

**ADDIS ABABA UNIVERSITY  
COLLEGE OF HEALTH SCIENCE  
SCHOOL OF MEDICINE  
DEPARTMENT OF NEUROLOGY**



**RESEARCH THESIS**

**One Stone, Two Birds: The Role of Families in Stroke Patients' Care: A qualitative study among Stroke Survivors at Tikur Anbessa Specialized Hospital**

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# **One Stone, Two Birds: The Role of Families in Stroke Patients' Care: A qualitative study among Stroke Survivors at Tikur Anbessa Specialized Hospital**

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## ABSTRACT

**Background:** Stroke is the second leading cause of death and third leading cause of disability worldwide. After three months of sustaining stroke, 26% of stroke survivors require long-term care for long-term disabilities which includes mostly hemiparesis, speech problem, swallowing problem, sphincter dysfunction, dementia and depression for which there will be dependence for performing activities of daily living. So far, the role of families in stroke care is not studied in the context of Ethiopia but it is obvious that they have to adapt themselves to take care of their patient with what they know and think is caring.

**Objective:** This study aims at explaining the role of families in stroke patients' care among stroke survivors at Tikur Anbessa Specialized Hospital.

**Methods:** A qualitative study was conducted using qualitative content analysis approach. We used a purposive sampling finding the maximum variation in participants by age, gender, residence, educational level, relationship to the patient, occupation, duration of stroke and monthly income. An in-depth interview using a semi-structured questionnaire was conducted to collect data by voice recording and the recording was transcribed verbatim then translated in to English language. Analysis was performed using an opencode software version 4.03.

**Result:** A total of 26 participants were included in the in-depth interview and saturation was achieved. There were 20 female and 6 male participants. Majority of the females were daughters (8 participants) of the patients. The caregivers' role included fulfilling patient's self-care with hygiene, physical support in ADL, psychological and financial support. The challenges experienced by the caregivers' were problems with their physical well-being, psychological disturbances and disruption of their social interaction. There are challenges due to financial crisis, inefficient health care facilities like pharmacies, laboratory services and unavailable rehabilitation centers. On top of these there was a challenge from knowledge gap from lack of proper health education provision. The study also found out the common support systems of the care givers which include families, friends, health professionals and others. There was a better recovery in patients with provision of rehabilitation and optimistic life styles like healthy diet, treatment adherence, continuation of follow up visits and provision of a health insurance free card for government services.

**Conclusion:** family caregivers have a notable role in the care of post-stroke patients' and there are undeniable challenges that are experienced by the caregivers which should also be taken in to consideration in planning a patient's post-stroke care.

## List of the Acronyms and Abbreviations

AA: African American

ADL: Activities of daily living

CP: Care partner

CRS: Caregiver role strain

HCP: Health care professional

LMIC: Low and middle income countries

QOL: Quality of life

RCT: Randomized controlled trial

SSA: Sub-Saharan Africa

TASH: Tikur Anbessa Specialized Hospital

TIA: Transient Ischemic Attack

WHO: World Health Organization

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# CHAPTER ONE

## 1. Introduction

### 1.1 Background

Stroke is an acute the sudden onset neurologic injury that causes death of some brain cells due to lack of oxygen, glucose and other nutrients when the blood flow to the brain is lost by blockage or rupture of an artery to the brain<sup>1</sup>. Worldwide, cerebrovascular accidents (stroke) are the second leading cause of death and the third leading cause of disability<sup>2</sup>.

Globally, 70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years occur in low- and middle-income countries. Over the last four decades, the stroke incidence in low- and middle-income countries has more than doubled. During these decades stroke incidence has declined by 42% in high-income countries. Strokes mainly affect individuals at the peak of their productive life in LMIC. Despite its enormous impact on countries' socio-economic development, this growing crisis has received very little attention to date. On average, stroke occurs 15 years earlier in – and causes more deaths of – people living in low- and middle-income countries, when compared to those in high-income countries<sup>(3,2)</sup>. However, no significant change has been seen in the incidence in low- and middle-income countries, and the absolute number of stroke deaths increased over that time<sup>4</sup>.

After three months of sustaining stroke, 26% of stroke survivors require long-term care. Long-term disabilities are mostly hemiparesis, inability to walk, complete or partial dependence for activities of daily living (ADL), speech problem, swallowing problem, sphincter dysfunction, dementia and depression.

In addition to the physical, cognitive, and emotional impact of the stroke on the stroke survivor, the stroke affects the lives of the stroke victim's caregiver and family. A stroke is a lifelong change for both the stroke survivor and the family<sup>5</sup>. Medical care, rehabilitation, and doing

activity daily living are related to family economy. Low salary and income make the family to find loan from other people such as another family member, neighbor, or people who have no relation with them. Family will have additional problem because of this<sup>6</sup>. Welfare is very necessary for family as the self-management system of the local communities<sup>7</sup>. Family has to adapt themselves to take care the patient. They usually got information from nurses when they accompanied patient at hospital, but sometimes the information is not clear and complete. They also got information from TV, newspaper, internet, and their neighbor. Family caregiver has burden when they live with stroke patient. The burdens are about physical, psychological, financial, social, informational, and spiritual (<sup>8</sup>).

Patients with stroke require additional support from family to live independently in the area of activities of daily living. People who assist stroke survivors are often called caregivers<sup>9</sup>. Family members are usually the main caregivers of stroke patients. Comprehensive explanation of ADL handling from family caregivers' view is lacking (<sup>10</sup>).

Informing caregivers early about problems they may experience is important for them to develop adequate coping strategies. Research in this area is becoming increasingly important and will guide the development of useful approaches to support the patients, their families, and their caregivers.

## 1.2 Statement of the problem

Stroke affects in a vast range of directions starting from the stroke survivor as an individual to a global level of the burden it causes as a result of all the sum of its effects worldwide<sup>11</sup>. When we see the index case of a stroke survivor, the individual will have physical disabilities, psychological sequels, emotional disturbances, social life derangements and even spiritual and belief systems of the person will be affected after the incident<sup>12</sup>.

Following the index case, the close relatives like families and caregivers overall will be experiencing a new set of life style due to this event that comes to be a new normal in their day-to-day life. They will need to or will be forced to assign a time redirecting and adjusting themselves from what they normally used to be accomplishing towards caring and supporting

their patient all varying from little portion of their time, energy and money to a great deal of investing to give the best they can. Therefore, families in the care of stroke survivors have a significant role in terms of patient recovery, prevention of complications and better quality of life<sup>13</sup>. At one time or another and depending on the level of disability of the patient they are giving care, they will be involved 24/7 from morning to night in each activity that the patient requires as a patient, as a person they love, as a relative and as a person per se. To mention some, we can think of going through a day of a stroke patient's life. In the morning, patient needs to wash up, brush and use toilet and get dressed before feeding breakfast then comes the rest of the day where by different things should be supported, communicated and exercised before going to bed with all the necessary cares included. Not to mention family members has to keep on their prior routines to some extent or leave it all together and involve in extra loads like doing the shopping, laundry and find financial support<sup>14</sup>.

Family caregivers play an important role in caring for their relatives who have suffered from strokes. The patients also have problem to do their activities such as daily care, personal hygiene, spiritual activity, rehabilitation, offering the medicine, financing support and decision maker when they are facing the problem<sup>15</sup>. For those who contributed and involved in stroke management in community are many people, not only health workers (physicians and nurses), but also family caregiver as the main person who stay long time with stroke patient<sup>16</sup>. They should work together to help the patient for enhancing the quality of life of patient. Role and functions of each person including family plays necessary in stroke management in community (<sup>17</sup>).

The recommendation for an outpatient therapy comprises different aspects these include: physical, occupational, and speech therapy as indicated, interdisciplinary outpatient programs, as available or indicated, psychology as indicated, neuropsychological testing as indicated, vocational rehabilitation as indicated and driving evaluation as indicated. In addition to this the home health care agency includes first the patient will be considered "homebound" and the patient/family will benefit from interventions specific to their home environment, there is inability to arrange logistics for attendance in an outpatient treatment program due to patient tolerance or program availability, still including physical occupational, and speech therapy, social worker as indicated and finally nursing/aide as indicated<sup>18</sup> but, so far we don't know what

kind of care our patient's get from their caregivers and whether that is enough or even closer to the minimum optimal care and the recommendations if at all. By describing what role families have been playing in the care of their patients, we can identify the kind and level of care our patients are getting and whether that was adequate or not. By doing so we can identify the gaps in post stroke care that can be done by families and come up with recommendations to address that in a convenient way that suits our lifestyles especially like in our setting as a developing country where there is inadequate if not no facility for stroke survivors. We can construct a suggestion a way forward to what can be improved or can be done to maximize the care to be efficient in our practice of home rehabilitation.

Patient caregivers, especially when family members, should be expected to require education and training and, if necessary, psychiatric support. Rehabilitation programs that include training components and interactive group therapies are thought to be helpful. Many authors have recommended that the correlation between stroke-related characteristics and sociocultural and economic conditions and psychosocial aspects should be analyzed in larger studies. The need remains for further research of this complex topic performed in various regions so as to be able to understand differences among populations in diverse cultures and environments<sup>(19)</sup>. Although the burden of stroke is high in SSA (Sub-Saharan Africa), post-stroke care is largely inadequate due to scarcity of resources. Task shifting to care givers and families could be an attractive alternative in post-stroke care<sup>20</sup>.

To date, there have been no research done in our country that describes what the level of care and the exact role of families and care givers have been to their relative who survived a stroke. And there is also few data in developing countries addressing this issue. From these one study done in Indonesia found the roles of family caregivers in stroke patients as a communicator with medical professionals and maintaining patient's health condition<sup>21</sup>.

As a developing country, there are not well systematized stroke rehabilitation centers for the public and no organized nursing homes too. Therefore, we can use this research to formulate a guide for families to use for caring for their patient and benefit both the patient and the caregiver. This will improve, as a whole, setting a benchmark practice from our experience in our hospital for the care of stroke survivors in our country.

By examining these multiple family roles on stroke patients' care, using qualitative approaches and involving family members, we can better understand the roles families play in caring stroke patients with their understanding of what is expected from them and what exactly they are helping the patient with and compare it with the standard of care for stroke patients especially with regards to what families and caregivers are capable of. We can construct a suggestion a way forward to what can be improved or can be done to maximize the care to be efficient in our practice of home rehabilitation. As a developing country, we don't have well organized stroke rehabilitation centers and we can use this research to formulate a guide for families to use for caring for their patient and benefit both the patient and the caregiver and as a whole the stroke care in our country setting a benchmark practice from our experience in our hospital.

### 1.3 Significance of the Study

Post stroke care is very important in enhancing the recovery of a stroke survivor given the optimal care is provided and reduce/prevent serious complications. With the most possible optimal care, patients will attain the maximum recovery increasing the chance of independence and even joining the normal routine of everyday life including being productive. For the best outcome of care, families and care givers have a great deal of role contributing for the patient's rehabilitation and helping the patient reach the goal of fast and sustainable recovery since they are the ones who live with the patient 24/7.

Conducting this research will help the health worker to identify the type and quality of care that is provided to stroke survivors by their families and compare it to the habitual post stroke care. With this we can identify the focus areas to educate and council families on post-stroke care for patients with recommended rehabilitation methods. For health institutions, the study can list the gaps of care provided by the care givers or families also taking into consideration our living standards and resource limitations. Since we are living in a country with a single stroke care unit so far which is not in Addis Ababa and to our understanding there are no research done in this area so far. Therefore, this research can be used as an input for knowing the roles of families in stroke care in

TASH and can be a ground work for other researchers and hopefully will also be an input for policy makers in the healthcare system.

With this research, support groups can use the study to fill the gaps of care by listing recommendations that could be implemented by the families bringing the trend of home rehabilitation which have been implemented and recommended in other countries especially with low/middle income countries like ours. Last but not least, the study will help to contribute for preparing a guide that walks families or care providers through a post stroke care components and levels of care which could be a great input for ease of understanding the situation they have faced and how they can handle and contribute with their capacity at hand for the better recovery of the stroke survivor.

## 1.4 Objective

### 1.4.1 General objective

To describe the role of families in stroke patients' care among stroke survivors at Tikur Anbessa Specialized Hospital (TASH)

### 1.4.2 Specific objective

To describe the types of care family caregivers provide to stroke survivors

To understand the challenges related with giving care to stroke survivors

To understand the help or assistance they need to provide their best care for their stroke survivor family

## CHAPTER TWO

### 2.1 Literature Review

#### **OVERVIEW OF STROKE**

Stroke is one of the leading causes of adult death and disability worldwide especially in the developing world. According to the latest World Health Organization (WHO) statistics cerebrovascular disease accounted for 10.8% of total deaths and 3.1% of disease burden worldwide. The burden of disease from stroke has been increasing in sub-Saharan Africa (SSA). Approximately 85% of death from stroke occurs in low to middle income countries. Age and disability adjusted life-years loss rates and stroke mortality rates are 3.5-3.8-fold higher in low-income countries than in middle income and high-income countries. Although the exact prevalence and emergency burden of stroke in these communities are not known, it has been reported to be increasing. In TASH, stroke accounted for 23.6% of all neurological admissions (3) and 5% of all head CT indications <sup>(22)</sup>. Currently, community based stroke prevention programs and the use of community health workers are recommended to increase access to medical information and stroke care <sup>(23)</sup>

#### **POST DISCHARGE OF STROKE PATIENTS**

Many stroke patients are discharged home with functional limitations requiring assistance with ADL. This assistance is usually provided by family members who often feel unprepared or “unready” to assume the caregiving role. Moreover, many caregivers describe feeling abandoned and alone with no one to turn to post-discharge. During the period immediately after discharge into the community, family caregivers often report that they were not supplied with the necessary training to enable a successful transition to the home environment. These findings are supported in other studies and reports focusing on the needs of stroke survivors and caregivers as they are discharged home <sup>(24)</sup>. Poorly prepared caregivers present a safety risk for patients and caregivers and may increase preventable readmissions. If gaps in caregiver readiness cannot be addressed, other temporary or long-term options that provide more support should be considered <sup>(25)</sup>.

When stroke survivors are discharged home, most of the care provided will be by family members; the inclusion of family caregivers in treatment planning and needs assessments in the rehabilitation setting should therefore be implemented. Despite this, families are not generally included as integral within the trajectory of stroke care. Nurses and other rehabilitation providers should view stroke patients and family caregivers as a unit. <sup>(26)</sup>.

For stroke survivors, the transition to stroke recovery required time, life goal reconfiguration, willpower, humor, and network support. Post-stroke caregiving is a daily navigation and negotiation influenced by internal and external processes. Personal, economic, and socio-cultural nuances play a role in how post stroke recovery is lived and experienced. Study findings highlight the importance of policies to support family-centered and system-level advocacy in post-stroke care <sup>(27)</sup>.

### **THE CONCEPT OF CAREGIVING**

Meaning in caregiving plays an influential role in stroke family caregiver's perception and adaptation to caregiving. Meaning in stroke family caregiving was interpreted as suffering, an obligation, a personal choice, a meaningful opportunity, and a natural part of living. These meanings were dynamic and interconnected and were affected deeply by the Chinese culture in how caregivers experience, interpret, and cope with caregiving. Findings highlight the need to understand the culture-shaped meanings in caregiving to better support family caregivers and develop culturally tailored interventions <sup>(28)</sup>.

It is not enough to tell individuals to exercise. This guideline concordant recommendation needs to be accompanied by specific details on where and how fitness activities that could be accessed in a given community. Healthcare systems and providers need to include community services information and linkage in addition to more general fitness instructions. Blixen C. et al. 2015. Describe that African-American) AA men with stroke/TIA and their CPs (Care partners) can provide valuable input on appropriate and generalizable approaches to reduce stroke disparities. Care that goes beyond clinician-centered or hospital based guidelines to focus on the AA man, his family, and his community may potentially help rehabilitation programs and providers improve outcomes and reduce disparities in younger AA men. <sup>(29)</sup>.

Canadian researchers also found that for most of the daughters of stroke survivors, parent care became their first priority. They dedicated considerable time and effort to the caregiving role and, as a result, their own lives and activities often became secondary. Some daughters attempted to attend to all their roles but explained that they did so in a distracted manner or with limited capacity. Two major themes relating to the experience of and response to role overload: 1) caregiving-related role overload affects other valued relationships; and 2) caregiving-related role overload affects daughters' participation in valued activities (<sup>30</sup>).

In general, Cameron J. et al. 2012 discussed caregivers and Health care Professionals (HCPs) agreed on the types of informational, emotional, and instrumental supports caregivers needed and how these needs changed over the course of a stroke survivor's recovery. During the preparation phase, caregivers received some training to support ADLs and rehabilitation therapy, but felt that these needs were only "somewhat met". Caregivers received support from primarily three sources: (1) HCPs, (2) family members and friends, and (3) peers (i.e. individuals caring for family members who had experienced a stroke). Each group provided different types of support at different times and used different approaches (<sup>31</sup>).

## **CAREGIVERS' FUNCTIONALITY AND SUPPORT**

Disability is no longer understood as a feature of the individual, but as the outcome of an interaction between the person with a health condition and the environmental factors. Five categories of variables are known to be important determinants for caregiver (dys)functioning: Stroke patient's characteristics (e.g., physical and cognitive impairment, disability or behavioral problems), caregiver's demographic characteristics (age, health problems), psychological factors (e.g., coping strategy, sense of coherence and depressive symptoms), relational aspects (e.g., (dis)harmony in the relationship and marital satisfaction) and social factors (e.g., support and loneliness). A better outcome can be expected when stroke rehabilitation is organized as family-centered care. When the family is functioning better, the patient will function and feel better too. The strengths and needs of all family members, the patient with stroke included, have to be considered throughout all phases of the rehabilitation process. Family care should be part of the lifelong care for stroke patients. Further research on this topic is still needed (<sup>32</sup>).

Family support significantly increased social activities and improved quality of life for carers, with no significant effects on patients (<sup>33</sup>). Regardless of the cause, if patients do not practice the

rehabilitation they conducted while in the hospital at home, in the long-term they would be wasting both their time and money. Family members also have an important role to play in the reintegration of the patient into society. Therefore, both the patient and his or her family members must be provided with guidance while the patient is still in the hospital. Family members must understand the illness and learn techniques to assist the patient. When family members are engaged in rehabilitation with the patient, the duration of training sessions often lengthens and functionality improves <sup>(34)</sup>.

High levels of family support—instrumental and emotional—are associated with progressive improvement of functional status, mainly in severely impaired patients, while the psychosocial status is also affected <sup>(35)</sup>. The process of caregiving can disrupt the economic balance in families. Alongside the economic dimensions of caregiving, the caregivers also can't work, and these may cause economic problems in the family (Asiret and Kapucu, 2012). In the process of caregiving, 28% of caregivers have reported decreases in their income, 50% stated increases in their expenditures (Andrew et al., 2015), 21% said they had financial problems (Das et al., 2010), 34% reported that their income couldn't cover their expenditures (Asiret and Kapucu, 2013), and 29% stated that they couldn't cover care expenditures (Sirzai et al., 2015) <sup>(36)</sup>.

## **PATIENT/CAREGIVER EDUCATION AND COUNCILING**

Education is more common than counseling as a strategy to promote patient adjustment in stroke rehabilitation. Caregiver education would facilitate and maintain adaptive changes in family function. Further, counseling helped maintain the benefits of education in several areas of family function and resulted in better patient adjustment. Rehabilitation programs contemplating family intervention should consider the added benefits of counseling <sup>(37)</sup>

The caregivers of dependent people play a key role in the continuity of care when the patients return home, thus emerging the figure of the caregiver. We underline that the overburden experienced by the so-called caregivers is often overlooked, and they are the central point of reference in the care process, suddenly and unexpectedly assuming responsibility for care, without being prepared. The majority of the caregivers were married (72.2%), 13% were single, 7.4% were divorced and 7.4% were cohabiting. With regard to the professional situation of the

caregivers, 29.6% were employees, 20.4% were self-employed or liberal professionals, 16.7% were homemakers, 14.8% were unemployed, 13% were retired and 5.6% were disabled or on sick leave. Many care providers revealed that they have no conditions to care for their relative at home, either due to their daily demands, such as their profession, or due to financial reasons. Most caregivers feel the impact of their relative's disease and report facing great difficulties, with a greater overburden due to lack of professional support, problems related to the patient and inadequate family support. Since the quality of Life (QOL) of patients and caregivers is affected after a stroke in which the patient has some degree of dependence, it seems to us that our role as health professionals is determinant to help caregivers and patients deal with this new reality, namely through educational interventions (<sup>38</sup>).

## **REHABILITATION AND RECOVERY**

Family caregivers tried to handle their patients ADL in various ways. Handling is a special care in the domains of personal care, movement and social performance, with or without aids and equipment, which can be done by practitioners or caregivers. Its range varies from the maximum of complete care to the minimum of the least care. Family members have a crucial role in teaching physiotherapy to the patient. In fact, physical dysfunction is the major concern for both the survivors and their family caregivers in their everyday life situation. For people with a physical disability, a physically active lifestyle could improve everyday functioning, reduce disability and decrease the risk of secondary health problems (<sup>9,39</sup>).

The psychiatric component of stroke therapy and rehabilitation should not only be patient-oriented. Patient relatives, and particularly their caregivers, may need training and psychiatric support. A rehabilitation program that includes education and interactive group therapies could be very useful (<sup>10,40</sup>). Although the increased workload, restricted social life, physical problems, and knowledge and financial deficits were challenging for the family caregivers, self-strength and supportive social networks helped them to compassionately care for their stroke survivor. The phenomenon of family caregivers providing informal care for stroke survivors was explicated as compassionate care, notwithstanding numerous difficulties (<sup>41</sup>). Ana Railka et al. found that 73.8% of family caregivers of patients suffering from stroke developed CRS (caregiver role strain). The defining characteristics for more accuracy were: lack of time to meet

personal needs; increased emotional liability; withdrawals from social life; and changes in leisure activities <sup>(42)</sup>.

It is known that caregiving is not a burden-free zone, yet the sudden installation of post-stroke care demands on family members are accompanied by major emotional, financial, and social strains. This burden could be prevented from appearing, minimized or even curtailed in duration if caregivers were to be targeted by interventions that provide psychological support and basic training on post-stroke care <sup>(43)</sup>.

Closing the gap between existing knowledge on how to improve quality of stroke care in LMICs has the potential to be successful if unique and context specific measures from the views of stroke care providers are considered in developing quality improvement strategies and health systems and policy reforms. Overall, the proffered strategies respond to recent recommendations by the Lancet Neurology Commission on the need to have locally based measures to effectively tackle the growing burden of stroke in LMICs (low and middle income countries) <sup>(44)</sup>

The efficacy of home based rehabilitation after discharge from inpatient care compared to outpatient (or hospital based/day hospital) rehabilitation was addressed by a number of RCTs. The trials found no difference in effectiveness between post-stroke rehabilitation provided in a domiciliary setting compared to a hospital based (outpatient or day hospital) setting. A Home based or hospital based (outpatient or day hospital) rehabilitation should be considered for people after stroke. A characteristic feature of stroke unit care is the provision of information about stroke and stroke rehabilitation to patients and carers. What is less clear is how best to disseminate such information. The evidence suggests that information should be provided routinely using active information provision strategies which involve patients and carers, and include a mixed approach of education and counseling. The class A recommendations are: Information should be available to patients and carers routinely and offered using active information strategies, which include a mixture of education and counseling techniques. And Information should be tailored to the information needs of individual patients and carers, followed up to check understanding and ensure clarity, and repeated as appropriate <sup>(45)</sup>.

## 2.2 Methods

### 2.2.1 Study area

The study was conducted at Tikur Anbessa (Black Lion) Specialized Hospital, College of Health Sciences of Addis Ababa University. It is located in Addis Ababa and was established in 1964. To date, it is the largest referral hospital in Ethiopia and is now the main teaching center for both clinical and preclinical training of most disciplines. It is also an institution where specialized clinical services that are not available in other public or private institutions are rendered to the whole nation<sup>46</sup>.

Staffed with the best known Neurologists and consultant Neurology subspecialists, it is the only hospital with the capacity to give Neurology specialty program for residents and pediatrics fellows<sup>47</sup>. In addition to this, the presence of substantial amount of patients following at neurology referral clinic makes it the perfect place to undertake this study<sup>48</sup>. For instance, there were a total of 465 male and 406 female stroke patients both ischemic and hemorrhagic stroke patients who came for follow up from Dec,2019 to May,2020 over six month period of time as the data from the audit of neurology department clinical activities show.

### 2.2.2 Study Approach

A qualitative conventional content analysis was conducted with interviews using a semi-structured type of guided interview. This is selected as the most robust technique since it emphasizes an integrated view of speech/texts and their specific contexts. We examined meanings, themes and patterns that were manifest in a particular text. This allowed us (the researchers) to understand social reality in a subjective but scientific manner<sup>49</sup>. By that it enabled us to have a thoughtful understanding of the complexity of caregivers' everyday lives as well as ensuring a close rapport between interviewer and interviewee that facilitated discussing the more sensible topics of providing care to a relative with disabilities<sup>(50)</sup>.

### 2.2.3 Participants and recruitment

The source participants were all stroke patients' families who came with the patients on appointment dates of the patients or appointed via virtual clinic (phone) whom were on follow up at neurology stroke clinic of TASH

Participants inclusion criteria are: 1) they are a family member or caregivers of stroke patients; 2) age above 18 ; 3) taking care for a minimum of three months since the stroke occurred. The exclusion criteria are : 1) an attendant who was not giving care primarily for the patient and just came to accompany at the follow up clinic; 2) age below 18 years; 3) the stroke is less than three month time. Participants were recruited despite their gender, level of education, monthly income or residence which was either urban or rural area.

The sample was a purposive type of sampling which is a non-probability sample that is selected based on the characteristics of a participant and the objective of the study. The study used a maximum variation/heterogeneous purposive sampling to include a diverse range of participants by age, gender, residence, educational level, relationship to the patient, prior role, presence of a hired nurse or not and monthly income and this enabled us to collect a data that sufficiently represented majority of care giving families of stroke patients.

#### 2.2.4 Data collection

In-depth interviews were conducted both in-person and via telephone depending on the availability of the participants. After taking verbal consent, first demographic data was asked followed by open ended questions regarding their overall cares and challenges encountered on stroke care since they faced the event. These questions mainly focus on the cares given by the care giver, physiotherapy, medications taken by the patient, diet and the challenges the care givers face with their opinion on how to improve their situation as to where to give support that is their most need. Each interview was provided using a semi-structured interview guide having a planned structure and with the interviewer's guidance having a flexible course and open-ended probing questions in Amharic language.

All the in-person interviews done were carried at follow-up clinics room and on phone was conducted in office room by the primary investigator. The interviews were audio-recorded while taking appropriate notes and the duration on average was 30 minutes.

#### 2.2.5 Data analysis

Qualitative content analysis was used because of the need to interpret meaning from the textual data. This analysis was conducted in several steps (<sup>51</sup>). All audio-records were transcribed

verbatim and translated into English by two experienced translators for analysis. Both the transcriber and translators were provided with a brief description about the research scope and objectives of the data to enhance their understanding of the subject matter. The transcripts and translations were cross-checked for consistency and the translated notes were read by the primary investigator multiple times to put different meaning units of words, phrases or sentences identified and labeled these as codes to define in to sub-categories and categories according to the objective of the study. A code book was prepared and was reviewed by different advisors (at least three of the advisors). Content analysis software OpenCode version 4.03 was used for organizing the analysis.

### 2.2.6 Operational Definition

1. Stroke can be defined as an episode of acute neurological dysfunction presumed to be caused by Ischemia or Hemorrhage. the term is broadly used to include CNS Infarction, CNS Ischemia, Intracerebral hemorrhage, Subarachnoid Hemorrhage, Cerebral Thrombosis, and not otherwise specified<sup>(52)</sup>.
2. Caregiver n. <sup>(53)</sup>
  - a. A person who attends to the needs of and provides assistance to someone else who is not fully independent, such as an infant or an ill adult. A person who does the majority of the work is called the primary caregiver.
  - b. In health care, any individual involved in the process of identifying, preventing, or treating an illness or disability. —caregiving adj.

## 2.3. Trustworthiness

### 2.3.1. Credibility

Familiarity with the study area and the patients on follow-up clinics helped us for the development of trust worthy data. The participants chosen were the only ones who were genuinely willing to take part and were prepared to offer data freely<sup>54</sup>. The data collected from people with different background and at different time intervals. The advisors involved in this research were also well experienced with conducting qualitative research.

### 2.3.2. Dependability and Conformability

Frequent debriefing sessions were conducted between the researcher and advisors. There were also be member checks done. In the analysis process, two senior researchers were involved to

reduce the bias associated with having only one researcher's perspective to enhance the reliability of the interpretation<sup>55</sup>

### 2.3.3. Transferability

The data collection was done by the primary investigator and used probing questions to gather sufficient data that are complete and adequate for an input. The participants involved were from different demographic background and in-depth interview were done at private quiet rooms with no other person from the participant side in order to make them free and explain their answers with no reservation. The recordings were transcribed and translated verbatim after a briefing was given for both the transcriber and translator and all the data was made available for other researchers to make judgments about the transferability of our research findings in different contexts.

## 2.4 Ethical consideration

Letter of support was obtained from student research program. And then Ethical approval obtained from the Institutional Review Committee of the College of Health Sciences of Addis Ababa University. Permission was obtained from the hospital for interviewing participants. After explaining the objectives and importance of the study, consent was taken from all participants for participation and audio recording before the commencement of each interviews. Confidentiality and anonymity was kept throughout the study.

## 2.5 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 the culprit for need of care as a reason for patients to fall under others care, care provision given by the care givers, the overall challenges and the impacts on the caregivers and the recovery of patients through different support systems that revolve around the main caregiver,

Out of the total 26 participants, 20 were females who are the patient's mothers (3), daughters (8), sisters (2), wives (3) and 6 were males who are the patient's brothers (2), husband (1) and sons (2). All of the care givers were providing a home based care. (Table 1)

Table 1(Participants' background characteristics result, TASH, 2021)

Characteristics		Caregivers
		N=26
Age	19-68 year	Median=41 year
Gender	Male	6
	Female	20
Education level	Higher education	11
	Secondary level	9
	Elementary level	4
	Didn't go to school	2
Residence	Urban	24
	Rural	2
Occupation caregiver's	Government	8
	Private	11
	Student	3
	None	4
Relationship with the patient	Parent	3
	Child	10
	Spouse	5
	Sibling	4
	Other	4
Stroke duration	3-6month	4
	6 month – 3 years	11
	More than 3 years	11
Monthly income	Median (min -max)	5,400 (1200-20000)
	Below GDP per capita	13
	Below GDP per capita	13

### 2.5.1 Culprit for need of care

Stroke by its nature is like a terrorist that attack in an erratic manner that some may have injury to a brain area with significant representation and some may result in minor disabilities there by making it a disease with a multitude possible attacks leaving participants indicated that with patients having different forms of dysfunctions resulting in varied degrees of disabilities. Their patients may have physical disability, memory loss, speech and language abnormality, problems with vision, difficulty with feeding and swallowing, incontinence for bladder and or bowel, in addition to these, participants also mentioned the patients may have new development of some emotional and psychological sequels and a downcast on their social interactions.

*“..... The right leg and right arm doesn't work both are weak in addition to that her speech is also weak she can't speak” (Participant #11, M, IDI)*

*“ .....She also tells us that she want to urinate but I put her on diaper because she is incontinent until we put her on the movable toilet....” (Participant #15, F, IDI).*

All of the participants agreed that these impacts leave the patient incapable of achieving performances in different activities of daily living (ADL) and other non-performable interactions prompting for someone who will undertake these life matters to improve their health in general and betterment of the patient's quality of life (QOL) as much as possible.

*“... yes it is very hard for her. Because she used to gain her own money and now she is being helped from people so this also makes her sad frequently, she cries. She used to cook her food by herself but now she receive food from someone's hand so this caused a stress on her” (Participant#23, F, IDI)*

### 2.5.2 Care provision

It is clear that the types of care being provided by the care givers depend on the level of severity of the patient's condition. All of the patients have physical disabilities at least as the initial time of the stroke and would require assistance from their caregivers go handle their self-cares with hygiene. This includes giving bath or shower, giving oral care, changing clothes, and providing bladder and perineal care.

In addition to that patient also require physical support with ambulation or moving around, turning in bed and avoiding pressure sores, sitting on a wheelchair and also feeding a meal when provided.

*'' Cooking timely and feeding on time by NG tube, every three hours preparing and feeding him liquid- We do not miss his time..... Change position if he is in bed .... Another we put him wheelchair every day, we take him to the living room and let him watch TV...When the sun is around, we take him outside and get some sunlight. And we give him bath...Bed bath. We give him a full bath every 3 to 4 Days. And the other times, we provide him daily Care, perennial care, changing diapers and so on .... All this and that, I am the one who change and the NG Tube and the Catheter''*  
(Participant #1, IDI, F)

On top of that care givers also give psychological support with what the patients are going through and prevent the possibilities of patients getting in to depression and all its sequences.

*''.....as much as we can, now our daughter is not looking for a job because she would be alone and what you said can happen so with the thought of that she stays with her and we chat with her we make jokes and we tell her some talks and we spend the day chatting.''* (Participant#11, M, IDI)

Well it is not only with the physical and psychological help a caregiver's support is limited but also they have to carry the financial burdens there by increasing their expenses in their day to day life due to additional expenses from buying medication,

transporting patients for follow up and completing laboratory and imaging investigations which has a direct impact on the caregiver.

*“.....Mostly I use the health insurance book from the kebele’s support but if I couldn’t get any I try to collect money from people, friends and families support me and we buy.....When we did the MRI it cost us around 3000 birr and I begged at people from work place and they helped me, so that’s how I was able to do that.....They even ordered for second time but I couldn’t afford for another one and left it without it”*  
(Participant #7, F, IDI)

*“.....Our brother is out there so I get money from here and there asking for buying medications and also I add some part from me..... We will keep our appointments because an illness is a huge burden we do whatever we can even if we have to sell what we have just to save him.”* (Participant #4, F, IDI) 19 &---

### 2.5.3 Challenges and impact on care givers

Every caregiver faces different challenges depending on the level of disability their loved ones have. In association with the care giving the presence of significant work load and impacts on the physical wellbeing of the care giver’s, the psychological effect with emotional disturbances and the lack of owning a personal time for social interaction are the main challenges that directly affects the caregivers.

*“....the other thing I can think is I worry a lot not to make him under nourished and I want to keep him well with his diet and that worries me until he gets to his next follow up, when I get short of what I give him it worries me.”* (Participant #7, F, IDI)

*“.....it’s me I give her on time all the medications on time, you put aside social interaction and many things ..... You will have a problem with moving the patient, turning in bed, and you can’t sleep you have sleepless nights attending her. At least I have to wake up 3 times at night to position her in bed.....It is very difficult to take care of someone it is better off you are the one who got sick.....*

*..... Sometimes I just sit and cry like a baby, because it needs energy to move her. The hardest thing is that she won't be happy despite that all you do and strive. And there is your marriage also and your attention will be diverted from your husband and won't be caring for him as he wants and he is saddened, and can't please him when he comes from work...." (Participant #15, F, IDI)*

The financial crisis that results from increased money expenditure in addition to their previous budget and even worse decreasing their productivity because of lack of other attendants to keep an eye on the patient while they have to leave for work as a result of which they leave their job and stay home with their loved ones sacrificing what the future can hold for them.

*Participant #? " Yes, I had a job, I am a nurse and I used to work....No, I don't--- because of him --- because of his illness I'm the only one who's caring for him--- so I stopped" (IDI, Participant#1,F)*

In addition to that, caregivers also have to deal with the issues that result from inefficient healthcare system that doesn't support their current situation. With this, the presence of health facility problems in the hospital like medication unavailability, lack of laboratory and imaging modalities together with proper rehabilitation setup are the most reported complaints from the caregivers subjecting them to unnecessary expenses from private setups. Few participants also mentioned the presence of poor infection prevention measures that is practiced in the hospital and the lack of consideration for providing transportation service for the patients during their follow up visits as some of the challenges they have faced.

*".....mostly it is from outside at kenema ..... I never got them from here except only one time from our 8 month follow up otherwise I didn't find the medications from here when I come here monthly ..." (Participant #11, M, IDI)*

*“.....we don't find the medicine here most of the time. We buy from outside, they say it is not available here in the hospital .....We go to kenema so we buy from where ever it is available. It would have been cheaper if it was from here when we find here it is cheaper but if it is from outside it is double the price that is known.” (Participant #10, F, IDI)*

Professional in the healthcare system including physicians, nurses and physiotherapists also have given some headache to the caregivers with the fact that few of the practitioners have not plausible practice in addition to inappropriate work ethics and manners.

*“.....and a doctor said he may have a heart problem and told us to get him checked and threw a piece of paper at us in the middle of the night, 2 a.m. But he didn't even check anything, he didn't see him. I just told him he had a fever and he said that. This kind of things are such a pity. In fact, the doctor should first take a closer look at what the problem is otherwise giving some irrelevant investigation order in the middle of the night is not right....Regarding the nurses, they sit in their duty room and we couldn't get them mostly. Why is that? There is a nurse station in the front and they don't sit there to give service. This amazes me a lot and they don't leave their duty while we were there, we were tormented to go to their room and ask....With all that adequate desk which is left empty or the janitors sit on it....they just visit you once in the morning and next time you find them by searching, you don't find them....” (Participant #1, F, IDI)*

In relation to inefficient healthcare system, the poor practice of giving health education with regard to the disease itself and the treatments being given have created a knowledge gap between the now and the future for the achievement of better treatment outcomes

*“.....No, there is no health education and once there were doctors who interviewed me for a research purpose otherwise there was no health education given and we just understand by searching from Google and asking friends.” (Participant #26, F, IDI)*

The act of caregiving is a selfless act demanding determination and courage yet there are some patient related challenges that are difficult to amend like significant patient disability and challenges that come from patients with poor treatment adherence which is a behavioral factor that can possibly be amendable.

*“ ..... he didn't stop the medications but he didn't follow his diet and other things and got back to his job. So that means he stopped taking care of himself when he goes to work and everything, he began eating outside also drinks coffee and the second stroke happened. But now he is very careful because it happened for the second time and the first time he didn't thought it can occur again because he got better, he improved in very short time.” (Participant #10, F, IDI)*

#### 2.5.4 Support system and recovery

Team work is important in management of stroke patients and there is better outcome in patients showing recovery if they are provided with different support systems. The support systems includes different people starting from family members, friends, paid house maids, health professionals like nurses physicians and physiotherapists and even random people who have no direct relation with the patient or caregiver.

*“.....Anyone who is available at home buy the medication. Most of the time my younger sister buy and..... we take money from relatives and others for the test and take him to the laboratory.....our mother buys the ingredients to make the food” (Participant #26, F, IDI)*

*“.....and I ask for people saying I am in need for my daughter's checkup and I don't have enough money to take her to the hospital ..... oh, my neighbors are worse than me...Like if I tell one of the local people, another one will bring me that she got begging to our house, this is it.”(Participant #2, F, IDI)*

*“.....Mostly I use the health insurance book from the kebele’s support but if I couldn’t get any I try to collect money from people, friends and families support me and we buy.”*  
(Participant #7, F, IDI)

There are different forms of rehabilitation that should be implemented on stroke patients since this is the most important part of post-stroke care. Physical therapy, speech therapy, psychological therapy and even though not practiced as it should have been giving patients an occupational therapy is as important as other parts of treatments.

*“.....It is very difficult to stay at home for long time when you worked in governmental office. So, he was obliged to go and sign but when they saw him, they understand that he can’t teach as before.... He used to teach physics and geography and the school board agreed to undertake music and sport classes. Now he is working”*  
(Participant #16, F, IDI)

Having optimistic life goals has a positive impact on someone’s recovery which is brought a reality from well-educated patient and care giver through a good understandable health education over the disease condition and the treatment being given. In this way, there will be a better practice of using healthy diet, adherence to doctor’s advice, continuity of follow up visits and drug adherence especially in poor families with provision of a health insurance free card for buying medication as a financial constraint could hinder their adherence due to incapability.

*“.... We mostly use vegetables and fruits and shiro and lentils. We don’t use meat much.....Yes we were told, First not to take salt, to do exercise, not to get angry and irritable and to take care in everything. Also the medication shouldn’t be discontinued and to come every month and get the medication, they told us all this.”*(Participant #8, F, IDI)

*“.....Due to the health insurance paper is expired, we can't able to get the drug. The medication usually prescribed for 3 or 6 month. So that, we only buy outside for one month and between this she misses to take a little.”(Participant #18, F, IDI)*

Note that making sure of what they understood from a given health education over some topic is as important as giving the health education since some may misunderstood it and have their own version with malpractice.

*“.... About the stroke, the doctors told also him not to go back to drinking alcohol, smoke cigarette and chew khat, because they knew on their evaluation he used to take those and they warned him. As long as he is living we never gave him any but if he goes out and drinks that is his responsibility so the things he was told not to do including salt we control that which is on our side... (Participant#4, F, IDI)*

## 2.6 Discussion

Worldwide, cerebrovascular accidents (stroke) are the second leading cause of death and the third leading cause of disability<sup>56</sup>. After three months of sustaining stroke, 26% of stroke survivors require long-term care. Long-term disabilities are mostly hemiparesis, inability to walk, complete or partial dependence for activities of daily living (ADL), speech problem, swallowing problem, sphincter dysfunction, dementia and depression. The effects of stroke range in severity from minor disabilities that may resolve rapidly to severe and long lasting disabilities. These effects include physical disabilities, psychosocial and cognitive impairments<sup>57</sup>.

With regard of the care givers, there were 20 females out of 26 participants who are first degree relatives with a mixed meanings of caregiving. Caregivers can be the spouse, family members or friends. Often, one person: spouse, adult child or parent provides most of the care<sup>58</sup>. Our study can show the burden on females is much higher and this is consistent with a WHO series on long-term care stating the reliance on families also places a heavy burden on female relatives who are called upon to forego education, employment or other economic engagement in order to care for older relatives<sup>59</sup>. The acceptance of one self as a care giver is as important as giving the

care since there are different meanings what a caregiver has in mind for being the one at front line. As Diana T.f. et al stated in the lived experiences of caregivers, meanings in stroke family caregiving were interpreted as a physical, psychological, and social suffering; an obligation resulting from moral ethics, religion doctrines, others' expectations, and social norms; and a subjective choice based on love, hope, and a sense of reciprocity<sup>60</sup>. There by the first step in the lives of caregivers is accepting the responsibility of taking care of the patient in the pathway to post-stroke care and recovery.

In our study, we found that all of the participants were unpaid care givers. According to WHO, Caregivers can be grouped into two broad categories: those who are paid for their work and those who are not. Paid caregivers may include professionals and paraprofessionals or family members who receive compensation for the long-term care services they provide to relatives<sup>61</sup>.

Long-term care can be provided in a range of settings – including people's homes – and by a range of people. Currently, families provide most long-term care in sub-Saharan Africa and do so without any organized training or support. Reliance on families alone to provide this care results in inconsistent care quality and places a particularly heavy burden on women and girls<sup>62</sup>.

The roles of family caregivers' include fulfilment of patient's basic needs like self-care, providing physical support with ADL and psychological support in preventing depression. These findings are consistent with Sara P. et al<sup>63</sup>. 2003 stating 'Family function, broadly defined, clearly exerts an influence on stroke survivor recovery. In particular, there is evidence for the positive effects of family availability; better family communication and problem-solving skills; and emotional support, closeness, and empathy.'

As Caleb A.G. et al<sup>64</sup>. 2015 found in their report, caring for stroke survivors put burdens and strains on caregivers in different forms their life aspects comprising their social, emotional, health and financial state. In our study, we have noticed the challenges on caregivers are direct and indirect ones. The direct effects are physical burdens resulting in excessive workloads and to some resulting in health problems requiring treatments for themselves and some experience psychological affection with stress and leading unhappy life and yet others have mentioned about the impact on their social life interactions lacking time for themselves and disconnecting from their previous interactive practices. Even though it is not studies in this paper, it is found in

Caleb A.G. et al<sup>65</sup>. study, that these burdens and strains increase with duration of stroke, intimacy, smaller number of caregivers and length of daily caregiving.

The inefficient healthcare system contributes to caregivers' challenge and poor recovery of patients as we tried to see what the issues caregivers experience on the ground. From this we found healthcare personnel inefficiency and health facility inefficiency with drug unavailability, poor laboratory and imaging modalities and absent rehabilitation centers for most rehabilitation therapies have a contribution. This is consistent with the findings in SSA countries as Clovis Nkoke et al<sup>66</sup>. with regard to scarcity in specialized rehabilitation facilities and limited personnel and indicates that empowering patients and families on home based evidence based practices that offer similar gains like standard in hospital care could be cost saving and potentially more convenient, acceptable and sustainable in economically challenged regions as such.

Overseeing the importance of clear and understandable health education provision is one additional challenge that impacts the caregivers practice and treatment adherence issues that we explored on our study, as this is also stated in Bhogal S. et al<sup>67</sup>. in the article as, "There was evidence that improved social support as an intervention improves outcomes and that an active educational-counseling approach has a positive impact on family functioning post stroke".

## 2.7 Conclusion

Stroke not only attacks the patients but also the caregivers at the same time. The study showed most caregivers are female first degree relatives who are unpaid. The roles of stroke patient caregivers are mainly handling patient's self-care, providing psychological and general physical support in addition to financial support. There are different challenges the care givers are prone to having direct effect on their well-being physically, psychologically and with their social interactions. There are also challenges due to inefficient healthcare systems and knowledge gap due to inadequate health education provision. With all this the care givers manage to handle the situation via different support systems for the better outcome of the patients collaborating with other people like family members, friends, health professionals and others together with optimistic lifestyle modifications with healthy diet, treatment adherence and continuation of

follow-up visits. The provision of health insurance cards for free services also has a role in easing the burden of financial crisis that caregivers face.

## 2.8 The way forward

The results of this study form a springboard for future researches to address further aspects of holistic post-stroke care approach on the current practice and might add evidence in the importance of post-stroke care with fully functional hospital facilities with adequate provision of medications and accessible work-up modalities, well equipped physical rehabilitation center, fully organized occupational rehabilitation center, psychological support and group therapy center, financial support for care givers and transportation services that would be applicable for patients during hospital visits and other related services. Caring for the caregiver is also as important as caring for the patient and there should be an attempt to incorporate the strategies that help the caregiver in the treatment plan or guideline for post-stroke patients recovery hence, bringing the sense of being a ‘care-partner’ with the patient and other support systems for better patient outcome.

## 2.9 Strength and Limitations of the study

This is the first qualitative study done so far in our country and the first that is conducted on the role of family in post-stroke care. The advisors for the primary investigator are well experienced on the area of conducting research including qualitative studies.

The limitations of this study includes the use of in-depth interview only and other methods like focused group discussions were not conducted for two reasons, one reason is due to the Covid pandemic and triangulation was not done.



## Appendixes

### Appendix 1: Information sheet

Greetings; I am \_\_\_\_\_ and I am here to understand what your role is on caring for your stroke survivor family member from your own 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 discussion after finishing the discussion.

**Title of the study:** The Role of Families in Stroke Patients' Care: A qualitative study among Stroke Survivors at Tikur Anbessa Specialized Hospital

**Objective:** This study aims at explaining the role of families in stroke patients' care among stroke survivors at Tikur Anbessa Specialized Hospital.

**Benefits:** This study will not give any direct benefit to the participants; but the detail information you provide us will help to recommend the government and other health sectors to design appropriate intervention to address the problems related to post stroke care from the families perspectives. The findings also will help to identify the gaps in patient care which could be addressed by family members or caregivers and prepare a guide to use after patient discharge from the hospital.

**Risk:** There is no any risk associated with this study and overall of process of the interview.

**Right of the respondents:** Any participant will participate on this study voluntarily. You can quit from 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:** All the recorded discussions and transcript will not be accessed by anyone other than the study team and any information that you will give will be confidential. Your name and other information related to your private life will not be mentioned at individual level showing your identity.

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

1. Dr. Emnet Adane,(Neurology Resident), Email: [emnettaye@gmail.com](mailto:emnettaye@gmail.com)
2. Dr. Guta Zenebe (MD, Consultant Neurologist), Email: [gutazenebe@icloud.com](mailto:gutazenebe@icloud.com)
3. Dr. Hanna Demissie (MD, Consultant Neurologist), Email: [hanna.demissie@gmail.com](mailto:hanna.demissie@gmail.com)
4. Dr. Seid Gugssa (MD, Consultant Neurologist), Email: [neuroeth@yahoo.com](mailto:neuroeth@yahoo.com)
5. Dr. Hussien Nuri (Consultant Neurologist), Email: [Nurihussen26@gmail.com](mailto:Nurihussen26@gmail.com)
6. Ato Mulugeta Tamire (MPH, PhD Student), Email: [Mulugetatamire18@gmail.com](mailto:Mulugetatamire18@gmail.com)

**Are you willing to participate?**

#### Appendix 2: consent form

I, the undersigned, 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 have understood that it is my right to withdraw from the study at any time; the proposal has been explained to me in the language I understand.

Participant

Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Interviewer

Name \_\_\_\_\_ Signature \_\_\_\_\_

Interview code \_\_\_\_\_ -

## Appendix 3: Interview Guide (English Version)

### **Semi-structured Interview questionnaire on Role of Families on stroke patients' care**

#### **Demographic Data**

Male/Female

Age -----

Region/Residence- (Urban/Rural)

Educational level- -----

Monthly income – (ask if any type of fund they get from other sources)

Prior role-----

How long has it been since the stroke? ----- (months)

What is your relationship with the patient -----

#### **A. Interview Introduction**

Length: 30-60mins

Primary goal: to know the things how 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. Verbal consent**

Would you like to participate in this interview?

Consent was obtained

Consent was not obtained

#### **C. Background Information**

Overview: General Information- Invite interviewee to briefly tell the interviewer about him/herself and way of living before his/her relative experienced stroke. Then mostly about the experiences and challenges on caregiving for a stroke survivor.

#### **D. Type of cares given**

1. What is the patient suffering from? What part of his/her body is not functioning?

**Probe:** The neurologic deficits involved; ask about presence of weakness, speech, understanding when talked with, urine and bowel function, any visual problems if they are not clear about the question?

2. What do you do for your patient from morning to evening?

**Probe:** concerning ADL; tell us what you do on a normal week day, on weekends and on holidays

3. Does the patient engage in physiotherapy? Do you help your patient in physical rehabilitation?

**Probe:** If yes, Where? At home or in a health facility. How often? Duration on each session? What type of physical exercises? Any speech therapy?

4. What are the medications the patient is taking? Who provides or buys the medications

**Probe:** do you know what the names are? The uses? Dosages? The side effects? How often is it refilled? Where do you find the medications, in the hospital or other pharmacies? Who goes to pharmacy and buys them? With whose money?

5. How does the patient come for follow up?

**Probe:** the transportations used? Who helps on the way? Who pays for the travel?

6. How does the patient complete the investigations requested by the physician?

**Probe:** who takes the patient to the laboratory or diagnostic setup? Who collects the results? Who pays for the fees?

7. Does the patient ever been helped to get back to his /her previous work?

**Probe:** occupational rehabilitation if any? What does he/she does at home if capable of performing any work?

8. What do you do for keeping the patient interested in life? Any social event or activity that you do? Any entertainment that the patient likes?

**Probe:** to prevent depression? Psychosocial support?

9. What diet the patient gets mostly? Is there any advice given or told not to take from the physician?

**Probe:** who prepares or cooks the meals? Who brings/buys the ingredients? What are the portions content mostly? Do you think it is balanced? Does the patient feed by him/herself or do you assist on that? (Supports Q#1)

10. What is your expectation from recovery of the patient to normal before stroke condition?

**Probe:** on a scale 0 to 10 (1 being no recovery or change to 10 complete recovery or back to a state of before stroke happened), where do you put your expectation?

11. What is the most troubling issue for you so far and also currently as a care giver?

**Probe:** where you or anyone from the family given any health education about stroke and the patient's support needs? What is the most difficult thing to do so far?

12. If you are given the chance to get help or assistance on the care you have been giving your patient so far, what would that be?

**Probe:** the help could be from the government, from the health sector, from the physician, from the nurse, from other family members or even friends?

አባሪ 3: የቃለ መጠይቅ መመሪያ (አማራጭ ጽሁፍ)

ቤተሰብ በስትሮክ ታካሚዎች እንክብካቤ ላይ የሚኖራቸው ሚናን በተመለከተ በክፊል የተጠናከረ የቃለ መጠይቅ ጥያቄዎች

የግል መረጃ

ወንድ/ሴት

ክልል/መኖሪያ (ከተማ/ገጠር)

የትምህርት ደረጃ \_\_\_\_\_

ወርሃዊ ገቢ \_\_\_\_\_ (ከሌሎች ምንጮች ምንም አይነት የገንዘብ ድጋፍ የሚያገኙ ከሆነ ይጠይቁ)

የቀድሞ ሚና \_\_\_\_\_

በሽታው ከጀመረ ምን ያህል ጊዜ ነው? \_\_\_\_\_ (ወራት)

U/ የቃለ መጠይቅ መግቢያ

የቆይታ ጊዜ 30 / 60 ደቂቃ

የመጀመሪያ ግብ: ከስትሮክ ህመሙ በኋላ ባለዎት ልምድ ላይ ትኩረት በማድረግ በንግግር የበለጠ ያወቁትን/የተረዱትን ነገሮች ለማወቅ እና እንዴት ተግዳሮቶችን እየፈቱ እንደቆዩ ለማወቅ ፤

ለ) የቃል ስምምነት

በዚህ ቃለመጠይቅ ላይ ለመካፈል ፈቃደኛ ነዎት?

ስምምነት ተገኝቷል

አልተስማሙም

ሐ) መሰረታዊ መረጃ

ማጠቃለያ: አጠቃላይ መረጃ: ቃለመጠይቅ ተጠያቂ ዘመዱ/ዲ ስትሮክ ችግር ከማጋጠሙ በፊት ስለ ራሱ/ ስለ ራሷ እና የአኗኗር ዘይቤውን/ዋን በአጭሩ እንዲገልፅ /እንድትገልፅ ይጋብዙ በተለይም በስትሮክ የተጠቃ ሰው እንክብካቤ ላይ ያላቸው ልምዶች እና የሚያጋጥሙ ተግዳሮቶች ላይ ያተኮረ ነው፤

የሚሰጠው የጤና አገልግሎት

1. ታካሚው የጤና ችግር ምንድን ነው? የትኛው የሰውነት/ተ ክፍል አይሰራም?  
ሀሳብ: የነርቭ ጉዳት አለ? ስለአካል የአካል መስነፍ:- ንግግቶች? ሲናገሩ መግባባት? የሽንትና የአንጀት ስራ? ሌሎች ማናቸውም የእይታ ችግሮች፤
2. ከጠዋት እስከ ማታ ለታካሚው ምን ያደርጋል?  
ሀሳብ:- የቀን ተቀን አኗኗርን በተመለከተ የመደበኛ የሰውነት ቀን፣ በሰውነት የረፍት ቀናት እና በበአል ቀናት ምን እንደሚሰሩ ወይም እንደሚረዱ ይነገሩ?
3. ታካሚው ፊደላዊ ቴራፒ ተደርጎላቸዋል? በአካላዊ ማገገሚያ ላይ ድጋፍ ያደርጋል?  
ሀሳብ: አዎ ከሆነ የት? በቤት ሆነ በጤና አገልግሎት፤ ምን ያህል ጊዜ? ምን አይነት አካላዊ እንቅስቃሴ ፤ የንግግር ህክምና ከተደረገላቸው ?
4. ታካሚው እወሰደ ያለው መድሀኒቶች ምንድን ናቸው? መድሀኒቶቹን የሚሰጥ ወይም የሚገዛ ማነው?  
ሀሳብ:- የመድሀኒቶችን ስም፤ ጥቅምቸውን፤ አደሰሰድ መጠን፤ የጎንደሽ ጉዳቶች ያውቃል? በምን ያህል ጊዜ እየመጡ ማዘዣ ይወስዳሉ ? መድሀኒቶቹን የት ያገኛሉ? ወደ መድሀኒት መደብር ሄዶ የሚገዛው ማነው? በማን ገንዘብ?
5. ታካሚው ለክትትል እንዴት ይመጣሉ?  
ሀሳብ፤ በምን ትራንስፖርት? መንገድ ላይ ድጋፍ ይፈልጋል? ክፍያውን ማን ይከፍላል?
6. ታካሚው በሃኪም የተጠየቁትን ምርመራዎች እንዴት ያጠናቅቃል?  
ሀሳብ:- ታካሚው ወደ ላብራቶሪው የሚወስደው ማነው? ውጤት ማይቀበላል? ክፍያ ማን ይከፍላል ?
7. ታካሚው ወደ ቀድሞው ስራው/ዋ እዳመለስ/ እድትመለስ ድጋፍ ተደርጎለት/ላት ያውቃል?  
ሀሳብ :- የስራ ቦታ ማገገሚያ ካለ ምን አይነት ስራ ?መስራት ከቻሉ? እቤት ውስጥ ምን ይሰራሉ?

8. ታካሚው በህይወቱ ደስተኛ ሆኖ እዲኖር ምን ደርጋሉ? እርስዎ መስራት የሚችሉት ማናቸውም የማህበረሰብ ድርጊቶች ወይም ስራ? ታካሚው የሚወዳቸውን ማናቸውም መዝናኛ ወይም ጊዜ ማሳለፊያ ካሉ?

ሀሳብ:- ድብርትን ( ድባቱን) ለመከላከል? የስነልቦና-ማህበረሰባዊ ድጋፍ?

9. ታካሚው ብዙውን ጊዜ የሚያገኘው ምግብ ምን አይነት ነው? ከሀኪሙ እንዳይሰጠው ወይም እዳይወስደው የተነገረው ምክር አለን?

ሀሳብ:- ምግብን የሚያዘጋጅ የሚያበስል ማነው? የምግብ ግብአቶችን የሚያቀርብ/ የሚገዛ ማን ነው? አብዛኛውን የግብአቶች ይዘቶች ምድናቸው? ይህ የተመጣጠነ ነው ብለው ያምናሉ? ታካሚው በራሱ/ሷ የመገባል/ትመገባለች ወይም አመጋገብ ላይ ድጋፍ ያደርጋሉ? (ድጋፍ ጥያቄ 1)

10. የስተሮክ ሁኔታዎች ከመታየታቸው በፊት ወደ ነበረበት ታካሚው ወደ ጤና ሁኔታ ስለማገገሙ የሚሉት ምንድን ነው?

ሀሳብ:- ከ 0-10 ነጥብ (1 ምንም አይነት የማገገም ሁኔታ ወይም ለውጥ የለም ቢሆን፣ 10 ደግሞ ሙሉ በሙሉ አገግሟል ወይም ስትሮኩ ከማጋጠሙ በፊት ወደነበረበት ሁኔታ ተመልሷል ቢሆን እርሶ የሚያስቡት ለውጥ ምን ያክል ይሰጣሉ?

11. ለእርስዎ እስካሁን ድረስ አስቸጋሪ ጉዳዮች ምንድናቸው? እዲሁም በአሁኑ ጊዜ እንደ ተንከባካቢ ከሁሉም ነገር በጣም እቸጋሪ ጉዳይ ምንድን ነው? የጤና ትምህርት አገኝተዋል?

ሀሳብ:- ስለ ስትሮክ እርስዎም ሆነ ከቤተሰብ ውስጥ ማንኛውም ሰው የጤና ትምህርት እና የታካሚ ፍላጎት ድጋፍ አገኝታችኋል?

12. እስካሁን ድረስ ለታካሚው ሲሰጡ ከነበረው በእንክብካቤ ላይ ድጋፍ እዲያገኙ እድል ቢሰጡት ይህ ድጋፍ ምንድን ነው?

ሀሳብ:- ድጋፍ ከመንግስት፣ ከጤና ተቋም፣ ከሀኪም፣ ከነርስ ወይም ከሌሎች ከቤተሰብ አባላት ወይም ጓደኞች ጭምር ሊሆን ይችላል።

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