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Experiences of Family Caregivers Providing Home Based Care to Stroke Survivors in Dar es Salaam, Tanzania

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ABSTRACT

Background: Stroke is a leading cause of death and long term disability worldwide. After hospital discharge, family caregivers assume responsibility for caring for survivors at home and facilitating follow-up care. However, the challenges they face and how they cope within the Tanzanian context remain underexplored. This study aimed to explore the experiences of family caregivers providing home based care to stroke survivors in Dar es Salaam, Tanzania.

Methods: An exploratory qualitative design was employed. Sixteen family caregivers accompanying patients to the hospital were purposively selected for in-depth interviews. Data were collected using audio recordings and transcribed verbatim. Inductive thematic analysis, following Braun and Clarke's six-phase framework, was used to generate themes and subthemes.

Results: Two main themes emerged from data analysis: (1) Challenges of caring for stroke survivors at home. The theme had three subthemes: Financial burden, Limited access to medical equipment and essential supplies and Knowledge deficits in caregiving. (2) Coping with caregiving challenges with subthemes: Acceptance of caregiving responsibilities and Seeking social and spiritual support.

Conclusion: The study revealed that family caregivers remain willing to care for stroke affected relatives despite encountering significant challenges. To enhance their capacity, it is crucial to develop or strengthen strategies that empower family caregivers, enabling them to make informed decisions and adapt to their new caregiving roles. Furthermore, improving pre and post discharge education and strengthening connections to social support systems are essential steps in supporting the caregivers.

BACKGROUND

Cardiovascular diseases (CVDs) are one of the non-communicable diseases, accounting for more than 30% of deaths worldwide. Among CVDs, stroke is the second leading cause of death and the third leading cause of disability globally.[1] Stroke results when blood clots block blood flow to the brain (ischemic stroke) or blood vessels in the brain rupture (haemorrhagic stroke). The most important behavioural risk factors of stroke are unhealthy diet, physical inactivity, tobacco use, and harmful use of alcohol.[2] Hypertension is the leading risk factor for stroke.[3] It is predicted that by 2025, the number of adults with hypertension will increase by about 60 % from 46%, resulting in a total of 1.56 billion people with hypertension, with disproportionate prevalence in Sub-Saharan Africa (SSA).[4] In Tanzania, hypertension accounts for more than 80% of all stroke admissions.[5]

Stroke often results in long term complications that affect physical, cognitive, and psychosocial functioning. The recovery depends on the severity of a stroke and the quality of treatment and care provided, both at the hospital and at home. Management of stroke at home includes strategies that focus on the restoration or maintenance of the physical, mental, intellectual, and social abilities of an individual affected by stroke. This may be determined by several factors, including the availability of rehabilitation resources, support from the community and family, home environment, individual characteristics, beliefs, and knowledge about stroke.[6–8] Being a long term illness, the responsibility of caring for patients with stroke is increasingly performed in the patient's home by the caregivers after the end of the acute phase. Therefore, family caregivers (FCGs) can play an important role in the recovery process and in improving patients' quality of health. For example, a study conducted in Nigeria found that most FCGs were willing to provide care and support for their relatives, despite experiencing a considerable caregiving burden.[9] Evidence indicates that empowering FCGs with appropriate knowledge improves their caring experience, which may translate into improved quality of life for both caregiver and survivor.[10]

Given that much of stroke recovery occurs after discharge, following stabilisation of the acute phase,

FCGs in Tanzania are provided with discharge instructions which include guidance on medication use, follow-up clinic attendance, rehabilitation appointments, nutrition, and basic home care. However, discharge preparation is often not standardised, and hands-on caregiver training may be limited due to resource and time constraints. A study conducted in Tanzania among 130 first-ever stroke patients who survived the initial 30 days reported high one-year mortality (40.8%) and disability (37.7%) rates,[11] which may reflect challenges related to home based care. However, there is still limited understanding of how caregivers cope with the responsibilities of caring for stroke survivors at home and the challenges they encounter. Although quantitative studies have provided important information on caregiver burden and associated factors, they offer limited insight into caregivers' perspectives and the meanings they attach to the day to day realities of caregiving within the home setting. While a few qualitative studies in SSA have explored caregivers' challenges and coping strategies and highlighted issues such as limited rehabilitation services, inadequate discharge planning, and poor access to professional support,[12–14] caregiving dynamics within the home environment and FCGs' readiness to provide care following hospital discharge remain underexplored. Therefore, this study aimed to explore the experiences of FCGs providing home-based care to stroke survivors in the Tanzanian context.

METHODS

Study Design

This study employed an exploratory descriptive qualitative study design, which is appropriate for investigating relatively under researched phenomena by providing rich, in-depth descriptions of participants' experiences in their natural context.[15] The design allows for the exploration of meanings and perspectives as expressed by participants, with findings emerging inductively from their narratives, ensuring that the results remain closely grounded in the actual experiences of FCGs.

Study Setting

The study was conducted at Muhimbili National Hospital (MNH) in Dar es Salaam region. The hospital serves as a tertiary national hospital in the country, providing inpatient and outpatient advanced services, including emergency care, critical care and rehabilitation services for patients with stroke. On average, more than 50 stroke patients are admitted to the hospital each month.

Study Participants and Selection

FCGs who were primarily responsible for the patient were purposively selected with the assistance of the unit in charge of the hospital.[16] Eligible FCGs were identified when they accompanied patients for routine follow-up visits at the outpatient department and rehabilitation unit between 6 weeks and 2 years post-discharge. The inclusion criteria required that participants be aged 18 years or older and have provided care for at least one month. All eligible FCGs who met the inclusion criteria during the data collection period were invited to participate; among them, two FCGs declined due to time constraints.

Data saturation was assessed concurrently with data collection and analysis through ongoing comparison of emerging codes.[17,18] After the 14th interview, no new codes or themes were identified, and two additional interviews were conducted to confirm that no further new insights were emerging.

Data Collection and Procedure

FCGs of stroke survivors were approached while waiting for their patients to receive services. The researcher interacted with them individually, explained the purpose of the study and assessed their eligibility to participate in the study, including being a consistent caregiver for at least one month.

Participants who agreed to participate on the same day were asked to leave their patients under the supervision of a companion or hospital attendant and were taken to a prearranged room for interviews, which was free from external interactions. Those who were not available on the same day were scheduled for an interview at their convenience within the data collection period. Interviews were conducted between 2nd and 27th May 2022 after participants had provided written informed consent.

The semi-structured interview guide used for data collection was developed based on a literature review by three members of the research team and one subject expert. The guide consisted of open-ended questions and probes that explored FCGs' experiences of providing home-based care and the challenges related to stroke management at home.

The main questions were: 1) Can you describe a typical day of caring for the stroke survivor?, 2) What challenges have you experienced while caring for the stroke survivor at home? and 3) How do you manage or cope with the challenges of caregiving? The interview guide was pilot-tested with two FCGs to assess clarity, relevance, and the flow of questions, and necessary refinements were made before the main data collection.

All interviews were conducted in Kiswahili, the national language, and audio-recorded with participants' permission. Field notes were taken to capture non-verbal cues. On average, each interview lasted approximately 50 minutes.

To ensure translation accuracy, a committee-based translation approach was used.[19] The interview guide was first translated from English to Kiswahili by two bilingual experts fluent in both languages and familiar with health terminology. It was then back-translated into English by two independent translators who were not involved in the forward translation and were blinded to the original version. A committee comprising the translators and members of the research team compared the original, translated, and back-translated versions and resolved discrepancies through consensus to ensure consistency in meaning and interpretation.

Data Analysis

The voice-recorded data were transcribed verbatim. Thematic analysis was conducted using Braun and Clarke's six-phase inductive approach.[20] This approach allowed for the systematic identification, coding, and interpretation of patterns within the data, enabling themes to emerge directly from participants' narratives without the use of a pre-existing coding framework. This ensured that the

analysis remained grounded in participants' experiences.

Microsoft Excel was used to organise and manage the data. All interviews were conducted in Kiswahili and transcribed in the original language by EN, the primary researcher. The research team (EN, RH, and MN) engaged in data familiarisation through repeated reading of the transcripts. EN, a bilingual researcher, conducted systematic line-by-line coding by identifying meaning units in Kiswahili and translating them into English during the coding process. Codes were then systematically grouped based on recurring patterns and similarities to generate potential themes. The thematic development process was iterative and reflexive,[21,22] with the research team actively involved in reorganising codes, merging overlapping themes, and refining subthemes. To enhance analytical rigour, the research team, together with an external qualitative research expert, engaged in collaborative discussions to reach consensus on the final thematic structure. This systematic approach ensured that the derived themes accurately represented the essence of the data. The findings were synthesised and supported by illustrative participant quotes to provide contextual depth.

Researchers' Characteristics and Reflexivity

EN, RH, and MN are nurse researchers with clinical and academic expertise in specialised nursing care. EN is a postgraduate nurse specialising in cardiovascular nursing. RH is a nurse educator with academic experience in nursing education and research. MN is a critical care nurse and nurse educator with experience in research and intensive care practice. While the team's professional backgrounds provided valuable contextual insight, reflexivity was maintained throughout the research process through regular team discussions, during which emerging codes and themes were critically examined to ensure they remained grounded in the data. EN maintained analytic memos documenting reflections and decisions after each interview, enhancing transparency and supporting the traceability of theme development. Reflexive practices were also used to bracket prior assumptions and remain grounded in participants' perspectives during analysis.

Study Trustworthiness

The researcher engaged with participants respectfully and transparently, clearly explaining the study's purpose to foster a trusting relationship. Participants were informed of their rights, including the freedom to withdraw at any time without consequence, which encouraged open and honest responses.

To enhance analytical rigour, the research team collaboratively analysed data, ensuring consistency and reflexivity throughout the analysis process. An audit trail was maintained to document key methodological and analytical decisions, including coding development, theme generation, and changes made during the analysis, thereby enhancing transparency and dependability. Additionally, member checking was conducted by sharing preliminary findings with a few participants, allowing them to verify whether the interpretations accurately reflected their experiences.[23]

Ethical Considerations

This study obtained ethical clearance from the Institutional Review Board of Muhimbili University of Health and Allied Sciences (MUHAS) (Approval No. DA.282/298/01.C/1037) and administrative approval from Muhimbili National Hospital (Ref. No. MNH/TRCU/Perm/2022/105). Before data collection, the principal researcher provided participants with a detailed explanation of the study objectives, procedures, and confidentiality safeguards, including measures for anonymity and de-identification of all interview data during transcription and reporting. Participants were explicitly informed of their right to withdraw consent at any stage or to decline answering any questions they found uncomfortable. Written informed consent was obtained from all participants before conducting interviews, ensuring voluntary and fully informed participation throughout the research process.

RESULTS

Sixteen participants with a median age of 40 years were included in the study. The majority, 14(87.5%), were females aged between 40 and 59 years. 11(68.7%) of the participants had completed secondary or tertiary education. The majority of the participants, 15(93.7%) were self-employed (Table 1).

TABLE 1: Participants' Background Information

Variable	n
Gender	
Male	2
Female	14
Median Age 40 years	
20-39	4
40-59	10
≥60	2
Level of education	
Primary education	5
Secondary education	5
College and above	6
Duration of caregiving	
1–6 months	6
7–12 months	4
>12 months	6
Relationship to the patient	
Spouse	5
Sibling	2
Others (e.g., daughter, son, in-laws, relatives)	9
Employment status	
Formal employment	1
Self-employed	15

Two main themes were generated through iterative analysis of the data. 1) Challenges of caring for stroke survivors, and 2) Coping with caregiving challenges. The two themes comprised five subthemes, each represented with codes. (Table 2)

Theme 1. Challenges of Caring For Stroke Survivors

Participants described multiple and interrelated

challenges encountered in providing home-based care for stroke survivors. These challenges were shaped not only by the condition of the survivors but also by broader socio-economic constraints and limited formal support systems. Three subthemes, namely financial burden, care limitation related to the availability of medical equipment and products, and knowledge deficit about caring for stroke survivors, describe these challenges.

Financial Burden

Financial burden was the most prominent challenge across narratives. FCGs explained that stroke often resulted in the complete loss of income for survivors, shifting the economic responsibility to family members. This transition frequently strained already limited household resources, especially in contexts where most caregivers were self-employed and lacked stable income or financial protection mechanisms. The emergence of financial burden as a dominant theme reflects the absence of structured long-term care support and limited health insurance coverage for chronic disability care. As a result, families absorbed the full cost of treatment, transport, nutrition, and rehabilitation needs, often at the expense of other household needs.

One participant expressed this strain:

"Taking care of my father has never been easy. What little I earn from welding work also goes to his treatment… I feel stuck." (Participant 07, male, 28 years, son)

While most participants described severe financial strain, a few indicated that the burden was partially mitigated through pooled family contributions or occasional external assistance, although such support was inconsistent and insufficient.

Limited Access to Medical Equipment and Essential Supplies

Participants reported that inadequate access to assistive devices and essential supplies significantly complicated home-based care. Items such as wheelchairs, adult diapers, and pressure-relieving equipment were often unaffordable or unavailable. This challenge was closely linked to financial constraints but also reflected systemic gaps in post-discharge rehabilitation services. Without essential equipment, FCGs had to improvise care, which increased physical strain and reduced the quality of care provided.

One participant noted:

"I wish I had a wheelchair that could easily enable me to take the patient outside to get fresh air and to the toilet." (Participant 12, female, 44 years, spouse)

Knowledge Deficits in Caregiving

Many participants reported limited knowledge and confidence in managing stroke-related disabilities at home. This lack of preparedness was largely attributed to insufficient discharge education and minimal post-hospital guidance from health professionals. The knowledge gap contributed to feelings of insecurity and fear of causing harm, particularly during the early stages of caregiving. However, a small number of participants reported receiving basic instructions at discharge, which they found helpful in the initial transition period.

One participant stated:

"It is important to have any form of education before the patient is discharged home, as this will help us to be able to understand how to live well with our patients." (Participant 09, female, 37 years, daughter)

Overall, the findings suggest that inadequate caregiver training is a critical gap in continuity of care between hospital and home settings.

Theme 2. Coping With Caregiving Challenges

Participants described coping as a dynamic process that evolved over time, beginning with emotional distress and gradually shifting toward adaptation and acceptance. Coping strategies functioned primarily as emotional and social buffers rather than solutions to structural caregiving challenges.

Acceptance of Caregiving Responsibilities

Acceptance of caregiving responsibilities emerged as both a coping mechanism and a culturally shaped obligation. Many participants described caregiving as an unavoidable duty grounded in family responsibility, love, and moral expectation. Cultural norms emphasising familial solidarity and reciprocity strongly influenced this acceptance, particularly among spouses and children. Despite personal sacrifices, FCGs often felt that delegating care was not acceptable within their social context.

One participant explained:

"*I cannot leave him (husband) alone; who else but myself can take care of him? I must make sure I take care of him until he somehow recovers from this condition."* (Participant 04, female, 42 years, spouse)

This acceptance helped FCGs emotionally adjust to their role over time; however, it did not reduce the physical or financial burden of care.

Seeking Social and Spiritual Support

Social and spiritual support played a central role in helping FCGs manage emotional stress and sustain caregiving responsibilities. They relied on extended family members, friends, and community networks for financial, practical, and emotional assistance. These support systems were particularly important in filling gaps left by formal health and social services. In many cases, they provided not only material aid but also emotional validation, helping them normalise their experiences.

One participant noted:

"I asked for financial contributions from a support group I belong to… My family and I alone cannot afford it." (Participant 16, female, 62 years, spouse)

Additionally, peer conversations with individuals in similar situations provided emotional relief and practical advice, enabling caregivers to learn adaptive strategies through shared experience.

Spiritual support was also widely reported. Prayer and religious engagement were described as key sources of strength and resilience. However, while spiritual coping enhanced emotional endurance, it did not reduce caregiving demands.

One participant reflected:

"Praying and meeting with my brothers and sisters in faith gives me strength… sometimes, I even forget the burden." (Participant 08, male, 36 years, son)

TABLE 2: Themes, Sub themes and Codes

Themes	Sub themes	Codes
1. Challenges of caring for stroke survivors	Financial burden	Transport costs; Meeting treatment and rehabilitation expenses; Reduced house hold income
	Limited access to medical equipment and essential supplies	Lack of wheelchair; Lack of special bed; Lack of supportive materials (e.g., diapers, gloves)
	Knowledge deficits in caregiving	Inadequate knowledge of proper positioning; Limited knowledge of passive exercises
2. Coping with caregiving challenges	Acceptance of caregiving responsibilities	I have to do it; I'm responsible; No one else can do it; God ordained it
	Seeking social and spiritual support	Opening up to others; Building support networks; Reliance on faith/spirituality

DISCUSSION

This study explored the experiences of FCGs providing home-based care to stroke survivors following hospital discharge, specifically addressing how caregivers experience and cope with caregiving demands in the Tanzanian context. The findings indicate that caregiving is shaped by the interaction between structural constraints such as financial hardship, limited access to equipment, and inadequate training and socio-cultural expectations that encourage acceptance and sustained caregiving despite adversity.

A key finding of this study is the prominence of financial burden experienced by FCGs. While similar financial challenges have been reported in studies from Uganda and Nigeria.[24,25] Our findings suggest that in the Tanzanian context, this burden is intensified by the near absence of structured long-term care systems and limited insurance coverage for chronic disability care. FCGs not only compensate for lost household income but also assume responsibility for ongoing rehabilitation-related costs. This reflects broader systemic gaps in health financing and social protection across many SSA settings, where out-of-pocket expenditure remains the dominant mode of healthcare financing.[26,27] While in other settings, FCGs receive professional home support,[28] participants in this study reported minimal formal support and limited post-discharge follow-up, indicating a greater reliance on informal care systems. This comparison highlights how differences in health system organisation across the countries may shape the intensity of the FCGs burden.

The limited access to medical equipment and essential supplies further illustrates how structural health system constraints translate into daily caregiving challenges. The inability to obtain basic assistive devices not only compromises patients' mobility and recovery, as reported in a previous study,[26] but also increases FCGs' physical strain. This finding further suggests that the challenge is not solely financial, but also reflects gaps in post-discharge support and rehabilitation infrastructure. In contexts where rehabilitation services are scarce or centralised in urban facilities, FCGs are left to bridge the gap between hospital and home care with minimal support, reinforcing inequities in access to recovery resources.

Knowledge deficits among caregivers were also widely reported and appear to reflect gaps in the transition from hospital to home-based care. While prior studies have documented similar gaps,[12,29,30] our findings suggest that inadequate discharge preparation may reflect systemic pressures within healthcare settings, including high patient loads and limited time for caregiver education. This lack of preparedness contributes to uncertainty and fear among FCGs, which may negatively affect both caregiver confidence and patient outcomes. Importantly, the few participants who reported receiving guidance described it as beneficial, indicating that even basic structured education could significantly improve caregiving experiences. The findings highlight the need for structured stroke care education before and after discharge to build the capacity of FCGs to properly manage patients at home. Post-discharge physical or phone contacts between healthcare providers and FCGs need to be established or strengthened as a strategy to reinforce education provided in hospitals. Evidence indicates that providing FCGs with pre- and post-discharge education on stroke improves their problem-solving coping abilities, caregiving competence, and quality of life.[31–33]

Despite these substantial challenges, FCGs demonstrated a strong willingness to continue providing care, primarily by accepting their roles and relying on social and spiritual support. Similar findings have been reported in studies from Zimbabwe and Uganda, where FCGs continued providing care despite significant economic and emotional burdens, largely due to perceived family responsibility.[34,35] This was a cross-sectional survey using the World Health Organization QOL-BREF and Caregiver Strain Index (CSI This raises concerns about the long-term sustainability of caregiving under current conditions and underscores the need for interventions that complement informal resilience with formal support systems.

Cultural context plays a central role in shaping caregiving

experiences in this study. In Tanzania and most other African countries, caregiving is deeply embedded in social norms emphasising family responsibility, reciprocity, and collective care. These norms strongly influenced participants' acceptance of caregiving roles, particularly among spouses and adult children. However, such expectations may also limit FCGs' ability to seek external support or redistribute caregiving responsibilities outside a close relationship. Gender dynamics are also important to consider. Although not the primary focus of this study, the predominance of female FCGs reflects broader gender norms in which women are socially positioned as primary caregivers. This may influence both the expectation to provide care and how caregiving burden is experienced and expressed. Women may be more likely to internalise caregiving as an obligation, potentially increasing their vulnerability to unrecognised stress and reduced economic opportunities.

Coping strategies identified in this study, particularly social and spiritual support, functioned primarily as mechanisms for emotional endurance rather than solutions to structural challenges. Social networks provided intermittent financial and practical assistance, highlighting their importance as informal safety nets in resource-limited settings. This is consistent with findings from studies in Uganda and South Africa, where extended family and community networks were also reported as key informal support systems for stroke caregivers.[25,34,38] Similarly, spiritual practices offered psychological comfort and meaning, reinforcing resilience, as has also been reported in other studies in Africa, where faith and prayer were central coping mechanisms among caregivers.[39] However, these strategies do not address the underlying drivers of caregiver burden, such as poverty, lack of equipment, and inadequate health system support. This suggests that coping should be understood within a broader framework of constrained adaptation, where FCGs adjust to difficult circumstances without necessarily improving them.

From a conceptual perspective, the findings align with frameworks of caregiver stress and coping, particularly the notion of role adaptation and resilience in the face of chronic stress.[40,41] FCGs in this study appear to move from initial distress toward gradual acceptance and adaptation, supported by cultural values and social networks. However, this adaptation occurs within significant structural limitations, suggesting that resilience is context-dependent and may coexist with ongoing vulnerability. These findings contribute to the understanding of caregiving in low resource settings by highlighting the interaction between individual coping mechanisms and systemic constraints.

Overall, this study underscores the need for multi level interventions that address both the structural and social dimensions of caregiving. These include strengthening discharge education, improving access to affordable assistive devices, expanding community-based rehabilitation services, and enhancing financial protection mechanisms, including affordable and expanded insurance schemes for stroke survivors. At the same time, culturally sensitive approaches that acknowledge existing family and social support systems are essential to ensure that interventions are contextually appropriate and sustainable.

Study Implications

The findings of this study highlight the complex challenges faced by FCGs of stroke survivors in Tanzania and suggest important implications for practice, policy, and research. Clinically, healthcare providers should adopt a more systematic approach to caregiver support that begins during hospitalisation and extends into home care. Structured pre- and post-discharge education, reinforced through follow-up visits, phone calls, or community health worker support, could help bridge knowledge gaps and improve caregiving competence. Routine psychological screening and counselling may also help reduce caregiver burnout, while recognition of spiritual and social support systems already embedded within Tanzanian communities is important for strengthening caregiver resilience.

At the health system and policy level, interventions are needed to address financial and equipment-related barriers. Expanding health insurance coverage to better accommodate stroke care needs may be feasible through existing mechanisms such as the Community Health Fund and National Health Insurance Fund, although current benefit packages provide limited support for long-term rehabilitation and assistive devices. In addition, pilot equipment loan schemes could be explored as a feasible strategy to improve access to essential assistive devices. Strengthening community-based networks, peer support groups, and partnerships with faith-based organisations, which already form an important component of social support in Tanzania, may further enhance FCG's capacity and reduce isolation.

Strengths and Limitations

To our knowledge, this is among the few qualitative studies exploring the experiences of FCGs providing home-based care to stroke survivors in the Tanzanian context. The study provides in-depth insights into the financial, practical, and psychosocial challenges faced by caregivers, as well as the coping strategies they employ within a resource limited setting.

However, several limitations should be considered. Male FCGs represented less than one-quarter of the sample, which may have limited exploration of gender specific caregiving experiences and perspectives. In addition, the use of purposive sampling and the qualitative design limits the generalizability of the findings. Nevertheless, detailed descriptions of the study setting, participants, and analytical process have been provided to support readers in assessing the transferability of the findings to similar contexts.

CONCLUSION

The study revealed that family FCGs remain willing to care for stroke survivors despite substantial financial, physical, and emotional challenges. Caregiving experiences were shaped by limited rehabilitation support, inadequate caregiver preparation, and socio-cultural expectations that promoted continued caregiving despite adversity. These findings highlight the need to strengthen pre- and post-discharge caregiver education, improve access to affordable assistive devices and community-based rehabilitation services, and enhance financial and social support for caregivers. Further studies should explore the

experiences of male caregivers and evaluate interventions to improve caregiver preparedness, coping, and well-being.

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