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

RESEARCH THESIS

STIGMA AMONG STROKE SURVIVORS: EXPERIENCE FROM A TERTIARY HOSPITAL, TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA

BY

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THIRD YEAR NEUROLOGY RESIDENT

NOVEMBER, 2021

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November, 2021

ADDIS ABABA, ETHIOPIA

ACKNOWLEDGEMENTS

I would like to express my gratitude to Addis Ababa University and Department of Neurology, School of Medicine, College of Health Science, Tikur Anbessa Specialized Hospital, for giving me this opportunity to conduct a research on an issue that I am curious about, the result would be vital for intervention. I would also like to express my heartfelt gratitude to my advisors Dr.Yared Mamushet, Dr. Biniyam Alemayehu and Dr.Girma Diltata for their continuous support and constructive advice. I would also like to thank the participants for giving their consent to participate in the study, and for openly discussing on issues that may be sensitive.

ABSTRACT

Background:
Stigma among neurologic disease is a widely recognized global health issue. The negative impact it has on different neurologic diseases has been described. Although stroke survivors have different degree of stigma which may contributes to negative outcomes, there is shortage of study on stigma among stroke survivors and its predictors, especially in low and middle income countries.

Study title:
Stigma among stroke survivors: Experience from a tertiary hospital in Addis Ababa, Ethiopia

Objective:
To assess the prevalence of stigma and its associated factors among stroke survivors having a follow up at the Neurologic Out-patient Clinic in Tikur Anbessa Specialized Hospital.

Methods:
Institution based quantitative cross sectional study was conducted among 123 stroke patients having a follow up at Tikur Anbessa Specialized Hospital Neurology Out-patient Clinics. Data were collected by interviewer administered questionnaire. Stigma was measured using Stigma scale for chronic illness (SSCI-8) tool and included self, family, and community perceived stigma. Depression was assessed using Patient Health related Questionnaire (PHQ9), and functional status using modified Rankin Scale. Data were entered and analyzed using Statistical Package for Social Sciences (SPSS V25) software package. Binary logistic regression and multinomial logistic regression was used. Adjusted odds ratios with 95% confidence interval were used to identify associated factors with perceived stigma.

Results:
Overall, the prevalence of perceived stigma was 55%. For the perceived family and community, it was 17.9%, and 13.8% respectively. Functional disability [moderate to severe disability (AOR=6.88, CI: 2.257, 22.46) *P*=.001.], Depression (AOR=19, CI: 2.24, 161.34)*P*=.007 and residual weakness (AOR=9.71, CI: 0.94, 94.95) *P*=.051were factors associated with perceived stigma in stroke patients.

Conclusion and recommendation:
Around half of stroke survivors who participated in this study described some form of perceived stigma. The personal perceived stigma was higher when compared to family or community perceived stigma. Factors associated with perceived stigma were Depression, residual weakness post stroke, and moderate to severe disability functional status. The rehabilitation services for patients with stroke should be strengthened. These should include physical, emotional, and social aspect of disabilities. In addition, establishing patient support groups for stroke survivors, and educating the community about stroke may be important to address stigma.

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ACRONYMS AND ABBREVIATIONS

A.A	Addis Ababa
AOR	Adjusted odds ratio
CI	Confidence Interval
COR	Crudes odds ratio
DALY	Disability adjusted life years
DRPC	Department of Neurology Research and Publication committee
GBD	Global burden of disease
HMIS	Health management information system
LMIC	Low and middle income countries
mRS	modified Rankin scale
OPD	Out-patient department
PHQ9	Patient Health Questionnaire-9
PI	Principal Investigators
PSD	Post Stroke Depression
TASH	Tikur Anbessa Specialized Hospital
SPSS	Statistical package for social sciences
SSA	Sub-Saharan Africa
SSCI	Stigma scale for chronic illness
UK	United Kingdom
WHO	World Health Organization

INTRODUCTION

1.1 Background

Stroke is ranked as the second leading cause of death worldwide with an annual mortality rate of about 5.5 million (1). Fifty percent of stroke survivors are chronically disabled due to its high morbidity. The estimated global lifetime risk of stroke has increased from 22.8 to 24.9% in the past two decades (1). Stroke is a disease of great public health importance with serious social and economic and consequences. The public health burden of stroke is set to rise over future decades due demographic transitions of populations, particularly in developing countries (1).

Stroke is defined according to WHO as "rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin (2). Based on pathologic processed, It is mainly classified as Ischemic stroke and hemorrhagic stroke (3).

In Sub-Saharan Africa, the incidence, prevalence and death rate due to stroke is increasing. It is also disabling, with more than 80 million stroke survivors worldwide and an increased absolute number of DALYs (4). The prevalence of Ischemic stroke is higher than hemorrhagic stroke in the western population. Ischemic stroke was also more commonly seen in different regions of Ethiopia. Even though ischemic stroke is higher, the prevalence of hemorrhagic stroke was higher than the western population in studies done in Ethiopia (5). The incidence of stroke has increased worldwide, especially in those who have less access to medical care (5).

Stigma is an "attribute that is deeply discrediting" and that it diminishes a person in the eyes of others "from a whole and usual person to a tainted, discounted one" as written by Goffman in 1963 (6). Labeling a difference that is perceived as undesirable leads to the generation of stereotypes of individuals with those characteristics. These stereotypes can lead to a negative emotional reactions and lead to discrimination from the public.(7) Individuals with stigmatized conditions experience a status loss in society in addition to decrements in physical and psychological well-being(7).

Two key domains of stigma have been identified, namely "internalized or felt" stigma and "enacted" stigma. "Felt" stigma is the fear of "enacted" stigma experienced by the stigmatized person, while "enacted" stigma represents discrimination against the stigmatized person that is imposed by others (6).

Stigma is increasingly recognised to have a major impact on public health interventions. Stigma and (fear of) discrimination can lead to delay in seeking health services, poor adherence to treatment, drug resistance, prolonged risk of transmission, and increased risk of disability(8).

In the community, stroke survivors often live with different degrees of physical, psychosocial, and cognitive challenges such as hemiplegia, aphasia, depression, or low self-esteem. Those symptoms are visible to the public and may lead to a situation in which the individual is disqualified from full social acceptance, which was defined as a stigma (9).

Social stigma contributes to isolation which is included in psychological aspects of stroke adaptations a situation that could result in poorer post-stroke outcomes.

1.2 Statement of the problem

Stroke is the second most common cause of DALY (4). Stroke is still prevalent and remains disabling with more than 80 million stroke survivors worldwide (4). According to a data published by WHO in 2017, stroke deaths in Ethiopia reached 6.23% of total deaths, and the age-adjusted death rate was 89.82 per 100,000 of the population (10).

Neurological disorders can cause impairment in almost any aspect of emotional, physical, and cognitive functioning (11). These can be often caused by permanent disabilities. These impairments may cause stigmatizing social experiences (11).

Neurologic condition associated stigma may contribute to poorer quality of life outcomes (11). Many stroke survivors have a decreased quality of life due to their motor disabilities. This disability leads to less functional independence and increases the need for the assistance of patients by caregivers (12). Furthermore, those stigmatized individuals may isolate

themselves, not seek health care services, and have drug adherence issues, which may be a risk for other complications and recurrent stroke, and may have an impact on recovery (13).

However, no research was done in Ethiopia to assess stigma in stroke survivors and the factors that influence it. With the rising global burden of stroke, the small number of data on stigma show an important gap in knowledge which needs further documentation and if present, needs effective interventions.

1.3 Significance and aim of the study

As incidence and prevalence of stroke are increasing especially in low and middle income countries, and it being the second leading cause of DALYs, stroke survivors are often left with different degree of disability. These disabilities can lead to physical, emotional, and social impairments.

Stroke survivors are likely to face stigma due to their disabilities. There is also high risk of depression in stroke patients. And that could also be associated with stigma. Stigma in stroke may lead the patients not to seek care, isolate themselves, and get predisposed to depression. This may predispose the patient to develop preventable complications that may even lead to recurrent stroke.

Although stigma associated with neurologic disorders, particularly Epilepsy has been studied in Ethiopia, there is shortage of data on stigma associated with other neurologic disorders, including stroke.

Stigma among stroke patients has been described in different setups globally. The data are limited in Africa, especially sub-Saharan Africa. As stroke survivors have variable disabilities which may make them experience stigma, knowing the magnitude of stigma in stroke survivors in out setup is important for documentation as well as for intervention as needed.

This proposed study aspired to assess the prevalence and predictors of stigma among stroke survivors. The results of this study can be used to create better care for stroke survivors, to strengthen rehabilitation services. It could also be important, to establish support groups for stroke survivors, to educate the community about stroke. It can also be used by clinicians, Ministry of Health as well as policy makers to address stigma and its associated factors.

LITERATURE REVIEW

Literature Review

Cerebrovascular disease is the second leading cause of total DALYs among Non-communicable diseases, in 2016(14). The estimated global lifetime risk of stroke for patients aged 25 years or older has increased. The estimate includes an almost equal risk of stroke among women and men. The prevalence of stroke is expected to increase. This increase is attributable to a growing and aging population (4).

Approximately 85% of deaths due to stroke are in low and middle-income countries. From 2000 to 2008, the overall stroke incidence rates in low- to middle- income countries exceeded that of incidence rates seen in high income countries by 20% (15). Stroke represents an important part of the chronic disease burden in Sub- Saharan Africa. The prevalence and incidence of stroke in SSA remain unclear due to few population or community studies. Of the 85% of the people who survive stroke; 80% stroke patients are discharged to the community. However, the majority do not recover completely (15, 16).

According to WHO data published in 2017, stroke death in Ethiopia reached 6.23% of total deaths (10). The age adjusted death rate of stroke in the country is 89.82 per 100,000 of the population. Also the number of people with hypertension is expected to escalate by more-than two- third. There is high mortality and morbidity of stroke in the developing country owing to poor health care system and poor neurological interventions (10).

In 1963, Erving Goffman, a very influential sociologist, defined stigma as "the situation of the individual who is disqualified from full social acceptance" and since that time, social scientists have studied stigma manifested as stereotypes, prejudice, and discrimination (6).

Stigma was described as involving the co-occurrence of components: the distinguishing and labeling of human differences, the association of human difference with negative attributes, the separation of "us" from "them", status loss, and discrimination (7). Some differences can identify individuals as 'other' and lead to social consequences even though many human differences are overlooked and of little importance. This occur when social, economic, and political power allows for the identification and labeling of the 'other' and the implementation of disapproval, rejection, exclusion, and discrimination (7).

Public stigma impacts the self in three ways: Enacted stigma, Felt stigma, and internalized stigma. "Enacted" stigma (External stigma, discrimination) is discrimination against the stigmatized person that is imposed by others (17). Enacted stigma includes discrimination (e.g. being denied a job) as well as more subtle forms of social devaluation such as being stared at, being talked down to or treated unkindly, being taken less seriously, or being avoided (18). It involves any externally stigmatizing reaction that would result in the stigmatized individual being treated unfairly or negatively. It is what the public actually does to the person with a stigmatized condition. "Felt" stigma is the fear of "enacted" stigma experienced by the stigmatized person (18).

Felt, or anticipated stigma, is people's belief that they might encounter negative treatment from others if their stigmatized condition is exposed. It prevents people from talking about their experiences and stops them from seeking help(18). "Internalized stigma" is the reduction of self-worth and accompanying psychological distress experienced by people with a stigmatized condition. It is when individuals who experience stigma integrate the negative beliefs and feelings (18, 19).

Stigma is a widely recognized public health issue. Loss of employment, and social isolation are consequences individuals with stigmatizing conditions, such as loss of employment, or social isolation(20). Depression, low self-esteem, anxiety and reduced service utilization, increased (risk of) disability, and advanced disease poorer treatment prognosis in most conditions has been associated with the internalized cognitive, emotional, and behavioural impact of other's negative attitudes (20, 21). It has a strongly negative implication for public health efforts to combat the diseases or conditions concerned (21).

Neurological disorders with stigma adds to the social and economic burden. One of the most damaging results of stigmatization is that affected individuals or those responsible for their care may not seek treatment, to avoid the negative social consequences of diagnosis (22). In some communities, the stigma leads to the denial of basic human rights. Stigma exacerbate the vicious cycle of illness and social negative reaction and leads to social exclusion and discrimination (22).

Many studies have reported the negative influence of stigma on quality of life among patients with neurological disorders, such as epilepsy (23), Parkinson's disease (24), migraine (25)

neuromuscular diseases (26) and multiple sclerosis. However, little attention has been paid to stigma in stroke patients.

The majority of patients who survive stroke and are discharged to the community do not recover completely. Loss of identity is a commonly reported experience after a stroke.(27) In a situational analysis, grounded theory analysis of in-depth individual interviews with nine middle-aged survivors of stroke was undertaken to understand how family, social, and community resources might enhance stroke survivors' participation in personally meaningful activities over the long term (27). The qualitative descriptions of these stroke survivors show how social support helped them maintain or more importantly regain a position in society (27).

Stigma (both enacted and internal) contributes to psychological and physical recovery in stroke (28). Social stigma and difficulty in the cognitive and emotional function contributes to isolation in stroke patients (28).

One of the morbidities of stroke, which is hemiplegia, is visible to others. Having a chronic illness or condition and being different from the general population subjects a person to possible stigmatization by those who do not have the illness (9).

In one cross sectional study Stroke survivors who felt stigmatized significantly had more residual neurological deficits than those who felt no stigma although type and duration of stroke were not associated with stigma[i]. Absence of family history of stroke was a predictor of stroke related stigma (29).

There are different factors influencing stigma in Neurologic disorder. Among these is a lack of accurate knowledge about the disease, familiarity (knowing someone who or having had experience with the neurological disease), and belief (perception and opinions about the neurologic disease) (30). Increased stigma was seen more in the rural areas than urban areas, which was attributed to people in the rural areas having less knowledge about their neurologic illness (30).

The primary concern for many younger stroke survivors is returning to paid and unpaid work, not only for financial reasons but to regain independence, enhance recovery, help rebuild confidence, and reduce the social stigma of stroke (31). In a qualitative study done in the UK

to explore stroke survivor's needs, participants after having stroke described loss of role and perceived lack of purpose, whether socially or work related (31). Participants often felt that they did not have a place within their community with feeling of loss of role and purpose. In addition their negative perception of their disability, gave them a sense of 'otherness' which made them separate from the active world. In order to rebuild their lives positively after stroke, internal and external resources are needed (31).

A significant proportion of stroke survivors experience physical, social, and emotional consequences after stroke (32). In a cross-sectional study in China which included 200 people, the stigma level among stroke patients in China was of a mild to a moderate degree according to the total stigma score. Felt stigma (90%) was more prevalent than enacted stigma (72.5%). Higher degree of depression, recurrence of stroke and lower functional ability influenced a higher level of stigma (33).

In another cross-sectional study the total stigma, internalized stigma, and enacted stigma levels of the cohort were moderate, and all of these three types of stroke-related stigma had negative impacts on early rehabilitation (depression level, functional independence, and functional outcome) (34).

Stigma was one of the factors for the perceived barrier to recovery in stroke patients, along with other factors such as physical and cognitive deficits, mood, medication issues, lack of support and resources, culture, and faith (35).

In a cross-sectional study conducted in Ghana to assess the prevalence, severity, determinants, and psychosocial consequences of stigma among LMIC stroke survivors, a survey of 200 consecutive stroke survivors attending a neurology clinic in a tertiary medical center in Ghana were assessed (29).

Four out of five stroke survivors in this Ghanaian cohort reported experiencing some form of stigma. It was also observed that urban dwellers significantly experienced more stigma compared with rural or semi-urban dwellers. Furthermore, individuals who felt stigmatized significantly had more residual neurological deficits than those who felt no stigma (29).

Stigmatized individuals were also more likely to be depressed and have lower levels of quality of life (29). Depression is common in stroke survivors. Post Stroke Depression (PSD)

is present in at least 30% of survivors from a stroke (36). It negatively interferes with functional outcome. Individuals with PSD are at a higher risk for suboptimal recovery, recurrent vascular events, poor quality of life, and mortality. It has an impact on functional recovery through decreasing motivation and cognitive abilities (37).

In an institutional based cross sectional study conducted at tertiary hospitals in Ethiopia, from a total of 180 stroke patients the overall prevalence of depression was 49.6% (38). In another cross-sectional study of post stroke depression in ischemic stroke patients in Tikur Anbessa specialized hospital and Zewditu memorial hospital, Addis Ababa Ethiopia, 32.2% had depressive symptoms (39). Occupation, marital status, level of education was significantly associated with post stroke depression (39). Women and Aphasic patients were more likely to have depressive symptoms (38).

In a cross- sectional study which assessed stigma in stroke patients during inpatient rehabilitation and its correlated, Stigma was moderate, and internalized stigma may be more apparent. Stigma was more noted in those with continuing physical impairment and poor functional outcome (34).

OBJECTIVES

3.1. General objective

- To assess the prevalence and predictors of stigma among stroke survivors at least 3 months post stroke having a follow up in TASH, Neurology clinic A.A Ethiopia.

3.2. Specific objectives

- To determine the magnitude of perceived self, perceived family and perceived community stigma among stroke survivors.
- To identify predictors of stigma in stroke survivors.

MATERIALS AND METHODS

4.1 Study area

The study was conducted at a tertiary hospital, TASH, Neurology outpatient clinic in Addis Ababa, Ethiopia. The Hospital offers comprehensive health care services for around 400,000 patients per year through specialty clinics and inpatient service departments. It has over 1025 beds, and about 1,700 professional and support staff in inpatient, outpatient, and emergency units. The Neurology unit consists of Outpatient clinics (including stroke clinic), Inpatient and Emergency services, different diagnostic services, such as Nerve conduction study, and Electroencephalography.

4.2 study period

The study was conducted from JULY 1st 2020- OCTOBER 30th 2021.

4.3 Study Design

Institutional based cross-sectional study

4.4 Selection of study population

4.4.1 Source population

The source population were adult stroke patients who had a follow up at Neurology outpatient clinic at TASH.

4.4.2 Study population

The study population were adult stroke patients who were at least 3 months post-stroke visiting neurology clinic in TASH who were present during the time of data collection.

4.5 Inclusion criteria

4.5.1 Inclusion criteria

- All stroke survivors who were at least 3 months post stroke.

- All stroke survivors who were greater ≥ 18 years of age.
- All participant who gave consent to participate in the study.

4.5.2 Exclusion criteria

- Patients who were < 18 years of age.
- Patients who did not give consent to participate in the study.
- Stroke survivors with severe aphasia
- Stroke survivors who had difficulty to hear, understand or unable to answer the questions.

4.6 Sampling technique and sample size

4.6.1 Sampling technique

Sample size determination for single population proportion was used. As there was no previous prevalence study done in Ethiopia on stigma among stroke patients, we assumed it to be 50% as the prevalence for the overall stigma among stroke survivors for the optimum sample size. Number of patients was extracted from monthly HMIS registrations, average number of Stroke patient seen in 4 month in the same time frame of the study from the previous year, repeat registrations were not included.

Simple sampling method was implemented to select the participants and they will be enrolled in the study in the order of their presentation to the clinic till total sample size met.

4.6.2 Sample size

$$n = \frac{Z^2 P(1-P)}{d^2}$$

Where n= sample size

Z= Standard proportion population at 95% confidence interval (1.96)

P= Estimated proportion of stigma among stroke survivors (50%)

d= Margin of error (5%)

Sample size, n = Give us 384 We deducted the sample size by finite population correction formula because our source of population were less than 10,000 patients diagnosed to have stroke , and the calculated sample size was larger than 5% of the source population. Considering 10% incompleteness the corrected sample size was n_o= 422.

$$n = \frac{n_0}{\left(1 + \frac{n_0}{N}\right)}$$

The sample from an infinite population N = 174, source population, number of Stroke patients seen within 4 months period. Final sample size was **123** patients.

4.7 Data collecting procedure

Data were collected at TASH Neurology clinic, by face to face interviewing all patients who fulfilled inclusion criteria after getting informed consent. Data were collected mainly by the principal investigators. Data were also collected by Neurology residents and Interns. Training was given for the data collectors on how to conduct the questionnaire beforehand and on-site and supervised. Some information like comorbidities or risk factors was also documented from the patient's charts.

A pilot study was done on 6 patients (5% of the participants). Following that, after discussion with advisors, some questions were reformed. Those who participated in the pilot study were not included in the analysis.

The questionnaires had five parts, socio-demographic status, stroke related clinical profiles, functional status by using modified Rankin scale (mRS), PHQ9 Depression scale ,and stigma scales questions(perceived personal, family and community level).

4.7.1 The 8-Item Stigma Scale for Chronic Illness (SSCI-8) questionnaire:

The SSCI-8 (stigma scale for chronic illness) developed and validated by Molina et al. (2013) is a short, reliable, and valid instrument to assess the impact of stigma in subjects with neurological disorders (11). The SSCI-8 questionnaire has 8 questions which assesses internalized and enacted domains of stigma at the personal dimension. Responses on the SSCI-8 were scored from 1-5 for each item, where 1=never, 2=rarely, 3=sometimes, 4=often and 5=always with a score range of 8-40.It is a structured questionnaire which was adapted from previously published studies (11). This study included family and community level stigma identified by the stroke participants adopted from a previous study in Ghana (29).From a total of 8 items, 2 items were expected to measure internalised stigma, 5 were expected to measure enacted stigma, and 1 item, which exhibited split-loading, was noted to potentially measure either or both internalised and enacted stigma (11).

4.7.2 Patient Health Questionnaire (PHQ9)

The PHQ-9 is the depression module, which scores each of the nine DSM-IV criteria as "0" (not at all) to "3" (nearly every day) Depression Severity can be assessed as: 0-4 none, 5-9 mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe. It has been validated for use in primary care (40). It can be used to make a tentative diagnosis of depression in at-risk populations. The PHQ-9 is one of optimal measures for screening in Post stroke Depression. It proved to be a reliable and valid instrument that may be used to screen major depressive disorders in Ethiopia demonstrated in 2 studies. It is also easy and practical (40).

4.7.3 The Modified Rankin scale (mRS)

The modified Rankin scale (mRS) was published in 1988 and has 7 categories. mRS is heavily used as a measure of global disability (in particular, physical disability) and the need for assistance. The mRS is the most commonly used functional assessment measure and is recommended by professional societies and regulatory bodies for outcomes assessment in stroke trials. It has advantage of minimal time requirement, and flexibility of either face- to-face or telephone interview (41, 42).

4.8 Data analysis and presentation

Questionnaire standard, validity and completeness were reviewed. Data were entered and analyzed using Statistical package for social sciences (SPSS) version 25 after checking for completeness. Descriptive summaries (frequencies, tables, percentages, means and standard deviations) were used to describe socio-demographic characteristics, clinical and stigma profiles. Chi-square tests were done to determine the P value. Binary logistic regression and adjusted odds ratio with 95% CI were used to identify the associated factors of outcome variables. All factors with a P-value of <0.25 in the bivariate logistic regression were entered into the multivariate model. Statistical significance was accepted at the 5% level (P value less than 0.05).

4.9 Operational definitions

1. Stroke is defined according to WHO as "rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin.(2)

2. Stigma is defined by WHO as a socially and culturally embedded process through which individuals experience stereotyping, devaluation, and Discrimination. While "enacted" stigma represents discrimination against the stigmatized person that is imposed by others, "felt" stigma is the fear of "enacted" stigma experienced by the stigmatized person. "Internalized stigma" is the reduction of self-worth and accompanying psychological distress experienced by people with a stigmatized condition. It is when individuals who experience stigma integrate the negative beliefs and feelings. (6)

4.10 Study Variables

4.10.1 Dependent variable

- Stigma among stroke survivors (Perceived personal, Family and Community)

4.10.2 Independent variables

- Age, Gender , Religion, Address (rural/city), Marital status, Occupation, Educational level, Source of income, Comorbidities/Risk factor, History of Alcohol, History of smoking,

History of khat, Type of stroke, Number of stroke, Duration of stroke, Family history of stroke, Prior knowledge of stroke or know someone with stroke, complications post stroke, modified Rankin scale, PHQ9 Depression scale.

4.11 Data quality control

Questionnaires were translated to local language (Amharic) and translated back to English during analysis. Pilot study was done before data collection. Based on the finding of the pre-test, the questionnaires were revised, adopted and time needed for interview was estimated. Results from the pilot study were not included in the main study. The questionnaires were reviewed for completeness. Filled questionnaires were checked for completeness and consistency of information by the collector and the investigator once weekly during data collection. Generally, technical quality issues like inconsistent structures, standard issues, missing data and errors in the data field were identified and addressed timely.

4.12 Dissemination of results

The study result will be disseminated to key stakeholders including Neurology Department research committee, TASH, Neurology department. The results will also be disseminated for local and International publishing in a peer reviewed journals.

4.13 Ethical Clearance

Protocol approval was obtained before the beginning of data collection from the Department of Neurology Research and Promotion Committee (DRPC). Written consent was taken from the respondents. Personal identifier information was not included in the questionnaire, codes were used instead. Place of data collection was in a private room at OPD clinics with only the interviewer and the participant present to keep privacy of the participants. All information obtained through questionnaire was kept confidential and the information collected will be used solely for the intended purpose. Completed questionnaires were stored safely by the Primary investigator. When appropriate, patients were linked to psychiatric clinic, after discussion with the participants and their primary care physician.

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RESULTS

5.1: Socio- demographic and clinical characteristics of the participants

Table 1 shows the socio-demographic characteristics of the study participants. 123 subjects were eligible for the present analysis, of the 123 stroke survivors; the mean ±SD age of stroke survivors was 53.5±13.17. Males accounted for 66(53.7%). Around 122(99%) were from urban area of which 104(84.6) lived in Addis Ababa (Capital city of Ethiopia). 89(72.4%) were married, while 34% were non- married (single, divorced or separated). 97(78.9%) were orthodox Christian in religion. The educational level of participants showed, nearly 40% had no or primary education, while around 60% had high school training or higher. Of the participants, 44(35.8%) were employed, 51(41.5%) were unemployed and 28(22.8%) were pensioners. 69(56.1%) had their source of income by themselves including those who earned from pension. Others had their source of income either from children, relatives, spouse, sibling or two or more source of income.

According to the clinical profiles of the participants Ischemic stroke accounted for 100(81.3%) of the cases, while hemorrhagic stroke was 23(18.7%). For the majority of the participants 111(90.2%), it was their first time for stroke, while 12(9.8%) had recurrent stroke.

The mean ± SD duration of stroke was 3.3 ± 0.47 years with 66.7% of stroke survivors seen had their stroke within 3.3 years. The most common identified Risk factor/ comorbidity for stroke was Hypertension which accounted for 52.8%. Other risk factors identified were Diabetes mellitus with or without hypertension (21%), two or more risk factors (29%), and cardiac disease (23%).

History of alcohol, smoking and khat use were 23(18.7%), 20(16.3%), and 22(17.9%) respectively. 10(8.1%) had family history of stroke, and 73.2% had no prior knowledge of stroke or know someone with a stroke**.** Epilepsy post stroke was noted in 13(10.6%) According to the mRS score moderate to severe disability was seen in 38(30.9%), while 85(69.1%) had either no or mild disability. On PHQ-9 depression score 109 (88.6%) participants scored 0-4 (no or minimal depression). Eleven (8.9%) had a score of 5-9. Residual weakness was noted in 72(58.5%) of the participants, other complication noted were dysarthria, pain and fatigue. **(Table 2)**

Table 1 Socio-demographic characteristics of study participants in TASH, July-October, 2021(n=123)

Variable	Frequency (%)
Age in years (mean ±SD)	53.5±13.17
Gender	
Male	66(53.7%)
Female	57(46.3%)
Address	
Urban	121(98.4%)
Rural	2(1.6%)
Marital status	
Married	89(72.4)
Unmarried/separated/widowed	34(27.6)
Religion	
Orthodox Christian	97(78.9%)
Muslim/others	26(21.1%)
Educational level	
None/Elementary	49(39.8%)
High school or above	74(60.2%)
Occupation	
Employed	44(35.8%)
Unemployed	51(41.5%)
Pension	28(22.8%)
Source of income	
Self	69(56.1%)
Others	34(27.6%)
Self and others	20(16.3%)

SD- Standard deviation

Table 2 Clinical profile of study participants in TASH, July-October, 2021(n=123)

Variable	N(%)
Type of stroke	
Ischemic	100(81.3%)
hemorrhagic	23(18.7%)
No. of stroke	
First	111(90.2%)
Recurrent	12(9.8%)
Duration of stroke(in years)	
Below 3.3 years	82(66.7%)
Above 3.3 years	40.4(33.3%)
Risk factor/comorbidity	
Residual weakness	58.5%
Others	41.4%
History of Smoking	
Yes	20(16.3%)
No	103(83.7%)
History of Khat intake	
Yes	22(17.9%)
No	101(82.1%)
History of Alcohol	
Yes	23(18.7%)
No	100(81.3%)
Prior knowledge of stroke	
Yes	33(26.8%)
No	90(73.2%)
Family history of stroke	
Yes	10(8.1%)
No	113(91.9)
Epilepsy	
Yes	13(10.6%)
No	110(89.4%)
modified Rankin Scale(mRS)	
No to mild disability	85(69.1%)
Moderate to severe	38(30.9%)
PHQ9 depression scale	
0-4	109(88.6%)
5-27	14(11.4%)
Post stroke complication	
Residual weakness	72(58.5%)
Others (None/seizure/dysarthria)	51(41.5%)
Risk Factor/comorbidity	
Hypertension	65(52.8%)
Diabetes Mellitus	26.5(21%)
Two or more	36(29.2%)
Cardiac disease	29(23.5%)

5.2 Frequency of stroke related stigma (Table 3)

From the perceived personal stigma questions, 55 (44.7%) of the participants had no stigma (answered ‘never’ to all questions, 68(55.3%) had a score of > 8. With a mean ± SD score of 11.86±5.4.From the answered stigma questions, twenty participants answered “sometimes” to “Because of my illness (stroke), I avoided some family and friends”.

From the perceived family stigma questions, 101(82.1%) had a score of 8, answered 'never' to all questions. 22(17.9%) had a score of >8, with a mean score of 8.96 ±3.28. From the perceived community questions, 106(86.2%) had a score of 8, answered 'never to all questions. 17(13.8%) had a score of >8 with a mean of 9.04 ±3.6.

From those who reported to have some form of stigma, majority of the participants 'rarely' and 'sometimes' felt stigma. The Enacted stigma was seen more than the Internalized stigma ('I felt embarrassed about my illness, and 'I felt embarrassed because of my physical limitation').

Table 3 Frequencies of Perceived Personal, Family, Social/Community Stigma among Stroke Survivors of study participants, at TASH, July-October ,2021 (n=123)

Questions on perceived personal stigma	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
Because of my illness (stroke), I felt uncomfortable with some family and friends	66.7	4.9	19.5	7.3	1.6
Because of my illness (stroke), I avoided some family and friends.	63.4	9.8	20.3	5.7	0.8
Because of my illness (stroke), I felt left out of things.	103	6	10	3	1
Because of my illness (stroke), I was unkind to some family and friends	96	13	12	2	0
Because of my illness (stress), I avoided looking at me (in mirror)	102	8	7	6	0
I felt embarrassed about my illness (stroke).	96	8	13	2	4
I felt embarrassed because of my physical limitations.	94	12	12	2	3
I thought it was my fault I have this illness (stroke).	98	7	5	8	5
N(%)	55(44.7%)	49(39.8%)	15(12.1%)	5(4%)	1(0.8%)
Questions on perceived family stigma					
Because of my illness(stroke) some of my family seemed uncomfortable with me.	110	5	5	2	1
Because of my illness (stroke), some of my family avoided me	113	6	2	1	1
Because of my illness(stroke), some of my family left me out of things	116	3	2	1	1
Because of illness (stroke), some family members were unkind to me.	118	1	2	1	1
Because of my illness (stroke), some family members avoided looking at me	118	2	2	0	1
Some of my family felt embarrassed about my illness (stroke)	118	2	1	1	1
Some of my family felt embarrassed because of my physical limitations	117	4	1	1	1
Some family members acted as though it was my fault I have this illness (stroke)	115	1	4	4	0
N(%)	101(82.1%)	19(15.4%)	2(1.6%)	1(0.8%)	1(0.8%)
Questions on perceived community/social stigma					
Because of my illness (stroke), some other people seemed uncomfortable with me.	115	3	4	1	0
Because of my illness (stroke), some other people avoided me.	107	6	7	2	1
Because of my illness (stroke), some of my friends left me out of things	113	3	3	3	1
Because of my illness (stroke), people w ere unkind to me	114	3	3	1	2
Because of my illness (stroke), some people avoided looking at me	112	5	3	1	2
Some of my friends felt embarrassed about my illness (stroke).	117	4	4	0	1
Some of my friends felt embarrassed because of my physical limitations	121	0	0	2	0
Some people acted as though it was my fault I have this illness (stroke).	121	1	0	1	0
N(%)	106(86.2%)	13(10.5%)	2(1.6%)	1(0.8%)	1(0.8%)

5.3 Factors associated with perceived stigma

Perceived self/personal stigma: From the bivariate analysis**(Table 4),** history of use of alcohol , smoking, epilepsy, residual weakness, moderate to severe disability and depression were factors associated with perceived self-stigma at P- value <0.2. Individual factors that were significant with this analysis were entered to a subsequent multivariate analysis. Other variables: Age, gender, marital status, living area, educational status, stroke number and duration were not associated with perceived self-stigma, so they were not analyzed further.

Those who have moderate to severe disability had association with self-perceived stigma, as shown in **Figure 1**. From the multivariate analysis; moderate to severe disability as per the modified Rankin scale had 6.8 times more association with perceived self-stigma than those with no or mild disability (AOR= 6.88, CI:2.257,22.46) with a P value of 0.001 when adjusted for depression, alcohol use, smoking, post stroke complication with residual weakness and epilepsy. (**Table 5**)

Depression was also significantly associated with perceived self-stigma (AOR=19, CI: 2.24, 161.34) with *P*=.007(**Figure 2**). Other predictor which was associated with self-stigma was the presence of post stroke epilepsy (AOR= 6.025,CI: 1.28, 28.43), *P*=.023.

Perceived family stigma: As indicated in **Table 4**, from the bivariate analysis marital status, occupation, source of income, gender , post stroke complication(residual weakness) were associated with perceived family-stigma at *P*- value <0.2. In a subsequent multivariate analysis, there was no statistically significant association when adjusted for covariates.

Perceived community stigma: From the bivariate analysis depression, disability, post stroke residual weakness and smoking were associated with perceived community- stigma at *P- value* <.2 In a subsequent multivariate analysis, Depression has 25 times more association with perceived community stigma than those with no depression (AOR=25.74, CI: 5.49, 120.77), *P* < .001 when adjusted for disability, weakness, and smoking. Post stroke complication, residual weakness, was nine times more associated with perceived community stigma than other complications (AOR=9.71, CI: 0.94, 94.95) *P*=.051(**Table 4**)

Table 4: Association of predictors of stigma (personal perceived/family perceived and community perceived) of the study participants at TASH ,July- October 2021

Variables	No stigma	Stigma	P-value
Personal perceived stigma			
Source of income			
Self	34(27.6%)	35(28.5%)	
Others	21(17.1%)	33(26.8%	0.250
Alcohol			
Yes	7(5.7%)	16(13%)	
No	48(39%)	52(42.3%)	0.127
Smoking			
Yes	6(4.9%)	14(11.4%)	
No	49(39.8%)	54(43.9%)	0.148
Epilepsy(post stroke)			
Yes	3(2.4%)	10(8.1%)	
No	52(42.3%)	58(47.2%)	0.097
Disability (mRS score)			
No-mild disability	49(39.8%)	36(29.3%)	
Moderate to severe	6(4.9%)	32(26%)	**0.000***
Post stroke complication			
Residual weakness	25(20.3%)	47 (38.2%)	
Others	30(24.4%)	21(17%)	**0.008***
Depression (PHQ9 score)			
None- Mild	53(43.1%)	52(42.3%)	
Moderate- severe	2(1.6%)	16(13%)	**0.002***
Family perceived stigma			
Marital status			
Married	77(62.6%)	12(9.8%)	
Non married	24(19.5%)	10(8.1%)	**0.039***
Education			
None-elementary	37(30.7%)	12(9.8%)	
High school and above	64(52%)	10(8.1%)	0.12
Occupation			
Employed	40(32.5%)	4(3.3%)	
Unemployed	61(49.6%)	18(14.6%)	0.057
Source of income			
Self	62(50.4%)	7(5.7%)	
Others	39(31.7%)	15(12.2%)	**0.011***
Gender			
Male	60(48.8%)	6(4.9%)	
Female	41(33.3%)	16(13%)	**0.006***
Post stroke complication			
Residual weakness	56(45.5%)	16(13%)	
Others	45(36.6%)	6(4.9%)	0.136
Depression (PHQ9)			
None-mild	100(81.3%)	20(16.3%)	
Moderate- severe	1(0.8%)	2(1.6%)	**0.026***
Community perceived stigma			
Smoking			
Yes	15(12.2%)	5(4.1%)	
No	91(74%)	12(9.3%)	0.113
Functional status (mRS)			
No to mild disability	77(62.6%)	8(4.9%)	
Moderate to severe	29(23.6%)	9(7.3%)	**0.034***
Post stroke complication			
Residual weakness	56(45.5%)	16(13%)	
Others	50(40.7%)	1(0.8%)	**0.001***
Depression (PHQ9 score)			
None	106(86.2%)	14(11.4%)	
Mild/moderate	0	3(2.4%)	**0.000***

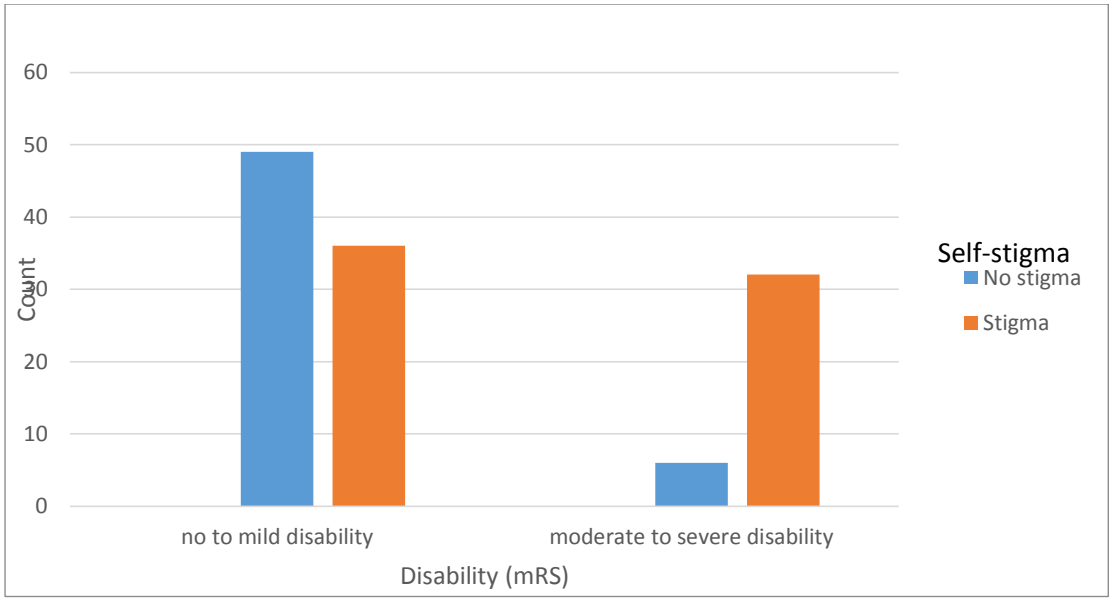

Figure 1 Association between Disability and self-perceived stigma of study participants in TASH, July-October, 2021

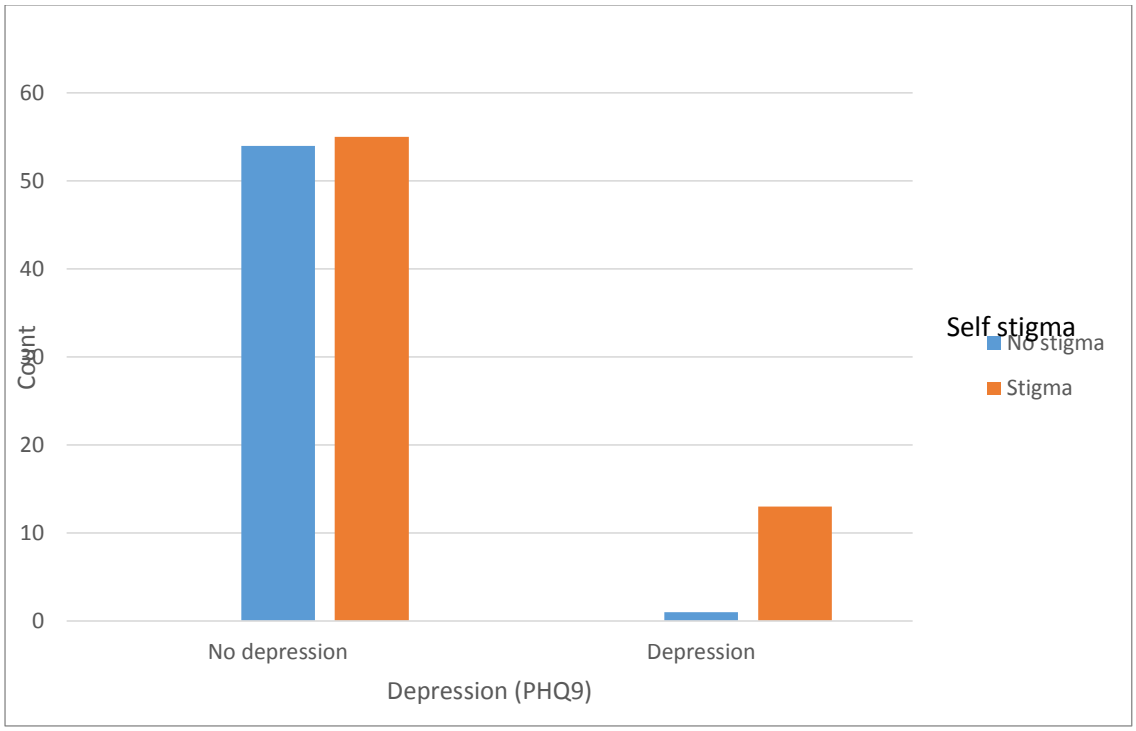

Figure 2 Association between Depression and perceived self-stigma of study participants in TASH, July-October, 2021

Table 5 Results for final multivariable binary logistic regression model for perceived self stigma of the study participants in TASH, July- Ocotober, 2021

Covariates	COR(CI)	P-value	AOR(CI)	P-value
Perceived personal stigma				
Smoking				
No	Ref		Ref	
Yes	2.1 (0.755,5.94)	0.154	2.4 (0.393,7.188)	0.483
Epilepsy				
No	Ref		Ref	
Yes	2.9 (0.78,11.452)	0.11	6.025 (1.277,28.433)	**0.023***
Source of income				
Self	Ref		Ref	
Others	1.52 (0.741,3.144)	0.251	2.18 (0.847-5,602)	0.106
Disability				
None-mild	Ref		Ref	
Moderate-Severe	7.2 (2.746-19.194)	0.000	6.88 (2.257-20.950)	**0.001***
Alcohol use				
No	Ref		Ref	
Yes	2.11 (0.799-5.571)	0.132	2.246(0.592-8.518)	0.234
Post stroke complication				
Others	Ref		Ref	
weakness	2.67 (1.282-5.624)	0.009	1.215 (0.487-3.029)	0.676
Depression				
No depression	Ref		Ref	
Depression	12.764 (1.613-100.98)	0.016	19.023 (2.243-161.338)	**0.007***
Perceived family stigma				
Marital status				
Married	Ref		Ref	
Non married	2.673 (1.028-6.956)	0.044	2.079 (0.662-6.526)	0.21
Occupation				
Employed	Ref		Ref	
Non employed	2.951 (0.93-9.36)	0.066	2.013 (0.722-5.615)	0.181
Source of income				
Self	Ref		Ref	
Others	3.407(1.275-9.1)	0.014	1.977(0.590-6.627)	0.270
Educational level				
None to elementary	Ref		Ref	
High school and above	1.082 (0.591-2)	0.788	0.819(0.293-2.642)	0.819
Gender				
Male	Ref		Ref	
Female	3.902(0.101-0.935)	0.009	2.579(0.857-7.76)	0.092
Depression				
No depression	Ref		Ref	
Depression	2.022 (0.571-7.165)	0.275	1.842 (0.440-7.715)	0.403
Complication				
Residual weakness	Ref		Ref	
Others	2.143 (0.775-5.925)	0.142	1.473(0.494-4.392)	0.488
Perceived community stigma				
Smoking				
No	Ref		Ref	
Yes	2.528(0.779-8.207)	0.123	2.504 (0.561-11.171)	0.229
Disability				
None to mild	Ref		Ref	
Moderate to severe	2.987 (1.052-8.483)	0.04	2.109 (0.529-8.399)	0.290
Complication				
Others	Ref		Ref	
Residual weakness	14.286 (1.828-111.634)	0.011	9.715(0.994-94.951)	**0.051***
Depression				
No depression	Ref		Ref	
Depression	22.725 (6.138-84.134)	0.000	25.737 (5.485-120.765)	**0.000***

COR Crude Odds ratio, AOR Adjusted Odds ratio, CI Confidence interval, Rf Reference, * Statistically significant

DISCUSSION

Stigma among patients with various neurologic disorders has been described, such as epilepsy, PD, MS, migraine and neuromuscular disorders (23-26), but there are small number of studies about stroke and stigma, particularly in Sub- Saharan Africa. The main aim of the study was to assess the prevalence of stigma and associated factors among people with stroke. To our knowledge this is the first study in Ethiopia to assess the prevalence and determinants of stigma among stroke survivors.

Overall the prevalence of perceived stigma were assessed, Around half of the participants had self perceived stigma, While the prevalence of family and community perceived stigma was less than 20% This result is lower as compared with other study done in Ghana, which showed more than two third had some form of self- perceived stigma. The family and community perceived stigma was also much higher than our study (29).

In a study conducted in china to assess factors associated with stigma in stroke, majority (90%) reported experiencing felt stigma although they used the SSCI-24 scale which measured both felt and enacted stigma. The variations in results can possibly be due to sample size, different cultural experiences and different tools used in the study.

The perceived personal stigma was higher in our study than perceived family, community which is a similar finding from other studies. The Enacted stigma is also higher than Internalized stigma (29). Although there is lower prevalence of perceived stigma in our study as compared to West Africa and Chinese studies, the prevalence is still high. The lower results could also be due to small sample size and short study period.

Regarding the predictors for stigma, those patients with moderate to severe disability were about 7 times more likely to have perceived personal stigma than those with no or mild disability. In another similar study lower functional ability was also associated with stigma (33).In a study in China; more stigmas were also noted in those with continuing physical impairment (34). Patients who have more severe disability due to stroke have shown a higher stigmatizing experience , as the disability would be visible to the public than those with no or mild disability. They may be less likely to be involved in work or other social interaction, and may have to depend on others due to the limitation of their disabilities. This may lead to a situation in which the individual is disqualified from full social acceptance.

From the complication patients had post stroke, having a residual weakness was about 10 times more associated with stigma especially the community perceived stigma than who felt no stigma, One of the morbidities post stroke is residual weakness which is visible to others. Having a chronic illness or condition that is visible to others and being different from the general population subjects a person to possible stigmatization by those who do not have the illness.

Depression was also significantly associated with stigma in this study. It was 19 times more associated with perceived self stigma than those with no depression when adjusted with other significant covariates. Depression was also seen to be highly significant, twenty five times more associated with stigma than those with no depression in the community perceived stigma. Depression was the one of the strongest predictors of stigma associated with stroke in two studies done in China and a study done in Ghana which is a similar finding with this study (29, 33, 34).

Depression and stigma have a two way relationship. Those who are depressed may feel isolated by others which lead to high level of stigma. And those who have stigma exacerbate the development of depression by feeling devalued, which has consequences such as not seeking health care.

Other factors which showed high association with stigma include being non married, being unemployed, or having to rely on others for their source of income, being female, epilepsy, History of use of alcohol, and smoking . These factors however, did not show statistically significant when adjusted for other factors. In other studies the results revealed that being unmarried and absent from work were associated with significantly higher stigma scores (33).

There was no association with recurrence of stroke and stigma in this study as it was demonstrated in one similar study. Type of stroke and duration of stroke were not associated with stigma in this study which is a similar finding in a study done in Ghana (29). Absence of family history of stroke was a predictor in this Ghanian study, but in our study this association was not seen (29).

Living in rural area as opposed to urban area was shown to have a higher stigma experience due to people living in rural areas may not be aware or have the knowledge about the illness as it was demonstrated by other study. In this study it was difficult to assess area of living with stigma, as most of our participants were from the urban area, so it makes it difficult to conclude on the association.

CONCLUSIONS AND RECOMMENDATIONS

7.1 Conclusions

In this study about 55% of stroke survivors encountered some level of stigma. Perceived self-stigma was higher than either perceived family or community stigma. Stroke survivors who experienced stigma were more likely to have higher rate of depressive symptoms. Residual weakness after stroke and higher disability scores were also associated with stigma. These results are important because stigma associated with stroke is under estimated and assessment and addressing of this issue in stroke patients should be incorporated in routine clinical practice and rehabilitation services.

7.2 Recommendations

Stigma in stroke patients is an under studied, but important in post stroke rehabilitation. A larger study is needed to assess other factors not included here that may affect stigma. It is important to address if there is any stigma and associated factors in patients having follow up at the stroke clinics. The post stroke care of patients should be strengthened and should include different aspect of disabilities including physical, emotional, and social in the standard of care. It would also be beneficial for the patients to have support groups for stroke survivors. It would be important to educate the public on different aspects of stroke. It is vital to start one of the important acute treatments of ischemic stroke, such as thrombolysis treatment in our country, which may significantly decrease the morbidity of stroke, hence associated stigma.

STRENGTHS AND LIMITATIONS

One of the strength of our study was it was the first to assess stigma and its associated factors among stroke survivors. Patients were linked to psychiatry clinic when appropriate after discussion with the participants and primary care physician. Our study has several limitations. First sample size was small, and study site was in one tertiary hospital. This may make it difficult to conclude the results to a larger population. Majority of the participants were from urban areas, specifically Addis Ababa. Stroke patients from other areas were underrepresented and there might be cultural differences and coping mechanisms for stigma in different areas. Consecutive sampling technique was used, not a systematic sampling method. Limited numbers of variables were included, and effects of other variables were not included. Large scale studies are important to address those limitations and also to see the effect of stigma in stroke survivors.

.ANNEX 1: Consent form

Addis Ababa University, College of health science, School of Medicine

Department of Neurology

Consent to participate in research

Stigma among stroke survivors: Experience at a tertiary hospital, TASH, Addis Ababa, Ethiopia

Dear study Participant,

My Name is Keberte Tsegaye. I am a third year student of postgraduate Neurology Residency Program in Addis Ababa University, College of Health Sciences. I am doing a research as a completion for my residency program on my topic of interest assessing Stigma among stroke survivors: Experience at a tertiary hospital, TASH, Addis Ababa, Ethiopia

I am going to give you information and invite you to be part of this research. Before you decide, you can talk to anyone you feel comfortable with about the research.

If there are some words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me, the study doctor.

The purpose of this study was to assess if there is any stigma among patients with stroke and any associated factors. The results would be important to plan for having better rehabilitation centers and to teach the public on the disease. We are inviting all adults with stroke for at least three months who attend Neurology outpatient clinic to participate in the study

You may not directly benefit from this study. However, the results could contribute to have better rehabilitation centers and to have possible support groups that will help stroke patients

The information that we collect from this research will be kept confidential. Information about you that will be collected during the research will be put away and no-one but the researchers will be able to see it. Any information about you will have a code on it instead of your name. Only researchers will know what your code is. Filling the questionnaire will take approximately 20-25 minutes.

After reading the above statement, I sincerely request to sign on the consent form as indicative of your willingness to participate and please fill and complete the questionnaires.

Your participation in this survey is completely voluntary. You may withdraw from participation at any time. If you have any questions or concerns regarding this study you can contact me either via phone or email address written at the end. Thank you for your kind cooperation.

I have read the foregoing information, or it has been read to me. I had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research

Signature of the participant _____ Date _____

If unable to read and write, I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ AND Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

Contact information- Keberte Tsegaye Email: kebert45@gmail.com Phone number: 0911-15-67-80

ANNEX 2 Questionnaires

PART 1: Socio-demographic characteristics for research on stigma among stroke survivors

		Response
1.1	**Study**	
1.2	**Date**	
1.3	**Age**	
1.4	**Gender** (A)Male (B) Female	
1.5	**Address**	
1.6	**Religion** (A) Orthodox (B)Muslim (C) Protestant (D) Catholic (E) Others	
1.7	**Marital status** (A)Married (B) Single (C)Divorced (D) Widowed (E) Separated (F) Living together	
1.8	**Occupation** (A) Government employee (B) Private employee (C)Private business (D) Farmer (E) Housewife (F) Pension (H) Unemployed	
1.9	**Income/ support** (A)Self (B) Spouse (C) Sibling (D) Parents (E)Relatives (F)NGO (G)Pension (H)Children (I)Others, specify_____	
1.10	**Educational level** (A) Elementary (B) High school (C) Diploma (D) Degree (E) Masters (F)PHD/Doctorate (G) can read and write (H)None	

PART 2 : Clinical profiles characteristics for research on stigma among stroke survivors

1.11	**Risk factors/Comorbidities** (A)HTN (B)DM (C) Cardiac disease (D) Dyslipidemia (E) Others, specify____	
1.12	**History of alcohol intake** (A) Yes (B) No	
1.13	**History of Khat chewing** (A) Yes (B)No	
1.14	**Smoking** (A) Yes (B)	
1.15	**Type of stroke** (A) Hemorrhagic (B) Ischemic	
1.16	**No. of Stroke** (A) First Stroke (B) Recurrent stroke	
1.17	**Family history of stroke** (A) Yes (B)No	
1.18	**Prior knowledge of stroke/ know a person with stroke** (A) Yes (B) No	
1.19	**Complication post stroke** (A) Weakness (B) Aphasia (C) Incontinence (D) DVT (E) Pneumonia (F) Seizure (H) Others _____	

Part 3 Functional status: Modified Rankin scale,

Variable	Assessment	Comments
0. No symptoms at all		
1. No significant disability despite symptoms; able to carry out usual duties and activities		
2. Slight disability; unable to carry out all previous activities but able to look after own affairs without assistance		
3. Moderate disability; requiring some help (e.g with shopping) but able to walk without assistance		
4. Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assisstance		
5. Severe Disability; bedridden, incontinent and requiring constant nursing care and attention		

Part 4 PHQ-9 (patient health questionnaire) score for Depression

Over the last two weeks, how often have you been bothered by any of the following problems?

No.	Question	Not at all	Several days	More than half the days	Nearly Everyday
1.	Little interest or pleasure in doing things				
2.	Feeling down, depressed or hopeless?				
3.	Trouble falling or staying asleep, or sleeping too much?				
4.	Feeling tired or having little energy?				
5.	Poor appetite or overeating?				
6.	Feeling bad about yourself or that you are a failure or have let yourself or your family down?				
7.	Trouble concentrating on things, such as reading the newspaper or watching television?				
8.	Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?				
9.	Thoughts that you would be better off dead, or of hurting yourself in some way?				
10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people ?			Not difficult at all_____ Somewhat difficult_____ Very difficult_____ Extremely difficult_____		

Part 5: Questions on Perceived Personal Stigma

Questions on Perceived Personal Stigma Stigma	Never	Rarely	Sometimes	Often	Always
Because of my illness (stroke), I felt uncomfortable with some family and friends					
Because of my illness (stroke), I avoided some family and friends.					
Because of my illness (stroke), I felt left out of things.					
Because of my illness (stroke), I was unkind to some family and friends					
Because of my illness (stress), I avoided looking at me (in mirror					
I felt embarrassed about my illness (stroke).					
I felt embarrassed because of my physical limitations.					
I thought it was my fault I have this illness (stroke).					

Questions on perceived Family stigma

Questions on perceived Family stigma	Never	rarely	sometimes	often	Always
Because of my illness(stroke) some of my family seemed uncomfortable with me.					
Because of my illness (stroke), some of my family avoided me					
Because of my illness(stroke), some of my family left me out of things					
Because of illness (stroke), some family members were unkind to me.					
Because of my illness (stroke), some family members avoided looking at me					
Some of my family felt embarrassed about my illness (stroke)					
Some of my family felt embarrassed because of my physical limitations					
Some family members acted as though it was my fault I have this illness (stroke)					

Questions on perceived community/social stigma

Questions on perceived community/social stigma	Never	Rarely	Sometimes	Often	Always
Because of my illness (stroke), some other people seemed uncomfortable with me.					
Because of my illness (stroke), some other people avoided me.					
Because of my illness (stroke), some of my friends left me out of things					
Because of my illness (stroke), people w ere unkind to me					
Because of my illness (stroke), some people avoided looking at me					
Some of my friends felt embarrassed about my illness (stroke).					
Some of my friends felt embarrassed because of my physical limitations					
Some people acted as though it was my fault I have this illness (stroke).					

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<u>አዲስ አበባ ዩኒቨርሲቲ, የጠ/ ሳይንስ ኮሌጅ፣ የሕክምና ትምህርት የኒዎሮሎጂ ክፍል</u>

በጥናት ላይ ለመሳተፍ ፍቃድ

ከስትሮክ የተረፉ ሰዎች የሚ ጥምቹውመ ለል፥ በሶስተኛ ደረጃ ሆስፒታል ወስጥ ያለ ተሞክሮ, ጥቁር አንበሳ እስፔሽያላይዝድ ሆስፒታል,አዲስ አበባ, ኢትዮጵያ

ወድ የ ጥናቱ ተሳታፊ፣

ዶ/ር ክብርተ ጸጋዬ እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ የጠ/ ሳይንስ ኮሌጅ በኒዎሮሎጂ ሬዚደንሲ ሚሃ ግብር የ3ኛ ዓመት ደህረ ምረቃ ተማሪ ነኝ። ከስትሮክ የተረፉ ሰዎች የሚ ጥምቹውመ ለል፥ በሶስተኛ ደረጃ ሆስፒታል ወስጥ ያለ ተሞክሮ, ጥቁር አንበሳ እስፔሽያላይዝድ ሆስፒታል, አዲስ አበባ, ኢትዮጵያ በሚል የሚ ጥኩት ርዕሰ ላይ ለሬዚደንሲ ፕሮግራም ማጠናቀቂያ ምርምር እያደረግሁ ነ ው።

ሚጃዎችን እየሰጠኝሁ የዚህ ምርምር አካል እንዲሆኑ እጋብዞታለሁ። ከመወሰንዎ በፊት ፣ ከሚፈልጉት ሰውጋር ስለዚህ ጥናት መወያየ ት ይችላሉ።

ሚጃወን ስንነ ጋገ ር የሚሪዱዋቸው አንዳንድ ቃላት ካሉ እባክዎ እንዳቆም ይጠይቁኝ እና ለማበራራት ጊዜ እወስዳለሁ። ወደ በኃላ ጥያቄዎች ካሉዎት ጥናቱን የሚ ካሄደወን ሃኪምመጠየ ቅ ይችላሉ።

የ ዚህ ጥናት ዓላማከስትሮክ ጋር ተያይዞ የሚመጣመ ለል እንዳለ እና ምን ሊያስከትለውወይምሊያባብሰውእንደሚቻል በመ ምገ ም የተሻሉ የማ ገ ሚያ ሜቴከላትን ለማዘ ጋጀት፣ ለማቅድ እና ህብረተሰቡን ስለበሽታው ለማ ስተማር ነ ው። በኒዎሮሎጂ ተመላላሽ ህመማን ክሊኒክ ቢያንስ ለሶስት ወራት የስትሮክ በሽታ ይዟቸው የተመላለሱ አዋቂዎችን ሁሉ በዚህ ጥናት እንዲሳተፉ እንጋብዘለን።

ከዚህ ጥናት እርስዎ በቀጥታ ላይጠቀሙይችላሉ፣ ነ ገ ር ግን ወጠጩቹ የተሻሉ የሚሉ ማቋቋም ሜቴከሎች እንዲኖሩ እና የስትሮክ ህመምተኞችን የሚ ዱየ ድጋፍ ቡድን እንዲኖሩ አስተዋጽኦ ሊያደርግ ይችላል።

ከዚህ ምርምር የምንሰበስበው መረጃ በሚስጥር የሚቆመጥ ይሆናል። በጥናቱ ወቅት ስለእርስዎ የተሰበሰቡትን መረጃዎች ከተመራማሪዎቹ ወጪ ማንም የሚያየ ው አይኖርምኒ። ስለእርስዎ ያለ ማንኛውም መረጃ በስምዎ ምትክ የሚጠ ፈው ቁጥር ይሆናል። የእርስዎ ቁጥር የትኛውእንደሆነ የሚያወቀውተመራማሪው ብቻ ነ ው። መጠይቁን ለመመላ ት በግምት ከ20-25 ደቂቃዎች ይወስዳል።

ከላይ የ ተጠቀሱትን መግለጫካነ በቡ በኋላ በዚህ ጥናት ላይ ለመሳተፍ ፈቃደኛነ ትዎን የሚያመላክት የ ፈቃድ ፎርምላይ እንዲፈርሙ በትህትና እጠይቃለሁ። እባክዎን መጠይቆቹን ይመሉ እና ያጠናቅቁ፡ ፡ በዚህ የ ዳሰሳ ጥናት ወስጥ ያሎት ተሳትፎ መሉ በመሉ በፈቃደኝነ ትዎ ነ ው። በማንኛውምጊዜ ከተሳትፎ መውጣት ይችላሉ።

ይህንን ጥናት አስመልክቶ ሜቸወም ጥያቄዎች ወይም ያሳሰብዎት ነገሮች ካሉ ሜጨሻ ላይ በተጠቀሰውስልክ ወይም ኢሜል አድራሻ ማ ጋገር ይችላሉ።

ስለ መልካም ትብብርዎ አመሰግናለሁ።

ከላይ የተጠቀሱትን መረጃዎች አንብቤያቸዋለሁ ወይም ተነ በወልኛል ፡፡ ስለጉዳዩ ጥያቄዎችን የማጠየቅ እድል አግኝቻለሁ እናም ለጠየቅኳቸውጥያቄዎች ሁሉ በቂ መልስ አግኝቻለሁ፡፡ በዚህ ምርምር ወስጥ እንደ ተሳታፊ ለመሳተፍ በፍቃደኝነ ት እስማማለሁ።

የ ተሳታፊውሬርማ_____ እና የ ተሳታፊ አወራ ጣት አሻራ ----------

ቀን _____

ቀን / ወር / ዓመት

Contact information- ዶ/ር ክብርተ ጸጋዬ

ኢሜል: kebert45@gmail.com

ስልክ ቁጥር: 0911-15-67-80

ተ.ቁ	የ ራስ (የ ግል)	በጭራስ	ከስንት አንዴ	አልፎ አልፎ	ብዙ ጊዜ	ሁል ጊዜ
1	**አሁን በዚ ህመም ወስጥ ሆኜ ከአንዳንድ ቤተሰቦቼና ጓደኞቼ ጋር አብሮ መሆን ብዙም አይመቼኝም** ይላሉ/ ትላለህ/ትያለሽ					
2	**ካለኝ ከዚህ አካላዊ ችግርጋር ሆኜ ከአንዳንድ ቤተሰብ /ዘመድ ጓደኞቼ ጋር ብዙም መገናኘት አልፈልግም** ይላሉ/ ትላለህ/ትያለሽ					
3	**ከህመሜጋር ተያይዞ ባለ ሁኔታ ምክንያት ባጠቃላይ ከእለት ተዕለት ከነገሮች/ ጉዳዮች በቃ የወጣው የተረሳሁብት፣ የተገለልኩበት ሁኔታ ወስጥ ያለው ይመስለኛል** ብለውያስባሉ/ታስባለህ/ታስቢያለሽ					
4	**ህመሜ ከተፈጠረ በኋላ እኔ ለቤተሰቤና ጓደኞቼ ስጭ ብዙምአልጨቤቅም ከፉ እልባቸዋለሁም፣ አስቀይማቸዋለሁም** ብለውያስባሉ/ታስባለህ/ታስቢያለሽ					
5	**ህመሜከተፈጠረ በኋላ ገጽታዬን በሚታወት ሜ ት ትቻለሁ/ሜ ት አልፈልግም** ይላሉ/ትላለህ/ ትያለሽ					
6	**በዚ በሽታዬ እሸማቅቃለሁ፣ እፈራለሁ** /ይላሉ/ ትላለህ/ትያለሽ					
7	**በሽታው በፈጠረብኝ (በዚህ ባለኝ አካላዊ ጉድለት) እሸማቅቃለሁ እፈራለሁ** /ይላሉ/ ትላለህ/ትያለሽ					
8	**ይሄ በሽታ የመጣብኝ በራሴ ስህተት (ጥፋት) ነ ው** ብለወ(ብለህ)ብለሽ ያስባሉ?					

ተ.ቁ	የ ቤተሰብ	በጭራስ	ከስንት አንዴ	አልፎ አልፎ	ብዙ ጊዜ	ሁል ጊዜ
1	**ባለኝ በዚህ በሽታ ምክንያት አንዳንድ የ ቤተሰብ አባላት ባለሁበት ሁኔታ ምክንያት በኔ ደስተኛ አይደሉም/ አልመጡም** ብለው)ብለህ/ብለሽ/ ያስባሉ					
2	**ዚህ በሽታዬ የተነሳ አንዳንድ የ ራሴ ቤተሰቦች ችላ ብለውኛል/ ትተውኛል** ይላሉ/ ትላለህ/ ትያለሽ					
3	**ከህመሜ በኋላ የተወሰኑ የ ቤተሰቤ አባላት በአንዳንድ ጉዳዮች/ሁኔታዎች አያሳተፉኝም አስወጥተውኛል** ብለውያስባሉ/ታስባለህ/ታስቢያለሽ					
4	**ከህመሜጋር በተገናኘ አንዳንድ የ ቤተሰብ አባላት ለኔ ጥሩ ፊት አያሳዩኝምሃዘኔታ የላቸውም** ይላሉ/ትላለህ/ትያለሽ					
5	**ይሄ በሽታ ከተከሰተ በኋላ አንዳንድ ቤተሰብ፣ /ዘመዶቼ ርቀውኛል/ሸሽተውኛል** ይላሉ/ትላለህ/ትያለሽ					
6	**በበሽታዬ ሁኔታ አንዳንድ ቤተሰቦቼ ሲሸሟሙቀቁ ፣ እንደሜር ሲሉ አያለሁ** ይላሉ/ትላለህ/ትያለሽ					
7	**በሽታው ከመጣብኝ አካላዊ ጉድለት ጋር በተገናኘ ቤተሰቦቼ ሲያፍሩ፣ ሲሸማቅቁ አያለሁ፣** ይላሉ/ትላለህ/ትያለሽ					
8	**አንዳንድ የ ቤተሰቦቼ አባላት ለደረሰብኝችግር ተጠያቂው እኔ ራሴ እንዳሆንኩ አይነት ሁኔታ ያሳዩኛል** ይላሉ/ትላለህ/ትያለሽ/					

ተ.ቁ	የ ማህበረሰቡ	በጭራሽ	ከስንት አንዴ	አልፎ አልፎ	ብዙ ጊዜ	ሁል ጊዜ
1	**ህመመብአካሌ ላይ ካደረሰውሁኔታ ጋር በተያያዘ አንዳንድ ሰዎች ፣ከእኔ ጋር አብሮ ሚሆን ብዙ አይመቻቸውም** ይላሉ/ ትላለህ/ ትያለሽ					
2	**ይሄ በሽታ ከመጣ በኋላ አንዳንድ ሰዎች ርቀውኛል(ከኔ ሸሽተዋል) (እንደበፊቱ ሊቀርቡኝ አይፈልጉም** ይላሉ/ ትላለህ/ ትያለሽ					
3	**ከዚህ ህመሜ በኋላ አንዳንድ ጓደኞቼ፣ ወዳጆቼ ከተለያዩ ጉዳዮችና /ነገሮች አርቀውኛል/አስወጥተውኛል/ ተገልያለሁ** ይላሉ/ ትላለህ/ትያለሽ					
4	**በህመሜ ሁኔታ ሰዎች ጥሩ ፊት አያሳዩኝም፣ ለስሜም አይጠቅ ቀቁም** ይላሉ/ ትላለህ/ትያለሽ					
5	**በዚህ ባለብኝ ህመም ምክንያት አንዳንድ ሰዎች ሊያገኙኝ አይፈልጉም፣ ርቀዋል፣ ሸሽተውኛል** ይላሉ/ ትላለህ/ትያለሽ					
6	**አንዳንድ ጓደኞቼ በዚህ በሽታዬ ሲሸማቅቁ፣ ሲያፍሩ አያለሁ** ይላሉ/ ትላለህ/ትያለሽ					
7	**አንዳንድ ጓደኞቼ በሽታው አካሌ ላይ ካደረሰው ጉድለት ጋር በተገኘ ሲያፍሩ /ሲሸማቅቁ አያለሁ** ይላሉ/ ትላለህ/ትያለሽ					
8	**አንዳንድ ሰዎች ስለተፈጠረብኝ (ህመም) ራሱ ነው ተጠያቂ አይነ ት ሁኔታ ያሳዩኛል** ይላሉ/ ትላለህ/ትያለሽ					

የPHQ-9 የታ·ማሚ ጤንነት መጠየቂያ

የታ·ማሚው ስም_____ **የጎበኘበት ቀን** _____

ተ.ቁ	ከዚህ በታች የምንጠይቆት ጉዳዮች፣ ችግሮች አሉ እና እነዚህ ነገሮች ባለፉት ሁለት ሳምንት ውስጥ ምን ያህል አስቸግሮዎት እንደነበር ይነግሩናል።	በጭራሽ (ጭራሽ)	ብዙ በሚባሉ ቀናት	ከሁለቱ ሳምንት ቀናት ከግማሹ ጊዜ በላይ	ሁሌ ማለት ይቻላል
1	ከዚህ በፊት የሚያስደስተኝ/የሚስቡኝ ነገሮችና ሁኔታዎች አሁንም ብዙም አይስቡኝም/ አያስደስተኝም (ይላሉ?)				
2	ውስጤ ያዘናል፣ ይከፋል፣ እንዲሁም ተስፋ አቆርጣለሁ (ይላሉ?)				
3	እንቅልፍም ቶሎ አይመጣም፣ አይዘኝም ቢይዘኝም ቶሎ አነቃለሁ (እንዳንዴ ደግሞ ከመጠን በላይ እንቅልፍ ይበዛብኛል)				
4	ስሙነቱ ሃል ይላል /ይደክመኛል/ ሃይል ጉልበትም የለኝም (ይላሉ?)				
5	የምገብ ፍላጎቴ ተንሷል/ ወይም **ከወትሮ (ከሌላ ጊዜ) የበለጠ ብዙ እበላለሁ (ይላሉ?)**				
6	ስለራሴ ጥሩ ስሜት አይሰማኝም ነገሮቼን ሳሞቸው በነገሮና በአጠቃላይ ለቤተሰቡ ያልሆነ /ብዙ የማይጠቅም/ ስው አድርጌ አስባለሁ				
7	ነገሮች ላይ (እንደቀድሞው) በትኩረት ፤በንቃት መከታተል ላይ (ለምሳሌ ራድዮ፣ ቴሌቪዥን፣ የሚነበቡም ነገር) ተከታትሎ መጨረስ ላይ ችግር አለ ወይም ትኩረት ተንሶብኛል በትኩረት አልከታተልም (ይላሉ?)				
8	ንግግሬን /እንቅስቃሴዬን በአጠቃላይ ዝቅ ያለ/ የቀዘቀዘ ሆኗል/ ወይም በተቃራኒው አልረጋጋም ከቦታ ቦታ፣ ከክፍል ክፍል ከወትሮ በተለየ ሁኔታ እንቀሳቀሳለሁ (እንደመቁነጥነጥ ያደርገኛል) (ይላሉ?)				
9	አንዳንዴ ከምሞር ብሞት ይሻላል ይላሉ (አራስዎት ላይ ጉዳት ለማድረስ) አራስዎን ለማጥፋት አስበው ያውቃሉ?				

የአንድ ስንጠረዥ ድምር _____+ _____ + _____ +

የሰንጠረዦቹ ጠቅላላ ድምር _____

10. ከችግሮቹ መሃል የቱት ካለ ያ ችግር ምን ያህል ነው? ስራዎትን /ቤትና ቤተሰብን መንከባከብ ወይም ከሌሎች ሰዎች ጋር መግባባት ላይ ምን ያህል ችግር ፈጥሮቦታል?

- ☐ ምንም ችግር የለም
- ☐ በመጠኑ ችግር ነበር
- ☐ በጣም ተቸግሬ ነበር
- ☐ እጅግ በጣም ተቸግሬ ነበር

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