

ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE
DEPARTMENT OF NEUROLOGY



RESEARCH THESIS

**HEALTH-RELATED QUALITY OF LIFE OF STROKE
SURVIVORS HAVING FOLLOW-UP AT THE STROKE CLINIC
IN TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS
ABABA, ETHIOPIA: A QUALITATIVE STUDY**

**WALELIGN WORKU (MD)
THIRD YEAR NEUROLOGY RESIDENT**

**A RESEARCH THESIS TO BE SUBMITTED TO THE, DEPARTMENT OF
NEUROLOGY, COLLEGE OF HEALTH SCIENCES, ADDIS ABABA
UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR
THE SPECIALTY CERTIFICATE IN NEUROLOGY**

FEBRUARY 2025

Health-Related Quality of Life of Stroke Survivors Having Follow-Up
at the Stroke Clinic in Tikur Anbessa Specialized Hospital, Addis
Ababa, Ethiopia: A qualitative study

Research Thesis

Investigator: - Walegn Worku (MD) Neurology Resident

Advisors: -

Dr. Abenet Tafesse (MD) Consultant Internist and Neurologist, Associate
Professor of Neurology)

Dr. Yared Zenebe (MD) Neurologist, Assistant Professor of Neurology,
Cognitive Neurology Subspecialist)

Dr. Seblewongel Asmare (MD) Neurologist, Assistant Professor of
Neurology)

Dr. Mulugeta Tamire (MPH, PhD.) Assistant Professor of Public Health

Address of the Investigator: Walegn1992@Gmail.Com, +251923163459

February 2025
Addis Ababa, Ethiopia

Acknowledgment

First, I give glory to GOD, and then I would like to thank the Department of Neurology for giving me the chance to conduct this research project which is closest to my heart and I am curious about. Also, I would like to express my heartfelt gratitude to my advisors Dr. Abenet Tafesse, Dr. Yared Zenebe, Dr. Mulugeta Tamire, and Dr. Seblewongel Asmare for their continuous support, valuable comments, and constructive advice.

Finally, I would like to thank everyone who will contribute to the success of this research study.

Table of Contents

ADDIS ABABA UNIVERSITY	i
COLLEGE OF HEALTH SCIENCES	i
SCHOOL OF MEDICINE	i
DEPARTMENT OF NEUROLOGY	i
Acknowledgment	iii
Acronyms	v
ABSTRACT	vi
1. Introduction	1
1.1 Background	1
1.2 Statement of the Problem	2
1.3 Significance of the study	3
2. Literature Review	4
2.1. Brief Historical Account of Stroke	4
2.2. Epidemiology and causes of stroke	4
2.3. Health-Related Quality of Life in Stroke	6
2.4 Rehabilitation and recovery after stroke	7
3. Objectives	8
3.1. General objective	8
4. Methods and Materials	9
4.1. Study setting and period	9
4.2. Study Approach	9
4.3 Participants and Recruitment	9
4.4 Sample size	10
4.5. Data Collection	10
4.6. Data analysis	10
4.7. Trustworthiness	10
4.8. Ethical considerations:	11
4.9. Operational Definition	11
5. Results	12
Physically and Psychologically Disempowerment	13
<i>Physically struggle</i>	13
<i>Psychological and Emotional Struggles</i>	15

Social and Economic Impact	16
<i>Social Impact</i>	16
<i>Economic impact</i>	17
Spirituality (The belief in God).....	18
Work area challenges.	19
6. Discussion	20
7. Strengths and Limitations of the Study.....	21
8. Conclusions.....	21
References.....	22
Appendixes	27
Appendix 1: Information sheet	27
Appendix II: Consent form	28
Appendix III: Interview Guide (English Version	29
አባሪ III: የቃለ መጠይቅ መመሪያ (በእማርኛ ጽሁፍ).....	32

List of Tables

Table 5. Participants' background characteristics results, TASH, 2025

Acronyms

AAU	Addis Ababa University
ADL	activities of daily living
AHA	American Heart Association
CHS	College of Health Sciences
CT	Computerized tomographic scan
EuroQol	European Quality of Life
HRQOL	Health-related quality of life
HRQLISP	Health-Related Quality of Life in Stroke Patients
MD	Medical Doctor
MRI	Magnetic resonance imaging
NEWSQOL	Newcastle Stroke-Specific Quality of Life
PSD	Post-stroke depression
RCT	Randomized controlled trial
SAQoL-39	Stroke and Aphasia Quality of Life Scale -39
SF-36	Short Form 36 Health Survey Questionnaire
SNNPR	Southern Nations, Nationalities, and Peoples' Region
SSQoL	Stroke-Specific Quality of Life Scale
TASH	Tikur Anbesa Specialized Hospital
TOAST	Trial of organization” 10172 in Acute Stroke Treatment
WHO	World Health Organization

ABSTRACT

Background: Stroke is the second leading cause of death and the third leading cause of disability worldwide. Patients who survive the acute insult often suffer from multiple morbidities including physical, psychological, cognitive and socio-economic burdens. Prior studies have shown that most stroke survivors face a low health-related quality of life (HRQOL). Despite the growing prevalence and incidence of stroke in Ethiopia, there is a dearth of information on the health-related quality of life (HRQOL) of stroke survivors in the country. Our study aims to bridge this knowledge gap and inform the responsible bodies to design mitigating strategies that will improve stroke patients' quality of life.

Objectives: This study aims to understand the health-related quality of life (HRQOL) of adult stroke survivors who have follow-up at the stroke clinic of in Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Methods: A qualitative study using a descriptive phenomenology approach was conducted. The study used a non-probability purposive sampling method to find the maximum variation in participants by age, gender, residence, type, and duration of stroke. After explaining the objectives and importance of the study, consent in written form was taken from all participants. Data was collected through an in-depth interview using a semi-structured questionnaire and voice recorder. The audio recordings were transcribed and qualitative thematic analysis was performed using the NVIVO 15 software.

Result: A total of 16 participants were enrolled for an in-depth interview until saturation was achieved. There were 10 male and 6 female participants. 13 Participants were from Addis Ababa. Four themes emerged from the data. The first was physical and psychological disempowerment, in which survivors reported severe motor deficits (e.g., limb weakness, speech impairments...), dependency, and emotional struggles, including identity crises, anxiety, and depression. The second theme was the socioeconomic burden from substantial personal spending on medications, transportation, and physiotherapy service which exacerbated the decrease in activities of daily living (ADL). The third theme, which is work area challenges like job loss and workplace discrimination, on the other hand, was a challenge for our stroke survivors. Social stigma and isolation also had a major impact on performing their ADLs. According to the findings, Spirituality as a resilience factor, on the other hand, had the most positive impact on survivors.

Conclusions: Our findings showed that stroke survivors faced multidimensional challenges spanning from their home to their environment that severely impair their HRQoL. The challenges identified in this study were related to physical disability, psychological distress, economic crisis, social isolation and stigma, and work place challenges. These findings underscore the need for a comprehensive intervention that will address the physical, emotional, and socioeconomic needs of stroke survivors. Notably, spirituality had a positive impact on survivors' HRQOL, suggesting its potential integration into care plans.

1. Introduction

1.1 Background

A stroke, or cerebrovascular accident, is defined as an abrupt onset of a neurologic deficit that is attributable to a local vascular cause(1). Therefore, the definition of stroke is clinical, and laboratory tests, including brain imaging, are used to confirm the diagnosis. These include ischemic and hemorrhagic stroke, which are the most common and devastating diseases(1). Approximately 88% of these strokes are ischemic, and 8%–12% of ischemic strokes result in death within 30 days(2)

Worldwide, cerebrovascular disease (stroke) is the second leading cause of death and the third leading cause of disability. Stroke is one of the most important global health problems affecting life expectancy (3)Unlike other disorders, strokes occur suddenly, leaving patients and families unprepared for the consequences. Over the past 20 years, the global incidence of stroke among adults aged 20 to 64 years has increased by 25 %. Each year, more than 83,000 children and adolescents under the age of 20 also suffer a stroke worldwide (4)

At least 7 million people in China suffer a stroke each year. The incidence and recurrence rates of stroke are high. With the increase in the aging population in China, cardiovascular and cerebrovascular diseases, including stroke, become the leading causes of death. Stroke patients are physically, psychologically, socially, and economically burdened, and their health-related quality of life (QOL) is low (5,6). In low- and middle-income countries, both stroke incidence and prevalence have increased(4). The years of potential life lost from stroke are thus large and have significant socioeconomic consequences in sub-Saharan Africa(7)

Ethiopia also shares the global problem, and strokes are becoming more common. The global Burden of Disease Study reported that there were 52,548 cases of stroke and 38,353 deaths in Ethiopia in 2016 (8,9). Previous studies showed that in-hospital mortality rates for stroke patients ranged from 11% to 44%. Most patients were disabled in some way, such as physical weakness and inability to communicate. In addition, in all studies, the proportion of patients with hypertension, a known stroke risk factor, was high. (10–12) In Gondar, Ethiopia, a study showed that social support and lower disability status were associated with higher health-related quality of life (HRQOL), whereas disability and depression were associated with higher HRQOL (9)

HRQOL is a broad concept that incorporates a person's physical health, psychological state, level of independence, social relationships, and personal beliefs in a complex way and focused manner, focusing on the impact of health status on HRQOL (13). Thus, it is a subjective assessment of the patient's current level of functioning and satisfaction with his/her health compared to what they believe to be ideal. In other words, it is an inherent attribute of self-perception of various aspects of the patient's overall health. HRQOL is an aspect of quality of life that is affected by a disease, or the impact of health status or healthcare interventions on an individual's subjective experience of functional, cognitive, social, and psychological processes (14).

Impairment in activities of daily living (ADL) is common in stroke patients.

One study showed that nearly 1 in 5 stroke patients with independent mobility experienced ADL worsening 2 years after onset(15). Risk factors for ADL impairment include older age, vascular risk factors>3, and post-stroke depression (PSD)(15). The study also recommended enhanced education on post-stroke health management, drug compliance, and additional measures to improve balance and depression among stroke patients(15).

More efficient treatment of stroke in the acute phase, significant reductions in hypertension, tobacco smoking, increased use of anticoagulants for atrial fibrillation, and the fact that Most strokes are not fatal, leading to an increase in stroke-disabled survivors(16).

1.2 Statement of the Problem

Today, stroke remains one of the leading causes of death and disability worldwide. Mortality from stroke is particularly high in Eastern Europe and Asia. Although the number of strokes has decreased in the United States, 7 million Americans over the age of 20 still have a stroke. By 2020 19 of the 25 million annual stroke deaths were in developing countries(17).

In one study conducted in sub-Saharan Africa (Zimbabwe, Tanzania, Gambia, South Africa, and Burkina Faso) among survivors, approximately 30% require assistance with activities of daily living, 20% require assistance with ambulation, and 16% require institutional care(18).

In Ethiopia, stroke is becoming more common and the death rate is increasing. For example, a 2020 meta-analysis showed that the mortality rate in stroke patients was 18%. The highest magnitude of in-hospital mortality of stroke was observed in the Southern Nations, Nationalities, and Peoples' Region (SNNPR), while the lowest was noted in the Tigray region(19)

Although stroke causes significant functional sequelae, morbidity, and mortality, objective assessment approaches such as clinical assessment and biochemical assessment fail to show the impact of the disease. HRQOL is becoming a significant tool for assessing the disease's effects from the patient's perspective, especially in stroke(20).

However, despite its significance, there are few institutional-based cross-sectional quantitative studies done so far around stroke patients and the majority failed to address the HRQOL of stroke survivors. Therefore, this study aimed to assess the HRQOL of adult stroke survivors and identify factors associated with poor HRQOL among stroke patients who are on follow-up at the stroke clinic in Tikur Anbesa Hospital. Identifying factors significantly associated with HRQOL may serve as useful pointers for health professionals in providing customized interventions to improve the HRQL of this group of people

1. 3 Significance of the study

In Ethiopia, very little is known about factors associated with decreased health-related quality of life of stroke patients. There is little published data or research done on HRQOL on stroke patients and among those published, the majority of them failed to address the HRQOL of stroke survivors. This study will try to assess the health-related quality of life of adult stroke survivors. We will try to identify some of the factors associated with poor quality of life and we will assess how patients are living with their disability. Comparing the health-related quality of life of our patients to the rest of the world so that areas that need to be improved can be identified for intervention.

The study is useful in providing baseline information as well as forwarding recommendations, as well as initiating other investigators to work further on the same and/or other related issues based on the gaps that were identified. It will also provide crucial baseline information for, public health planners, policymakers, and implementers to plan and design appropriate intervention strategies.

For health institutions, the study can list the gaps and identify factors that decrease the quality of life of stroke survivors also taking into consideration our living standards and resource limitations.

2. Literature Review

2.1. Brief Historical Account of Stroke

Before the common era, by Hippocrates, strokes were first noted in 460 to 370 B.C. He recorded that occlusion of the “stout” carotid artery caused loss of consciousness(21).

Stroke symptoms at this time were called apoplexy. Johann Jacob Wepfer in 1658, reported that apoplexy resulted from obstruction of the carotid or vertebral artery or bleeding into the brain.

After the work of Giovanni Battista Morgagni, John Cheyne, and other scientists Between 1682 and 1836, they can relate clinical presentations of stroke with morbid anatomical findings of the brain (21). In 1828 John Abercombie classified apoplexy into primary apoplexy (focal deficit or stupor with large intra-cerebral hemorrhage or infarction), probable subarachnoid hemorrhage (with stupor and headache but no focal deficit), and small infarct or hemorrhage with focal deficit (21). In the last 20th century, the invention of computerized tomographic scan (CT) and magnetic resonant imaging allowed the definition of the site of brain infarction and hemorrhage.

Later in the 21st century functional imaging procedures allowed the evaluation of cerebral perfusion and metabolism, which opened the door for the establishment of stroke units that offer effective care for stroke patients and survivors. (22)

2.2. Epidemiology and causes of stroke

Stroke is defined by the World Health Organization (WHO) as the sudden development of focal or global brain dysfunction lasting 24 hours or longer. The most recent definition of central cerebral infarction is based on neuropathology, neuroimaging, and/or evidence of ischemic injury (symptoms persist for ≥ 24 hours or until death and exclude other causes). It is one of the leading causes of life-threatening cerebrovascular disease leading to long-term disability (23).

Stroke can be divided into ischemic stroke and hemorrhagic stroke. Ischemic strokes are caused by an interruption of the blood supply to a part of the brain resulting in sudden loss of function, while hemorrhagic strokes are caused by rupture of blood vessels or structural abnormalities in the vessels. Approximately 88% of strokes are ischemic, and 8% to 12% of ischemic strokes lead to death within 30 days (17). There are many classifications for ischemic stroke; the ORG 10172 Trial of Acute Stroke Treatment (TOAST) protocol is the most widely used. Accordingly, ischemic stroke can be divided into five types, pathologically or etiologically. Hemorrhagic stroke is further divided into cerebral hemorrhage (80%) and subarachnoid hemorrhage (17).

There are a wide range of stroke risk factors. The traditional stroke risk factors can be divided into modifiable and non-modifiable. Modifiable risk factors include diabetes, heart disease, high blood pressure, high cholesterol, sedentary lifestyle, atrial fibrillation, alcohol consumption, and smoking. Nonmodifiable stroke risk factors include older age, male gender, ethnicity, family history, and prior history of stroke. Among non-modifiable risk factors, age is the most common and stroke occurs twice every ten years in people over the age of 55(17,21).

Strokes rarely occur in people under 40. When this happens, the main cause is high blood pressure. Hypertension is estimated to cause more than 12.7 million strokes worldwide. (2) High blood pressure is the most common risk factor after age. A study conducted in Ethiopia also showed that hypertension is the leading cause of modifiable risk factors in stroke (19) However, the difference in overall survival time between hypertensive patients with their first adult stroke and non-hypertensive patients was not significant. Early recognition and treatment of stroke complications and comorbidities and close monitoring of comatose patients may increase the hospital survival rate of stroke patients. (24)

The burden of stroke in the world has increased significantly in recent years. Some of the reasons for the increase in stroke frequency are aging population growth and the increased frequency of modifiable risk factors in low and middle-income nations(25). Stroke can have an impact on cognitive and motor function, depression, and imbalance(26). A study done in 2018, found that more than 50 % of stroke survivors were chronically impaired, which affected their social, economic, and overall quality of life(27).

In the past, stroke was considered a disease of the developed world, but now the burden of stroke seems to be shifting to the developing world, where there are currently 4.85 million stroke deaths and 91.4 million disabilities annually, compared with 1.6 million deaths and 21.5 million disabilities in high-income countries. It is largely due to efforts to lower blood pressure and reduce smoking. However, the overall rate of stroke remains high due to the aging of the population. (25). According to a 2021 study in Ethiopia, the recovery rate after stroke in the study population after 2017 was low, which was due to an increased rate of exposure to risk factors due to ongoing epidemiological and demographic transition(28). Limited data are available on the incidence of stroke in Ethiopia, including a lack of patient demographics and risk factors, diagnostic outcomes, and interventions for care (29).

Problems such as lack of ability to afford, optimal medical infrastructure and personnel, unequal access to medical care, limited medical knowledge in the medical field, and problems with adherence and compliance all limit the effectiveness of primary and secondary prevention in stroke care(27).

2.3. Health-Related Quality of Life in Stroke

It is well known that stroke has significant effects on physical, mental, and social aspects of life. The areas most affected include self-care (e.g., eating, bathing, dressing), mobility (e.g., transferring, pushing a chair, walking), memory, language, problem-solving, and intelligence. Moreover, people who have had a stroke also suffer from depression. The nature and severity of disability depend on clinical parameters such as the location of the lesion and demographic characteristics such as age(20,26,30–33).

The World Health Organization defined the term health in 1948 as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. After 1984, the World Health Organization revised this that any health measure must take into consideration “to the extent which an individual or group can realize and satisfy needs and to change or cope with his environment”.

Following the definition of health in 1993 the WHO quality of life group defined “quality of life” as “an individual’s perception of his/her position in life in the context of the culture and value system in which he/she lives and about his/her goals, standards, expectations, and concerns(34).

Stroke has a significant impact on society through its negative effects on emotional, physical, and socio-economic status. It affects the abilities and quality of life of those who survive cerebrovascular damage. Measuring this impact is nontrivial, not only because patients’ disabilities (such as communication impairments) themselves interfere with assessment, but also because many different domains of well-being and functioning can be affected. (35)

Health-Related Quality of Life (HRQoL) is there for use as a valuable parameter for measuring outcomes in modern medicine and is highly important in the assessment of the impact of disease on the patient’s life and evaluation of the utility and disability associated with various health states(36). HRQOL measures emotional, social, physical, economic, and subjective feelings of well-being and hence can be used in identifying and prioritizing areas of need of individual patients. A study in Auckland found that HRQoL was better in stroke patients compared to normal controls, and despite significant ongoing physical disability, stroke patients appeared to adjust well psychologically to their illness.

In contrast, a study conducted in Canada found significant impairment in all HRQoL dimensions except the autonomy and purpose of life dimensions(37). This was supported by a study out of Kansas City that showed that even in people who have had a stroke that are thought to have recovered, stroke still affects hand function as well as activities of daily living and participation. In another study conducted in 2023 at the People’s Hospital of Deyang City, Sichuan Province, China, ADL deterioration was common among stroke patients with independent mobility worsening at 2 years after onset. Among the risk factors for ADL deterioration were aging, vascular risk factors>3, and PSD while elevated Berg Balance Scale (BBS) score at discharge was protective(38).

In African studies including Nigeria, Ghana, and Ethiopia, stroke exerted a multidimensional impact on HRQoL, which was most pronounced in the physical, psychological, cognitive, and social interaction domains (20,39,40)

Evidence from many studies shows that the determinants of HRQoL in stroke patients include a wide spectrum including depression, social support, caregiver characteristics, social class and economic status, functional status, age, comorbidity, and frequency of laughter and time after stroke(20,40). Measuring HRQoL is important. This could be measured through generic or disease-specific QOL measures. Generic measures assess the HRQoL of different diseases across populations.

While disease-specific measures are more patient-centered, sensitive, and responsive in assessing HRQoL, examples of generic HRQoL measures are the SF-36 and EuroQol.

Stroke-specific measures include the Niemi QoL scale, Stroke Impact Scale (SIS), Stroke and Aphasia Quality of Life Scale -39 (SAQoL-39), Newcastle Stroke-Specific Quality of Life Measure (NEWSQOL), Health-Related Quality of Life in Stroke Patients (HRQoLISP)Stroke-Specific Quality of Life Scale (SSQoL) (41).

Disability affects HRQoL in stroke patients. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) defines disability as a restriction or lack of ability to perform an activity within the range considered normal for a normal human being (42).

Disability measures included the Modified Rankin Scale, the AHA Stroke Outcomes Scale, the Barthel Index Scale, and the Stroke Severity Scale. They assess basic daily activities such as eating, dressing, bathing, toileting, and moving (36)

2.4 Rehabilitation and recovery after stroke

A rehabilitation program that includes education and interactive group therapies could be very useful(43). Despite increased workload, limited social life, physical problems, and knowledge, financial deficits were challenges for family caregivers, but their own strength and supportive social networks helped them to compassionately care for their stroke survivors.

The effectiveness of home-based rehabilitation after discharge from inpatient care compared with outpatient (or hospital-based/day hospital) rehabilitation has been studied in several RCTs. The study found no difference in the effectiveness of home-based rehabilitation provided in a domiciliary setting compared to a hospital-based (outpatient or day hospital) setting. Home-based or hospital-based (outpatient or day hospital) rehabilitation should be considered for people who have had a stroke(43)

3. Objectives

3.1. General objective

- To assess the health-related quality of life of adult stroke survivors who are having a follow-up at stroke clinics in TASH.

3.2. Specific objectives:

- To understand the health-related quality of life in adult stroke survivors.
- To explore factors that contribute to decreased health-related quality of life in adult stroke survivors.

4. Methods and Materials

4.1. Study setting and period

The study was conducted at the stroke clinic of Tikur Anbessa Specialized Hospital, from November 2023 – February 2025. Tikur Anbessa Specialized Hospital is located in Addis Ababa and was established in 1964. It is Ethiopia's largest tertiary referral hospital with a total bed number of approximately 700 and is now a major training center for treatment and advanced training in most disciplines. It also provides country-specific treatment not found in other public or private schools.

It has the first and largest Neurology training center which is staffed with specialist and sub-specialist Neurologists, giving Neurology specialty programs for residents and pediatric fellows. It has a stroke unit which was established in September 2022. It consists of 5 beds, Neurologists, Stroke Nurses (Stroke trained Nurses), Neurology residents, and primarily led by well-experienced Neurologists assigned by the Department of Neurology. It has a specialized ward for acute stroke patients with administration of IV thrombolysis for the indicated patients and continuous monitoring of vital parameters.

The stroke clinic of Tikur Anbessa Hospital is a specialized outpatient clinic for patients who have completed their acute stroke care and need follow up. The clinic runs once a week with an average of 40-50 patients seen each day.

The presence of a substantial number of patients following this clinic made it the perfect place to undertake this study.

4.2. Study Approach

A qualitative study using a descriptive phenomenology approach was conducted with interviews using a semi-structured type of open-guided interview. This was chosen as the most powerful technique because descriptive phenomenology is a common methodology employed in social science research to investigate and describe people's lived experiences(44)

It is a very recent approach, which was first developed in Gothenburg, Sweden by Ferences Marton and co-workers in the 1970s. In this approach, the aim is to study the variation of people's conceptions or perspectives of a given phenomenon in their surrounding world; about different ways of understanding(45).

We chose this approach to gain an in-depth understanding of the quality of life of adult stroke survivors in their everyday life experiences as well as to ensure a close rapport between interviewer and interviewee.

4.3 Participants and Recruitment

Participants were all stroke survivors who had no preexisting physical or cognitive disability prior to the stroke, were age ≥ 18 years, and had a minimum of three months since the stroke occurred who came on appointment dates and had follow-up at the neurology stroke clinic of TASH.

Participants were included regardless of their gender, level of education, monthly income, or whether they were from urban or rural areas.

4.4 Sample size

The study used a maximum variation/heterogeneous non-probability purposive sampling to include a diverse range of participants.

Participants are selected based on their characteristics and the objectives of the study.

16 participants were involved in this study .

4.5. Data Collection

After obtaining written consent from the participant, first demographic data were collected by trained data collectors followed by a semi-structured guide that includes open-ended questions. An in-depth interview was conducted in person using an open-ended interview guide. The interview guide was prepared in English and translated into Amharic language. All interviews were carried out in the follow-up clinic room in person last an average 25-40 minute and audio-recorded using a digital recorder while taking appropriate notes.

The interviews were carried out in Amharic language; however, translators were used for patients who were unable to understand Amharic.

4.6. Data analysis

Qualitative thematic analysis was used because of the need to analyze data by closely examining text (like interview transcripts) to identify recurring, patterns, ideas, and Themes (46). The analysis was conducted in several steps. All audio recordings were transcribed verbatim and were translated into English for analysis. A codebook was prepared , data reduction and coding and development was started after review. Then we looked over the code we had created, identified patterns among it, and started coming up with themes. Lastly, we reviewed, named, and defined the themes. Nvivo 15 software was used for the analysis.

4.7. Trustworthiness

Before starting the data collection different steps were taken to determine the rigor of the research findings. To ensure credibility, the researcher had qualitative research knowledge, was familiarized with the study area and the patients in the follow-up clinics, and he/she led the interview. To ensure transferability, data collectors were familiarized on each component of the interview and probing, with documentation. The principal investigator was checking the completeness and adequacy of ideas during data collection. Frequent debriefing sessions were conducted between the researcher and advisors to ensure dependability. To ensure replicability and reliability, the primary investigator applied appropriate and consistent analysis of the data. To ensure Dependability and Conformability Frequent debriefing sessions were conducted between the researcher. The analysis involved the involvement peer review to reduce the bias associated with only one perspective of a single investigator, so that it enhanced the reliability of the interpretation of the study.

4.8. Ethical considerations:

The study was conducted in accordance with the ethical principles stated in applicable guidelines on good clinical practice, whichever represents the greater protection of the individual. Ethical approval was obtained from the neurology department research review committee and the Addis Ababa University institutional review board. After explaining the objectives and importance of the study, consent in written form was taken from all participants for participation and audio recording before the commencement. Confidentiality and anonymity were kept throughout the study by keeping data in a secret and safe place.

4.9. Operational Definition

1. Stroke is defined as an abrupt onset of a neurologic deficit that is attributable to a focal vascular cause presumed to be caused by ischemia or hemorrhage. The term is broadly used to include CNS infarction, CNS ischemia, intracerebral hemorrhage, subarachnoid hemorrhage, and cerebral thrombosis.
2. Health-related quality of life is an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and about his/her goals, standards, expectations, and concerns

5. Results

The first part of the results is the demographic background characteristics of the participants involved in the research. After that, there are four main categories which include disempowerment both physically and psychologically, social and Economic Impact, Spirituality and work area challenge,

Out of the total 16 participants involved in the research, 6 were females and 10 were males who were the source of the interview.

Table 5. Participants' background characteristics results, TASH, 2025

Table 1.1. Demographic detail of participants ,February 2025/TASH

Variable	Category	Count
Gender	Male	10
	Female	6
Age Group	18–25	1
	26–45	9
	46–55	3
	56–65	2
	65–75	1
Marital Status	Married	10
	Single	3
	Divorced	3
Address	Urban	13
	Rural	3

Table 1.2. Socio economic detail of participants February 2025, TASH ,AAU

Variable	Category	Count
Occupation	Unemployed	8
	Private sector	6
	NGO	1
	Employed	1
Monthly Income	No income	2
	<500	1
	600–1000	2
	1100–1500	3
	1600–5000	4
	5000–10000	3
Education	Primary school	6
	High school	6
	College and above	4

Physically and Psychologically Disempowerment

Physically struggle

Stroke significantly impacts various aspects of life, with physical disability and impairment particularly affecting the majority of participants by limiting their activities of daily living (ADLs). It disrupts the body's ability to function optimally. The primary concern for survivors is the impairment of motor functions, such as disability, loss of strength, difficulty in performing personal tasks, and the need for assistance. This concern leads to feelings of worthlessness and helplessness. The loss of independence due to various functional disabilities is the most significant factor affecting the quality of life (QoL) of stroke patients, as highlighted by the study participants. Stroke results in multiple and varied dysfunctions, leading to different degrees of disabilities. Patients reported experiencing physical disabilities, memory loss, speech and language abnormalities, physical and functional limitations, and a sense of dependency. One participant described the seriousness of stroke in one word as:

“...Stroke is a very rude disease. There is no standard to compare the stroke you know to the one I know ...” (participant #13)

All the participants emphasized the challenges with mobility, daily tasks, and the long-term physical effects of stroke.

....” After that...it is so hard. You can’t use a taxi or a bus to move around, even to go to a nearby place, you call a ride. The expense is very high. Living depending on others is very difficult... Living independently is a challenge.” (Participant #10)

“...I used to write on a laptop computer, but now my left-hand fingers cannot do that, so I write while other people are touching the letters... It limits many things, working with two hands... Now, for example, I ask them to wash my clothes, and when I take a bath, I only wash the area that one hand can reach” (participant 12)

The quotes above illustrate how a stroke impairs limb function in performing tasks that were easily completed before the stroke, due to muscle weakness. 12 participants concurred that these effects render them unable to perform various activities of daily living (ADL).

*...” My body, including my hands and legs, don't work. I can't move or do anything anymore.”
“I stayed in the room from 2:00 PM to 7:00 PM without eating or drinking...” Participant #1
’...” When I tried to speak, I could not, when I tried to move, I could not, then I became more angry. In the end, I slowly realized that I could not do anything...” (participant #10)*

All participants in the study highlighted a negative impact on their quality of life (QoL). Stroke was perceived as a major disruption that fundamentally altered their life narrative and self-identity. Many participants found it challenging to reconcile their current selves with who they were before the stroke, frequently describing themselves in terms of their pre- and post-stroke identities.

“... Due to the stroke, I was limited to certain types of work. Before the stroke, I was active and could do anything. But now I can't do that. When I work a light job my heart rate increases, feel shortness of breath, I can't go long distances, and I can't stand for a long time like when I use bus transportation. I can't control my hands when I eat rice with injera. I stopped going long distances...” Participant 11

*“...Yes. I can't perform things the way I did before I got sick. Now I can't control some of my body parts the way I did it before...(participant#15)
”... So, it affects my communication skills...so it has an impact on my daily life....it is hard...” (participant #6)*

These experiences can be understood as a total loss of control over one's physical movements, the incapacity to carry out actions in the same manner as before the stroke. This sense of powerlessness led to feelings of hopelessness, which was particularly overwhelming for the participants. Nonetheless, 3 participants viewed this as a challenge that they could tackle through their own efforts, embracing and adapting to their disability.

“...I will also say it happened for a good and for a reason. I don't feel bad. I only feel something on my inability to walk outside... (participant #4)

Psychological and Emotional Struggles

Five of the participants reported that after experiencing a stroke, or once their physical condition began to improve, they initially felt a sense of hopelessness. But again, they are able to find ways to cope with their losses and disabilities. Participant #1 stated that he stopped and was asking himself how to cope and accept his deficit.

“...I hadn’t eaten or drunk anything for that long. I stopped and asked myself, “Why is this happening? Why can’t we detect how stroke happens?...” (participant #1)

Other participants became hopeless when they found out their diagnosis was a stroke. This was clearly stated by one of the stroke survivors:

“... You will lose hope on many aspects. You may feel you can't do as previously...” (participant 14)

Other participants were psychologically affected and revealed that they were shocked upon receiving a stroke diagnosis.

“...I was a bit shocked at first, but no, it is easy. It just needs care and attention...” (participant #16)

They did, however, describe a resigned acceptance of the stroke. When discussing their experiences, some participants became emotional and cried during the interviews, with some needing to take breaks.

“...I will also say it happened for a good and for a reason. I don't feel bad. I only feel something on my inability to walk ...” (participant #4)

“...I slowly realized that I could not do anything...” Participant #10)

Six participants also stated that they had anxiety, depression and were even irritable due to the disability they experienced as a result of the stroke.

“.... I sometimes easily get provoked and get sad on myself...” (participant #3)

“...I have very high anxiety. I mean, there are many things I want to do but I cannot...” participant#10)

“...I was happy. I used to work and live independently. (she starts crying). I used to work and manage my life... (Still crying).. Okay Okay. It is difficult for me to work. (crying)...” (participant#11)

Their caregivers also noted that participants preferred being alone and disengaging with friends. One of the participant #7 's caregivers stated that:

"...She feels lonely... disengaged from friends..." (participant #7 caregiver)

Participants also compared themselves with others of their own age and similar illnesses, feeling themselves to be in relatively good health despite the stroke.

"...Thanks to God my stroke level is the simplest one when compared to other illnesses. Some of them didn't improve. They continued to be bedridden. For me, thanks to God, I had good progress. When they saw me they wondered how I had improved. What can I say other than being thankful to God." (participant #15)

Social and Economic Impact

Discussions of Social and Economic Impact focused on 2 sub-themes: social isolation and stigma and economic impact, which included insurance issues, cost of medication, and transportation. The majority of study participants largely depended on family support for assistance with activities of daily living (ADLs) and financial aid. The financial strain on the family affected the patient's physical and emotional recovery.

Social Impact

Out of 16 participants, 14 stroke survivors interviewed reported a number of social influences shaping perceptions of social relationships in both positive and negative ways.

The negative perceptions led them to feel stigmatized and reluctant to engage with others or share their condition due to the fear of being stigmatized. As a result, many chose to isolate themselves, ultimately experiencing profound loneliness.

The majority of participants reported changes in the type and quality of their social interactions after stroke. Some reported that friends and neighbors became more supportive and helpful, for example, in terms of visiting more often and helping with tasks, although others reported friends and neighbors subsequently avoiding them.

These social impacts included social isolation, social stigma, and also loss of support from their immediate, home environment, work, family, social circumstances, and their ability to get out

"... Some people laughed at me when I went abroad for treatment..." (participant #2)

"...When you are healthy and have money, you can join them and they give you everything, when you lack something, you cannot join them. First, it will hurt you psychologically, then you will isolate yourself from social life ... " (Participant #12)

"..., I used to live a monastic life, but from now on, I cannot live in a monastery, I am stigmatized, because I cannot work as much as them... Because I cannot move with them. I am stigmatized because I cannot fetch water, pick wood, bake, etc. I am stigmatized by them " (Participant #12)

Most stroke survivors identified family members as key sources of social support and encouragement when undertaking activities of daily living as part of their ongoing recovery.

“...It has a good effect. It will help more. I personally have good support from family and friends and it has a positive effect...” (participant #04)

Economic impact

Fifteen participants were mostly getting assistance in executing ADLs and financial help from family and friends.

Financial support from family was unmistakably noticeable from the responses of participant stroke survivors.

They were suffering from transportation costs, unavailability of insurance, money for medication expenses and even to fulfill daily needs in performing ADLs as is evident from the responses of participants

“...The economic crisis has been the most difficult...” (Participant 1)

“...Before insurance, the costs were unaffordable, but now also the insurance no longer cover my treatment or my children’s expenses...” (participant #2)

“...I do have nothing, as I told you.... I am in a charity organization because I cannot afford the medication expenses...” (participant#12)

Clearly stated by two of the study participants that the transportation cost in stroke survivors is unaffordable and the expense is high

“... After that...it is so hard. You can’t use a taxi or a bus to move around, even to go to a nearby place, you call a ride. The expense is very high. Living depending on others is very difficult... Living depending on others is a challenge.” (participant #10)

“...Transport is a major problem. I rely on taxis or private cars, but sometimes people help me get into the car and back. Transportation is a significant issue for all stroke patients...” (participant #1)

The financial strain on both families and patients hindered the physical rehabilitation efforts of the patients. The same fact was exemplified from the following quotes of participants who had played a lot for survival but gave up due to the cost of medication, physiotherapy, and performing ADL

“... I do not have a monthly income. I am using what I have. My wife is the one who works. I have spent a lot of money in the past three years. I came to health insurance because I ran out of money and I was in trouble. For physiotherapy, I was paying 1200 – 1300 birr per day...” (participant #10)

High transportation costs, unemployment, and stigma intensify HRQoL challenges. Family support emerged as a double-edged sword, critical yet insufficient for many patients to fulfill their daily needs.

Spirituality (The belief in God)

Spirituality is centered on values and can be viewed as a source of meaning and purpose for what humans do (47). This is a key component of a person's daily occupation, and having one's spiritual needs met is, therefore, an essential for engagement and empowerment. This sub-theme had a significant positive impact on the QOL of the survivors. It is an important component and may be a key factor in how survivors cope with the illness and achieve a sense of coherence.

According to our participants in the study, faith in God was crucial to overcoming the disease. They had a firm religious belief.

A study by Pat Fosarelli argues that the lives of healthy people can be enhanced by their spirituality, which gives meaning to their lives and provides comfort in difficult times(48). The findings of the study by (Hanne people ton satink et al) similarly express that spirituality helps to support and sustain a positive outlook.

Our study participants stated the name of God, especially Participant #7, 60 years old woman who frequently calls on the name of God as her Helper and healer.

"... For example, when I felt such a thing, since I believe in God. I felt nothing bad. If you believe that it is God's plan, there might not be any stress. I pray that one day I might be healthy if God allows me..." (participant #4)

"...Thanks to God I have improvements. In the beginning, I was unable to move my hands and legs and also had facial paralysis but now it has improved a lot and I can move my legs and hands, and my facial paralysis has also improved a lot. Thanks to God... I am passing through challenges, sometimes crying to God, complaining, sometimes praying, etc..." (participant #5)

These show that only God can assist them, that God would eventually heal them, and that God is in control of the circumstances.

It also indicates that spirituality as a coping mechanism reflects Ethiopia's cultural context, highlighting faith as a critical resilience factor.

Work area challenges.

Reintegration into the workplace can indeed be a significant challenge, particularly for individuals who prefer to work reduced hours, which may not always be feasible due to organizational policies or workplace demands(49). The participants in this scenario experienced several issues.

Several participants felt that they could not meet the demands placed on them, leading to feelings of inadequacy and stress. This might be due to a variety of factors such as increased workload, lack of updated skills, or personal health issues. A sense of discrimination in the workplace was evident among the participants. This could stem from their health conditions, or other personal characteristics, which can affect their confidence and job satisfaction. Most Participants are also jobless due to their illness.

“...It also causes problems at the workplace; It reduces my efficiency for example, when I write... It reduces my communication... It keeps the work from being efficient. It reduces my ability to work. I cannot write quickly with a pen, and I cannot deliver the message I want...” (Participant #6)

“....., I lost my job and asked for my share, but we ended up in conflict. But before my illness, we were peaceful. Now, I am in economic trouble., when I said to them,” I have no job now and give me my share they don't “ this has led us to a conflict” (Participant #10)

“..she said things to me that were offensive and hurtful, but I just ignored it and responded with peace...” (Participant 11)

6. Discussion

The findings of this study provide an understanding of the health-related quality of life (HRQoL) of stroke survivors attending the stroke clinic at Tikur Anbessa Specialized Hospital (TASH) in Addis Ababa, Ethiopia. By exploring themes of physical/psychological disempowerment, social/economic impact, spirituality, and workplace challenges, the study illuminates the multifaceted burdens faced by stroke survivors, contextualized within a resource-limited setting.

Worldwide, cerebrovascular accidents (stroke) are the second leading cause of death and the third leading cause of disability. The effects of stroke range in severity from minor disabilities that may resolve rapidly to severe and long-lasting disabilities. Patients who survive the acute insult often suffer from multiple morbidities including physical, psychological, and socio-economic burdens. Prior studies have shown that most stroke survivors face a low health-related quality of life (HRQOL) (50)

In this study, participants reported profound physical limitations, including loss of mobility, dependency on caregivers, and challenges in performing activities of daily living (ADLs). This aligns with global studies where motor deficits and functional disability are consistently linked to reduced HRQoL (15,51). However, the psychological impacts expressed through hopelessness, anxiety, and identity crises were particularly striking. For instance, one participant stated, *“I realized slowly that I could not do anything”*, echoing the high prevalence of post-stroke depression (PSD) documented in Ethiopia ((52) and globally (53)

Our study also shows that economic challenges, such as unemployment, transportation costs, and medication expenses were critical barriers to HRQoL. Similar challenges have been reported in other low-income settings, where out-of-pocket healthcare expenditures lead families into poverty (50). Social stigma and isolation further compounded these struggles, with participants describing avoidance by peers and workplace discrimination. This is also similar to qualitative studies from Nigeria and Ghana, where stigma reduced social participation and worsened mental health (54)

Faith in God emerged as a pivotal resilience factor, with participants attributing their recovery and emotional stability to divine intervention (*“Thanks to God my stroke level is the simplest one”*). This contrasts with Western studies, where spirituality is less frequently emphasized in HRQoL (55)

Discrimination and reduced productivity among post-stroke survivors were prevalent, mirroring findings from sub-Saharan Africa where disability rights remain underdeveloped (7). Participants' words, such as *“It reduces my ability to work... I cannot write quickly with a pen”*, highlight the urgent need for workplace accommodations and policy reforms to protect stroke survivors' employment rights.

7. Strengths and Limitations of the Study

This qualitative study provides in-depth live experiences of stroke survivors affecting dimensions of HRQoL (physical, psychological, social, economic, and spiritual).

The study also highlights spirituality as a key resilience factor, which reflects Ethiopia's sociocultural context that might offer locally meaningful strategies for early recovery and coping mechanisms.

The study also offers critical insights into the HRQoL of stroke survivors, but there are also limitations. First, the small sample size (N=16) and its narrow geographic scope (13 participants were from Addis Ababa) limit generalizability to rural populations, who may face greater challenges. Second, the absence of caregiver involvement narrows the understanding of familial dynamics affecting the HRQoL of survivors. Third, the study was conducted at one tertiary hospital in the TASH stroke clinic, and findings may not represent the whole stroke survivors in the country.

8. Conclusions

Stroke disrupts the body's ability to function optimally. The primary concern for survivors is the impairment of motor functions, such as disability, loss of strength, difficulty in performing personal tasks, and the need for assistance. Stroke also affects the psychological, social, and other aspects of HRQoL of stroke survivors.

Our findings show that stroke survivors face multidimensional challenges from their home to their environment that severely impair their HRQoL. The challenges include physical disability, psychological distress, economic crisis, social isolation and stigma, and work area challenges. These findings underscore the need for comprehensive interventions that address physical, emotional, and economic needs. Notably, spirituality, on the other hand, had a positive impact on survivors, suggesting its potential integration into care plans. This study calls for tailored strategies to improve HRQOL among stroke survivors in low-resource contexts like Ethiopia.

9. Recommendation

Although this study serves as a springboard for future researchers to address further aspects of the HRQoL of stroke survivors, a further large-scale study is recommended by including caregivers and a broad geographical area. A mixed study is also recommended for future researchers.

References

1. Fauci AS, Hauser SL, Kasper DL, Longo DL, Jameson JL, Loscalzo J. Harrison's Neurology in Clinical Medicine. 4th ed. New York: McGraw-Hill Education; 2016.
2. Jankovic J, Mazziotta JC, Pomeroy SL, Newman NJ, editors. Bradley and Daroff's Neurology in Clinical Practice. 8th ed. Amsterdam: Elsevier; 2021. p. 1745–82.
3. Paradise MB, Shepherd CE, Wen W, Sachdev PS. Neuroimaging and neuropathology indices of cerebrovascular disease burden. *Neurology*. 2018;91(7):310–20.
4. Krishnamurthi RV, Feigin VL. Global Burden of Stroke. In: *Stroke*. Elsevier; 2022. p. 163–178.
5. Zhu L, He D, Han L, Cao H. Stroke Research in China over the Past Decade: Analysis of NSFC Funding. *Transl Stroke Res*. 2015;6(4):253–6.
6. Zhu X, Zhou X, Zhang Y, Sun X, Liu H, Zhang Y. Reporting and methodological quality of survival analysis in articles published in Chinese oncology journals. *Medicine (Baltimore)*. 2017;96(50):
7. Lemogoum D, Degaute JP, Bovet P. Stroke prevention, treatment, and rehabilitation in Sub-Saharan Africa. *Am J Prev Med*. 2005;29(5 Suppl 1):95–101.
8. Johnson W, Onuma O, Owolabi M, Sachdev S. Stroke: A global response is needed. *Bull World Health Organ*. 2016;94(9):634–5.
9. Zemed A, Chala KN, Eriku GA, Aschalew AY. Health-related quality of life and associated factors among patients with stroke at tertiary level hospitals in Ethiopia. *PLoS One*. 2021;16(3).
10. Wondim MA. Health-related quality of life of stroke survivors in two selected hospitals, Addis Ababa, Ethiopia: A cross-sectional study. *Int J Stroke*. 2018;13(1):NP6–7.
11. Abate TW, Zeleke B, Genanew A, Abate BW. The burden of stroke and modifiable risk factors in Ethiopia: A systematic review and meta-analysis. *PLoS One*. 2021;16(11):e0259244.

12. Alene M, Assemie MA, Yismaw L, Ketema DB. Magnitude of risk factors and in-hospital mortality of stroke in Ethiopia: A systematic review and meta-analysis. *BMC Neurol.* 2020;20(1):1–10.
13. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics.* 2016;34(7):645–9.
14. Rancic NK, Mandic MN, Kocic BN, Veljkovic DR, Kocic ID, Otasevic SA. Health-related quality of life in stroke survivors in relation to the type of inpatient rehabilitation in Serbia: A prospective cohort study. *Medicina (Kaunas).* 2020;56(12):709.
15. Shao C, Wang Y, Gou H, Chen T. The factors associated with the deterioration of activities of daily life in stroke patients: A retrospective cohort study. *Top Stroke Rehabil.* 2023;1–8.
16. Roth GA, Abate D, Abate KH, et al. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980–2017: A systematic analysis for the Global Burden of Disease Study 2017. *Lancet.* 2018;392(10159):1736–88.
17. Jankovic J, Mazziotta JC, Pomeroy SL, Newman NJ. *Bradley and Daroff's Neurology in Clinical Practice.* 8th ed. Amsterdam: Elsevier; 2021. p. 1745–82.
18. Lemogoum D, Degaute JP, Bovet P. Stroke prevention, treatment, and rehabilitation in Sub-Saharan Africa. *Am J Prev Med.* 2005;29(5 Suppl 1):95–101.
19. Alene M, Assemie MA, Yismaw L, Ketema DB. Magnitude of risk factors and in-hospital mortality of stroke in Ethiopia: A systematic review and meta-analysis. *BMC Neurol.* 2020;20(1):1–10.
20. Zemed A, Chala KN, Eriku GA, Aschalew AY. Health-related quality of life and associated factors among patients with stroke at tertiary level hospitals in Ethiopia. *PLoS One.* 2021;16(3):e0248481.
21. Caplan LR. *Caplan's Stroke: A Clinical Approach.* 5th ed. Philadelphia: Elsevier; 2016.
22. Temesgen TG, Teshome B, Njogu P. Treatment Outcomes and Associated Factors among Hospitalized Stroke Patients at Shashemene Referral Hospital, Ethiopia. *Stroke Res Treat.* 2018;2018:8079578.

23. Temesgen TG, Teshome B, Njogu P. Treatment Outcomes and Associated Factors among Hospitalized Stroke Patients at Shashemene Referral Hospital, Ethiopia. *Stroke Res Treat.* 2018;2018:8079578.
24. Gufue ZH, Gizaw NF, Ayele W, et al. Survival of stroke patients according to hypertension status in Northern Ethiopia: Seven years retrospective cohort study. *Vasc Health Risk Manag.* 2020;16:389–401.
25. Moran A, Forouzanfar M, Sampson U, Chugh S, Feigin V, Mensah G. The epidemiology of cardiovascular diseases in sub-Saharan Africa: The Global Burden of Diseases, Injuries and Risk Factors 2010 Study. *Prog Cardiovasc Dis.* 2013;56(3):234–9.
26. Handayani F, Utami RS, Ropyanto CB, Kusumaningrum NSD, Hastuti YD. The Associated Factors of Quality of Life among Stroke Survivors: A Study in Indonesia. *Nurse Media J Nurs.* 2022;12(3):404–13.
27. Katan M, Luft A. Global Health Neurology. *Semin Neurol.* 2018;38(2):208–11.
28. Abate TW, Zeleke B, Genanew A, Abate BW. The burden of stroke and modifiable risk factors in Ethiopia: A systematic review and meta-analysis. *PLoS One.* 2021;16(11):e0259244.
29. Zewdie A, Debebe F, Kebede S, et al. Prospective assessment of patients with stroke in Tikur Anbessa Specialised Hospital, Addis Ababa, Ethiopia. *Afr J Emerg Med.* 2018;8(1):21–4.
30. Wayessa DI, Chala MB, Demissie SF, et al. Cross-cultural translation, adaptation, and validation of the stroke-specific quality of life (SSQOL) scale 2.0 into Amharic language. *Health Qual Life Outcomes.* 2023;21(1):1–14.
31. Golomb BA, Vickrey BG, Hays RD. A review of health-related quality-of-life measures in stroke. *Pharmacoeconomics.* 2001;19(2):155–85.
32. Pham TTM, Vu MT, Luong TC, et al. Negative Impact of Comorbidity on Health-Related Quality of Life Among Patients With Stroke as Modified by Good Diet Quality. *Front Med (Lausanne).* 2022;9:853911.
33. Tsehayneh F, Tafesse A. High prevalence of poststroke depression in ischemic stroke patients in Ethiopia. *Neurol Res Int.* 2020;2020:8834299.

34. Harper A, Power M, Orley J, et al. Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychol Med*. 1998;28(3):551–8.
35. Mohammed S, Haidar J, Ayele BA, Mamushet Yifru Y. Post-stroke Limitations in Daily Activities: Experience from a Tertiary care Hospital in Ethiopia. *J Multidiscip Healthc*. 2023;16:577–85.
36. Donkor ES. Stroke in the 21st Century: A Snapshot of the Burden, Epidemiology, and Quality of Life. *Stroke Res Treat*. 2018;2018:3238165.
37. Clarke P, Marshall V, Black SE, Colantonio A. Well-being after stroke in Canadian seniors: Findings from the Canadian Study of Health and Aging. *Stroke*. 2002;33(4):1016–21.
38. Shao C, Wang Y, Gou H, Chen T. The factors associated with the deterioration of activities of daily life in stroke patients: A retrospective cohort study. *Top Stroke Rehabil*. 2023;1–8.
39. Adigwe GA, Tribe R, Alloah F, Smith P. The Impact of Stroke on the Quality of Life (QOL) of Stroke Survivors in the Southeast (SE) Communities of Nigeria: A Qualitative Study. *Disabilities*. 2022;2(3):501–15.
40. Donkor ES, Owolabi MO, Bampoh PO, Amoo PK, Aspelund T, Gudnason V. Profile and health-related quality of life of Ghanaian stroke survivors. *Clin Interv Aging*. 2014;9:1701–8.
41. Krančiukaitė D, Rastenytė D. Measurement of quality of life in stroke patients. *Medicina (Kaunas)*. 2006;42(9):709–16.
42. World Health Organization. International Classification of Impairments, Disabilities, and Handicaps. Geneva: WHO; 1980.
43. Nuntaboot K. Role and Function of Family in Care of Patients With Stroke in Community. *Nurse Media J Nurs*. [Internet]. 2018; Available from: [URL]
44. Gumarang BK, Mallannao RC, Gumarang BK. Colaizzi's Methods in Descriptive Phenomenology: Basis of A Filipino Novice Researcher. *Int J Multidiscip Appl Bus Educ Res*. 2021;2(10):928–33.
45. Marton F. Phenomenography - Describing conceptions of the world around us. *Instr Sci*. 1981;10(2):177–200.

46. Naeem M, Ozuem W, Howell K, Ranfagni S. A Step-by-Step Process of Thematic Analysis to Develop a Conceptual Model in Qualitative Research. *Int J Qual Methods*. 2023;22:1–15.
47. Katerndahl D. Impact of spiritual symptoms and their interactions on health services and life satisfaction. *Ann Fam Med*. 2008;6(4):412–20.
48. Fosarelli P. Medicine, spirituality, and patient care. *JAMA*. 2008;300(7):836–8.
49. Timothy EK, Graham FP. Transitions in the Embodied Experience after stroke: Grounded theory study. *Phys Ther*. 2016;96(5):687–97.
50. Donkor ES. Stroke in the 21st Century: A Snapshot of the Burden, Epidemiology, and Quality of Life. *Stroke Res Treat*. 2018;2018:3238165.
51. Clarke P, Marshall V, Black SE, Colantonio A. Well-being after stroke in Canadian seniors: Findings from the Canadian Study of Health and Aging. *Stroke*. 2002;33(4):1016–21.
52. Tsehayneh F, Tafesse A. High prevalence of poststroke depression in ischemic stroke patients in Ethiopia. *Neurol Res Int*. 2020;2020:8834299.
53. Ayerbe L, Ayis S, Wolfe CDA, Rudd AG. Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *Br J Psychiatry*. 2013;202(1):14–21.
54. Adigwe GA, Tribe R, Alloh F, Smith P. The Impact of Stroke on the Quality of Life (QOL) of Stroke Survivors in the Southeast (SE) Communities of Nigeria: A Qualitative Study. *Disabilities*. 2022;2(3):501–15.
55. Krančiukaitė D, Rastenytė D. Measurement of quality of life in stroke patients. *Medicina (Kaunas)*. 2006;42(9):709–16.

Appendixes

Appendix 1: Information sheet

Greetings; I am Dr. Walelign a second-year neurology resident and I am here to understand how you live with stroke and your quality of life since the illness from your perspective. We will proceed with discussion, which will take around 30-60 minutes, after hearing the following general information about the study. All our discussions will be audio recorded as it will be difficult to remember all the discussions after finishing the discussion.

Title of the study: Health-related Quality of Life of Stroke Survivors: A Qualitative Study among Stroke Survivors at Tikur Anbessa Specialized Hospital.

Objective: This study aims to assess the health-related quality of life of adult stroke survivors at neurology stroke clinics of TASH.

Benefits: This study will not give direct benefit to the participants; but the detailed information you provide us will help to recommend TASH, the government, and other health sectors to design appropriate interventions to address the problems related to quality of life in adult stroke survivors from your perspectives. The findings also will help identify factors that affect the patient's quality of life, which will be addressed at discharge, and help to prepare a guide in patient care that could be addressed by family members or caregivers and prepare a guide use after patient discharge from the hospital.

Risks: The participants will not face any harm by participating in this study

Right of the respondents: Any participant will participate in this study voluntarily. You can quit giving answers to the questions you are not willing to answer and even you can stop at all. The audio recording of the interview will also depend on your willingness and you have the right to refuse if you do not need it at all.

Confidentiality: We would like to assure you that privacy will be strictly maintained throughout. Your responses to any of the questions will not be given to anyone else other than the study team and no reports of the study will ever identify you. Your name and other information related to your private life will not be mentioned at an individual level showing your identity.

Whom to contact: If you have any questions about the research or need further information, please contact the following research team members from the College of Health Sciences of Addis Ababa University.

1. Dr. Walelign Worku, Phone.+251923163459, Email. Walelgn1992@Gmail.com
2. Dr. Abenet Tafesse, Phone. +251 911183332, Email. abew03@yahoo.com
3. Dr. Yared Zenebe, Phone +251-911983447, Email: yaredzene121@gmail.com
4. Dr. Seblewongel Asmare, Phone. +251 918267037, Email. sebleasmare21@gmail.com
5. Dr. Mulugeta Tamire Phone. +251 911805081, Email. mulugetatamire18@gmail.com

Are you willing to participate?

Appendix II: Consent form

I, ----- confirm that it is with a clear understanding of the objectives and conditions of the study that I give my consent to be part of the study. I have been given the necessary information about the research. I understand that it is my right to withdraw from the study at any time; the proposal has been explained to me in a language I understand.

Participant
Name _____ Signature _____ Date _____
Interviewer
Name _____ Signature _____
Interview code _____ -

አባሪ II: የስምምነት ፎርም

እኔ _____ በጥናቱ ዓላማዎች እና ሁኔታዎች ግልጽ በሆነ ግንዛቤ ውስጥ በመሆን የጥናቱ አካል ለመሆን ፈቃዴን እንደማሳውቅ አረጋግጣለሁ። ስለ ጥናቱ አስፈላጊው መረጃ ተሰጥቶኛል። በማንኛውም ጊዜ ከጥናቱ የመውጣት መብት እንዳለኝ ተረድቻለሁ፤ የጥናቱ ሀሳብ በምረዳው ቋንቋ ተገልጾልኛል።

ተሳታፊ
ስም _____ ፊርማ _____ ቀን _____

ቃለ መጠይቁን ያዘጋጀው
ስም _____ ፊርማ _____
የቃለ መጠይቅ ኮድ _____

Appendix III: Interview Guide (English Version)

Semi-structured Interview questionnaire on Health-related Quality of Life in Stroke Survivors

Part I: Sociodemographic characteristics of the participants

Code -----

1. Gender ☐ Male ☐ Female
2. Age-----
3. Address _____ -
4. Highest level of educational status?
 - None
 - Write and read-only
 - Primary School
 - High School
 - College and above
5. Marital status?
 - Single
 - Married
 - Separated
 - Divorced
 - Widowed
6. Current occupation?
 - Unemployed ☐ self-employed ☐ NGO ☐ Governmental organization ☐
 - Others (specify) _____
7. Monthly income:
 - <500-birr
 - 500–1000-birr
 - 1000-1500 birr
 - >1500 birr

Part II

Discussion points

A. Interview introduction

Length: 30-60mins

Primary goal: to understand the things you experienced more like a conversation with a focus on your experience after the incident of stroke and how you have been dealing with it.

B. Written consent

Would you like to participate in this interview?

consent was obtained

consent was not obtained

C. Background information

Overview: General Information - Inviting the Interviewee

Briefly tell me about yourself and your way of living before you experienced a stroke.

How long has it been since the stroke?

If you were told what was the cause of the stroke?

Did you experience any illness before the stroke?

Were you using any drugs like alcohol, chat, or cigarettes?

D. Your quality of life

1. How to live with stroke and how do you feel when you know your diagnosis

Probe: Tell me what you do on a weekday, on weekends, and throughout the months

2. How do adult stroke survivors perceive their overall health-related quality of life? What does quality of life mean to you?

Probe: It could be from what you read, from your experience, or what you were told from another person including health professionals, or what you think it is

Probe: What things do you think it includes from your perspective?

Probe: What do you think about how to improve the quality of life of stroke patients?

3. Can you describe the various aspects of health that are most affected in your daily life as a stroke survivor?

Probe: Compared to what you were before the stroke, what things are you not able to do now due to the stroke?

4. In what ways has the experience of stroke impacted your physical well-being and functionality?

5. What aspects of your health do you consider most significant in determining your overall quality of life post-stroke?

6. Can you share your perspectives on the social aspects of your life after experiencing a stroke? How would you describe the impact of stroke on your ability to engage in meaningful activities and hobbies?

7. Can you identify specific challenges or barriers that hinder your health-related quality of life as a stroke survivor?

Probe: In your opinion, what factors contribute to the decreased health-related quality of life in adult stroke survivors?

Probe: Are there societal or environmental factors that you believe contribute to the challenges faced by stroke survivors in maintaining a good quality of life?

Probe: How do lifestyle factors, such as diet and physical activity, influence the health-related quality of life in stroke survivors?

8. How do psychological factors, such as stress and coping mechanisms, play a role in shaping the health-related quality of life for adult stroke survivors?

9. What role does the support of family and friends play in shaping your post-stroke quality of life?

Probe. Do you get any support from those who are living with you?

10. To what extent do you feel satisfied with the support and care received during your follow-up at the stroke clinics in TASH

Probe: Was anyone telling you what to do and what to expect after you went home?

What are the treatments and support you getting from this hospital?

Probe: Did you have physiotherapy regularly? Did you get any psychiatric evaluation?

Any medications you are currently taking? If any do you know why they are given or used for?

Probe: Do you know what could happen if the medication is discontinued or not taken properly?

Do you know the side effects of the medications?

11. How frequently have you followed up in the clinics so far?

Probe: In your experience, what interventions or support mechanisms do you think would improve the health-related quality of life for adult stroke survivors receiving follow-up at TASH stroke clinics?

12. How well-informed do you feel about the common causes of stroke based on your experiences and interactions within the stroke clinics at TASH?

Probe: Can you identify any patterns or commonalities in the causes of stroke among stroke survivors in TASH?

Probe: Could you please explain how it is to be cared for with stroke in the health care system in Ethiopia?

13. Can you describe any challenges in accessing necessary healthcare services that may contribute to the decreased quality of life among stroke survivors?

Probe: Did you have any difficulty coming from home, during transportation, or in the hospital?

Probe: What mode of transportation will you use to come for the follow-up?

14. How do you see your response and recovery?

Probe: What are the things you did to improve?

15. Please tell me about how you cope with the challenges resulting from the disease in your daily life.

16. Do you have any additional views or questions?

Thank you

አባሪ III: የቃለ መጠይቅ መመሪያ (በአማርኛ ጽሁፍ)

በስትሮክ ታካሚዎች የጤና ተዛማጅ የሕይወት ጥራት ላይ በተመለከተ በከፊል የተጠናከሩ የቃለ መጠየቅ ጥያቄዎች

ክፍል I: የግል መረጃ

ኮድ: -----

1. ጾታ

ወንድ ☐

ሴት ☐

2. እድሜ: -----

3. አድራሻ: _____

4. ከፍተኛ የትምህርት ደረጃ

- ☐ የለም ☐
- ☐ ማንብብ/መጻፍ ብቻ ☐
- ☐ የመጀመሪያ ደረጃ ትምህርት ☐
- ☐ ሁለተኛ ደረጃ ትምህርት ☐
- ☐ ኮሌጅ/ከዚያ በላይ ☐

5. የትዳር ሁኔታ

- ☐ ያላገባ/ች ☐
- ☐ ያገባ/ች ☐
- ☐ የተለየ/ች ☐
- ☐ የፈታ/ች ☐

6. የአሁን ሥራ

- ☐ ሥራ የሌለው ☐
- ☐ በራስ ሥራ ☐
- ☐ ከመንግስት በቀር ድርጅት (NGO) ☐
- ☐ የመንግስት ድርጅት ☐
- ☐ ሌሎች (እባክዎን ይግለጹ): _____

7. ወርሃዊ ገቢ:

- ☐ <500 ብር ☐
 - ☐ 500–1000 ብር ☐
 - ☐ 1000-1500 ብር ☐
 - ☐ 1500 ብር ☐
 - ☐ 1500-5000 ☐
 - ☐ 5000-10000 ☐
 - ☐ >10000 ☐
-

ክፍል II: የውይይት ነጥቦች

A. የቃለ መጠይቅ መግቢያ

የቆይታ ጊዜ: 30-60 ደቂቃ

ዋና ዓላማ: ከስትሮክ በኋላ ያጋጠሙትን ሁኔታዎች እና ከዚያ ጋር እንዴት እየተጋፈጡ እንደሆነ የሚያሳይ ውይይት ለማድረግ ነው።

B. ስምምነት

- በዚህ ቃለ መጠይቅ ውስጥ መሳተፍ ይፈልጋሉ?
 - ፈቃድ ተሰጥቷል ☐
 - ፈቃድ አልተሰጠም ☐

C. ዳራ መረጃ

ከስትሮክ በፊት ስለእርስዎ እና የዕለት ተዕለት ኑሮዎ በአጭር ሊነግሩን ይችላሉ?

ከስትሮክ ወዲህ ምን ያህል ጊዜ ሆኖታል?

የስትሮኩ ምክንያት ምን እንደነበር ያውቃሉ?

ከስትሮክ በፊት ማንኛውም የጤና ችግር ነበረዎት?

ከስትሮክ በፊት አልኮል፣ ጫት፣ ሲጋራ ወይም ሌሎች ንጹህ ያልሆኑ መድሃኒቶችን ይጠቀሙ ነበር?

D. የጤና ተዛማጅ የሕይወት ጥራት

1. ከስትሮክ ጋር እንዴት እየኖሩ ነው? ምርመራውን ሲያውቁ ስሜትዎ ምን ነበር?

ሀሳብ: በሳምንት፣ በቅዳሜ/እሁድ፣ እና በወር ውስጥ ምን ምን እንደሚሰሩ ይገነዝቡ።

2. የስትሮክ ተጠቂዎች የጤና ተዛማጅ የሕይወት ጥራት እንዴት እንደሚገነዘቡት? ለእርስዎ "የሕይወት ጥራት" ምን ማለት ነው?

ሀሳብ: ካነበቡት ፣ ከልምድዎ፣ ከሌሎች ሰዎች በሰሙት (ከጤና ባለሙያዎች ጨምሮ) የሰማችው ወይም የሚያስቡትን ይናገሩ።

3. በዕለት ተዕለት ሕይወትዎ ውስጥ በጤናዎ ላይ በጣም ተጽዕኖ የሚፈጥሩ ገጽታዎች ምንድን ናቸው?

ሀሳብ: ከስትሮክ በፊት ከሚያደርጉት ጋር ሲነፃፀር አሁን ምን ማድረግ አቅቶዎታል?

4. ስትሮክ የሰውነት ጤናዎን እና ተግባራትዎን በምን መንገድ ተጽዕኖ አሳድሯል?

5. ከስትሮክ በኋላ የሕይወት ጥራትዎን የሚወስኑት በጣም አስፈላጊ የሆኑት የጤና ገጽታዎች ምንድን ናቸው?

6. ከስትሮክ በኋላ ያለዎትን ማህበራዊ ሕይወት እና መደሰት የሚያስችሉ እንቅስቃሴዎች ላይ ያሉ ተጽዕኖዎችን እንዴት ይገልጻሉ?

7. እንደ ስትሮክ ተጠቂ የጤና ተዛማጅ የሕይወት ጥራትዎን የሚጎዱ ችግሮች ምንድን ናቸው?

ሀሳብ: በሕይወት ዘይቤ (ምግብ፣ አካላዊ እንቅስቃሴ)፣ ማህበራዊ ወይም አካባቢያዊ ሁኔታዎች ወዘተ.

8. ሳይኮሎጂካል ምክንያቶች፣ ለምሳሌ ጭንቀት እና መቋቋም ዘዴዎች፣ ጤናዊ የሕይወት ጥራት ላይ እንዴት ተጽዕኖ ያሳድራሉ?

9. የቤተሰብ እና የጓደኞች ድጋፍ ለእርስዎ ከስትሮክ በኋላ ያለዎትን የሕይወት ጥራት ለማሻሻል ምን ያህል አስተዋጽኦ አለው?

- ሀሳብ: አብረው ከሚኖሩት ሰዎች ድጋፍ ይደርስዎታል?

10. በጥቁር አንበሳ ሆስፒታል ስትሮክ ከሊኒኮች በሚደረግልዎት ክትትል እና እርዳታ ምን ያህል እረክተዋል?
 ሀሳብ: ወደ ቤት ሲመለሱ ምን ማድረግ እንዳለብዎት ተነግሮዎታል?
 ከዚህ ሆስፒታል ምን ዓይነት ሕክምና ወይም ድጋፍ ይደርስዎታል? (ለምሳሌ፥ ፊዚዮቴራፒ፣ የስነልቦና ግምገማ፣ መድሃኒት)
 የሚወስዱትን መድሃኒት ዓላማውን ያውቃሉ? ካልተወሰደ ወይም በትክክል ካልተጠቀሙት ምን ይከሰታል?
11. በክሊኒኮቹ ውስጥ በምን ያህል ጊዜ ልዩነት ክትትል ያደርጋሉ?
12. በጥቁር አንበሳ ሆስፒታል ስትሮክ ከሊኒክ ውስጥ ስለ ስትሮክ ምክንያቶች ምን ያህል መረጃ አግኝተዋል?
 ሀሳብ: በኢትዮጵያ ውስጥ የስትሮክ ታካሚዎችን የጤና እንክብካቤ ስርዓት እንዴት ይገልጻሉ?
13. ወደ ክሊኒክ ለመምጣት የመጓጓዣ፣ ወይም በሆስፒታል ውስጥ ያጋጠሙዎት ችግሮች አሉ?
 ሀሳብ: ለክትትል ሲመጡ ምን ዓይነት ትራንስፖርት ይጠቀማሉ?
14. ለመልሶ ማገገም ምን እንደሰሩ ይገነዩን።
15. በዕለት ተዕለት ሕይወትዎ ውስጥ የሚያጋጥሙ ችግሮችን እንዴት እንደተቋቋሙ ይገነዩኝ?
16. ሌሎች ማንኛውም አስተያየቶች ወይም ጥያቄዎች አሉዎት?

አመሰግናለሁ!

