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ORIGINAL RESEARCH

"I Did What I Could Manage": Caregiver Burden and Rational Triage of Stroke Discharge Instructions in Rural Uganda – A Qualitative Study

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Background: In rural Uganda, informal caregivers provide most post-discharge stroke care, often without formal training, written guidance, or community rehabilitation support. This study explored caregiver burden and factors shaping implementation of stroke discharge instructions in rural southwestern Uganda.

Methods: We conducted a qualitative study at Mbarara and Kabale Regional Referral Hospitals. Eleven informal caregivers of stroke survivors participated in semi-structured in-depth interviews. Interviews were audio-recorded, transcribed, translated into English, and analysed in Atlas.ti 9 using thematic analysis with a deductive codebook refined inductively during analysis.

Results: Four themes were identified: multidimensional caregiving burden; variable discharge instruction content and delivery; barriers to implementing instructions; and facilitators that sustained care. Burden was physical, financial, psychological, and social, often concentrated on one family member. Discharge instructions commonly focused on exercises, medications, diet, and follow-up, but were frequently verbal and lacked clear medication resupply or review plans. A central finding was caregivers' rational "triage logic": when resources were insufficient, they prioritized zero-cost instructions such as exercises and delayed or abandoned costly instructions such as medicines, transport, and follow-up visits. Facilitators included love and duty, family support, retained discharge knowledge, resource mobilisation, and occasional home-based health worker visits.

Conclusion: Caregivers of stroke survivors in rural southwestern Uganda experience substantial multidimensional burden and implement discharge instructions within severe structural constraints. Written discharge protocols, caregiver screening, clearer follow-up pathways, and task-shared community rehabilitation may improve post-stroke continuity of care in similar low-resource settings.

Keywords: stroke, caregiver burden, barriers to implementation, discharge instructions, rural Uganda, physiotherapy

Introduction

Stroke is a leading cause of death and disability globally, with approximately 12.2 million new cases and 6.55 million deaths in 2019.[1] The burden falls disproportionately on low- and middle-income countries (LMICs), which account for 70% of stroke deaths and 87% of stroke-related disability.[2] In sub-Saharan Africa, three-year fatality exceeds 80%, and stroke occurs at a mean age of 57 years, nine years younger than in high-income countries.[3]

In Uganda, stroke is a leading cause of chronic neurological disability, yet the country lacks a comprehensive stroke care policy.[4,5] Post-discharge care is transferred to informal family caregivers who assume this role with no formal training or institutional support.[6] Evidence from sub-Saharan Africa confirms that caregivers in resource-limited settings experience a greater burden than their higher-income counterparts because of limited formal community-based support.[7]

A critical but understudied dimension is the quality of discharge instructions and the extent to which they can be implemented under rural conditions. Discharge education is a cornerstone of secondary prevention,[8] but when it is delivered only verbally or without actionable guidance on medication resupply, follow-up, and rehabilitation access, its

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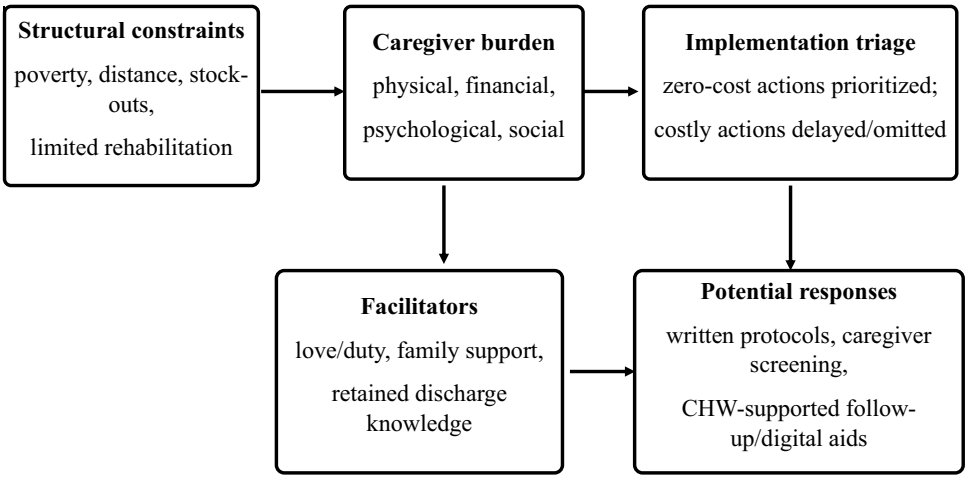


Figure 1 Conceptual pathway linking structural constraints, caregiver burden, rational triage of discharge instructions, and potential support responses.

utility is constrained. In rural LMICs, these deficiencies are compounded by geographic remoteness, transport costs, medication stock-outs, household poverty, limited access to physiotherapy, and weak continuity between hospital and community care.[7,9]

In Uganda, existing stroke caregiver research is concentrated largely in urban or mixed settings,[5,6] leaving a gap for rural communities where the structural context of care differs fundamentally. This study addressed that gap by exploring caregiver burden and the factors facilitating or impeding implementation of discharge instructions for stroke patients in rural southwestern Uganda.

In this study, we conceptualize caregiver burden and the implementation of discharge instructions through the lens of structural violence, the systematic ways in which social structures such as poverty, geographic isolation, and absent rehabilitation infrastructure harm individuals by constraining their ability to act on medical advice.[10] This framework moves beyond individual-level "non-adherence" to examine how health systems may prescribe actions that are difficult or impossible for rural poor households to execute. We also draw on health capability theory, which emphasizes that effective care requires not only knowledge but also the internal and external resources to act on that knowledge.[11]

Methods

Study Design

This was a qualitative study employing individual in-depth semi-structured interviews. Qualitative methods were selected as the most appropriate approach for exploring the subjective lived experiences, perceptions, and contextual challenges of caregivers managing complex post-stroke care demands in a resource-limited setting.[12] The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[13]

Study Setting

The study was conducted in rural southwestern Uganda at two Regional Referral Hospitals: Mbarara Regional Referral Hospital (MRRH) in the northern part of the region, and Kabale Regional Referral Hospital (KRRH) in the southern part. Both facilities serve the southwestern region of the country, receiving patients from lower-level health facilities across sixteen districts: Kabale, Kisoro, Kanungu, Rukungiri, Rukiga, Ntungamo, Mbarara, Isingiro, Sheema, Rwampara, Buhweju, Rubiriizi, Kirihura, Kazo, Ibanda, and Bushenyi, and two refugee settlement camps of Nakivaale and Rwamanja. The combined catchment population is approximately five million people, extending to a radius of approximately 150 km from each referral hospital. Participants were recruited from the specialised clinics for Neurology, Hypertension, and Diabetes, and from the medical ward.

Study Population and Sampling

The study population comprised informal caregivers directly involved in the care of patients with a confirmed diagnosis of stroke. Purposive sampling was employed to recruit information-rich participants who could provide detailed accounts of their caregiving experiences.[14] Participants were identified with the assistance of health workers at the clinics and wards as they attended review appointments. Caregivers were eligible for inclusion if they: (i) were directly involved in the care of a stroke patient for a minimum of two weeks; (ii) were 18 years of age or older; and (iii) provided written informed consent. Caregivers were excluded if they were unable to provide adequate information. Recruitment continued until data saturation was reached. Data saturation was assessed iteratively and considered achieved when no new codes or themes emerged in three consecutive interviews.

Data Collection

Data were collected using an interview guide developed from the study objectives and informed by prior literature on caregiver burden and post-discharge adherence. Trained research assistants and a nursing officer conducted the interviews in a private room within the health facility to ensure confidentiality. Written informed consent was obtained from all participants before interview commencement, including consent for audio-recording. Interviews explored the following domains: daily caregiving activities and perceived burden; experiences of receiving and implementing discharge instructions; and the factors that facilitated or impeded compliance with those instructions. Clinical information, including stroke type, duration of illness, and comorbidities, was obtained from patients' medical records.

Data Analysis

The research team transcribed the audio recordings verbatim and translated them into English, managing the data within Atlas.ti 9 qualitative data analysis software. We employed an integrated thematic analysis approach, combining deductive and inductive methods. Initially, we deductively developed a structured codebook grounded in the study objectives and existing literature on caregiver burden and discharge adherence. Through iterative reading, we inductively refined these codes and actively identified new patterns not anticipated in the initial framework, most notably the "triage logic" whereby caregivers systematically prioritized cost-free instructions. To strengthen trustworthiness, the team held regular reflexive discussions, compared emerging codes across interviews, reviewed deviant or contradictory accounts, and retained an audit trail of coding decisions. Reflexivity was important because members of the research team had clinical and rehabilitation backgrounds; during analysis, the team deliberately examined how professional assumptions about adherence, physiotherapy, and discharge education could shape interpretation. Findings are grounded in the data using direct participant quotations.

Ethical Considerations

Ethical approval was obtained from the Mbarara University of Science and Technology Research Ethics Committee (MUST-REC No. 26/01-20). All participants provided written informed consent for study participation, audio-recording of interviews, and publication of anonymized responses/direct quotations. To maintain confidentiality, interviews were conducted in a private room, and participant anonymity was protected through the use of unique respondent codes (001–011) in place of names during data collection, analysis, and reporting. All digital data, including audio recordings and transcripts, were stored in password-protected files accessible only to the research team. Participants were informed that their participation was entirely voluntary and that they could withdraw from the study at any time without penalty.

Results

Participant Characteristics

Eleven caregivers participated in the study. Participants' sociodemographic characteristics and patients' comorbidities are summarised in Table 1. The majority were female (n = 9, 81.8%), and most were married (n = 9, 81.8%). Ages ranged from 24 to 77 years, with a median of 42 years among those for whom data were available. Educational attainment was predominantly low, with approximately two-thirds having attained primary schooling or no formal education; however,

Table 1 Summary of Sociodemographic Characteristics of Study Participants (N = 11)

Characteristic	Category	n	%
Sex	Female	9	81.8
	Male	2	18.2
Age (years)	Median (range)	—	42 (24–77)
Marital Status	Married	9	81.8
	Single	2	18.2
Highest Education	No formal/Primary	7	63.6
	Secondary/Vocational	1	9.1
	University degree	3	27.3
Occupation	Subsistence farmer/Peasant	6	54.5
	Employed (formal sector)	3	27.3
	Unemployed	1	9.1
	Not recorded	1	9.1
Relationship to Patient	Spouse/Partner	6	54.5
	Adult child	4	36.4
	Not recorded	1	9.1
Caregiving Duration	≤1 month	2	18.2
	2 months–1 year	3	27.3
	1–5 years	4	36.4
	>5 years	1	9.1
	Not recorded	1	9.1
Patient Comorbidities	Hypertension only	4	36.4
	Diabetes mellitus only	1	9.1
	Hypertension and diabetes	3	27.3
	No comorbidities recorded	2	18.2
	Not recorded	1	9.1

Notes: Percentages are based on N = 11. Age median computed for n = 8 participants with data available (three participants not recorded). Cells marked "not recorded" reflect missing data in the original interview record.

three caregivers held university degrees. Over half were subsistence farmers or peasants. The predominant relationship to the patient was spouse or partner (n = 6, 54.5%), followed by adult child (n = 4, 36.4%). Caregiving durations spanned from one month to eleven years, reflecting both acute and long-established caregiving situations. Most patients had comorbidities alongside stroke, most commonly hypertension alone or in combination with diabetes mellitus.

Thematic Findings

Analysis generated four major themes directly responsive to the study objectives. The first addresses the multidimensional nature of caregiving burden. The remaining three address factors shaping implementation of discharge instructions, encompassing the content and quality of discharge education, the barriers caregivers encountered, and the facilitators that enabled them to sustain care. Across all themes, the data reveal a tightly interconnected set of structural, relational, and personal challenges situated within a context of poverty, geographic remoteness, and near-absent community rehabilitation services. Financial constraints emerged as the most pervasive barrier; caregiver motivation and love for the patient emerged as the most consistent facilitator.

Theme 1: The Multidimensional Burden of Stroke Caregiving

Caregiving for a stroke patient was unanimously described as burdensome. Across all eleven accounts, burden manifested across physical, financial, psychological, and social domains, each intensifying the others. These dimensions were further compounded by the all-consuming temporal demands of caregiving and by the universal unpreparedness with which respondents entered the role.

Physical Burden

Physical burden was universal and often resulted in measurable injury. One caregiver described the gynecological consequences of lifting her dependent patient:

> I have doubled my periods, and my scar for C-section is now painful due to workload (Respondent 09, Adult female)

This quote illustrates how caregiving compromises the caregiver's own body, creating secondary morbidity in this case, the recurrence of post-surgical pain that is never addressed in discharge planning. Management of incontinence, requiring repeated laundering and round-the-clock vigilance, was described as both physically demanding and emotionally wearing.

Financial Burden as Structural Impoverishment

Financial burden appeared across all accounts, but its mechanism was not merely expense; it was the inability to replace income while caregiving. One participant articulated the cascading consequences:

> I work all the time, no money, failed to educate my children, no time to associate with others (Respondent 03, Adult female)

This single sentence captures the poverty trap: caregiving consumes time that could be used for farming or wage labor, which reduces income, which prevents children's education, which erodes social capital. Stroke caregiving in this context does not simply add expenses; it systematically dismantles the household's economic future.

Psychological and Emotional Burden

Psychological burden was characterised by uncertainty about the patient's prognosis, emotional exhaustion from sustained caregiving under adversity, and the particular distress of being subjected to verbal abuse or physical violence by the person being cared for. The chronicity of stroke meant that emotional strain was cumulative, building over months and years without relief.

> There is also an aspect of psychological trauma that caregivers always go through where it is so challenging taking care of someone, you're not sure of whether is going to get healed and when, or even not sure when God will decide to take him or her away. So, it is so much traumatising on the side of a caretaker, and you need to have a high degree of perseverance, patience, and kindness. (Respondent 011, Adult male)

> When he beats me, yet I see what I have sacrificed to make sure he is in a good condition, he is not lacking anything, I feel like I have struggled for nothing since he is not appreciative at all. (Respondent 02, Adult female)

Faith and religious acceptance emerged as a significant internal coping resource. However, this sometimes-discouraged help-seeking.

> Now we have resorted to praying, and it is helping us, and since then we have not gone back to the hospital to check and see the situation. (Respondent 02, Adult female)

Social and Temporal Foreclosure

Caregiving consumed time with such totality that social participation became impossible. Participants described withdrawal from women's savings groups, church attendance, and burials not as a choice but as a structural outcome. One participant noted:

> Coming together with other people now there is a very big gap… even attending Sunday services was all cut off (Respondent 01, Adult female)

Critically, the same social networks from which caregivers withdrew were those that could have provided material and emotional support, creating a self-reinforcing cycle. Several employed caregivers described leaving or substantially reducing their employment; one stated simply, "I even left my job to always be available" (Respondent 07, Adult female). These cascading role shifts illustrate how stroke caregiving reshapes household structures beyond the individual caregiver.

Underpinning all of these burdens was the universal report that stroke onset was sudden and that participants had received no preparation for the caregiving role, a system-level failure that discharge education could, but currently does not, address.

Theme 2: Hospital Discharge Instructions – Content, Delivery, and Comprehension

The degree to which discharge instructions were complete, comprehensible, and appropriately communicated shaped whether caregivers had the knowledge and tools to implement them. Instruction quality was not uniform across respondents.

Content of Discharge Instructions

Discharge education converged around four domains: physical exercise and physiotherapy, dietary modification, medication adherence, and attendance for follow-up reviews. Exercise and physiotherapy were the most consistently emphasised.

> There are some foods that doctors recommended for him to keep eating and those that should be stopped, like red meat, which was stopped, and encouraged white meat, even medicines were to be given after taking meals, especially for diabetes. Also exercises every morning and evening as another big instruction that can help on his legs and to also check for pressure and diabetes all the time, as we record such that when we go back for review at the hospital, the doctor can use those records to give the appropriate medication. (Respondent 01, Adult male)

The level of specificity varied considerably across accounts. One caregiver who had been caregiving for eleven years reported being unable to recall any specific instructions, illustrating the practical limitation of verbal-only discharge education without written reference materials.

Mode of Instruction Delivery

Most caregivers received verbal-only instructions; a smaller group received both verbal and written guidance. Where written materials were provided, caregivers described them as practically enabling.

> They were all given to us in writing where the dos and don'ts were well outlined and explained to us, for instance, like the dose for diabetes, we were to do injections morning and evening, ie, 10cc and 15cc respectively. Even when I am not around, there is my young brother who can also do it better since doctors explained everything to us very well. (Respondent 01, Adult male)

This account illustrates how written instructions enabled household knowledge transfer - a benefit that verbal-only delivery cannot support.

Understanding and Quality of Explanation

Most caregivers reported that instructions were thoroughly explained at discharge. However, two critical gaps emerged consistently: unclear follow-up plans and an absence of guidance on medication resupply.

> It is now a year without taking medicine, and they didn't tell us to go back for review. (Respondent 02, Adult female)

> Follow-up plan was not clear because doctors said when we see there is a need, that's when we should always take him to the hospital. (Respondent 07, Adult female)

> We were not told about that. In fact, I was wondering if the medicine we were given gets finished, what should we do? It was my worry. (Respondent 08, Adult female)

These gaps are clinically consequential. In a rural population living far from the referral hospital, an ambiguous follow-up instruction may function as an instruction not to return.

Theme 3: I Did What I Managed and Left Out What I Could Not – The Rational Triage of Discharge Instructions

Six categories of barriers were identified. Financial barriers, geographic distance, irregular medication supply, and limited rehabilitation access formed a mutually reinforcing cluster. Patient non-compliance and inadequate family support operated more distinctly but were equally shaped by the structural context.

The Triage Logic – Cost as the Primary Organizer of Adherence

The most important finding regarding barriers was not a simple list of obstacles but a systematic decision-making logic that caregivers applied to discharge instructions. When money was insufficient to implement all prescribed actions, caregivers prioritized those with no direct financial cost. As one participant explained:

> I did what I managed and left out what I couldn't manage, but due to lack of money, I was forced to leave a number of them, like going back for review (Respondent 03, Adult female)

Exercise and physiotherapy, the only discharge instructions requiring no money, were consistently attempted. Medications, follow-up transport, and dietary modifications, all requiring expenditure, were selectively abandoned. This triage logic is not irrational or ignorant; it is a rational adaptation to structural scarcity. The clinical consequence is that discharge instructions that assume equal capacity to implement all components systematically fail for the rural poor.

Patient Resistance as an Unmet Clinical Need

Caregivers extensively documented patient refusal to cooperate with prescribed care, most consistently directed at physical exercise. However, reframing this as "non-compliance" obscures the underlying causes. Participants described patients refusing exercise due to "being tired and exhausted" (Respondent 01), "pain" (Respondent 05, Adult female), and stigma about being seen in public: "He doesn't want to move in public, maybe he still has that stigma" (Respondent 06, Adult female). These are not willful non-compliance, but likely manifestations of post-stroke depression, post-stroke fatigue, and fear of falling, all recognized clinical sequelae that were neither assessed nor treated. In the absence of professional physiotherapy guidance to manage pain and fear, patient resistance was predictable.

Irregular Medication Supply

Medication continuity was disrupted by facility stockouts and household unaffordability. In the most extreme case, a patient had been without stroke medication for over one year at the time of the interview.

> We used to buy, but now we have failed because you need over 100,000 UGX monthly just to buy medicine… It is now a year without taking medicine. (Respondent 02, Adult female)

> When I have money, I buy medicine for him; when I don't have, I leave. (Respondent 03, Adult female)

In one household, the family had ceased seeking medical review entirely and replaced medication with prayer, not out of indifference to health but out of exhausted pragmatism in the face of unaffordable care.

Limited Access to Rehabilitation Services

Physiotherapy was the most consistently emphasized element of discharge education, yet access to ongoing community-based rehabilitation was severely limited for virtually all respondents. Caregivers were instructed to ensure patients exercised without being given the professional support to facilitate this safely or effectively.

> After discharging her, they sent them one and made her do some exercises and massage just once, but up to now he had never come back. Physiotherapy has been a problem since we have not had any person to do it, and the one we have tried costs a lot of money. (Respondent 09, Adult female)

> Physiotherapy was the most challenging part, but my brother tries as much as possible when they go showering, he tries to do it. (Respondent 07, Adult female)

Geographic Distance from Hospital

Geographic distance compounded financial constraints and made scheduled follow-up review practically unsustainable for households in remote areas.

> We also stay far, all the way near Bwindi, almost near Congo, so it would be hard to always come back for review in Mbarara. (Respondent 08, Adult female)

> Doctors told us to always go for review at Mbarara University, which needs to first hire a car for transporting her, yet there is no money…When we last went for review, they advised us to always come on Thursday so that they can make her talk, but I cannot manage the transport cost. (Respondent 03, Adult female)

Inadequate Family Support

Several caregivers who might have shared the caregiving role with siblings or other household members found themselves functionally alone. Other family members either did not acknowledge the extent of care required or actively avoided responsibility.

> Remember, he has siblings, but they have never come to check on him, even call, which is very bad. (Respondent 06, Adult female)

> Also, being alone am overwhelmed by the workload at home, and I get fatigue hence ending up not doing well in my role. (Respondent 03, Adult female)

When one person manages all domestic tasks, all physical care, and all care coordination, there is insufficient capacity to consistently implement a multi-component rehabilitation plan. Several caregivers described a progressive incapacitation: doing less and less, not out of unwillingness, but out of physical and emotional depletion.

Collectively, these six barrier categories are not independent. Financial constraints magnify geographic distance (no money for transport). Medication stock-outs are a financial problem (unaffordable to buy privately) and a systems problem (facility-level failures). The triage logic described in 3.1 operates as the central organizing principle, with all other barriers feeding into it.

Theme 4: Facilitators to Implementation of Discharge Instructions

Despite substantial barriers, caregivers were not passive. They drew on a range of internal and external resources to implement care instructions to the extent they could, often under conditions of considerable adversity.

Caregiver Motivation, Love, and Sense of Duty

The most powerful and consistent facilitator was the caregiver's intrinsic motivation. The emotional bond between caregiver and patient, whether rooted in spousal love, filial devotion, or moral obligation, functioned as the primary engine of care, sustaining caregivers through physical injury, financial strain, and repeated aggression.

> Remember this is my father, so I have that love for my father, and when he says do this, I have to, even if he abuses you, you can't feel angry because you do all the caring with love and passion. (Respondent 01, Adult female)

> I got used to his condition, which has helped me to cope with the situation, however much he abuses me, even sometimes he reached an extent of beating me, but the love and commitment I had, and I still have, it helps me to handle every situation. (Respondent 02, Adult female)

However, this motivation was not unconditional or inexhaustible. Several caregivers described moments of near-collapse, and the data contain evidence that love functioned as an extractive resource the health system relied on caregivers' emotional commitment to provide free labor, but offered nothing to sustain that commitment. No participant reported receiving any form of psychosocial support or mental health assessment. The absence of such support suggests that current discharge practices implicitly assume that love is sufficient, a hypothesis this study's data directly contradict.

Family and Social Support

Where available, support from siblings, extended family, neighbours, and community structures provided concrete and meaningful assistance in financial, physical, emotional, and informational forms.

> Even my other siblings have helped a lot since we have worked together as a team and made us succeed. (Respondent 01, Adult male)

> There is a friend who is a nurse, and she has a friend who tries to counsel him. She could also give him some money as upkeep. Also, her sister-in-law could call her to calm her down and comfort her, really. (Respondent 06, Adult female)

The nurse friend in Respondent 06's account provided something beyond material resources: lived experience of chronic illness management and peer-level counselling that enabled the patient to engage with care in a way that family members could not.

Knowledge Retained from Discharge Education

For caregivers who received thorough and specific discharge instructions and retained them, that knowledge functioned directly as a facilitator, providing both the practical capacity and the confidence to act.

> Even the instructions were explained to me, so I have to do it because I have the knowledge. (Respondent 10, Adult female)

Conversely, gaps in discharge knowledge were explicitly identified as limiting factors, with direct implications for how discharge education is designed and delivered.

> It's very hard to heal someone with a stroke when you're not specialized in doing so. (Respondent 09, Adult female)

Financial Resource Mobilisation

A small number of caregivers accessed financial resources that enabled fuller implementation of care instructions, including land asset sales, international remittances, personal savings, and community savings schemes (SACCOs). The fragility of these arrangements was a recurrent theme: most were episodic or subject to withdrawal, and their cessation typically meant a reversion to constrained care.

> Our child who went abroad kept sending us some money that is helping us, but now the child said he wants to do his own development and he is coming back home soon, so the support was cut off now. (Respondent 02, Adult female)

Home-Based Health Worker Visits

Two respondents referenced home visits by health workers as a mechanism that partially circumvented geographic distance. In one case, the arrangement was working well; in another, a single physiotherapy visit at discharge was followed by no further contact, leaving the caregiver without ongoing professional guidance.

> Then, for review, we just invite the doctor to come and see her from home, that one is sorted. (Respondent 011, Adult male)

> After discharging her, they sent them one and made her do some exercises and massage just once, but up to now he had never come back. (Respondent 09, Adult female)

Discussion

This study explored the multidimensional burden experienced by informal caregivers of stroke survivors in rural southwestern Uganda and the systemic factors impeding their ability to implement hospital discharge instructions. The accounts of these eleven caregivers suggest that what is often labelled as "non-adherence" may, in some rural contexts, reflect the predictable outcome of care plans that exceed household resources. Framed through structural violence and health capability theory,[10,11] the findings show that caregivers were motivated and able to make rational care decisions, but were frequently denied the external resources required to implement all recommended actions as illustrated in Figure 1.

The Structural Production of Multidimensional Burden

Our findings align with existing sub-Saharan African literature, which characterizes stroke caregiving as a profound burden spanning physical, financial, psychological, and social domains.[6,15,16] This study adds contextual detail by showing how these domains were produced and reinforced in rural post-discharge care. Physically, caregivers sustained unmonitored secondary morbidity because they manually transferred dependent patients without assistive devices, training, or professional guidance.[7] Financially, caregiving functioned as a self-reinforcing poverty trap by consuming time needed for farming, paid work, and other income-generating activity.[17]

Psychologically, the data highlight caregiver-directed aggression and emotional strain as clinically important but often hidden aspects of post-stroke care. Such experiences may be linked to unmanaged post-stroke neuropsychiatric and behavioural sequelae and can weaken caregiver-patient mutuality over time.[18] Socially, the all-consuming temporal demands of caregiving led to the progressive depletion of social capital, as caregivers withdrew from community networks that might otherwise have provided material and emotional support.[19]

The Triage Logic and the Fragility of Love

A central conceptual contribution of this study is the identification of a rational triage logic applied by caregivers. When resources were insufficient to implement the entire prescribed care plan, caregivers systematically prioritized instructions with zero direct financial cost, such as physical exercises, while selectively delaying or abandoning those requiring expenditure, such as medications and transport for follow-up. This suggests that treatment discontinuation was not simply ignorance or disengagement, but a forced adaptation to structural scarcity.[17] Consequently, discharge plans that require sustained financial outlay without clear support pathways risk predictable partial implementation.

In the absence of formal support, the post-stroke care system relied heavily on the intrinsic motivation and emotional bonds of family members. While love and duty were the most powerful facilitators of care,[6,15] the data indicate that emotional commitment alone was insufficient to sustain complex rehabilitation under conditions of poverty, distance, and caregiver exhaustion. Ad-hoc facilitators such as remittances or singular home visits were helpful when present, but they were fragile substitutes for an organized support system.

Systemic Failures in Discharge Education

This study supports the need to improve discharge education for rural post-stroke care. Verbal-only discharge instructions may be insufficient for sustaining complex chronic care in high-stress, low-literacy environments. Current international guidelines recommend comprehensive, structured caregiver education, including written materials, as a standard

component of discharge practice.[8] In this study, written instructions enabled household knowledge transfer and reduced reliance on a single exhausted caregiver's memory.

Furthermore, the absence of unambiguous follow-up plans and clear guidance on medication resupply compounded geographic and financial barriers.[7,20] For a rural population living hours away from a referral facility, vague instructions to return "when necessary" may function as implicit directives not to return, thereby compromising long-term continuity of care.

Strengths and Limitations

This study has several strengths. It addresses a rural evidence gap, uses in-depth interviews, and achieved thematic saturation, with findings supported by internally coherent participant narratives.[12,14] However, the sample size was small and the study was not designed to estimate prevalence or generate statistically generalizable conclusions. The cross-sectional design cannot capture how triage logic and caregiver burden evolve over the prolonged illness trajectory. In addition, hospital-based recruitment may have excluded caregivers facing the greatest barriers, including households that had entirely disengaged from formal care because of distance, cost, or loss of trust. These findings should therefore be interpreted as contextually transferable rather than universally generalizable.

Implications for Policy and Practice

Closing the gap between prescribed discharge instructions and rural execution requires pragmatic, low-cost, and context-sensitive reforms. Based on the present findings and existing stroke rehabilitation literature, we propose the following options for implementation and further evaluation:

Written discharge protocols and ready-made caregiver brochures: Discharge instructions should be provided verbally and in writing, using simple language and, where possible, local language translations. They should distinguish essential zero-cost actions from desirable but costly actions, specify follow-up dates, and provide clear medication resupply pathways. Ready-made brochures could support recall and allow other household members to participate in care when the primary caregiver is absent.

Routine caregiver screening: Caregivers should be treated as clinical stakeholders. Discharge protocols should include brief screening of the caregiver's physical capacity for manual handling, financial ability to execute the care plan, need for assistive devices, and psychological well-being. This would identify households requiring intensified counselling, referral, or social support before discharge.

Community and digital support pathways: To overcome geographic and financial barriers, basic post-stroke follow-up and rehabilitation support could be task-shared to trained community health workers or Village Health Teams. Where phone access exists, low-bandwidth tools such as phone calls, SMS reminders, WhatsApp-based education, or curated mobile health resources may reinforce discharge education and coordinate follow-up. Recent digital health literature highlights the potential of mobile health, telemedicine, and artificial intelligence to improve stroke prevention, rehabilitation, and continuity of care, while emphasizing that such tools require validation, digital literacy, data protection, and equity safeguards before implementation in resource-limited settings.[21,22]

Conclusion

In rural Uganda, informal caregivers are central to post-acute stroke care. The study findings suggest that expecting families to absorb the full clinical and logistical weight of rehabilitation without training, written guidance, or structural support creates predictable gaps between discharge advice and implementation. Recognizing, preparing, and supporting caregivers is therefore an important clinical and health-system requirement for improving long-term stroke outcomes in resource-limited settings.

Ethics Approval and Consent to Participate

Ethical approval was obtained from the Mbarara University of Science and Technology Research Ethics Committee (MUST-REC 26/01-20). The study was registered with the Uganda National Council of Science and Technology (UNCST). All participants provided written informed consent for participation, audio-recording, and publication of

anonymized responses/direct quotations. We respected the principles of the Declaration of Helsinki and CIOMS guidance regarding research with human participants, including avoidance of physical or moral harm.

Consent for Publication

All participants provided informed consent for publication of anonymized responses and direct quotations.

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Author Contributions

All authors made a significant contribution to the work reported, whether in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare that they have no competing interests in this work.

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