



# Stroke Survivors' Knowledge of Risk Factors for Stroke and their Post-Stroke Care Seeking Experiences: A cross-sectional study in rural southwestern Uganda

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## Summary

### INTRODUCTION

Stroke is a major cause of morbidity and mortality globally. The aim of this study was to examine the stroke survivors' knowledge of the risk factors for stroke, stroke warning signs and post stroke care seeking behaviour and signs of stroke in rural southwestern Uganda.

### MATERIALS AND METHODS

A mixed methods cross-sectional study was conducted from October 2018 to February 2019, with 25 stroke survivors in a general population cohort. Questionnaire were administered with 25 people and in-depth interviews conducted with 10 people. Descriptive statistics and thematic content analysis were applied to the quantitative and qualitative data, respectively.

### RESULTS

Participants described stroke as: a persistent numbness of a particular body part; a condition due to witchcraft; a sexually transmitted infection ('*obulwaddde bw'obukaba*'); a disease parents get when a daughter engages in pre-marital sex in their home ('*obuko*'). The participants reported that their awareness of their own hypertension and diabetes increased post-stroke. Participants also reported that their smoking prevalence decreased in the post-stroke period. Participants reported experiencing persistent headaches and numbness but did not associate them with stroke. Participants responding to the questionnaire described post-stroke care as biomedical (19/25), traditional (13/25) and for rehabilitation (10/25). The participants also described delays in seeking medical care because either they did not know what to do, or they thought the stroke was a self-limiting brief episode or that they required alternative treatment to biomedical care.



## CONCLUSION

**Misconceptions around the causes of stroke, and poor care seeking behaviour suggests a need for health education to improve community knowledge about risk factors and warning signs of stroke to help reduce incidence and improve post stroke treatment outcomes.**

**Keywords:** *Stroke; Non-Communicable Diseases; Hypertension; Africa; Qualitative Methods; Quantitative Methods*

*[Afr. J. Health Sci. 2021 34(2): 218-229]*

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## Introduction

Globally stroke is one of the leading causes of morbidity and mortality. In 2013 in adults aged 20 to 64 years the global prevalence of ischemic stroke was over seven million cases while for haemorrhagic stroke it was nearly four million people (1, 2). Most cases occur in low- and middle-income countries (3-6). In Uganda, estimated ischemic and haemorrhagic stroke incidence increased to 149.8 and 81.3 in 2010 from 126.9 and 57.2 per 100,000 people in 1990 (1-3, 7-9).

Stroke risk factors include hypertension, diabetes, smoking, abdominal obesity, overweight and harmful alcohol consumption as well as physical inactivity, hyperlipidaemia and HIV-infection (10, 11). Inadequate awareness of the risks for stroke and limited adoption of risk reduction strategies fuel a rising incidence of stroke in Africa (12, 13).

Reducing the risk of stroke requires individual, household/family, community and policy engagement to control alcohol consumption and tobacco use while ensuring a balanced, reduced salt intake and individual physical activity (14, 15) as well as reductions in stress (16-18). Successful primary preventive measures and timely medical attention soon after a stroke event is influenced by the knowledge and understanding people have (13, 19-21). However, evidence from reviews (19, 21) and research conducted in urban Kampala and surrounding areas among persons who had

suffered from a stroke, and the general population, have reported low levels of knowledge in recognizing and preventing stroke (16, 22-24).

In Uganda, information on stroke patients' and public knowledge about stroke risk factors, stroke warning signs and immediate medical care seeking behaviours is crucial to inform appropriate public health promotion campaigns. Such information can also be used to tailor people's education to prevent stroke and minimise stroke complications among people at high risk (25-27).

We report the findings of a study undertaken in rural Uganda to examine stroke survivors' knowledge of the risk factors for stroke, stroke warning signs and post stroke care seeking behaviour as well as their experiences of functioning and participating in everyday life.

## Materials and Methods

### *Setting*

The study was situated within a long-standing General Population Cohort (GPC), an open population cohort in a rural sub-county in Kalungu district in Uganda, about 150 km south of Kampala. The GPC, which covers a population of 22,000 people, was established in 1989 for the study of the HIV epidemic (28). Since 2010, the research questions have been widened to include the epidemiology and genomics of both communicable and non-communicable diseases. The population in the GPC is spread across the countryside in



villages defined by administrative boundaries with a few concentrated small trading centres. Rain-fed agriculture is the main economic activity. The major ethnic group are Baganda, (75%), immigrants from Rwanda (16%) and Burundi (3%) and other Uganda and Tanzanian tribes (6%). Only 13% of the residents attained education beyond primary level.

Among the research team of the GPC are village-based individuals known as “village recorders” who record and report monthly vital events (birth, death, in migration and out migration). This is in addition to operating a clinic overseen by a medical doctor from which health care is provided to research participants. Uncomplicated chronic conditions including HIV, hypertension and diabetes are diagnosed and managed through this clinic. Complicated cases are referred to the district or regional referral hospital for specialised care. Beyond a regional referral hospital are national referral hospitals offering specialised care for complicated cases countrywide (29).

People living in the study area have access to the government health care system which operates through a tiered system. At the district level, there is a district health office overseen by an experienced medical doctor, charged with resource distribution including staff deployment to districts and health centres IV, III and II. A health centre IV is run by a doctor and mandated to provide services at a district level and receives referrals from health centre IIIs. Health centre II is the first contact of professional health care, and these are either walk-ins or referrals from the ‘lowest’ tier, the village health teams. A village health team comprises two village members in charge of promoting health in the village, especially primary health care.

Diagnosis and management of uncomplicated chronic diseases including hypertension, diabetes, asthma, and HIV are

expected to be done at health centre II and IIIs. However, usually, health centre II refer suspected diabetic patients to health centre IIIs and higher-level facilities.

## *Sampling*

From December 2016, to gather information on the incidence of stroke in the population, a research assistant with medical training began visiting all the village recorders to obtain details of residents who the recorders suspected to have suffered a stroke. Evidence of suffering stroke was assessed using the Scandinavian Stroke Scale to determine the neurological impairment and stroke severity (30-32). Some of the people identified had documented evidence from a health facility of ever suffering from a stroke while others reported that they had paralysis or body weakness on one side of the body but had not sought professional help.

## *Participants*

Forty-nine people were assessed as having experienced a stroke in 2017. By October 2018, when this study took place, 25 (51%) were still alive. Between October 2018 and February 2019, these survivors were recruited into the study. The inclusion criteria were according to the assessment with the Scandinavian Stroke Scale, as noted above, and being able to respond to instructions in Luganda, local or English languages.

## *Data Collection*

After obtaining informed consent, both quantitative and qualitative data were collected from the participants by trained and experienced GPC survey team members and a social science researcher.

Quantitative data were collected using an electronic questionnaire programmed into a tablet from the 25 stroke survivors and care givers. The questionnaire explored the socio-demographic characteristics, stroke awareness, self-reported stroke risk factors (such as history of hypertension, diabetes, tobacco



smoking, alcohol use), side of body affected and health seeking behaviour before and after the stroke.

An experienced research assistant (FS) collected qualitative data from 10 of the 25 stroke survivors through in-depth interviews (IDI) using an interview-guide, observations, note taking technique for non-verbal communications. Ten participants were purposively selected based on ability to take part in the interviews (some participants were unable to engage in the interview because of the stroke).

The IDI guide covered the participants' health status with a focus on when the participant suffered a stroke, what health conditions they had before suffering a stroke, how the participant came to know that they had suffered a stroke, what care they sought, who helped, what challenges did they face in seeking care, their rehabilitation care awareness, risk factors about stroke and stroke warning signals. All interviews were conducted in the participants' homes, audio-recorded and lasted between 30 minutes and one hour.

## ***Data Analysis***

The questionnaire data were analysed using descriptive statistics to generate proportions.

The IDI data were transcribed and translated verbatim. Observations and notes taken during the interviews were incorporated into the translated scripts to enrich them with details about the interviews. All the enriched interview scripts were stored on password protected computers accessible only by the study team. At the first level of analysis, all scripts were read repeatedly by the research assistant (FS) to identify emerging themes, both inductive and deductive (based both on the study aim and themes emerging from the data). This process of theme identification was repeated by a social scientist (DB). Both the

research assistant (FS) and the social scientist (DB) discussed and agreed on the emerging themes and a coding framework. The second level of analysis involved coding the interviews thematically using the agreed coding framework. The third level of analysis involved developing detailed analytical memos on perceptions about stroke, awareness about stroke risk factors, access to hypertension and diabetes treatment prior to suffering a stroke, stroke impact experiences, and access to rehabilitation care. The detailed analytical memos were shared with the social science study team. Findings presented in this paper were distilled from the analytical memos illustrated with quotes extracted from the translated scripts.

## ***Ethical Considerations***

The Uganda Virus Research Institute Research Ethic Committee and the Uganda National Council for Science and Technology gave ethical approval (GC/127/18/10/688) and clearance to conduct this study. All study participants provided written or thumb print-witnessed informed consent prior to data collection. They were assured of privacy and confidentiality. They were compensated for their time and expenses related to study participation in accordance with Uganda National Council for Science and Technology guidelines.

## **Results**

### ***Socio-Demographic Information***

The 25 stroke survivors had a mean age of 61 (SD= 12.7), range: 25-84 years, 12 participants were women, 19 participants had completed primary education, two had not, and three had secondary/tertiary education. Fifteen of the participants had hypertension and three had diabetes mellitus (presented in Table 1 below).



*Table 1: Socio-Demographic Information of the Study Participants*

Variable	Categories	Frequency N =25 (%)
Sex	Male	13 (52)
	Female	12 (48)
Age (years)	Mean (SD)	61 (12.7)
	Range	25 - 84
Education level	No education	2 (8)
	Primary	19 (76)
	Secondary	1 (4)
	Tertiary	3 (12)
Marital status	Married, living together	11 (44)
	Married, not living together	12 (48)
	Single/widow	3 (12)
Hypertension	Yes	15 (60)
	No	10 (40)
Diabetes	Yes	3 (12)
	No	22 (88)
Smoking	Yes	5 (20)
	No	20 (80)

## *Perceptions about Stroke and its Causes*

Seven of the 10 respondents who took part in the IDIs described stroke as persistent numbness of a particular body part. Four of the participants said that stroke was a disease parents get when their daughters engage in pre-marital sex at their parents' home.

These respondents further described stroke as a spiritual condition where the remedy lay in non-biomedical treatment.

*'...friends advised me that this sickness is traditional and was called; 'obuko' [a disease affecting the nervous system] that had to be*

*treated using traditional herbs. They added that the sickness will take long to cure because I had started using western (biomedical) medicine. I started using traditional herbs in addition to western medicine' -72-year-old woman.*

Two respondents thought that stroke was a sexually transmitted infection (*'obulwadde bw'obukaba'*).

## *Awareness on Stroke Risk Factors*

Data from the questionnaire showed that prior to suffering a stroke, 15 and eight of the 25 stroke survivors reported that they took alcohol and smoked, respectively. Three



participants knew that they had hypertension and were on treatment. This number increased from 3/25 to 15/25 after suffering a stroke.

One respondent in the IDIs described that when they suffered a stroke and sought health care, they underwent several medical examinations and were found to have hypertension and immediately initiated on treatment:

*'I only came to know that I was sick with hypertension when I suffered the numbness and ended up at the health facility. .... the health workers there tested my heart and found that my heart was using a lot of force to pump the blood around my body. They put me on high blood pressure treatment until now'-*

**56-year-old male.**

None of the participants who were interviewed in the IDIs reported knowing about risk factors for suffering a stroke. Some of participants explained that they had been advised by health workers to reduce both alcohol and tobacco consumption after suffering a stroke. However, participants said that health workers did not explain that continued smoking and/or alcohol taking increased their risk of suffering another stroke.

### ***Access to Post Stroke Care***

Nineteen of the 25 stroke survivors reported seeking biomedical care for the stroke. More than half of the questionnaire respondents sought alternative or traditional/herbal care while about a quarter did not seek care at all.

The IDI respondents reported that there were delays in seeking post stroke care which were attributed to being unaware that once one suffered a stroke, they needed urgent medical attention. Seven out of 10 of the respondents explained that they thought that the stroke was a brief self-limiting condition. When the numbness did not disappear by itself, some participants then considered it worthwhile to seek biomedical care.

Eight of the 10 IDI respondents reported having sought both biomedical and alternative (traditional) care when they suffered the stroke and explained that they followed advice from the community members.

*"I first used herbal medicine when I got this illness of numbness because those who were coming to check on me insisted that it was a local illness called [obuko] which needs to be treated locally. When I could not notice a big improvement, I went to the health facility. The health workers there, examined me and initiated me on daily anti-hypertensive treatment. I am now using both local herbs and the medication I get from the health facility" -72-year-old female.*

Unlike this woman, who used both biomedical and traditional treatment at the same time, others said that they used either biomedical or alternative care but not both.

### ***Stroke Impact Experiences***

Eleven of the 25 study participants could not walk by themselves without being assisted after suffering the stroke. Of these, only two could not walk at all, while four could only walk with support of another person. Five participants could walk when assisted. Participants during the IDIs described their discomfort at being helpless in performing activities they used to do with a lot of ease.

*"Before, I suffered from this stroke I was well. I could do my work without any hindrance. I slept well and when I woke up, I sensed numbness in my right leg. I tried to walk but I could not, and I fell on a bed. The neighbours helped to lift me from the bed, and they hired a car that took me to the health facility. Although I was treated, my leg became lame, and I am now using a stick to walk. My right arm has no strength and my mouth turned on one side" -72-year-old female*



As this woman describes, her ability to function changed very drastically after suffering a stroke. Others described similar dramatic changes in their functioning which made them dependent on the care of others:

*“I was attending a meeting when I got this sickness. When I stood up, I realised that I couldn’t say any word. I felt like I was swollen in the face, failed to talk and I decided to sit down. I asked the person who was sitting next to me to tell me how my appearance looked like because I was feeling as if I had a swollen face. The person told me that I appeared normal. When I went back home, I failed to move from the car, my right leg was paralysed, and I was supported to go in the house. From that day, I never walked or sat up again. I felt paralysis all over the body. My wife and brother are the ones who bathe, dress and feed me” -62-year-old male.*

*“I am now helpless and in the morning before my granddaughter goes to the garden, she first helps me to go out in a shade of a mango tree. If it rains before she comes back from the garden, it rains on me because I can’t walk or stand” -72 old year-old female.*

Most of the respondents in the IDIs reported that even when they sought treatment, the experiences of having suffered a stroke continued. Health workers had explained to them that it would take some time before they could fully regain their pre-stroke body mobility and functions. The length of time it took for some to see signs of improvement led them to seek alternative (traditional) forms of care.

## ***Access to Rehabilitation Care***

Ten of the 25 study participants reported having sought rehabilitation care after suffering a stroke. In the IDIs, six participants said they were unaware of the location of the rehabilitation medical services. The four participants who were aware of the

rehabilitation services reported that these services were too far away. They also added that they could not afford the cost of the services and the transport fare to access them.

*“When I was discharged from the health facility having been admitted for a period of two weeks, the health workers told me that the sickness would take some time to heal. They [health workers] advised me to seek rehabilitation services twice a week but I had never heard of them [rehabilitation services]. The health facility was far away from my home, and I could not afford the transport costs. The friends who used to come to check on me advised that I use traditional medicine instead to treat the paralysis” - 58-year-old, married.*

A third of the 25 stroke survivors who participated in the questionnaire reported seeking and using alternative medicine to improve the affected body part function, which was also mentioned by IDI participants, in this case as a solution to the high cost of accessing rehabilitation care:

*“...the nurse told my carers that the sickness [stroke effects] will take some time to go away and that they had to bear with the situation. She advised that I had to go for rehabilitation services at the hospital. I have never gone back because I can’t afford the transport. I have resorted to using traditional medicine. It [traditional medicine] has helped me. I can now walk with the support of the stick” -60-year-old married.*

Our findings indicate that participants had little knowledge of the signs and symptoms of stroke despite having experienced them. About a quarter of the stroke survivors did not seek care at all. Among those who sought post stroke care, people accessed both biomedical and traditional/herbal medicine, sometimes resorting to one after the first form of treatment they tried had failed. Post stroke



rehabilitation care was seldom sought because of cost and distance.

## Discussion

Few stroke survivors in our study had knowledge of the causes and treatment of stroke, a finding which is consistent with other studies in Uganda (11, 23, 24) as well as research in South Africa (33), Ghana (34) and Nigeria (13, 20). We found little or no awareness about the stroke risk factors like smoking, alcohol taking, diabetes mellitus and hypertension. Seeking post stroke biomedical care was a pathway to diagnosis and initiation of treatment for diabetes mellitus and hypertension. Our findings differ from the results of a population based survey in Wakiso district, Uganda, where hypertension was the most identified stroke risk factor among both rural and urban participants (25). Elsewhere in Africa, knowledge of stroke risk factors has been reported to be variable (12, 24, 35, 36). Reports from some higher income countries report low knowledge levels about stroke risk factors and its warning signs (19, 37-39).

We found that the stroke survivors delayed seeking care mainly because they did not know that their condition required immediate medical attention. This was similar to what was found in research in Kampala, Uganda, India and South Africa where over half of those who suffered a stroke and died at home had not sought any care at all (16, 39-41).

Some of the stroke survivors in our study believed that their stroke had been caused by supernatural causes and would not respond to biomedical care. This finding is consistent with reports from Ghana, Nigeria and Sotho that stroke is often regarded as a spiritual disease (13, 36, 39, 42, 43). However, in a South African stroke prevention initiative study, the majority of stroke survivors sought care from a wide range of sources including biomedical, traditional and churches (44).

We found that barriers to seeking post stroke rehabilitation services included inability to afford the service and transport costs. The inability to afford the costs of rehabilitation services is similar to that reported from another study in urban Kampala where carers of stroke patients complained about the cost of rehabilitation services (45). Elsewhere in Sub Saharan Africa and India, availability and access to stroke care was also limited due to cost, among other barriers (36, 41, 43, 44, 46-49).

## Study Strengths and Limitations

Our study, using both qualitative and quantitative data collection methods is among the few studies that have reported on first-hand experiences of post stroke health care seeking behaviour among stroke survivors in a rural area. The knowledge from this study is based on both quantitative and qualitative data. However, a limitation of our study is the small sample size. Nevertheless, the mix of data provide insights into stroke survivors' health seeking behaviours. Overall, the study aimed at a detailed understanding of the stroke survivors' knowledge of risk factors for stroke, post stroke health care seeking experiences and behaviour.

## Conclusion

In a rural area in southwestern Uganda, we found that among people who had suffered a stroke, the knowledge of the causes of stroke, and the treatment required was low. This limited awareness and misconceptions about stroke risk factors and warning signs coupled with poor health seeking behaviour indicate that health education is needed to raise awareness.

## Conflict of Interest

All authors declare that there are no potential conflicting interests and therefore have nothing to declare.



## Authors' Contributions

DB, SG, GE, LvK, and JS conceived and designed the study. FS, DB and JS participated in data collection and analysis and drafted the original manuscript. All authors revised and approved the final version of the paper.

## Funding

The MRC/UVRI and LSHTM is jointly funded by the UK Medical Research Council (MRC) and the UK Department for International Development (DFID) under the MRC/DFID Concordat agreement and is also part of the EDCTP2 programme supported by the European Union. This study was funded by a grant from The Swedish Research Council grant number 2014–28–63 and the Karolinska Institutet, Stockholm, Sweden.

## Acknowledgements

We acknowledge the contributions of the MRC/UVRI and LSHTM Uganda Research Unit General Population Cohort study team. We are particularly grateful to all the study participants for the time and information they shared with us.

## Data Availability

The data are deposited in the MRC/UVRI and LSHTM archive. Access to the anonymised data is available on request to the corresponding author.

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