. Main Themes and Sub-themes

Theme	Sub-themes
Physical Depletion	<ul style="list-style-type: none"> • Increased Workload • Limited Rest and Sleep • Physical exhaustion
Emotional Distress	<ul style="list-style-type: none"> • Fear and Anxiety • Profound Sadness and Worry • Anger and Frustration

Theme 1: Physical Depletion

This theme captured how sustained caregiving eroded the physical stamina of caregivers. Notable sub-themes included, increased workload, persistent tiredness, and limited rest and sleep.

Sub-theme 1: Increased Workload

Participants indicated that providing for the basic care needs of the stroke survivor like feeding, lifting, and grooming substantially increased the workload. Yet, many others assumed additional responsibilities for roles previously performed by survivors. A participant explained:

"She used to do a lot of things in the house, like cooking and taking care of the house. ...but when it came and happened like that (referring to the stroke), I can say 70% of my time is now spent on her" (P2).

Some participants described devoting considerable time and energy preparing herbal remedies for survivors, compounding their workload. A participant stated,

"They will let us boil it [herbs], we'd use that one to bath him, and we'd cover him with blanket too. Those things [herbal remedies] are helping, but needs time, and maybe makes you tired at the end of the day" (P8).

Sub-theme 2: Limited Rest and Sleep

Participants lamented that the never-ending nature of stroke care activities made it nearly impossible to obtain adequate rest or sleep. According to a participant, *"it isn't easy. Sometimes, I have to wake up as early as 3:00am or 3.30am and come down to wash" (P4).*

Sub-theme 3: Persistent Tiredness

Cumulatively, the demanding routines of post-stroke left caregivers feeling persistently tired. A participant noted,

"It's always the tiredness. You become tired. Helping him is not easy." (P6).

Theme 2: Emotional Distress

This central theme highlighted the psychological burden endured by caregivers, and was captured in subthemes including, sadness and worry, fear and anxiety, as well as anger and frustrations.

Sub-theme 1: Fear and Anxiety

The abrupt and dramatic manner in which the patient's health rapidly changed from normalcy to a near-death situation left caregivers feeling shocked and terrified. According to one participant,

"When your human being [referring to the stroke survivor] is paralyzed like that, it's not always easy. The person was not like this. So, when it happens like that, it's not going to be easy" (P6).

Also, the risk of stroke recurrence or associated medical crisis made caregivers anxious and hypervigilant. A participant lamented,

"... I wouldn't want to leave her alone at home and attend funerals and all that" (P3).

Sub-theme 2: Sadness and Worry

Witnessing a once active relative reduced to a state of complete dependency made some caregivers sad and worried. In the words of one participant,

"... if you are living with someone you use to chat normally and it comes to a time that this person cannot even pick a phone to call you again, even to open the mouth and talk to you is now a problem. That is my worry" (P5).

Others were traumatized by the daily pain and anguish endured by the stroke survivor, describing it as a heartbreaking experience that left them profoundly sad. A participant stated,

"... you will see that she is suffering. She doesn't sleep in the night" (P1).

Sub-theme 3: Anger and Frustration

Participants described feeling frustrated whenever they were unable to understand what the stroke survivor was trying to communicate. As one participant put it;

"Hmm. He cannot talk, when he wants to tell you something, he cannot talk. I don't understand what he wants to say." (P11).

Others were constantly angered by the disruptive behaviors displayed by some stroke survivors.

4. Discussions

This study explored the lived experiences of people caring for family members with stroke in the Upper East Region of Ghana. Our findings revealed that post-stroke care is an extremely demanding responsibility that constantly stretched informal caregivers beyond adaptive limits, resulting in diverse physical and emotional experiences.

The complex web of responsibilities involved in post-stroke care particularly increased the workload of caregivers while eroding opportunities for rest and sleep, culminating in sheer physical exhaustion and chronic fatigue. With little to no practical support, caregivers described navigating difficult and labor-intensive routines like feeding, bathing, lifting, and repositioning survivors, which left them persistently tired. These findings are consistent with studies documenting the adverse physical impact of round-the-clock post-stroke care on informal caregivers [12, 27, 30, 31]. Indeed, evidence from comparable low-middle-income countries suggests that without adequate support, sustained engagement in such demanding routines places caregivers at heightened risk of adverse physical outcomes [28, 31, 32]. This

implies that in countries where access to respite and support services are limited, caring for a family member with a stroke becomes an embodied form of labour that depletes the physical reserves of informal caregivers. Our findings thus point to critical gaps in Ghana's post-stroke care framework, where the continued systemic neglect of informal caregivers following a stroke survivor's discharge exposes them to unmitigated physical strain that threatens the long-term sustainability of their role.

In addition to meeting the direct care needs of survivors, caregivers further assumed additional responsibility for roles previously performed by survivors. Many others spent considerable time and energy sourcing and administering herbal remedies to stroke survivors, adding to their already demanding role. These findings resonate with studies showing that accommodating the direct care needs of a stroke survivor, in addition to expanded family roles has dire physical consequences on informal caregivers [16, 33, 34]. The situation is said to be particularly dire where caregivers are required to take on stereotypical gender roles [10, 16, 27]. Strikingly, caregivers in the study endured this physical strain in silence, perhaps reflecting deeply entrenched Ghanaian cultural values that frame caring for sick family members as a reciprocal familial obligation [14]. This implies that the physical strain borne by informal stroke caregivers, is not a sole product of conventional caregiving tasks, but equally stem from the cumulative demands of expanded roles, coupled with culturally sanctioned values and practices. The prominence of complementary and alternative medical remedies as a significant contributor to caregiver strain, particularly highlights context-specific dimensions that remains underexplored in stroke care literature. This underscores the need for culturally responsive approaches to the assessment and management of caregiver burden. Reliance on standard models that overlook such cultural dimensions could underestimate the burden of stroke on informal caregivers in resource-poor settings.

Beyond the obvious physical toll, caregivers faced invisible yet profound emotional struggles that weighed heavily on them. Echoing the findings of earlier studies [35–37], the dramatic manner in which a loved one's health rapidly changed to a near-death situation, coupled with the risk of associated post-stroke sequelae, triggered intense fear and anxiety among caregivers. Also, the pain and anguish endured by stroke survivors caused profound sadness and worry for most caregivers. Similar experiences were documented by earlier studies [38–40], suggesting that emotional burden of stroke is not merely limited to the stroke survivors but equally affects their informal caregivers.. Indeed, existing evidence suggests that the post-stroke caregiving role can emotionally tether caregivers to a stroke survivor in such a way that it becomes nearly impossible to detach from their sufferings [12, 41]. Understandably, witnessing such intense suffering without any remedy evokes a feeling of guilt, as caregivers often misinterpret this to mean failure in their role. This points to perceived uncertainties and limited understanding about the trajectory of stroke recovery. Thus, underscores the need to strengthen caregivers' education about the clinical realities of stroke recovery before a survivor's discharge. This could help ease misplaced guilt, while promoting realistic expectations about rehabilitation outcomes.

The study further revealed that cognitive limitations imposed by stroke on survivors frequently result in communication difficulties and personality changes that frustrate caregivers. Amidst this, some survivors displayed behaviors that seemed counterproductive, making caregivers angry. These

experiences support the findings of studies showing that post-stroke amnesia and other communication difficulties are a significant contributor to emotional distress in caregivers [42, 43]. The findings further align with evidence showing that resistant or uncooperative behaviors from stroke survivors can derail the gains made in post-stroke rehabilitation [11]. This anger and frustration may over time expose caregivers to emotional exhaustion, compassion fatigue, and a gradual erosion of the very empathy needed to sustain them in the caregiving role. There is therefore the need to incorporate behavior-change psychoeducational training into discharge planning programs for stroke survivors. Such interventions may not only mitigate frustration and despair but improve self-efficacy and psychological wellbeing of caregivers.

Limitations

The study's use of a qualitative design coupled with a relatively small sample size ($n = 12$) limits generalization of our findings beyond the study area. Also, our reliance on self-reported data is subject to recall and social desirability biases, as such participants might have exaggerated or under-reported their experiences.

Conclusions

Caring for a family member with stroke emerged as a very challenging experience, marked by profound emotional distress, heavy responsibilities, and physical depletion. This burden was intensified by the use of complementary and alternative remedies, coupled with certain culturally sanctioned values. Findings of the study thus highlight the cumulative and context-specific nature of post-stroke care burden on families, particularly the contribution of complementary remedies and cultural values to this intense burden, underscoring the need for structured support systems that acknowledge and incorporate local caregiving practices into post-stroke care.

Declarations

Author Contributions

Philemon Adoliwine Amooba (SRN, BSc, MSc, PhD): Conceptualised and designed the study, provided primary supervision and intellectual guidance throughout study design, data analysis, and manuscript preparation, reviewed, critically revised all drafts of the manuscript, served as corresponding author and managed manuscript submission and revision processes.

Ebenezer Baba Asore (RN, BSc, MPhil): Conceptualised and designed the study, conducted data collection, performed primary data analysis, drafted the initial manuscript, and incorporated supervisory revisions throughout the writing process.

William Wilberforce Amoah (RN, BSc, MPhil, PhD): Contributed to the conceptual framework and literature review, participated in critical review and revision of the manuscript for important intellectual

content.

Francis Tibil (RN, BSc, MPhil): Contributed to the methodological design and quality assurance of data collection procedures, provided critical review of the manuscript.

Francisca Achaliwie (SRN, BSc., MSc. PhD): contributed to manuscript preparation, reviewed and critically revised all drafts of the manuscript.

Freda Asomlokiya Akampoi (RM, BSc): contributed to literature review, revision of the manuscript

Victoria Bubunyo Bam (SRN, BSc, MSc, PhD): Reviewed, critically revised all drafts of the manuscript, and proofread the final manuscript.

All authors read and approved the final manuscript.

Ethics Statement

Ethical clearance was obtained from the Committee on Human Research and Publication Ethics of KNUST (CHRPE/AP/1135/24). All study procedures were conducted in compliance with the ethical principles for medical research involving human subjects as articulated in the Declaration of Helsinki [22]. Written informed consent was obtained from all participants prior to inclusion. Confidentiality was maintained throughout through participant coding and secure data storage accessible only to the research team.

Funding

This work was an academic research venture undertaken as part of the requirements for the award of Master of Philosophy in Nursing at Kwame Nkrumah University of Science and Technology. The study received no external funding, either local or international. All costs were borne by the researchers.

Competing Interests

The authors declare that they have no competing interests.

Data Availability

The qualitative data generated and analysed during this study are not publicly available in order to protect participant confidentiality and anonymity, consistent with the ethical approval governing data use. Reasonable requests for anonymised excerpts to support specific research purposes may be directed to the corresponding author.

References

1. Feigin, V. L. et al. World Stroke Organization (WSO): Global Stroke Fact Sheet 2022. *Int. J. Stroke*. **17**, 18–29. <https://doi.org/10.1177/17474930211065917> (2022).
2. World Health Organization. Regional Office for South-East Asia. Integrating stroke services in health-care systems: a practical approach. (2020).
3. Tiwari, S., Joshi, A., Rai, N. & Satpathy, P. Impact of Stroke on Quality of Life of Stroke Survivors and Their Caregivers: A Qualitative Study from India. *J. Neurosci. Rural Pract.* **12**, 680–688. <https://doi.org/10.1055/s-0041-1735323> (2021).
4. Sohkhlet, G., Thakur, K., David, S. I., Verma, P. & Jadav, V. S J, et al. Stress in Caregivers of Stroke Patients During Rehabilitation: An Observational Study. *Cureus* 2023;15. <https://doi.org/10.7759/cureus.37410>
5. Whitehead, S. & Baalbergen, E. Post-stroke rehabilitation. *South. Afr. Med. J.* **109**, 81–83. <https://doi.org/10.7196/SAMJ.2019.v109i2.00011> (2019).
6. Langhorne, P. & Ramachandra, S. Organised inpatient (stroke unit) care for stroke: network meta-analysis. *Cochrane Database Syst. Rev.* 2020;2020. <https://doi.org/10.1002/14651858.CD000197.pub4>
7. Kayola, G. et al. Stroke Rehabilitation in Low- and Middle-Income Countries: Challenges and Opportunities. *Am. J. Phys. Med. Rehabil.* **102**, S24–32. <https://doi.org/10.1097/PHM.0000000000002128> (2023).
8. Sarfo, F. S. et al. Nationwide rates of outpatient clinic attendance by stroke survivors in Ghana: Analysis by region and facility. *J. Neurol. Sci.* **437**, 120250. <https://doi.org/10.1016/j.jns.2022.120250> (2022).
9. Predebon, M. L. et al. dos, The capacity of informal caregivers in the rehabilitation of older people after a stroke. *Investig y Educ En Enferm* 2021;39. <https://doi.org/10.17533/udea.iee.v39n2e03>
10. Lu, Q., Mårtensson, J., Zhao, Y. & Johansson, L. Living on the edge: Family caregivers' experiences of caring for post-stroke family members in China: A qualitative study. *Int. J. Nurs. Stud.* **94**, 1–8. <https://doi.org/10.1016/j.ijnurstu.2019.02.016> (2019).
11. Vidyanti, A. N. et al. Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta. *Indonesia F1000Research*. **10**, 380. <https://doi.org/10.12688/f1000research.52135.2> (2022).
12. Sidek, N. N. et al. Experiences and needs of the caregivers of stroke survivors in Malaysia-A phenomenological exploration. *Front. Neurol.* **13**, 996620. <https://doi.org/10.3389/fneur.2022.996620> (2022).
13. Agyemang-Duah, W., Abdullah, A., Mensah, C. M., Arthur-Holmes, F. & Addai, B. Caring for older persons in rural and urban communities: perspectives of Ghanaian informal caregivers on their coping mechanisms. *J. Public. Heal.* **28**, 729–736. <https://doi.org/10.1007/s10389-019-01082-4> (2020).

14. Atsu, F. S. et al. Care for the cerebrovascular accident survivors: experiences of family caregivers. *BMC Palliat. Care.* **23**, 1–9. <https://doi.org/10.1186/s12904-024-01468-6> (2024).
15. Abeasi, D. Depression and quality of life among family caregivers of Stroke Survivors in Ghana: The role of social support. *Arch. Ment Heal.* **21**, 83–89. https://doi.org/10.4103/AMH.AMH_21_19 (2020).
16. Hughes, A. K. & Cummings, C. E. Grief and Loss Associated With Stroke Recovery: A Qualitative Study of Stroke Survivors and Their Spousal Caregivers. *J. Patient Exp.* **7**, 1219–1226. <https://doi.org/10.1177/2374373520967796> (2020).
17. Purdani, K. S. & Rungreangkulkij, S. Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study. *Int. J. Multidiscip Res. Anal.* **06**, 1782–1788. <https://doi.org/10.47191/ijmra/v6-i4-50> (2023).
18. Zawawi, N. S. M., Aziz, N. A., Fisher, R., Ahmad, K. & Walker, M. F. The Unmet Needs of Stroke Survivors and Stroke Caregivers: A Systematic Narrative Review. *J. Stroke Cerebrovasc. Dis.* **29**, 104875. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.104875> (2020).
19. Achilike, S. et al. Caregiver Burden and Associated Factors among Informal Caregivers of Stroke Survivors. *J. Neurosci. Nurs.* **52**, 277–283. <https://doi.org/10.1097/JNN.0000000000000552> (2020).
20. Sánchez Silverio, V., Abuín Porras, V. & Rodríguez Costa, I. Caregiver burden in relation to cognitive status and dependence on activities of daily living in stroke patients: A cross-sectional study in the Dominican Republic. *Rev. Científica La. Soc. Enfermería Neurológica (English Ed).* **56**, 37–42. <https://doi.org/10.1016/j.sedeng.2021.05.001> (2022).
21. Boakye, H., Nsiah, A., Bello, A. & Quartey, J. Burden of Care and Quality of Life among Caregivers of Stroke Survivors: Influence of Clinical and Demographic Variables. *Br. J. Med. Med. Res.* **20**, 1–10. <https://doi.org/10.9734/bjmmr/2017/31903> (2017).
22. Okai, R. Burden of Caregiving on Informal Caregivers of Stroke Survivors in the Western Region. (2019).
23. Ghana Health Service - Upper East Regional Health Directorate. End of Year Report – Non communicable Disease (NCDs) and Occupational Health (OH) Unit 2023:0–5. (2022).
24. Liu, Z. & King, M. The influencing factors and coping styles of mental health stress responses of stroke caregivers. *Work* **69**, 499–513. <https://doi.org/10.3233/WOR-213495> (2021).
25. Okoye, E. C. et al. Informal caregivers' well-being and care recipients' quality of life and community reintegration – findings from a stroke survivor sample. *Scand. J. Caring Sci.* **33**, 641–650. <https://doi.org/10.1111/scs.12657> (2019).
26. Onwuakagba, I. U. et al. Population-based stroke risk profile from a West-African community. *ENeurologicalSci.* ;33:100483. (2023). <https://doi.org/10.1016/j.ensci.2023.100483>
27. Lin, S. et al. International Journal of Nursing Studies The experience of stroke survivors and caregivers during hospital-to-home transitional care: A qualitative longitudinal study. *Int. J. Nurs. Stud.* **130**, 104213. <https://doi.org/10.1016/j.ijnurstu.2022.104213> (2022).

28. Kalavina, R., Chisati, E., Mlenzana, N. & Wazakili, M. The challenges and experiences of stroke patients and their spouses in Blantyre, Malawi. *Malawi Med. J.* **31**, 112–117. <https://doi.org/10.4314/mmj.v31i2.2> (2019).
29. Sundler, A. J., Lindberg, E., Nilsson, C. & Palmér, L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs. Open.* **6**, 733–739. <https://doi.org/10.1002/nop2.275> (2019).
30. Wang, Y. et al. Burden of informal care in stroke survivors and its determinants: a prospective observational study in an Asian setting. *BMC Public. Health.* **21**, 1–14. <https://doi.org/10.1186/s12889-021-11991-3> (2021).
31. Tziaka, E. et al. A Holistic Approach to Expressing the Burden of Caregivers for Stroke Survivors: A Systematic Review. *Healthc* **12**, 1–31. <https://doi.org/10.3390/healthcare12050565> (2024).
32. Gertrude, N. et al. Caring for a stroke patient: The burden and experiences of primary caregivers in Uganda – A qualitative study. *Nurs. Open.* **6**, 1551–1558. <https://doi.org/10.1002/nop2.356> (2019).
33. Eriksson, G. M., Kamwesiga, J. T. & Guidetti, S. The everyday life situation of caregivers to family members who have had a stroke and received the rehabilitation intervention F@ce in Uganda. *Arch. Public. Heal.* **79**, 1–10. <https://doi.org/10.1186/s13690-021-00618-z> (2021).
34. Utaisang, A. et al. Experiences of family members in caring of stroke patients: A case study in the border provinces of the upper Northeast of Thailand. *Open. Access. Maced J. Med. Sci.* **9**, 172–179. <https://doi.org/10.3889/oamjms.2021.7125> (2021).
35. Shewangizaw, S., Fekadu, W., Sackley, C. & Alem, A. Life after stroke: exploring social and psychological consequences of stroke survivors and their caregivers. *Ethiop. Med. J.* **61**, 315–325. <https://doi.org/10.4314/emj.v61i4.3> (2023).
36. Merati-Fashi, F., Dalvandi, A. & Yekta, Z. P. Stroke Survivors and Their Family Caregivers' Experiences of Health Information Seeking: A Qualitative Study. *Int. J. Community Based Nurs. Midwifery.* **10**, 269–278. <https://doi.org/10.30476/IJCBNM.2022.94489.1997> (2022).
37. Lobo, E. H. et al. Information, involvement, self-care and support—The needs of caregivers of people with stroke: A grounded theory approach. *PLoS One.* **18**, 1–25. <https://doi.org/10.1371/journal.pone.0281198> (2023).
38. Moore, A. R., Yaa Owusu, A., Moore, S. & Knight, R. Caring for a Loved One with Stroke in Lomé, Togo: an Intersectional Framework. *Ageing Int.* **47**, 743–757. <https://doi.org/10.1007/s12126-021-09427-9> (2022).
39. Kavi, E., Bazrafshan, M., Taleghani, F., Abolhasani, S. & Akbari, L. Experiences of Strokes' Caregivers: A Qualitative Study. *Jundishapur J. Chronic Dis. Care* 2019;8. <https://doi.org/10.5812/jjcdc.90284>
40. Tumbar, C. J. F. S. T., ￼￼￼￼ & HHS Public Access. *Physiol. Behav.* ;**176**:139–148. <https://doi.org/10.1007/s12028-018-0641-6>. Preventing. (2017).
41. Subraja, R., Helen Shaji, J. C. & Bamini Devi, N. Unveiling the hidden struggles: a qualitative study on caregiver burden among stroke survivors. *BMC Nurs.* **25**. <https://doi.org/10.1186/s12912-025-04124-3> (2026).

42. Tang, E. Y. H., Price, C., Stephan, B. C. M., Robinson, L. & Exley, C. Impact of Memory Problems Post-stroke on Patients and Their Family Carers: A Qualitative Study. *Front. Med.* 2020;7. <https://doi.org/10.3389/fmed.2020.00267>
43. McCarthy, M. J., Lyons, K. S., Schellinger, J., Stapleton, K. & Bakas, T. Interpersonal relationship challenges among stroke survivors and family caregivers. *Soc. Work Health Care.* **59**, 91–107. <https://doi.org/10.1080/00981389.2020.1714827> (2020).

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [S1Tables.docx](#)
- [S2INTERVIEWGUIDE.docx](#)
- [S3DeldentifiedExcerpts.docx](#)