Addis Ababa University

College of Health Sciences

School of Pharmacy

Department of Pharmaceutics and Social Pharmacy

Assessment of psychometric properties, feasibility and usefulness of the EQ-5D-5L in Ethiopian stroke patients

By: Ewennat Wehib (B.Pharm.)

October, 2023

Addis Ababa, Ethiopia

Assessment of psychometric properties, feasibility and usefulness of the EQ- 5D-5L in Ethiopian stroke patients

Ewennat Wehib

A Thesis Submitted to the Department of Pharmaceutics and Social PharmacyPresented in Partial Fulfillment for the Requirements of Masters of Sciences Degree in Social Pharmacy and Pharmacoepidemiology

Addis Ababa University

Addis Ababa, Ethiopia

October, 2023

Addis Ababa University

School of Graduate Studies

This is to certify that the thesis prepared by Ewennat Wehib entitled: Assessment of Psychometric properties, feasibility and usefulness of the EQ- 5D-5L in Ethiopian stroke patients and submitted in partial fulfillment of the requirements for the Degree of Master of Science (Pharmacoepidemiology and Social Pharmacy) complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the Examining Committee

Examiner (External): Tariku Shimels Sig: _____ Date: _____

Examiner (Internal): Alemseged Beyene Sig: _____ Date: _____

Advisor: Dr. Eskinder Eshetu Ali Sig: _____ Date: _____

Co-advisor: Yared Belete Belay (MSc, PhD candidate) Sig:  Date: 11/10/2023

Assessment of Psychometric properties, feasibility and usefulness of the EQ- 5D-5L in Ethiopian stroke patients

Ewennat Wehib

Addis Ababa University, 2023

Abstract

Background: Stroke ranks as the second-leading global fatality and affects the quality of life for survivors. Despite limited knowledge about the impact of acute stroke on health-related quality of life in Ethiopia, longitudinal studies on stroke patients offer some insight internationally.

Objective: To assess the Psychometric properties, feasibility and usefulness of EQ-5D-5L among Ethiopian stroke patients.

Methods: A sequential mixed-method study design was conducted among 200 patient-proxy dyads at 6 public hospitals of Addis Ababa, Ethiopia from November 2021-November 2022. STATA version 15 was used for the quantitative analysis.The internal consistency was assessed using Cronbach's alpha (α). Chi-square test was used for the problem/no problem report comparison among patients and proxies across different interview periods. Mean difference between patient and proxy in the EQ-5D index and EQ VAS was reported using paired t-test. In addition, patient/proxy response agreement, convergent validity, and known group validity were assessed. Qualitative data was analyzed thematically using MaxQDA version 20.

Results: EQ-5D-5L demonstrated good internal consistency with a Cronbach's α of 0.86, 0.92 and 0.93 at baseline, Visit 2 and visit 3 respectively. In visits two and three compared to the baseline report, a better agreement was observed between patient and caregivers. There was a moderate to strong association between the mRS score and the EQ VAS and EQ-5D index. Significant differences in mean utility were noted among patients with different stroke disability levels, as measured by mRS. Patients, proxies, and data collectors found it easier to answer EQ-5D-5L questions during follow-up visits compared to baseline. Two major themes were identified with respect to discrepancies in patient and proxy ratings, which attributed to reflections on the feasibility of questions and concerns on perceived disease impact.

Conclusion: The EQ-5D-5L is a reliable and valid tool for assessing HRQoL in stroke patients. The findings also showed that proxy assessments acquired 3 and 6 months after stroke are more reliable than those obtained in the acute setting.

Key words: *EQ-5D-5L, Ethiopia, Feasibility, Psychometric property, Stroke*

Acknowledgments

First and foremost, I thank Almighty God for giving me the motivation and guidance I needed to successfully complete my research despite all challenges. I would like to express my sincere gratitude to my advisor, Dr. Ekinder Eshetu and collaborator Yared Belete for their unwavering support during this study.

This project receives a financial support from a grant awarded by the EurQol Research Foundation (Project ID: EQ project 79-2020RA). I would also like to thank the Institutional Review Boards and internal medicine departments at the six hospitals for their warm welcomes and ongoing support during the data collection process. This would not have been possible without the willing cooperation of the study participants and the tenacity of my data collectors.

I am very grateful to Addis Ababa University for sponsoring me to attend the MSc program. Last but not least, I want to pass on my heartfelt thanks to my family and friends for their great support. My deepest gratitude goes to Frezer Adefrs and Kidist Mesele for their continuous support.

Table of Contents

List of Tables

List of figures

Acronyms and Abbreviations

A/D	Anxiety/depression
BI	Barthel index
CG	Caregiver
DALY	Disability Adjusted Life Year
EQ-VAS	EuroQol Visual Analog Scale
EQ-5D -5L	EuroQol-5 Dimension-5 Level
HRQoL	Health related quality of life
ICC	Intraclass correlation coefficient
LICs	Low-income countries
LMICs	Low-Middle Income Countries
MO	Mobility
mRS	Modified Rankin Scale
P/D	Pain/discomfort
PT	Patient
QALY	Quality Adjusted Life Year
SC	Self-care
SPSS	Statistical Package for Social Sciences
TASH	Tikur Anbessa Specialized Hospital
TIA	Transient Ischemic Attack
UA	Usual activities
UICs	Upper Income Countries
UMICs	Upper-Middle Income Countries
WHO	World Health Organization

1. Introduction

1.1. Background

Stroke is a neurological problem characterized by cerebral infarction due to either blockage of blood supply reaching brain cells, or intracerebral or subarachnoid hemorrhage of blood vessels supplying the brain (Sacco et al., 2013). According to the most current Global Burden of Disease (GBD) 2019 stroke burden estimates, stroke is still the world's second leading cause of death and the third major cause of disability and disability combined (as measured by disability-adjusted life-years lost (DALYs)). (Gorelick, 2019). The condition accounts for 4.5% of all-cause DALYs leading to an annual loss of 132.1 million DALYs worldwide (Norrving & Mensah, 2017; Sacco et al., 2013). The most striking feature is that the mortality and morbidity burdens associated with stroke (86% of deaths due to stroke and 89% of DALYs) occur in lower income countries (LIC) and lower-middle-income countries (LMIC) (Feigin et al., 2022). Stroke is seen as one of the most frequent reasons for admission in many healthcare facilities and is developing into a serious public health issue in Ethiopia. (Gebremariam & Yang, 2016; Greffie, Mitiku, & Getahun, 2015). According to the World Health Organization (WHO) 2017 report, stroke death in Ethiopia reached 6.23% of total mortalities, ranking sixth with an age-adjusted death rate of 89.82 per 100,000 inhabitants (WHO, 2017).

With the recognized impact of stroke on quality of life, interventions are expected to be evaluated according to their impact on the health-related quality of life (HRQoL) of patients (Golomb, Vickrey, & Hays, 2001). For this purpose, several condition or disease-specific tools have been developed to assess overall HRQoL of stroke patients. However, such tools are not well suited for making comparisons among various disease conditions. As a result, generic HRQoL instruments are often promoted in economic evaluations of healthcare interventions (Coons, Rao, Keininger, & Hays, 2000; Tian-hui, Lu, & Michael M, 2005). In this regard, the EuroQol-5 Dimension (EQ-5D) tool is one of the most popular generic HRQoL measures for estimating the utility values necessary for such economic evaluations (Lin, Longworth, & Pickard, 2013; Longworth et al., 2014; Owolabi et al., 2015). With a general emphasis, the EQ-5D complements more specialised, disease-specific Patient reported outcome measures by including a health profile with wide applicability across health issues. Along with the latter, conciseness and reduced responder burden have further aided applicability (Brodin, Lohela-Karlsson, Swärdh, Opava, &

Rehabilitation, 2015; Ernstsson et al., 2022).

The five-level version of the EQ-5D (EQ-5D-5L) is available in over 130 languages and in a variety of administration modes (EuroQol, 2021). The EQ-5D's validity and reliability have been established in a variety of diseases as well as in the general population (Petrou & Hockley, 2005; Schweikert, Hahmann, & Leidl, 2006). Ethiopia has generated country-specific value sets for the EQ-5D-5L, the first valuation study in Africa (Welie et al., 2020). Despite the use of the tool in the general population, there is limited evidence about the psychometric performance and feasibility of using the EQ-5D-5L among stroke patients in the Ethiopian context. As such, this study aims to fill this research gap.

1.2. Statement of the problem

Stroke has a devastating nature and has the potential to culminate in catastrophic clinical results (Lloyd-Jones et al., 2009). Stroke affects the functions of the body, emotion and socioeconomic status of the patient, resulting in an immense burden, both in terms of human and economic costs. The impact is not only for the patient but also to their families and health care programs (Salter, Hellings, Foley, & Teasell, 2008). Stroke survivors also have a lower sense of well-being and are more likely to live with a larger number of other comorbid conditions losing 1.71 years due to mortality of a possible 5 years in perfect health, and another 1.08 due to decreased HRQoL, resulting in 2.21 Quality Adjusted Life Years (QALYs) (Clarke, Marshall, Black, & Colantonio, 2002; Dhamoon et al., 2010; Luengo-Fernandez et al., 2013). Despite recent advances in acute stroke treatment, the number of people suffering from the effects of stroke continues to rise (Campbell et al., 2015; Feigin et al., 2014). In Ethiopia, stroke was the third prevalent cardiovascular disease in all age groups, accounting for 6.23 percent of total deaths (Ali et al., 2021).

In certain stroke outcome trials, because of cognitive and language disabilities, 25% of the participants were excluded from HRQoL evaluations. Therefore, considering proxy caregiver responses and proxy agreement is an area of special interest for assessment of HRQOL in patients with stroke. However, there is paucity of information on the level of agreement between HRQoL reported by stroke patients and their proxies (Bansback et al., 2008; Oczkowski, O'Donnell, & Diseases, 2010; Pickard et al., 2004). With regard to reporting discrepancy, studies

have shown that proxy caregivers overestimate the problems experienced in health dimensions like selfcare, and underestimate problems with mobility (Oczkowski et al., 2010).

There are a few studies globally that have investigated the feasibility and usefulness of administering EQ-5D in acute care hospital admission and post-discharge community setting (Delcourt et al., 2017; Haacke et al., 2006; Jönsson et al., 2014; Luengo-Fernandez et al., 2013). However, this is often not well-understood among LICs such as Ethiopia. There are no validity and reliability analyses performed on stroke patients in Ethiopia. Then, demonstrating the psychometric properties and feasibility of administering the EQ-5D-5L in an LIC such as Ethiopia, where the population exceeds 110 million people, is likely to have positive impacts on the use of the EQ-5D-5L in similar studies in other LICs.

1.3. Significance of the study

Determining the feasibility and examining the psychometric properties of the EQ-5D among stroke patients, and their proxy caregivers, is important to determining the usefulness of the EQ-5D-5L in a large LIC. This will also help demonstrate the performance of the tool on capturing clinical improvement resulting in subsequent introduction of the tool for monitoring patients in clinical practice. Moreover, the utility value computed from this study for stroke patients will help to compute meaningful QALYs for economic evaluation, which in turn will be used as an input for health providers and policy-makers to assess the outcome of an intervention and to identify cost-effective interventions for the management of the disease.

A qualitative assessment of the feasibility of the the tool in the context of Ethiopian stroke patients and their proxies will also provide a possible explanation for the difference of responses to the EQ-5D-5L descriptive profile and EQ-VAS between the patient and proxy. Those explanations will provide clues on the clarity, comprehensiveness, strength and limitation of the tool making contributions to find the solutions for improving the performance of the tool in estimating HRQoL of unconscious and acutely ill patients from their proxy caregivers.

2. Literature Review

2.1. Burden of stroke

According to the World Health Organization (WHO), a stroke is characterized by the fast onset of localized (or global) disturbances in cerebral functioning that last for more than 24 hours or result in death and have no other evident cause than vascular origin (Aho et al., 1980).

Worldwide, stroke claimed 132.1 million DALYs in 2017 (42% more than in 1990), with ischemic strokes being the primary cause. By 2030, stroke is predicted to cause 7.8 million deaths per year and over 23 million new cases worldwide if there is no significant global public health response (Strong, Mathers, & Bonita, 2007). According to a 2022 World Stroke Organisation report, the lifetime risk of getting a stroke has climbed by 50% in the last 17 years, with 1 in 4 people now expected to experience a stroke in their lifetime (Feigin et al., 2022). According to the regional distribution of DALY losses, 63.1 million DALYs were lost in upper-middle income countries (UMICs), 14.2 million DALYs were lost in upper income countries (UICs), 6.8 million DALYs were in LICs and 47.1 million DALYs in low-middle income countries (LMICs) (Avan et al., 2019).

With an age-standardized prevalence of 981 per 100,000, the most recent projected stroke incidence rate for Africa is 316 per 100,000. The mean age-standardized increases in ischemic and hemorrhagic stroke incidence in Africa of 14.8% and 28.7%, respectively, between 1990 and 2010 show that the incidence and velocity of stroke are quite high (Owolabi et al., 2015). The 2019 update on global stroke statistics showed a consistent growth in stroke incidence in LMICs based on studies of stroke incidence conducted between 1971 and 2014 (Kim et al., 2020).

In Ethiopia, the ischemic subtype of stroke affected more than half of all stroke victims (51.40%), while the prevalence of hypertension among stroke patients was 49%, according to a meta-analysis done in Ethiopia on a total of 5064 stroke patients around the world (Abate, Zeleke, Genanew, & Abate, 2021). Stroke is becoming more common in Ethiopia, accounting for 7.5% to 19.3% of hospital admissions and about (11% to 42.8%) deaths between 2014 and 2019 (Fekadu, Adola, Mosisa, Shibiru, & Chelkeba, 2020; Mulat et al., 2016; Mulatu, 2017).Currently, stroke is the cause of over 24% of all neurological hospitalizations to Ethiopian hospitals (Zewdie et al., 2018).

2.2. Health outcome measures used in stroke patients

Stroke has a substantial societal impact due to the detrimental effects it has on the capacities and quality of life (QOL) of persons who have had and survived a stroke. Measuring this impact is a tough endeavour since people with impairments may find it challenging to be evaluated independently and because many different aspects of functioning and well-being may be affected. From the perspective of the patient, HRQoL assessment is becoming a more pertinent method for assessing the effects of disease and therapy, and it may even be more pertinent in chronic diseases than in acute situations, where there is no known cure for the condition. (Berzon, Donnelly, Simpson, Simeon, & Tilson, 1995). A thorough assessment of HRQoL is necessary to capture the full impact of stroke since stroke has a wide-ranging impact on physical, mental, and social aspects of HRQoL (Webster & Feinglass, 1997).

Since there are a range of different measures that may be used to assess HRQoL in stroke patients, researchers must be aware of them all in order to weigh the relative benefits and limitations of each measure when selecting an instrument to suit their research needs. Certain domains will be essential for all patient groups in generic QOL measures, but there may be an absence of areas important to stroke patients such as; hemi-paresis, vision, language, concentration and memory may not be addressed. Although generic assessments allow for comparisons between groups with a wide range of illnesses, a condition-specific instrument provides a more sensitive measure of HRQoL in stroke patients (Bowling, 2001; Russell, Dempster, & Donnelly, 2011).

Some of the generic HRQoL measures that have been used among people after stroke are; the Sickness Impact Profile (Bergner, Bobbit, Carter, Gilson, & White, 1992), the EuroQol (EuroQol, 1990), Health utility index (DH & trials, 1996), London handicap scale (Harwood, Gompertz, Ebrahim, & Psychiatry, 1994), Nottingham Health Profile (Hunt, McEwen, & McKenna, 1986) and the 36-Item Short Form (Ware Jr & Sherbourne, 1992). There are also condition-specific instruments that can be used in stroke patients,such as The Burden of Stroke Scale (Doyle et al., 2004), the Stroke Impact Scale (Duncan et al., 1999), the Stroke-Specific Quality of Life Scale (Williams, Weinberger, Harris, Clark, & Biller, 1999), the Quality-of-Life Index-Stroke Version (Robinson-Smith, Johnston, Allen, & rehabilitation, 2000), and the Stroke-Adapted Sickness Impact Profile-30 (Van Straten et al., 1997).

2.3. EQ-5D as the tool to Measure HRQoL in stroke patients

2.3.1. Feasibility and validity of EQ-5D in stroke patients

The EQ-5D-5L questionnaire is a straightforward, generic instrument for describing and assessing HRQOL. It essentially consists of 2 pages: the EQ-5D descriptive system with 5 dimensions: mobility (MO), self-care (SC), usual activities (UA), pain or discomfort (P/D) and anxiety or depression (A/D). There are five levels in each dimension: no problems, slight problems, moderate problems, severe problems and extreme problems and the EQ visual analogue scale (EQ VAS) which enables the patient to record their current self-rated health state on a vertical visual analogue scale with the endpoints are labelled the best health you can imagine' and the worst health you can imagine (EuroQol, 1990).

The EQ-5D-5L descriptive system is supported by evidence as a valid and reliable generic health outcome assessment for stroke patients (Golicki et al., 2015; Pinto, Maso, Vilela, Santos, & Oliveira-Filho, 2011). EQ-5D-5L was found to have good feasibility in patients with stroke. There were confirmed discriminant validity, reasonable criterion validity, construct validity of the instrument in terms of known-groups and convergent validity with other established stroke outcome measures (Golicki et al., 2015; Hunger, Sabariego, Stollenwerk, Cieza, & Leidl, 2012; Janssen et al., 2013; Katona, Schmidt, Schupp, Graessel, & outcomes, 2015). Correlations between the EQ-5D-5L and the modified Rankin Scale (mRS), Barthel index (BI), and EQ VAS ranged from moderate to strong. When compared to P/D and A/D dimensions, MO, SC, and UA dimensions had stronger correlations with mRS and BI (Golicki et al., 2015). In contrast to the report on a systematic review, where severe health impairments were reported in MO, SC, and UA (Feng, Kohlmann, Janssen, & Buchholz, 2021), more problems were reported in the dimensions UA and P/D, followed by A/D, MO, and SC (Hunger et al., 2012).

In a longitudinal cohort study that evaluated stroke patients at baseline and 6 months, the EQ-5D index was discovered to be more responsive than the EQ-VAS index. The study also found that EQ-VAS was strongly connected to changes in mental health or social elements of health, whereas EQ-Index was strongly related to changes in measures of disability and daily living activities (Pickard et al., 2004).

The findings of the study, which involved German stroke victims receiving neurological rehabilitation, revealed that the psychometric features of the EQ- 5D in the first 6 months

post-stroke were reasonably valid, reliable and responsive. The study also revealed that, EQ-5D was well accepted and understood, with only a small percentage of incomplete or invalid responses, small ceiling impact and good criterion validity (Hunger et al., 2012).

2.3.2. Agreement between patients and their proxies

According to a study on patient and proxy agreement, proxies had a higher proclivity to report more problems with SC, P/D, and A/D than patients on the EQ-5D at 6 months after an acute stroke. At baseline, agreement based on kappa (κ) was good for the more observable dimensions (MO, SC), and for the less visible dimensions (P/D, A/D), it was found to be poor. Exact agreement and Intraclass Correlation Coefficient (ICC) point estimates improved significantly during the six-month follow-up, most notably for P/D. When it comes to summary scores, there was either no difference at all or very little between patient and proxy mean ratings. For proxy assessments, the direct preference-based EQ-VAS was less reliable, particularly at baseline. The EQ-5D is quicker and simpler to complete for proxy, but it lacks skills like language, reasoning, and dexterity that are crucial for stroke recovery (Pickard et al., 2004).

A systematic review reviewed nine studies to see how reliable proxy responders were in measuring quality of life (QoL) in stroke patients. The research revealed that when measuring QoL using specific scales, proxy respondents demonstrated moderate to significant reliability, particularly in objective areas such as physical functioning and self-care. When it came to assessing pain, emotions, and social functioning, however, there was less agreement between patient and proxy replies. The study also discovered that increased stroke severity was consistently associated with more disagreement between the patient and proxy respondent. The majority of research that looked at the difference between patient and proxy replies found that proxy respondents underestimated the QOL deficits in stroke patients. (Oczkowski et al., 2010).

2.3.3. Health related quality of life among stroke patients using EQ-5D

According to a population-based study conducted in the United Kingdom on TIA and stroke patients, the EQ-5D mean utility value for stroke patients at one month was 0.64 compared to 0.78 for TIA patients. Although the utility value for patients who had TIAs did not change throughout the course of their 5-year follow-up, it had grown to 0.70 by the time they had their strokes. At one month, the average utility for patients with severe stroke was 0.13,

compared to 0.50 for patients with moderate stroke and 0.73 for those with minor stroke. According to the study, the utility score has decreased as stroke severity has increased. Being older, female, married, having a moderate-to-severe stroke, and having more strokes after the event commencement were revealed to be independent characteristics in this study that predicted reduced utility (Luengo-Fernandez et al., 2013).

The study at Philipps-Universität Marburg found that HRQoL decreased with increasing patient age and increased with marriage, with married patients having greater utilities than widowed, single, and separated/divorced patients. If there are no subsequent infarcts, patients with TIA have high HRQoL scores (Haacke et al., 2006).

Additionally, EQ-5D-5L has demonstrated lower index-based scores in patients with acute stroke who are female, have high mRS scores, low BI or VAS scores, have subarachnoid haemorrhage or intracerebral haemorrhage, or when the patient was unable to respond on their own and a proxy respondent was required (Golicki et al., 2015).
The mean for EQ-5D-5L in a Swedish study of acute stroke patients and those three months post-stroke was 0.68, with a median of 0.74. In contrast, the EQ VAS had a mean of 63.8 and a median of 70. Increased age, female sex, poor physical activity before stroke, and greater stroke severity were independent predictors of a low EQ-5D-5L index. In which, A/D showed the strongest correlation with the EQ VAS, followed by UA, P/D, MO and SC ability (Soderblom, 2018).

Men reported fewer problems with UA in the Swedish study done 10 years after the stroke, while women reported a higher prevalence of PD. After 10 years, 86% of stroke survivors gave their general health a positive rating (excellent, very good, good, or reasonably good), while only 10% gave it a poor rating. People over the age of 75 rated their health status positively, but their self-reported health status generally deteriorated (Jönsson et al., 2014).

The average EQ-5D index showed significant improvement between admission and discharge in a prospective cohort study conducted in Germany, focusing on stroke survivors. This improvement remained consistent in patients who stayed at home for 2.5 years following discharge, with their mean indices remaining constant between the time of discharge and the follow-up. During the period of follow-up, there were more enhancements than declines in the dimensions of MO and UA, while the proportion of improvements to declines remained consistent in the A/D and SC dimensions. However, on the P/D dimension, the number of

declines was twice as high as the number of improvements. Additionally, it was observed that the higher the HRQoL upon discharge, the higher it remained one to 2.5 years later (Katona et al., 2015).

3. Objective

3.1. General objective

- To assess the psychometric properties, feasibility and usefulness of EQ-5D-5L in Ethiopian stroke patients and their proxy, in public hospitals of Addis Ababa, Ethiopia.

3.2. Specific objectives

- To examine the psychometric properties of the EQ-5D-5L applied to stroke patients and their proxy caregivers.
- To assess the feasibility of administering the EQ-5D-5L to stroke patients and their proxy respondents at different time points following an acute onset illness (first-ever stroke).
- To examine patient-proxy agreement on the domains and summary scores of the EQ-5D-5L
- To qualitatively investigate, within patient-proxy dyads, patient and proxy perspectives of the reasons for any differences in HRQoL reporting on the descriptive profile of EQ-5D-5L between patients and their proxies

4. Methodology

4.1. Study area and period

The study conducted on public hospitals in Addis Ababa. Addis Ababa is Ethiopia's capital and biggest city.It contains 13 public hospitals, six of which are managed by the municipal administration's health bureau and the other seven by the federal ministry of health. The study was carried out in six hospitals: Tikur Anbessa Specialised Hospital (TASH), St. Paul's Hospital, Zewditu Memorial Hospital, Saint Peter's Specialised Hospital, Yekatit 12 Hospital, and Menelik II Hospital from November 2021 to November 2022.

4.2. Study design

An exploratory sequential mixed-method study design (quantitative survey followed by qualitative investigation within patient/proxy dyads) was used.

4.3. Population

4.3.1. Source population

For both the quantaitive and qualitative parts of the study, the study population was, all stroke patients hospitalised to Addis Ababa's public hospitals with an acute onset stroke, as well as their proxy caregivers.

4.3.2. Study population

For both the quantaitive and qualitative parts of the study, the study population was, stroke patients admitted to the selected hospitals in Addis Ababa with an acute onset stroke and their proxies who fulfilled the inclusion criteria within the study period.

4.4. Inclusion and exclusion criteria

4.4.1. Inclusion criteria

For both the quantative and qualitative studies, stroke patients and proxies who fulfill the following criteria were included in the study

- Age ≥18 years
- Willingness to participate in the study
- If the patient has more than one caregiver, the closest (e.g., who stay with the patient at home or during hospital visit) was selected.

4.4.2. Exclusion criteria

For both the quantative and qualitative studies, the exclusion criteria was

- Critically ill stroke patients (comatose patients and patients with aphasia)

4.5. Sample size determination and sampling technique

Quantitative study

The sample for the study was calculated using different literature recommendations based on the ‘rule of thumb. According to Hutcheson and Sofroniou (1999), a sample size of 150 is sufficient as a miminum sample size for research examining psychometric performance, and the sample size to item number ratio may be able to go to a maximum of 20:1. (Osborne *et al.*, 2011). Using this ratio, the sample size of this study gave us 120 participants. For our study, at baseline a total of 200 patients admitted with their first acute stroke and their proxies were recruited to participate, providing a total of 400 participants.

The six hospitals were selected using purposive sampling technique based on patient load, and all the selected hospitals' participants were recruited consecutively until the required sample size was reached (TASH = 65 dyads, St. Paul's Hospital = 14 dyads, Zewditu Memorial Hospital = 77 dyads, Saint Peter's specialized hospital = 11 dyads, Yekatit 12 Hospital = 12 dyads, and Menelik II Hospital = 21 dyads). A total of 152 patient/proxy dyads and 133 patient/proxy dyads were included in the second and third follow-up interviews, respectively.

Qualitative study

For the qualitative investigation, a purposive sampling technique was employed to select participants based on the discrepancy in response between patients and caregivers from the quantitative questions. A total of 30 participants (15 patient-proxy dyads) were interviewed, which makes for a reasonably sized qualitative study, as 10–20 interviews are recommended for medium-level thematic analysis projects such as this MSc thesis project (Braun, 2013). Among the patients, 7 were male and 8 were female, and for the caregivers, 6 male and 9 female participants were included.

4.6. Study variables

Study variables were only relevant for the quantitative part of the study and are described below:

4.6.1. Dependent variables

- ✓ Psychometric properties and feasibility of EQ-5D-5L
- ✓ HRQoL

4.6.2. Independent variable

- ✓ Socio-demographic variables like sex, age, marital status, employment status, educational status and income level
- ✓ Clinical characteristics of the patient like stroke type, presence of comorbid condition, number of medications and mRS score
- ✓ Time of the interview

4.7. Data collection and management

4.7.1. Data collection instruments

Quantitative study

Patients were asked to report their health at baseline and follow up visits using different versions of the EQ-5D-5L tool: 1) Amharic EQ-5D-5L Paper Self-complete version, 2) Amharic EQ-5D-5L Paper Interviewer Administered version 3) Amharic EQ-5D-5L Paper Proxy Self-complete version and 4) Amharic EQ-5D-5L Paper Proxy1 Interviewer Administered version. The data collection tool also contains EQ-VAS which is used to record a patient's self-rated health status on a 20- centimeter vertical scale with endpoints 0 ('the worst health you can imagine') and 100 ('the best health you can imagine'). The data collection tool also included questions about patients' socio-demographic characteristics (age, gender, educational status, marital status, occupation, and income) and clinical characteristics (type of stroke, comorbid disease and medication). In addition, the Modified Rankin Scale (mRS), a commonly used clinician-reported scale to measure the degree of disability after a stroke, with scores ranging from 0 (no disability) to 6 (death), was used at baseline and follow up visits. The feasibility of completing the questionnaire for the participants and administering the questionnaire for data collectors was measured on a scale of five: 5- very

easy, 4- easy; 3 -neutral; 2- difficult and; 1- very difficult to complete or administer.

Qualitative study

A semi-structured interview guide was used to qualitatively explore patient and proxy perspectives on the reasons for any difference in HRQoL reporting on the descriptive profile within patient-proxy dyads.

4.7.2. Data collection procedure

Quantitative study

One trained nurse who had access to patient records at each hospital was involved in data collection. Patients were waited to be stable and interviewed a day before their discharge from the first admission. Patients were interviewed at the admission bed, and caregivers were interviewed separately to avoid a discussion between patients and their proxies. Participants were asked for their telephone number at the end of their interview for the purpose of follow-up interviews. The follow-up interviews in the third and sixth months after the first admission were conducted in an outpatient setting in person and by telephone.

Qualitative study

After patients had completed their follow-up visit, they were invited to an in-depth interview. The principal investigator and one assistant conducted a face-to-face interview of approximately 15–30 minutes duration in the hospital compound. The discussion among the patient and proxy was audio recorded, and notes were taken to capture the information from the interview.

4.7.3. Data quality management

Quantitative study

A structured Amharic version of the EQ-5D-5L questionnaire was used, which was developed through forward and backward translation to Amharic by Eurocol Group. Data collectors received training in the strict application of study criteria, clarification of the study aim, obtaining consent from study participants and confidentiality of the acquired data. All the collected data was checked on site for completeness, accuracy, and consistency by the principal investigator.

Qualitative study

The interview was audio taped as a reference for the transcription. Two individuals (EW and YB) independently analysed the data.

4.8. Data processing and analysis

Quantitative study

For the quantitative investigation of the study, we used stata15 statistical software. The distribution of responses to the EQ-5D-5L was described across different groups (patient and proxy caregiver) for the baseline and follow up visits. Descriptive statistics were used to report the demographic and clinical characteristics of the respondents at baseline. The mean and standard deviation of disability/severity scores (mRS), EQ-5D index and EQ-VAS scores were computed. The descriptive health profiles from the standard EQ-5D-5L were converted into a utility score based on the general population's preferences in Ethiopia (Welie *et al.*, 2020).

Chronbach's alpha was calculated to determine internal consistency of EQ-5D-5L single index score. The problem/no problem report comparison was made among patients and proxies across different interview periods using chi-square. The mean difference in the EQ-5D index and EQ VAS was reported using paired t-test. In addition, weighted Cohen's Kappa statistics were computed to compare the agreement between patient and proxy rating for each dimension of EQ-5D-5L at baseline and follow-up visits. Convergent validity was assessed by examining the strength of association of EQ-5D-5L dimensions with mRS score and EQ-VAS and by using pearson correlation coefficient and known-groups validity was tested for EQ-5D-5L in regard to clinical characteristics of patients.

Qualitative study

Initially, the audio-recorded data was transcribed verbatim. Then the transcribed data was translated into English language. An inductive thematic approach was used to analyze the data. Two individuals (EW and YB) read and re-read the transcripts to develop codes involving words, phrases and clauses. After becoming familiar with the data by reading it repeatedly and carefully, the authors started the initial coding of the transcripts. To facilitate coding, organizing, summarizing, and selecting data from the interview transcripts, MaxQDA version 20, software for qualitative data management was used. After numerous meetings

focusing on understanding the transcribed data, the authors determined potential themes by sorting and organizing the initial codes.

4.9. Ethical consideration

An ethical clearance letter was obtained from the Ethics Review Committee of Addis Ababa University, College of Medicine and Health Science, School of Pharmacy and permission to use the EQ-5D-5L was obtained from Euro QoL group. Then, permission was obtained from the six public hospitals in which the research was conducted. Participants were informed about the aims of the study, the benefits and risks of the study, and asked for written and verbal consent before participating in the study. In each phase after data collection, the principal investigator stored all the paper-based data in a locked cabinet and all the electronic data in a password-locked computer for the confidentiality of individual information.

4.10. Operational definitions

Acute stroke: is accidental onset of focal neurological findings in a vascular territory as a result of underlying cerebrovascular disease.

Proxy caregiver: an individual who assists the patient in hospital and at home during this study period.

Psychometric property: refer to the validity and reliability of the measurement tool

Reliability: refers to the consistency of EQ-5D-5L measure over time (in hospital, and then 3 months and 6 months after stroke), across items (mobility, self-care, usual activity, pain/discomfort and anxiety/depression (internal consistency).

Validity: refer to discriminant validity (with assumption that participants during admission have lower EQ-5D-index and EQ-VAS score than the follow-up time).

5. Results

5.1. Sociodemographic Characteristics of the Study Participants

The study recruited a comparable number of male (47.5%) and female (52.5%) patients at baseline, and a larger number of proxy caregivers (63.5%) were female. The majority (88.5%) of patients were aged 45 and over, while most (79%) proxy caregivers were below 45. A higher proportion (64%) of caregivers were employed, and 51.5% of patients and 39% of proxy caregivers reported that they did not earn enough income (Table 1).

Table 1. Baseline socio-demographic characteristics of the study population in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patients/proxy dyads)

Demographic characteristics		**Patients n (%)**	**Proxies n (%)**
Gender	Male	95(47.50)	73(36.50)
	Female	105(52.50)	127(63.50)
Age*	<45	23(11.5)	158(79)
	45-64	90(45)	38(19)
	65-74	57(28.5)	4(2)
	>=75	30(15)	-
Marital status	Unmarried	27(13.50)	61(30.5)
	Married	146(73.00)	132(66)
	Divorced	8(4)	6(3)
	Widow	19(9.5)	1(0.5)
Education background	No formal education	64 (32)	5(2.5)
	Primary education	52 (26)	42(21)
	High school	46 (23)	74(37)
	Technicaland vocational/college diploma	24 (12)	30(15)
	Bachelor degree and above	14(7)	49(24.5)
Employment status	Employee	36(18)	62(31)
	Self-employed	61(30.5)	66(33)
	Retired	31(15.5)	-
	Student	-	21(10.5)
	Looking after home/family	72(36)	51(25.5)
Income	Not enough	103(51.5)	78(39)
	Enough	94(47)	120(60)
	More than enough	3(1.5)	2(1)

Age: the age classification was based on the report from American heart association (Roger et al., 2011).*

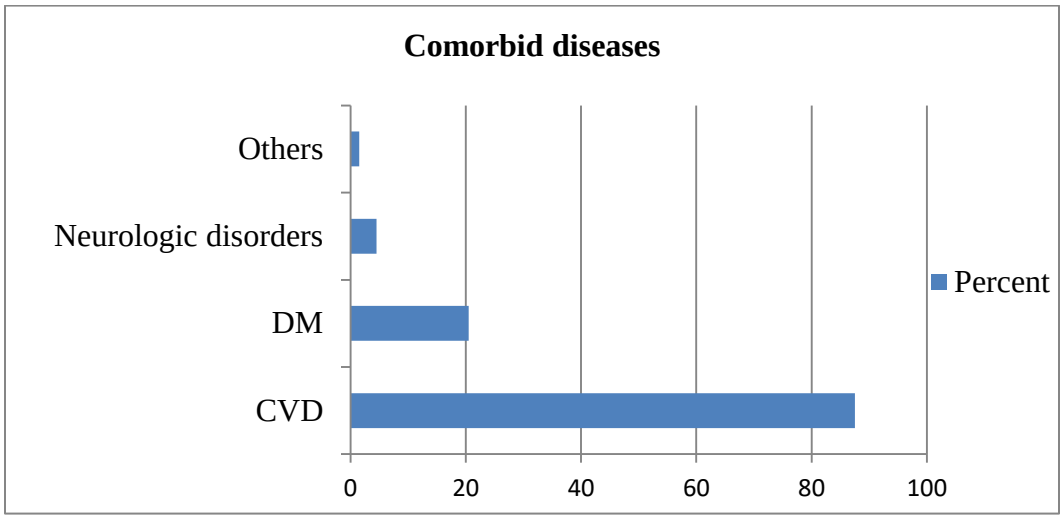
5.2. Clinical characteristics of patients

The majority (64.7%) of patients have a diagnosis of ischemic stroke (64%), followed by hemorrhagic stroke (33%). Most responders (61%) did take more than three medications (Table 2).

Table 2. Baseline clinical characteristics of patients in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200)

Clinical parameters		**n (%)**
Type of stroke	Hemorrhagic stroke	66(33)
	Ischemic stroke	128(64)
	Cardioembolic stroke	6(3)
Comorbidity	Yes	183(91.5)
	No	17(8.5)
Number of medications	<=3	78(39)
	3-5	90(45)
	>5	32(16)

The majority of the patients (91.5%) had one or more comorbid conditions. Furthermore, cardiovascular diseases (87.5%) and diabetes mellitus (20.5%) were the most common co-morbidities among stroke patients (Figure 1).



**Others:Acute kidney injury (n=1), Infectious diseases (n=2), Schizophrenia (n=1). Abbreviations: CVD: Cardio vascular disease; DM: Diabetes mellitus*

Figure 1: Common chronic comorbid conditions of stroke patients in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200)

5.3. Reported death and disability based on mRS score

Based on the mRS disability scale with possible scores ranging from 0 (no disability) to 6 (death), the patient's stroke-related disability was reported, and the mean score at baseline was 3.8 which declined to 3.2 and 2.2 at visit two and visited three respectively.

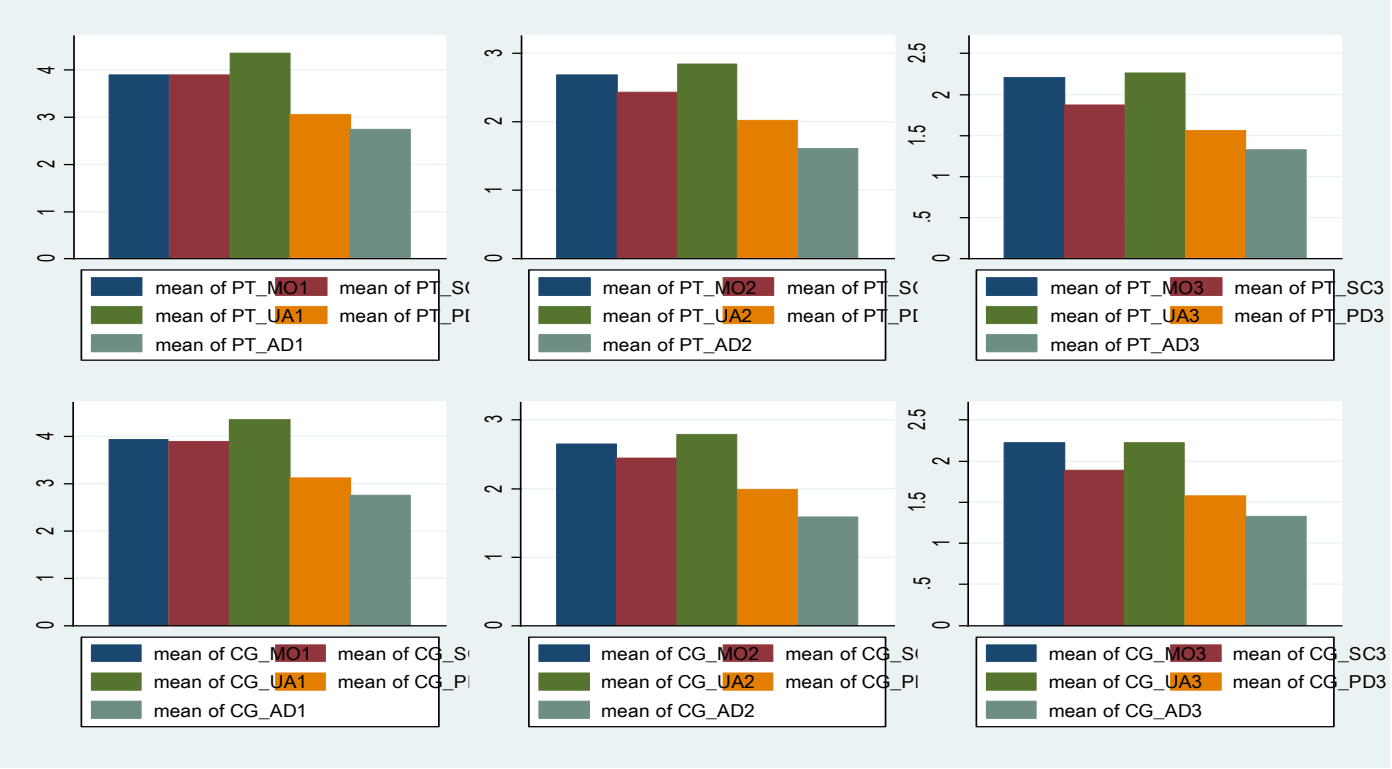
Table 3. Death or major disability of patients reported based on mRS score in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200).

mRS Score	Baseline n (%)	Visit 2 n (%)	Visit 3 n (%)
0 (no disability)	-	13(6.9)	22(15.7)
1	6(3)	22(11.7)	34(24.3)
2	32(16)	35(18.6)	29(20.7)
3	24(12)	32(17)	17(12.2)
4	80(40)	45(23.9)	30(21.4)
5	58(29)	5(2.7)	1(0.7)
6 (death)	-	36(19.2)	7(5)
Mean (SD)	3.8 (0.08)	3.2 (0.13)	2.2 (0.14)
Total	200	188	140

mRS: Modified Rankin Scale; SD: Standard Deviation

5.4. EQ-5D-5L response distribution

The response distribution for each domain across five levels is described using a bar graph (Figure 1). For example, the EQ-5D-5L response distribution demonstrated that more frequent problems were reported on UA and MO dimensions, with relatively low problems reported on A/D and P/D dimensions. In addition, a reduction in reported problems was observed in follow up visits compared to baseline assessment.



Baseline Visit 2 Visit 3

MO: Mobility; SC: Self-care; UA: Usual activity; PD: Pain/Discomfort; AD: Anxiety/Depression; PT: Patient; CG: Caregiver

Figure 2: EQ-5D response distribution for patients and proxy caregiver at baseline, visit 2 and visit 3 in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads)

EQ-5D-5L responses of patients and proxy caregivers were categorized into no problems (level 1) and any problems (levels 2 to 5). Both patient and proxy respondents reported any problems more frequently than no problems, and at baseline, respondents had reported any problems on MO (patient: 97%; proxy: 98.5%), UA (both patient & proxy: 100%), SC (patient: 94.5%; proxy: 95%), PD (patient: 93%; proxy: 89.5%) and AD (patient: 84%; proxy: 84.5%). The proportions of reported problems reduced in visit two and visit three in all five dimensions (e.g., UA was 100% at baseline and 84.9% and 69.2% at visit two and visit three consecutively for the patient and a similar pattern of change was observed for proxy caregivers: 100% for UA at baseline and followed by 84.2% and 66.9% at visit two and visit three). The proportion of no problems reported in the patient and proxy caregiver respective was compared using the chi-square test. No significant differences in reported problems between patient and proxy were observed across all dimensions (small χ^2 tests value and p-value>0.05) regardless of visit period (table 4).

Table 4. Comparison of response distributions towards EQ-5D dimensions between patient and proxy in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

Interview time	EQ-5D dimension	Respondents	Response		χ^2 tests	*P value*
			No problem n (%)	Any problem n (%)		
Baseline	MO1	Patient	6(3)	194(97)	1.02	0.31
		Caregiver	3(1.5)	197(98.5)		
	UA1	Patient	-	200(100)	-	-
		Caregiver	-	200(100)		
	SC1	Patient	11(5.5)	189(94.5)	0.05	0.82
		Caregiver	10(5)	190(95)		
	PD1	Patient	14(7)	186(93)	1.53	0.22
		Caregiver	21(10.5)	179(89.5)		
	AD1	Patient	32(16)	168(84)	0.02	0.89
		Caregiver	31(15.5)	169(84.5)		
Visit 2	MO2	Patient	32(21.05)	120(78.95)	0.08	0.78
		Caregiver	34(22.37)	118(77.63)		
	UA2	Patient	23(15.13)	129(84.87)	0.03	0.87
		Caregiver	24(15.79)	128(84.21)		
	SC2	Patient	49(32.24)	103(67.76)	0.14	0.7
		Caregiver	46(30.26)	106(69.74)		
	PD2	Patient	43(28.29)	109(71.71)	0.56	0.45
		Caregiver	49(32.24)	103(67.76)		
	AD2	Patient	80(52.63)	72(47.37)	0.21	0.65
		Caregiver	84(55.26)	68(44.74)		
Visit 3	MO3	Patient	44(33.08)	89(66.92)	0.07	0.80
		Caregiver	46(34.59)	89(65.41)		
	UA3	Patient	41(30.83)	92(69.17)	0.16	0.69
		Caregiver	44(33.08)	89(66.92)		
	SC3	Patient	73(54.89)	60(45.11)	0.14	0.71
		Caregiver	70(52.63)	63(47.34)		
	PD3	Patient	74(55.67)	59(44.36)	0.02	0.90
		Caregiver	73(54.59)	60(45.11)		
	AD3	Patient	96(72.18)	37(27.82)	0.07	0.79
		Caregiver	94(70.68)	39(29.32)		

EQ-5D: EuroQol-5-Dimension; MO: Mobility; SC: Self-care; UA: Usual activity; PD: Pain/Discomfort; AD: Anxiety/Depression

5.5. Psychometric properties of EQ-5D-5L

Internal consistency of EQ-5D-5L

Based on the cronbach's alpha value the interpretation is as follows: Cronbach's alpha value > 0.70 was considered as acceptable; alpha values > 0.8 were considered as good and alpha

values > 0.9 ware considered as excellent consistency (Leidy, Revicki, & Genesté, 1999). The internal consistency of the five dimensions (MO, SC, UA, P/D and A/D) of EQ-5D-5L was acceptable (Cronbach's alpha=0.86, 0.92 and 0.93) at baseline, Visit 2 and visit 3 respectively.

Agreement in patient and proxy response

The weighted Cohen's Kappa statistics compare the agreement between patient and proxy rating for each dimension of EQ-5D at baseline and follow-up visits. Kappa interpretation: ≤0 = poor, .01–.20 = slight, .21–.40 = fair, .41–.60 = moderate, .61–.80 = substantial, and .81–1 = almost perfect were considered (McHugh, 2012). At baseline, a lower agreement was observed for P/D (0.32) and A/D (0.43) dimensions, while a higher agreement was observed for MO (0.69) and SC (0.62) dimensions. In all cases, an improved agreement was observed in visits two and three compared to the baseline report.

Table 5. Agreement in patient and proxy response in EQ-5D dimensions in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

Dimension	**Baseline (n=200)**				**Visit 2(n=152)**				**Visit 3(n=133)**			
	Patient (%)	Proxy (%)	Exact agreement	K	Patient (%)	Proxy (%)	Exact agreement	K	Patient (%)	Proxy (%)	Exact agreement	K
MO =1	3	1.5	78	0.69	21.7	22.7	92	0.90	33.1	34.6	96.2	0.95
2	16.5	17.5			25.7	25.3			33.1	29.3		
3	13	14			21	20.7			14.3	15.8		
4	23	20.5			25.7	26.7			18.8	19.5		
5	44.5	46.5			5.9	4.7			0.8	0.8		
SC=1	5.5	5	73	0.62	32.2	30	82	0.76	54.9	52.6	92.4	0.88
2	13.5	12.5			25.7	26.7			18.1	20.3		
3	14	16			15.8	18.7			12.8	13.5		
4	21	20.5			19.1	18			13.5	12.8		
5	46	46			7.2	6.7			0.8	0.8		
UA=1	-	-	73.5	0.53	15.1	15.3	78.7	0.72	30.8	33.1	92.4	0.90
2	10.5	8.5			29	30			34.6	33.8		
3	5	8.5			20.4	23.3			14.3	13.5		
4	24	22.5			27.6	22.7			18	16.5		
5	60.5	60.5			7.9	8.7			2.3	3.1		
P/D=1	7	10.5	47.5	0.32	28.3	32.7	82.7	0.74	55.6	54.9	92.4	0.87
2	25.5	21			46	42			33.1	33.1		
3	33.5	31			20.4	20			10.5	11.2		
4	23	20.5			5.3	4.7			0.8	0.8		
5	11	17			-	0.7			-	-		
A/D=1	16.1	15.6	56.3	0.43	53	55.3	79.9	0.65	30.8	33.1	89.3	0.75
2	28.6	29.2			35	32			34.6	33.8		
3	28.6	25.6			9.3	12			14.3	13.5		
4	19.1	22.6			2.7	0.7			18	16.5		
5	7.5	7			-	-			2.3	3.1		

*p<0.05; *k: Cohen's kappa coefficient*; *MO: Mobility; SC: Self-care; UA: Usual activity; PD: Pain/Discomfort; AD: Anxiety/Depression*

Agreement in patient and proxy EQ-5D index and EQ-VAS scores

Differences between patient and proxy utility scores (based on EQ-5D index and EQ VAS) were assessed with paired t-test at baseline and follow-up visits. No difference in mean EQ-5D index and EQ VAS between patient and proxy at baseline and visit two; however, at visit three significant difference was observed for EQ-5D index or EQ-VAS score with t (131) = -0.88, p = .01 and t (126) = -2.68, p = .008 respectively.

Table 6. Agreement in patient and proxy EQ-5D index and EQ-VAS scores in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

	Measures	**Patients mean (SD)**	**Proxymean (SD)**	**Patient and proxy difference mean (SD)**	**T**	**Df**	**P**
Baseline	EQ-5D index	0.17(0.03)	0.15(0.03)	0.02 (0.01)	1.32	199	0.19
	EQ VAS	57.5(1.21)	56.9(1.30)	0.57(0.85)	0.67	187	0.09
Visit 2	EQ-5D index	0.70 (0.02)	0.71(0.02)	-0.01(0.01)	-1.7	149	0.38
	EQ VAS	77.87(1.22)	79.3(1.2)	-1.43(0.57)	-2.51	142	0.5
Visit 3	EQ-5D index	0.82(0.02)	0.82(0.02)	-0.003(0.003)	-0.88	131	**0.01***
	EQ VAS	86.7(1.3)	87.64(1.26)	-0.91(0.34)	-2.68	126	**0.008***

**Significant at p<0.05; SD: Standard Deviation; df: degree of freedo; T: t-value*

Convergent validity analysis

The correlation coefficient of < 0.4 weak, 04-0.7 moderate, and above 0.7 were considered strong (Schober, Boer, & Schwarte, 2018). EQ-5D index reported by patients at baseline shows a strong correlation (r=0.88) with the EQ-5D index reported by proxies at baseline; however, moderate correlation was observed with EQ VAS score (r=0.7 patients and r=0.66 for caregiver). Both EQ VAS and EQ-5D index showed moderate to strong correlation with mRS score (**Table 7**).

Table 7. Convergent validity assessment (Pearson correlation) in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

Respondent		**Patient**			**Caregiver**			**Patient**			**Caregiver**			**Patient**		
	Measures	EQ5D1	EQ5D2	EQ5D3	EQ5D1	EQ5D2	EQ5D3	VAS1	VAS2	VAS3	VAS1	VAS2	VAS3	mRS1	mRS2	mRS3
Patient	EQ5D1	1														
	EQ5D2	0.67	1													
	EQ5D3	0.60	0.89	1												
Caregiver	EQ5D1	0.88	0.64	0.64	1											
	EQ5D2	0.65	0.97	0.90	0.65	1										
	EQ5D3	0.58	0.88	0.98	0.62	0.89	1									
Patient	VAS1	0.70	0.42	0.41	0.68	0.38	0.40	1								
	VAS2	0.67	0.82	0.76	0.64	0.79	0.76	0.64	1							
	VAS3	0.59	0.85	0.90	0.62	0.85	0.89	0.47	0.86	1						
Caregiver	VAS1	0.66	0.41	0.44	0.72	0.39	0.43	0.78	0.49	0.44	1					
	VAS2	0.61	0.83	0.80	0.63	0.82	0.80	0.57	0.89	0.86	0.63	1				
	VAS3	0.56	0.81	0.90	0.60	0.82	0.90	0.44	0.82	0.97	0.46	0.86	1			
Patient	mRS1	-0.79	-0.61	-0.59	-0.80	-0.60	-0.57	-0.68	-0.64	-0.55	-0.66	-0.64	-0.54	1		
	mRS2	-0.70	-0.83	-0.79	-0.72	-0.82	-0.77	-0.58	-0.83	-0.78	-0.57	-0.82	-0.76	0.73	1	
	mRS3	-0.62	-0.87	-0.87	-0.63	-0.85	-0.83	-0.46	-0.83	-0.85	-0.43	-0.85	-0.84	0.67	0.91	1

EQ-5D: EuroQol 5-Dimension; VAS: Visual analogue scale; mRS: modified rankin scale

Known group validity analysis

The mean difference among known groups, such as type of stroke, medication burden and severity of the stroke, were assessed to determine known group validity for the EQ-5D index. The mean utility based on the type of stroke was reported. A higher mean utility was observed in cardioembolic stroke than in ischemic and hemorrhagic stroke; however, the difference was not significant based on the type of stroke. A significant difference in mean utility was observed among clients with different stroke disability scores measured by mRs score.

Table 8. Known group validity assessment (One-way ANOVA test) in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

Patient characteristic		**Baseline**				**Visit 2**				**Visit3**			
		Patient reported Mean (SD)	P-value	Proxy reported Mean (SD)	P-value	Patient Mean (SD)	P-value	Proxy Mean (SD)	P-value	Patient Mean (SD)	P-value	Proxy Mean (SD)	P-value
Type of stroke	Ischemic	0.17(0.04)	0.54	0.13(0.05)	0.79	0.67(0.03)	0.44	0.69(0.31)	0.51	0.81(0.02)	0.45	0.80(0.02)	0.36
	Hemorrhagic	0.14(0.05)		0.16(0.05)		0.74(0.038)		0.75(0.04)		0.84(0.03)		0.86(0.03)	
	Cardioembolic	0.36(0.11)		0.26(0.13)		0.63(0.27)		0.63(0.27)		0.93(0.04)		0.92(0.05)	
Severity of stroke (mRs score)	1	0.93(0.01)	<0.001	0.92(0.01)	<0.001	0.94(0.01)	<0.001	0.94(0.01)	<0.001	0.96(0.01)	<0.001	0.97(0.004)	<0.001*
	2	0.75(0.02)		0.70(0.36)		0.88(0.01)		0.89(0.01)		0.91(0.01)		0.91(0.007)	
	3	0.51(0.04)		0.58(0.05)		0.79(0.02)		0.79(0.02)		0.82(0.02)		0.82(0.02)	
	4	0.05(0.04)		0.04(0.03)		0.35(0.02)		0.38(0.03)		0.48(0.02)		0.48(0.03)	
	5	-0.21(0.04)		-0.28(0.04)		-0.06(0.1)		-0.07(0.1)		0.09		0.09	
Comorbid	HTN	0.19(0.04)	0.80	0.16(0.04)	0.86	0.73(0.03)	0.25	0.73(0.03)	0.028	0.82(0.02)	0.48	0.82(0.03)	0.055
	DM	0.12(0.08)		0.14(0.08)		0.63(0.06)		0.65(0.06)		0.79(0.05)		0.80(0.04)	
	CHF	0.11(0.11)		0.07(0.14)		0.70(0.08)		0.71(0.09)		0.91(0.03)		0.91(0.03)	
	Others*	0.19(0.24)		0.003(0.24)		0.91(0.05)		0.93(0.04)		0.95(0.03)		0.96(0.02)	
Number of medications	<=3	0.26(0.05)	0.02	0.27(0.05)	<0.001	0.74(0.03)	0.33	0.75(0.03)	0.32	0.86(0.02)	0.16	0.87(0.02)	0.13
	3-5	0.14(0.05)		0.09(0.05)		0.66(0.04)		0.67(0.04)		0.79(0.03)		0.78(0.03)	
	>5	0.01(0.08)		-0.001(0.09)		0.66(0.06)		0.68(0.06)		0.80(0.05)		0.80(0.06)	

CHF: Congestive Heart Failure; DM: Diabetes Mellitus; HTN: Hypertension; SD: Standard Deviation

5.6. Feasibility

The feasibility of completing the questionnaire for the client and administering the questionnaire for data collectors was measured on a five-point scale: 5 (very easy), 4 (easy); 3 (neutral); 2 (difficult) and 1 (very difficult to complete or administer). Based on this scale, the data collector reported a better feasibility score on administering the questionnaire for the proxy caregiver than the patient. Compared to the baseline, improvement in feasibility was observed at visit two and visit three in administering or completing the questions.

Table 9. Feasibility of completing EQ-5D by respondents in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 200 patient/proxy dyads).

	Patients			**Caregivers**			**Data collector**					
Feasibility							Patients			Caregivers		
	Baseline (200)	Visit 2 (152)	Visit 3 (133)	Baseline	Visit 2	Visit 3	Baseline	Visit 2	Visit 3	Baseline	Visit2	Visit3
1	37(18.5)	1(0.7)	-	2(1)	-	-	29(14.5)	3(2)	1 (0.7)	1 (0.5)	-	-
2	81(40.5)	16(10.5)	10(7.5)	2(1)	-	-	77 (38.5)	43(28.3)	25 (18.8)	1 (0.5)	-	-
3	42(21)	47(30.9)	27(20.3)	6(3)	-	-	20(10)	6(4)	7 (5.3)	1 (0.5)	-	-
4	39(19.5)	76(50)	65(48.9)	110(55)	94 (61.8)	56 (42.11)	68(34)	80(52.6)	42 (31.6)	59 (29.5)	47 (30.9)	25 (18.8)
5	1(0.5)	12(7.9)	31(23.3)	80(40)	58 (38.2)	77 (57.89)	6(3)	20(13.2)	58 (43.6)	138 (69.0)	105 (69.1)	108 (81.2)
Mean (SD)	2.4 (0.07)	3.54(0.06)	3.88(0.07)	4.3(0.04)	4.38 (0.04)	4.58 (0.04)	2.73(0.08)	3.47(0.09)	3.98(0.10)	4.66(0.04)	4.69(0.04)	4.81(0.03)

SD: Standard Deviation

5.7. Qualitative analysis of participants reason to respond differently to the EQ-5D-5L and EQ-VAS questions

Characteristics of participants

The qualitative interviews were conducted with 15 patient-proxy dyads. Seven of the stroke patients were men and nine of the proxy caregivers were female. Eleven of the patients were with ischemic type of stroke (table 10).

Table 10. Characteristics of participants for the qualitative interview in six public hospitals in Addis Ababa, Ethiopia, from November 2021–November 2022 (n = 15atient/proxy dyads).

Characteristics		Patients (n)	Proxy caregivers (n)
Gender	Male	7	6
	Female	8	9
Age	<45	4	13
	45-64	9	2
	65-74	2	-
Marital status	Unmarried	2	6
	Married	9	9
	Divorced	2	-
	Widow	2	-
Education background	No formal education	4	2
	Primary education	5	4
	High school	3	2
	Technicaland vocational/college diploma	1	3
	Bachelor degree and above	2	4
Employment status	Employee	1	5
	Self-employed	2	6
	Retired	5	-
	Student	-	3
	Looking after home/family	7	1
Type of stroke	Hemorrhagic stroke	4	-
	Ischemic stroke	11	-

Major themes identified in the thematic analysis

Hence we observed differences in responses of patients and caregivers in determining the QOL of the patient at different time interviews, the qualitative analysis focused on identifying the reason for the differences between patients and caregivers responses for the same questions asked on descriptive profile of EQ-5D-5L and EQ-VAS about patient health status. Based on

participants response the major themes found from the qualitative data were 1) Feasibility of the questions (two sub themes emerged) and 2) Perceived disease impact (three sub themes emerged)

Theme 1. Feasibility of the questions

As shown from the finding of the quantitative result, EQ-5D-5L demonstrated good feasibility. This finding was further supported by qualitative findings**.** Majority of respondents say the questions were easy to respond/comprehend and fewer respondents stated it was challenging. Different reasons were raised by participants for their easiness or difficulty of completing the interview. These reasons were categorized as subthemes of the main them "Feasibility of the questions" and discussed as follow:

Subtheme 1a. Clarity of the questions

Most respondents stated that the questions in the tool were understandable and good in describing the health condition of the patient, which they were able to grade with ease. The participants asserted the following regarding how well the questions related to the patient's health status:

> *The questions are easy and good since the health conditions are clearly visible on me (PT-2).*
>
> *By searching more about the disease symptoms on Google, I was able to easily understand what he experienced so that responding to the questions was not difficult by matching his health state condition with what I read on Google and what I observed (CG-2).*

Despite the fact that the majority of participants said rating on the EQ-5D-5L was simple for them, rating on the EQ-VAS domain was a little more challenging. Participants reported having difficulty evaluating due to cognitive difficulty, the question's ambiguity, a lack of clarity, etc. These are a few ideas directly taken from participants:

> *Putting numbers on the ruler was difficult and knowing what is moderate, what is slight was somehow confusing (PT-1).*
>
> *The five questions are easy since they have alternatives to choose but the number scoring part is confusing because it is difficult to express a person's health state with a number as it has no range on the numbering score part and randomly putting one number is*

difficult (CG-12).

Subtheme 1b: Health states imagination

Caregivers reported challenges in envisioning patients' health states as caregivers, relying on observation and patient communication; however, they were uncertain due to their lack of personal experience with the condition. Regarding these caregivers claimed that:

> *The health state of the patient is better determined by himself here; I am imagining his health condition from what I observed and from what I have asked him. Again, it is hard to answer the questions accurately (CG-14).*
>
> *While some questions, such as mobility, may be answered by observation, others, such as depression and pain, particularly the scoring number in the ruler-like object, are more difficult to answer because I do not directly experience the sickness (CG-8).*

Theme 2. Perceived disease impact

Subtheme 2a: Temporal health comparisons

It was discovered that the difference in responses between patients and caregivers was caused by comparing the patients' current health status using different point times as a benchmark. Participants used the patient's prior experiences before the stroke and health status at admission as a reference for their assessments. The quotes below exemplified the discrepancies occurred when caregivers referencing the patient's earlier experiences before the stroke for their assessment:

> *My wife's responses, in my opinion, are exaggerated because everyone in my family contrasts my current state of health with my previous state. My family is quite concerned to see me in this condition of health in the house after a stroke since before the disease; I was such a tireless man without rest that they never saw me in the house without any activity (PT-5).*
>
> *I said that she has a severe problem with walking, seeing that her leg is swollen and she is unable to walk perfectly. Before this disease, she was able to move without difficulty, but now she can't keep her balance if she doesn't put her one hand in the pocket of her clothes, and she also has problems with her one hand (CG-13).*

The qualitative finding also revealed that the reason for discrepancy of ratings between patients and caregivers was using the first admission functionality state of the patient as reference point of comparison. To this end participants stated as follows:

> *Compared to the first time I was completely under the control of my caregivers, my health has improved (PT- 5)*

> *I rated her moderate on her walking ability and functioning at her usual work because her condition is not the same as when you see it at first admission with her current health state, and there is an improvement. For example, she can walk by herself from the salon to the toilet, so I think this is progress. Overall, I am answering the questions comparing her current health state with her health state at her first admission (CG-7).*

Subtheme 2b: Adaptive patient responses

Stroke patients demonstrated remarkable adaptability in facing challenges, engaging in health-promoting activities, and maintaining a realistic view of their condition. Caregivers, in contrast, often held unrealistic expectations. This contrast is evident through provided patient quotes:

> *Given my faith in Allah and my efforts to reduce stress by interacting with those around me, I am not overly concerned about my pain. I am also doing what the doctors instructed me to do, such as participating in physiotherapy and attempting things on my own (PT-5).*

> *I don't feel depressed since I always keep myself occupied by watching movies or going for walks. I've accepted my situation, and I'm grateful for everything that happens. In order to lessen the stress brought on by the condition, I also started to engage in homework tasks like cooking and cleaning, which are good for my psychology (PT-4).*

With regard to patients' thoughts on taking their current health condition as normal and unrelated with stroke, participants asserted that:

> *My desire not to stay here for a long time is not related to the disease as my family assumed it to be that I am worried. The reason why they feel as though I am in pain is also that I have no appetite, but the reason for my lack of appetite is that I am fasting like I did before the stroke; it is nothing new (PT-2).*

Subtheme 2c: Caregiver burden

The qualitative finding of the interview suggests that proxy caregiving burden results in discordance between patient and proxy report, most commonly in the direction of over ratings of patients' health status. The following quotes taken from caregivers exemplified it:

> *He is unable to dress or wash himself, and I am the one who always washes or dresses him. You can also imagine how he can dress or wash if his right hand and leg are not functioning well. I also believe that he has severe problems with his usual activities, as he is not currently doing anything without support (CG- 5).*
>
> *My response to his walking ability is moderate since he is not able to walk by himself and feels uncomfortable or dizzy if we don't support him with walking. I rated his condition on self-care activities as severe since he is not able to dress and wash himself without support. For instance, he cannot wash himself standing up if he doesn't sit on a chair; he can only wash his face without support since his one hand is functioning well, and still we are helping him with washing and dressing (CG-2).*

According to the interview with caregivers, worry or fear as a family creates the discrepancy in ratings. This idea was also shared by patients. With respect to psychological distress of caregivers' impact on the agreement between patient and proxy, one caregiver stated that:

> *I responded severely to the question asked on usual activity. Although she has made progress since the first time, there are still issues. For example, she was a merchant prior to the stroke, but now she quit her job due to her difficulty (she can't go long distances because she may feel dizzy and fall), and even at home, all family members don't believe she is ok and we constantly pay attention to her (CG-10).*

In conformity to the above statement, patients also asserted about the tendency of caregivers to relate every activity of the patient with stroke disease which creates fear and stress on caregivers. To this end, patients support the idea of psychological distress effect as follows:

> *My families asked me about my health condition repeatedly, as they don't believe I am fine, and my always-repeated answer was that I am in good health. Before the disease, they didn't pay attention to my state, but now that I've had a stroke, they always pay attention to every activity of mine, and that is the reason for their increased imagination of my health state (PT-8).*

To emphasize the impact of caregivers' worry and fear in the discrepancy of answers, patients claimed that after their illness, caregivers started to give more attention to them. Regarding caregivers' concerns one patient reported that:

> *My mom rated me as having a severe problem regarding anxiety because she is comparing my current health status with my previous condition. She expects me to be happy and to laugh all the time. My mom rated many of the questions as severe, as she has the heart of a mother and has a fear of losing me like my other three sisters, and I am her only daughter left now (PT- 13).*

Additionally, caregivers thought that patients can conceal their emotions in order to not bother them, and patients also concur with this notion in an effort to avoid presenting themselves as a burden to others. The extract below speaks the participants' thought on concealing of their emotions:

> *I usually didn't tell her all my feelings and the pain that I experienced, not to bother her or make her worry about me. She is always worried about everything that I experience; even if I make normal sounds, she thinks that I am suffering a lot or that I am groaning. So I wanted her to be comfortable by telling her that I was fine (PT-4).*
>
> *I suspected that she is hiding from me about her health condition by telling me that she is fine in order to make me unworried and that is why I overrated her health condition (CG-1).*

6. Discussion

This study is the first evaluation of the EQ-5D-5L's psychometric attributes, viability, and value for Ethiopian stroke patients, as well as delves into divergent patient-proxy responses on the EQ-5D-5L profile and EQ-VAS scores. Findings underscore the EQ-5D-5L's reliability and validity for gauging the HRQoL among stroke patients in Ethiopia.

The distribution pattern of responses on EQ-5D-5L dimensions was similar for patients and their proxies at baseline and follow up visits, with a higher frequency of problems on the UA and MO dimensions and a relatively lower frequency of problem reports on the A/D and P/D dimensions. These reports were consistent with other studies in which reported health impairements among stroke patients were severe in MO and UA dimensions (Chen et al., 2016; Golicki et al., 2015).

This study also looked at agreement between patients with stroke and their proxies on the EQ-5D-5L overtime. The results of this study suggest that proxy assessments obtained 3 and 6 months after stroke are more reliable than those obtained at admission in which proxy caregivers can provide information on patients who had limited ability to self-assess HRQoL after stroke. It has practical implications to determine if patient self-assessment may be reliably replaced by proxy evaluations in assessments of HRQoL. It was expected that agreement based on kappa was good for the more observable dimensions (MO=0.69, SC=0.62) and poor for the less visible dimensions (P/D=0.32, A/D=0.43) at baseline. In all cases, an improved agreement was observed in visits two and three compared to the baseline report. This result was also comparable with the study conducted in Edmonton which reported agreement based on κ was good for MO and SC and poor for the P/D and A/D dimensions at baseline and agreement generally improved at the 6-month follow-up (Pickard et al., 2004). Other studies of patient-proxy assessments also found that Agreement is somewhat lower in more subjective dimensions and slightly greater in more objective domains like physical functioning (Duncan et al., 2002; Lapin, Thompson, Schuster, & Katzan, 2021; Magaziner, Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997; Neumann, Araki, & Gutterman, 2000; Novella et al., 2001; K. C. Sneeuw, Sprangers, M. A. ., & Aaronson, N. K., 2002; Tooth, McKenna, & Smith, 2003; Williams et al., 2006). Although we assume that patient report takes precedence in patients who are able to report for themselves, it is also feasible that the viewpoints of caregivers may complement rather than replace or substitute for self-report.

Overall, the findings of this study support the use of proxy reports to facilitate healthcare decision-making relevant to stroke patients.

This study demonstrated that the internal consistency of the five dimensions EQ-5D-5L was excellent (chronbach's alpha=0.86, 0.92 and 0.93) at baseline, Visit 1 and visit 2 respectively. This showed that the EQ-5D-5L met the general accepted standards of internal consistency (Leidy et al., 1999) ensuring that each items on EQ-5D-5L are correlated with eachother and indicates that the tool is reliable to assess the stroke patient's HRQoL. The finding was comparable to the research that was conducted in Netherland (Cronbach's alpha=0.75) (de Graaf, Kuijpers, Visser-Meily, Kappelle, & Post, 2020).

Most of the literature reviewed on the EQ-5D-5L compares it with other generic and specific measurements used to assess stroke patients' QOL (Golicki et al., 2015; Janssen et al., 2013; Sakthong, Sonsa-Ardjit, Sukarnjanaset, & Munpan, 2015). The present study demonstrated the correlation of the tool using pearson correlation coefficient in which the EQ-5D-5L has demonstrated convergent validty by correlating with stroke severity measurement and EQ-VAS. Based on the findings both patients or proxy caregivers reported EQ VAS and EQ-5D-5L index showed moderate to strong correlation with with external severity measures for stroke disability (mRS). The finding is congruent with the finding of the study conducted in Poland where moderate to strong correlations were detected between EQ-5D-5L and mRS (Golicki et al., 2015) and with (de Graaf et al., 2020) where strong correlations was found. The result shows that the parameters of EQ-5D-5L have measured the relevant constructs in the similar manner as that of mRS scores proving its construct validity. This indicates that HRQoL data gathered using EQ-5D has a meaningful implication to demonstrate health outcome/clinical progress happened on the stroke patients from a health care provided from a health professional or care settings.

In our study, one-way ANOVA analysis on difference of scores showed that no statistically significant variations were found between groups based on type of stroke, comorbid disease condition and number of medications. This finding is congruent to the finding of a study conducted in Edmonton which showed that there were no observed statistically significant differences among groups based on stroke subtype (Pickard et al., 2004). A known-group validity has been observed based on the known severity group of strokes based on mRS scores

which is similar to the study conducted in Poland where EQ-5D-5L index-based scores were lower in patients with high mRS score (Golicki et al., 2015). These findings indicate a good construct validity for the EQ-5D-5L index, in which, the tool, presented a greater discriminant capacity in distinguishing people with different mRS scores.

The judgement of patients, proxies and data collectors was considered to assess the feasibility. Compared to the baseline, both patients and proxies reported that completing EQ-5D-5L questions is easier at follow up visits. Similarly, for data collectors, administering EQ-5D-5L was easier at follow up visits. Furthermore, data collectors reported that administering EQ-5D to the proxy was more feasible than administering the questionnaires to the patient. Based on the findings of this study, for patients in an emergency setting or acute stroke attack who have difficulties in completing patient reported outcomes, data from their proxies would facilitate a healthcare decision. The proxy based EQ-5D-5L data was found to be reliable and valid in indicating the health status of patients. In comparison to patients, completing or administering the EQ-5D-5L was more practical in a proxy, and in terms of interview time compared to admission, follow up time is more feasible in both patient and proxies. In an emergency or hospital admission where patients are unable to complete HRQoL data, information from proxy may be useful in making a healthcare decision concerning the patient in a resource-constrained setting.

The study's qualitative findings revealed the viewpoints of the patients and their proxy regarding the underlying reasons of the disparities in HRQoL reporting on the EQ-5D-5L descriptive profile between patients and their proxy. Thoughts related to feasibility of the questions and perceived disease impact was stated as a reason for discrepancies in which patients tried to cope with the situation.

The majority of participants indicated that the EQ-5D-5L is more straightforward and uncomplicated based on qualitative findings on the feasibility of the questions, and difficulties were reported when completing the VAS, indicating that there is potential for future improvement of its presentation and instruction. Participants also reported that while imagining for more objective domains was simple, estimating the patients' state of health for subjective

domains was challenging. This claim is consistent with the quantitative analysis of our study that there was less agreement between patient and proxy for the A/D and P/D domain.

Patients' adaptation with the new reality was demonstrated as the possible reason for difference in rating in which QOL values change over time and is influenced by psychological factors such as adaptation and coping. This finding is supported by the Theory of Cognitive Adaptation, which states that humans deal with dangers in their lives by generating a network of optimistic illusions that safeguard their psychological health. According to research findings, a serious illness may alter the value attached to certain life domains. Patients who have been diagnosed with a serious illness may have gone through a lot of bad things. Since they may use a more negative situation as their point of comparison when making judgments about new situations (Michelson, 2002; Wettergren, 2002). This theory was also advanced in our qualitative investigation, which revealed that patients frequently contrast their current health status with their initial functional level when being admitted to the hospital.

Different literatures illustrated that observed discrepancies between patient and proxy assessments should not be taken as proof that the proxy data is inaccurate or biased (Essen, 2004; K. C. Sneeuw et al., 1997; K. C. Sneeuw, Sprangers, & Aaronson, 2002). Patients' own assessments are frequently used as the benchmark to which proxy ratings should adhere. However, patient ratings are not completely reliable; just like proxy ratings, patients' self-reports are also susceptible to a variety of biases due to different reasons (G. Kempen et al., 1996; G. I. Kempen, Jelicic, & Ormel, 1997; Magaziner et al., 1997). For instance, based on our qualitative finding of the study, Patients may downplay their troubles or symptoms in order not to appear to be an added stress to others. In addition, the value of patients' self-report may be questioned in diseases affecting the brain, when patients may lack the cognitive capacity to appropriately interpret the questions at a given point in time (Naci, Sinai, & Owen, 2017; K. C. Sneeuw et al., 2002). This idea was shared by other studies (Long, Sudha, & Mutran, 1998; Robertson et al., 2017; Rothman, Hedrick, Bulcroft, Hickam, & Rubenstein, 1991; Williams et al., 2006). In light of the importance of proxy information for stroke patients whose capacity for self-reporting is compromised, the qualitative results further demonstrated the value of proxy evaluations in HRQoL research.

7. Strength and limitations of the study

7.1. Strength of the study

This study is the first one to assess the psychometric properties, feasibility and usefulness of EQ-5D-5L in the context of an acute onset stroke and by following up patients and their proxy respondents in Ethiopia using a mixed study approach. It is also the pioneer study to explore the reason for the difference in responses between patient and proxy caregivers for EQ-5D-5L descriptive profile and EQ-VAS scores. Our study also uses recommended sample size for assessment of psychometric properties of a tool. In addition the study suggested that the EQ-5D data collected from the proxy caregiver of a stroke patient is in substantial agreement with the values reported by patients and this could support the use of proxy reports to facilitate healthcare decision-making relevant to stroke patients which was not examined in any of studies in Ethiopia before.

7.2. Limitation of the study

The study had some limitations in that the feasibility and psychometric properties of EQ-5D-5L were not assessed in critically ill stroke patients. Additionally, most of the follow-up interviews were conducted by telephone, which allowed discussion among patients and proxy caregivers which might introduce bias. Another limitation of the study was that it was conducted only using the Amharic version of the tool, which may affect the generalizability of the results of the study to other cultures as there are language variations in our country, Ethiopia.

8. Conclusion

The findings of this study demonstrated that EQ-5D-5L has confirmed reliability and validity in assessing HRQoL among stroke patients at acute phase and follow-up basis. Based on the findings of this study, Compared to the baseline, both patients and proxies reported that completing EQ-5D-5L questions is easier at follow up visits therefore for patients in an emergency setting or acute stroke attack who have difficulty completing patient reported outcomes, data from their proxy would facilitate a healthcare decision. The qualitative findings of this study revealed that feasibility of questions and perceived disease impact by participants had an effect on the discrepancy of ratings between patient and proxy caregivers.

9. Recommendation

We provide the following suggestions to practitioners, potential researchers and policy makers.

- ✓ It is suggested to use the EQ-5D-5L assessment tool as measurement of stroke patient's HRQoL since it is feasible to administer and has acceptable psychometric properties.
- ✓ Clinicians can use EQ-5D-5L data from patient proxy caregivers to demonstrate the patient’s health outcome.
- ✓ Researchers would be encouraged to conduct further research on the performance of the EQ-5D-5L in different cultural settings in the different parts of the country.
- ✓ Researchers and policy makers can use the utility index generated by this study as an input to conduct cost-utility analysis for stroke patients.

References

Abate, T. W., Zeleke, B., Genanew, A., & Abate, B. W. J. P. o. (2021). The burden of stroke and modifiable risk factors in Ethiopia: A systemic review and meta-analysis. *16*(11), e0259244.

Aho, K., Harmsen, P., Hatano, S., Marquardsen, J., Smirnov, V. E., & Strasser, T. J. B. o. t. W. H. O. (1980). Cerebrovascular disease in the community: results of a WHO collaborative study. *58*(1), 113.

Ali, S., Misganaw, A., Worku, A., Destaw, Z., Negash, L., Bekele, A., . . . Odell, C. J. I. H. (2021). The burden of cardiovascular diseases in Ethiopia from 1990 to 2017: evidence from the Global Burden of Disease Study. *13*(4), 318-326.

Avan, A., Digaleh, H., Di Napoli, M., Stranges, S., Behrouz, R., Shojaeianbabaei, G., . . . Spence, J. D. J. B. m. (2019). Socioeconomic status and stroke incidence, prevalence, mortality, and worldwide burden: an ecological analysis from the Global Burden of Disease Study 2017. *17*(1), 1-30.

Bansback, N., Sun, H., Guh, D. P., Li, X., Nosyk, B., Griffin, S., . . . Anis, A. H. J. H. e. (2008). Impact of the recall period on measuring health utilities for acute events. *17*(12), 1413-1419.

Bergner, M., Bobbit, R. A., Carter, W. B., Gilson, B. S., & White, K. L. (1992). The sickness impact profile: Development and final revision of a health status measure. In *Health services research: An anthology* (pp. 718-734).

Berzon, R., Donnelly, M., Simpson, R., Simeon, G., & Tilson, H. J. Q. o. L. R. (1995). Quality of life bibliography and indexes: 1994 update. *4*, 547-569.

Bowling, A. (2001). *Measuring disease*: Buckingham: Open University Press.

Brodin, N., Lohela-Karlsson, M., Swärdh, E., Opava, C. H. J. D., & Rehabilitation. (2015). Cost-effectiveness of a one-year coaching program for healthy physical activity in early rheumatoid arthritis. *37*(9), 757-762.

Campbell, B. C., Mitchell, P. J., Kleinig, T. J., Dewey, H. M., Churilov, L., Yassi, N., . . . Oxley, T. J. J. N. E. J. o. M. (2015). Endovascular therapy for ischemic stroke with perfusion-imaging selection. *372*(11), 1009-1018.

Chen, P., Lin, K.-C., Liing, R.-J., Wu, C.-Y., Chen, C.-L., & Chang, K.-C. J. Q. o. l. r. (2016). Validity, responsiveness, and minimal clinically important difference of EQ-5D-5L in

stroke patients undergoing rehabilitation. *25*, 1585-1596.

Clarke, P., Marshall, V., Black, S. E., & Colantonio, A. J. S. (2002). Well-being after stroke in Canadian seniors: findings from the Canadian Study of Health and Aging. *33*(4), 1016-1021.

Coons, S. J., Rao, S., Keininger, D. L., & Hays, R. D. J. P. (2000). A comparative review of generic quality-of-life instruments. *17*, 13-35.

de Graaf, J. A., Kuijpers, M. M., Visser-Meily, J. M., Kappelle, L. J., & Post, M. W. J. C. R. (2020). Validity of an enhanced EQ-5D-5L measure with an added cognitive dimension in patients with stroke. *34*(4), 545-550.

Delcourt, C., Zheng, D., Chen, X., Hackett, M., Arima, H., Hata, J., . . . Psychiatry. (2017). Associations with health-related quality of life after intracerebral haemorrhage: pooled analysis of INTERACT studies. *88*(1), 70-75.

DH, F. J. Q. o. l., & trials, p. i. c. (1996). Health utilities index. 239-252.

Dhamoon, M., Moon, Y., Paik, M., Boden-Albala, B., Rundek, T., Sacco, R., & Elkind, M. J. N. (2010). Quality of life declines after first ischemic stroke: The Northern Manhattan Study. *75*(4), 328-334.

Doyle, P. J., McNeil, M. R., Mikolic, J. M., Prieto, L., Hula, W. D., Lustig, A. P., . . . Elman, R. J. J. J. o. C. E. (2004). The Burden of Stroke Scale (BOSS) provides valid and reliable score estimates of functioning and well-being in stroke survivors with and without communication disorders. *57*(10), 997-1007.

Duncan, P. W., Lai, S. M., Tyler, D., Perera, S., Reker, D. M., & Studenski, S. J. S. (2002). Evaluation of proxy responses to the Stroke Impact Scale. *33*(11), 2593-2599.

Duncan, P. W., Wallace, D., Lai, S. M., Johnson, D., Embretson, S., & Laster, L. J. J. S. (1999). The stroke impact scale version 2.0: evaluation of reliability, validity, and sensitivity to change. *30*(10), 2131-2140.

Ernstsson, O., Hagberg, K., Janssen, M. F., Bonsel, G. J., Korkmaz, S., Zethraeus, N., . . . Rehabilitation. (2022). Health-related quality of life in patients with lower limb amputation–an assessment of the measurement properties of EQ-5D-3L and EQ-5D-5L using data from the Swedish Amputation and Prosthetics Registry. *44*(26), 8471-8479.

Essen, L. v. J. A. o. (2004). Proxy ratings of patient quality of life Factors related to patient–proxy agreement. *43*(3), 229-234.

EuroQol. (1990). EuroQol-a new facility for the measurement of health-related quality of life. *16*(3), 199-208.

EuroQol. (2021). EQ-5D. .

Feigin, V. L., Brainin, M., Norrving, B., Martins, S., Sacco, R. L., Hacke, W., . . . Lindsay, P. J. I. J. o. S. (2022). World Stroke Organization (WSO): global stroke fact sheet 2022. *17*(1), 18-29.

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., . . . Truelsen, T. J. T. l. (2014). Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. *383*(9913), 245-255.

Fekadu, G., Adola, B., Mosisa, G., Shibiru, T., & Chelkeba, L. J. J. o. C. N. (2020). Clinical characteristics and treatment outcomes among stroke patients hospitalized to Nekemte referral hospital, western Ethiopia. *71*, 170-176.

Feng, Y.-S., Kohlmann, T., Janssen, M. F., & Buchholz, I. J. Q. o. L. R. (2021). Psychometric properties of the EQ-5D-5L: a systematic review of the literature. *30*, 647-673.

Gebremariam, S. A., & Yang, H. S. J. E. (2016). Types, risk profiles, and outcomes of stroke patients in a tertiary teaching hospital in northern Ethiopia. *3*, 41-47.

Golicki, D., Niewada, M., Buczek, J., Karlińska, A., Kobayashi, A., Janssen, M., & Pickard, A. S. J. Q. o. l. r. (2015). Validity of EQ-5D-5L in stroke. *24*, 845-850.

Golomb, B. A., Vickrey, B. G., & Hays, R. D. J. P. (2001). A review of health-related quality-of-life measures in stroke. *19*, 155-185.

Gorelick, P. B. J. T. L. N. (2019). The global burden of stroke: persistent and disabling. *18*(5), 417-418.

Greffie, E. S., Mitiku, T., & Getahun, S. J. C. M. R. (2015). Risk factors, clinical pattern and outcome of stroke in a referral hospital, Northwest Ethiopia. *4*(6), 182-188.

Haacke, C., Althaus, A., Spottke, A., Siebert, U., Back, T., & Dodel, R. J. S. (2006). Long-term outcome after stroke: evaluating health-related quality of life using utility measurements. *37*(1), 193-198.

Harwood, R. H., Gompertz, P., Ebrahim, S. J. J. o. N., Neurosurgery, & Psychiatry. (1994). Handicap one year after a stroke: validity of a new scale. *57*(7), 825-829.

Hunger, M., Sabariego, C., Stollenwerk, B., Cieza, A., & Leidl, R. J. Q. o. L. R. (2012). Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing

rehabilitation. *21*, 1205-1216.

Hunt, S. M., McEwen, J., & McKenna, S. P. (1986). *Measuring health status*: Croom Helm London.

Janssen, M., Pickard, A. S., Golicki, D., Gudex, C., Niewada, M., Scalone, L., . . . Busschbach, J. J. Q. o. l. r. (2013). Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *22*, 1717-1727.

Jönsson, A.-C., Delavaran, H., Iwarsson, S., Ståhl, A., Norrving, B., & Lindgren, A. J. S. (2014). Functional status and patient-reported outcome 10 years after stroke: the Lund Stroke Register. *45*(6), 1784-1790.

Katona, M., Schmidt, R., Schupp, W., Graessel, E. J. H., & outcomes, q. o. l. (2015). Predictors of health-related quality of life in stroke patients after neurological inpatient rehabilitation: a prospective study. *13*(1), 1-7.

Kempen, G., Heuvelen, M. v., Brink, R. v. d., Kooijman, A., Klein, M., Houx, P., . . . Ageing. (1996). Factors affecting contrasting results between self-reported and performance-based levels of physical limitations. *25*(6), 458-464.

Kempen, G. I., Jelicic, M., & Ormel, J. J. H. P. (1997). Personality, chronic medical morbidity, and health-related quality of life among older persons. *16*(6), 539.

Kim, J., Thayabaranathan, T., Donnan, G. A., Howard, G., Howard, V. J., Rothwell, P. M., . . . Pandian, J. J. I. J. o. S. (2020). Global stroke statistics 2019. *15*(8), 819-838.

Lapin, B. R., Thompson, N. R., Schuster, A., & Katzan, I. L. J. J. o. P.-R. O. (2021). Patient-proxy agreement on change in acute stroke patient-reported outcome measures: a prospective study. *5*, 1-7.

Leidy, N. K., Revicki, D. A., & Genesté, B. J. V. i. H. (1999). Recommendations for evaluating the validity of quality of life claims for labeling and promotion. *2*(2), 113-127.

Lin, F.-J., Longworth, L., & Pickard, A. S. J. Q. o. L. R. (2013). Evaluation of content on EQ-5D as compared to disease-specific utility measures. *22*, 853-874.

Lloyd-Jones, D., Adams, R., Carnethon, M., De Simone, G., Ferguson, T. B., Flegal, K., . . . Circulation, S. S. S. (2009). American heart association statistics committee and stroke statistics subcommittee. *119*(3), 480-486.

Long, K., Sudha, S., & Mutran, E. J. J. J. o. t. A. G. S. (1998). Elder-proxy agreement concerning the functional status and medical history of the older person: The impact of

caregiver burden and depressive symptomatology. *46*(9), 1103-1111.

Longworth, L., Yang, Y., Young, T., Mulhern, B., Hernández Alava, M., Mukuria, C., . . . Evans, P. J. H. T. A. (2014). Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey.

Luengo-Fernandez, R., Gray, A. M., Bull, L., Welch, S., Cuthbertson, F., & Rothwell, P. M. J. N. (2013). Quality of life after TIA and stroke: ten-year results of the Oxford Vascular Study. *81*(18), 1588-1595.

Magaziner, J., Zimmerman, S. I., Gruber-Baldini, A. L., Hebel, J. R., & Fox, K. M. J. A. j. o. e. (1997). Proxy reporting in five areas of functional status: comparison with self-reports and observations of performance. *146*(5), 418-428.

McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia Medica, 22(3)*, 276-282.

Michelson, H. (2002). *Long term health-related quality of life among women with high-risk breast cancer receiving adjuvant high-dose chemotherapy: a comparison with the normal population*: Institutionen för onkologi-patologi/Department of Oncology-Pathology.

Mulat, B., Mohammed, J., Yeseni, M., Alamirew, M., Dermello, M., & Asemahagn, M. A. J. E. J. o. H. D. (2016). Magnitude of stroke and associated factors among patients who attended the medical ward of Felege Hiwot Referral Hospital, Bahir Dar town, Northwest Ethiopia. *30*(3), 129-134.

Mulatu, G. (2017). *Types and Associated Factor of Stroke at Selected Public Referral Hospitals in Addis Ababa; Ethiopia.* Addis Ababa University,

Naci, L., Sinai, L., & Owen, A. M. J. N. (2017). Detecting and interpreting conscious experiences in behaviorally non-responsive patients. *145*, 304-313.

Neumann, P. J., Araki, S. S., & Gutterman, E. M. J. J. o. t. A. G. S. (2000). The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. *48*(12), 1646-1654.

Norrving, B., & Mensah, G. J. C. R. (2017). Global burden of stroke. *120*(3), 439-448.

Novella, J., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F., & Blanchard, F. J. Q. o. l. r. (2001). Agreement between patients' and proxies' reports of quality of lifein Alzheimer's

disease. *10*, 443-452.

Oczkowski, C., O'Donnell, M. J. J. o. S., & Diseases, C. (2010). Reliability of proxy respondents for patients with stroke: a systematic review. *19*(5), 410-416.

Owolabi, M. O., Arulogun, O., Melikam, S., Adeoye, A. M., Akarolo-Anthony, S., Akinyemi, R., . . . Jenkins, C. J. C. j. o. A. (2015). The burden of stroke in Africa: a glance at the present and a glimpse into the future. *26*(2 H3Africa Suppl), S27.

Petrou, S., & Hockley, C. J. H. e. (2005). An investigation into the empirical validity of the EQ-5D and SF-6D based on hypothetical preferences in a general population. *14*(11), 1169-1189.

Pickard, A., Johnson, J., Feeny, D., Shuaib, A., Carriere, K., & Nasse, A. J. S. (2004). Agreement between self-and proxy assessment in stroke: a comparison of generic HRQL measures. *35*, 607-612.

Pinto, É. B., Maso, I., Vilela, R. N. R., Santos, L. C., & Oliveira-Filho, J. J. A. d. N.-p. (2011). Validation of the EuroQol quality of life questionnaire on stroke victims. *69*, 320-323.

Robertson, S., Cooper, C., Hoe, J., Hamilton, O., Stringer, A., & Livingston, G. J. I. p. (2017). Proxy rated quality of life of care home residents with dementia: a systematic review. *29*(4), 569-581.

Robinson-Smith, G., Johnston, M. V., Allen, J. J. A. o. p. m., & rehabilitation. (2000). Self-care self-efficacy, quality of life, and depression after stroke. *81*(4), 460-464.

Roger, V. L., Go, A. S., Lloyd-Jones, D. M., Adams, R. J., Berry, J. D., Brown, T. M., . . . Ford, E. S. J. C. (2011). Heart disease and stroke statistics—2011 update: a report from the American Heart Association. *123*(4), e18-e209.

Rothman, M. L., Hedrick, S. C., Bulcroft, K. A., Hickam, D. H., & Rubenstein, L. Z. J. M. c. (1991). The validity of proxy-generated scores as measures of patient health status. 115-124.

Russell, M., Dempster, M., & Donnelly, M. J. A. R. i. Q. o. L. (2011). Measuring health-related quality of life after stroke: a brief tool. *6*, 41-51.

Sacco, R. L., Kasner, S. E., Broderick, J. P., Caplan, L. R., Connors, J., Culebras, A., . . . Higashida, R. T. J. S. (2013). An updated definition of stroke for the 21st century: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *44*(7), 2064-2089.

Sakthong, P., Sonsa-Ardjit, N., Sukarnjanaset, P., & Munpan, W. J. Q. o. L. R. (2015). Psychometric properties of the EQ-5D-5L in Thai patients with chronic diseases. *24*, 3015-3022.

Salter, K., Hellings, C., Foley, N., & Teasell, R. J. J. o. r. m. (2008). The experience of living with stroke: a qualitative meta-synthesis. *40*(8), 595-602.

Schober, P., Boer, C., & Schwarte, L. A. (2018). Correlation coefficients: appropriate use and interpretation. *Anesthesia & Analgesia, 126*(5), 1763-1768.

Schweikert, B., Hahmann, H., & Leidl, R. J. H. (2006). Validation of the EuroQol questionnaire in cardiac rehabilitation. *92*(1), 62-67.

Sneeuw, K. C., Aaronson, N. K., Osoba, D., Muller, M. J., Hsu, M.-A., Yung, A., . . . Newlands, E. S. J. M. c. (1997). The use of significant others as proxy raters of the quality of life of patients with brain cancer. 490-506.

Sneeuw, K. C., Sprangers, M. A., & Aaronson, N. K. J. J. o. c. e. (2002). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *55*(11), 1130-1143.

Sneeuw, K. C., Sprangers, M. A. ., & Aaronson, N. K. (2002). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease *Journal of Clinical Epidemiology, 55(11),* 1130–1143. doi:10.1016/s0895-4356(02)00479-1

Strong, K., Mathers, C., & Bonita, R. J. T. L. N. (2007). Preventing stroke: saving lives around the world. *6*(2), 182-187.

Tian-hui, C., Lu, L., & Michael M, K. J. J. o. Z. U. S. B. (2005). A systematic review: how to choose appropriate health-related quality of life (HRQOL) measures in routine general practice? , *6*, 936-940.

Tooth, L. R., McKenna, K. T., & Smith, M. J. C. r. (2003). Further evidence for the agreement between patients with stroke and their proxies on the Frenchay Activities Index. *17*(6), 656-665.

Van Straten, A., De Haan, R., Limburg, M., Schuling, J., Bossuyt, P., & Van den Bos, G. J. S. (1997). A stroke-adapted 30-item version of the Sickness Impact Profile to assess quality of life (SA-SIP30). *28*(11), 2155-2161.

Ware Jr, J. E., & Sherbourne, C. D. J. M. c. (1992). The MOS 36-item short-form health survey

(SF-36): I. Conceptual framework and item selection. 473-483.

Webster, J. R., & Feinglass, J. J. J. (1997). Stroke patients, managed care, and distributive justice. *278*(2), 161-162.

Welie, A. G., Gebretekle, G. B., Stolk, E., Mukuria, C., Krahn, M. D., Enquoselassie, F., & Fenta, T. G. J. V. i. h. r. i. (2020). Valuing health state: an EQ-5D-5L value set for Ethiopians. *22*, 7-14.

Wettergren, L. (2002). *Quality of life in patients with malignant blood disorders: a clinical and methodological study*: Institutionen Neurobiologi, vårdvetenskap och samhälle/Neurobiology, Care ….

WHO. (2017). WORLD HEALTH RANKINGS.

Williams, L. S., Bakas, T., Brizendine, E., Plue, L., Tu, W., Hendrie, H., & Kroenke, K. J. S. (2006). How valid are family proxy assessments of stroke patients' health-related quality of life? , *37*(8), 2081-2085.

Williams, L. S., Weinberger, M., Harris, L. E., Clark, D. O., & Biller, J. J. S. (1999). Development of a stroke-specific quality of life scale. *30*(7), 1362-1369.

Zewdie, A., Debebe, F., Kebede, S., Azazh, A., Laytin, A., Pashmforoosh, G., & Hassen, G. W. J. A. J. o. E. M. (2018). Prospective assessment of patients with stroke in Tikur Anbessa specialised hospital, Addis Ababa, Ethiopia. *8*(1), 21-24.

Annex

Informed Consent Form

Study Title: Assessment of psychometric properties, feasibility and usefulness of the EQ-5D-5L in Ethiopian stroke patients

Introduction and study objective

I want to thank you for taking the time to meet with me today. My name is Ewennat Wehib and I am the principal investigator for the study. The study seeks to understand the use of a questionnaire, including questions about health (EQ- 5D-5L), to measure the quality of life in Ethiopian stroke patients. Your collaboration is valuable.

You will be asked to take part in an interview (approximately 15 minutes). Taking part in this study is completely voluntary. If you do consent to participate, you may withdraw at any time. Participation in this study or refusal to participate in the study has no influence on the services that you will receive from the health facility. In addition to the first interview, you will be invited to participate in two other interviews 3 months and 6 months after stroke. During the interviews, we was ask you some questions about you (e.g., your age), as well as questions about your health. You have the right not to answer any question if you do not feel comfortable answering them and you can withdraw from the study at any point. There aris no right or wrong answers to the questions.

Confidentiality

Your participation and all the information you provide was be confidential and we will not name you in any reports or publications. The completed surveys was be kept in a locked cabinet located at Addis Ababa University to which only the principal investigator and research team have access to. The non-identifiable data (without your name and contact details) was be entered electronically on a password protected computer. We was keep the data for a period of at least 5 years after final publication

Risks and benefit

Benefits include helping the research team to understand how to measure health-related quality of life. We do not think there are risks involved in taking part in this research. However, some participants may feel uncomfortable when asked to think about different aspects of their health. Although we believe the questions are unlikely to cause you to feel uncomfortable, if this did happen, we would to take a break from the interview and it is your choice to stop the interview entirely. If you do feel unsettled or upset during or after the interview, we encourage you to discuss this with your usual health care professional.

Who to contact

If you decide to participate in this interview and you have additional doubts or questions, you can communicate with the principal investigator at 0920577504

Verbal consent and agreement

If you would like to participate, please confirm that you understood everything I have told you about this study. Do you have any questions?

Agrees to participate	
Does NOT agree to participate	

I understand the study aims and objectives and have decided to allow the interview to go forward.

Name:	
Signature:	Day/Month/Year
Person Obtaining Consent:	
Name:	
Signature:	Day/Month/Year

SURVEY

Questions related to socio-demographic information. Please encircle the response option best describes you.

Background information	**Answers**
Gender	a. Male b. Female
Age [In years]	_____
Marital Status	a. Unmarried b. Married c. Divorced d. Widower/widow
Education	a. No formal education b. Primary education (1-8 Grade) c. High school (9-12 Grade) d. Technical and vocational training /college diploma e. Bachelor degree and above
Employment status	a. Employee b. Self-employed c. Retired d. Student e. Looking after home or family f. Other, please specify
In the last year, how well did your total household income meet your everyday needs for such things as accommodation, food, clothing and other necessities?	a. N~~ot en~~ough b. Enough c. More than enough

Checklist of clinical characteristics

This checklist aimed to collect clinical information of the patients from patients' medical records

1. Type of stroke	1. Hemorrhagic stroke 2. Ischemic stroke 3. Other, please specify ____
2. Comorbid condition	1. Congestive heart failure 2. Angina 3. Hypertension 4. Atrial fibrillation 5. Diabetes 6. Epilepsy 7. Hyperlipidemia 8. Other, please specify
3. Medications [List the name of medications the patient is currently on]	
4. Modified Rankin Scale (mRS)	

EQ-5D-5L

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems in walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g., work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

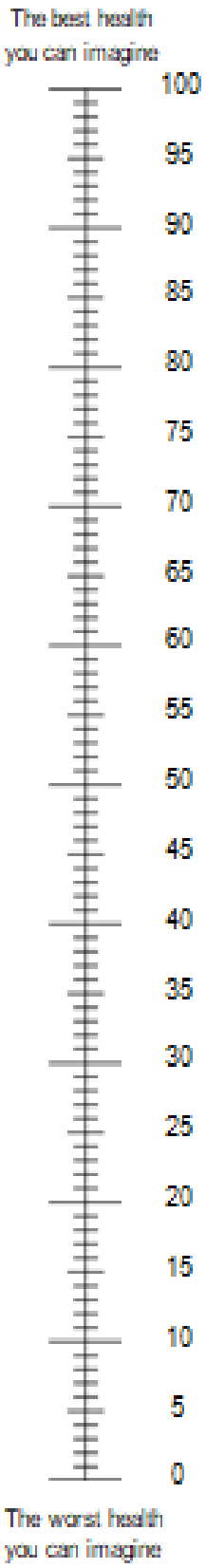
100 means the best health you can imagine.

0 means the worst health you can imagine.

Please mark an X on the scale to indicate how your health is TODAY.

Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



EQ-5D DESCRIPTIVE SYSTEM

First, I would like to ask you about MOBILITY. Would you say that:

1. You have no problems in walking about? ☐
2. You have slight problems in walking about? ☐
3. You have moderate problems in walking about? ☐
4. You have severe problems in walking about? ☐
5. You are unable to walk about? ☐

Next, I would like to ask you about SELF-CARE. Would you say that:

1. You have no problems washing or dressing yourself? ☐
2. You have slight problems washing or dressing yourself? ☐
3. You have moderate problems washing or dressing yourself? ☐
4. You have severe problems washing or dressing yourself? ☐
5. You are unable to wash or dress yourself? ☐

Next, I would like to ask you about USUAL ACTIVITIES, for example work, study, housework, family or leisure activities. Would you say that:

1. You have no problems doing your usual activities? ☐
2. You have slight problems doing your usual activities? ☐
3. You have moderate problems doing your usual activities? ☐
4. You have severe problems doing your usual activities? ☐
5. You are unable to do your usual activities? ☐

Next, I would like to ask you about PAIN OR DISCOMFORT. Would you say that:

1. You have no pain or discomfort? ☐
2. You have slight pain or discomfort? ☐
3. You have moderate pain or discomfort? ☐
4. You have severe pain or discomfort? ☐
5. You have extreme pain or discomfort? ☐

Finally, I would like to ask you about ANXIETY OR DEPRESSION. Would you say that:

1. You are not anxious or depressed? ☐
2. You are slightly anxious or depressed? ☐
3. You are moderately anxious or depressed? ☐
4. You are severely anxious or depressed? ☐
5. You are extremely anxious or depressed? ☐

EQ-5D VAS

Now, I would like to ask you to say how good or bad your health is TODAY.

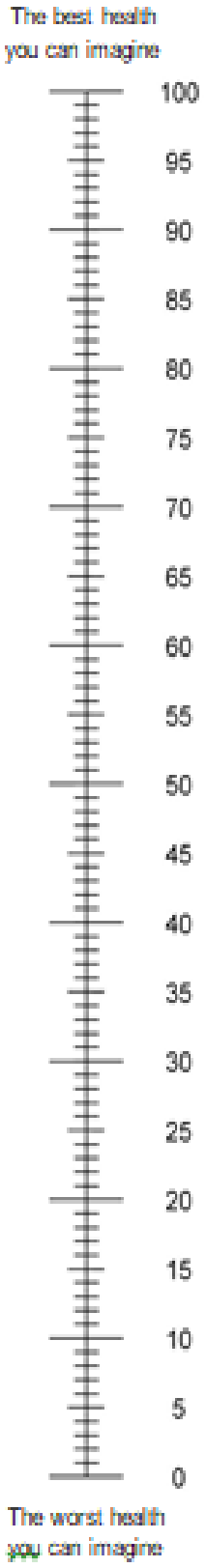
I would like you to picture in your mind a vertical line that is numbered from 0 to 100.
(Note to interviewer: if interviewing face-to-face, please show the respondent the VAS line.)

100 at the top of the line means the best health you can imagine.

0 at the bottom of the line means the worst health you can imagine.

I would now like you to tell me the point on this line where you would put your health TODAY.
(Note to interviewer: mark the line at the point indicating the respondent's health today. Now, please write the number you marked on the line in the box below.)

THE RESPONDENT'S HEALTH TODAY = ☐



Thank you for taking the time to answer these questions.

EQ-5D DESCRIPTIVE SYSTEM

First, I would like to ask you about MOBILITY. Do you think that the person:

1. Has no problems in walking about? ❑
2. Has slight problems in walking about? ❑
3. Has moderate problems in walking about? ❑
4. Has severe problems in walking about? ❑
5. Is unable to walk about? ❑

Next, I would like to ask you about SELF-CARE. Do you think that the person:

1. Has no problems washing or dressing him/herself? ❑
2. Has slight problems washing or dressing him/herself? ❑
3. Has moderate problems washing or dressing him/herself? ❑
4. Has severe problems washing or dressing him/herself? ❑
5. Is unable to wash or dress him/herself? ❑

Next, I would like to ask you about USUAL ACTIVITIES, for example work, study, housework, family or leisure activities. Do you think that the person:

1. Has no problems doing his/her usual activities? ❑
2. Has slight problems doing his/her usual activities? ❑
3. Has moderate problems doing his/her usual activities? ❑
4. Has severe problems doing his/her usual activities? ❑
5. Is unable to do his/her usual activities? ❑

Next, I would like to ask you about PAIN OR DISCOMFORT. Do you think that the person:

1. Has no pain or discomfort? ❑
2. Has slight pain or discomfort? ❑
3. Has moderate pain or discomfort? ❑
4. Has severe pain or discomfort? ❑
5. Has extreme pain or discomfort? ❑

Finally, I would like to ask you about ANXIETY OR DEPRESSION. Do you think that the person:

1. Is not anxious or depressed? ❑
2. Is slightly anxious or depressed? ❑
3. Is moderately anxious or depressed? ❑
4. Is severely anxious or depressed? ❑
5. Is extremely anxious or depressed? ❑

EQ-5D VAS

Now, I would like to ask you to say how good or bad you think the person's health is TODAY.

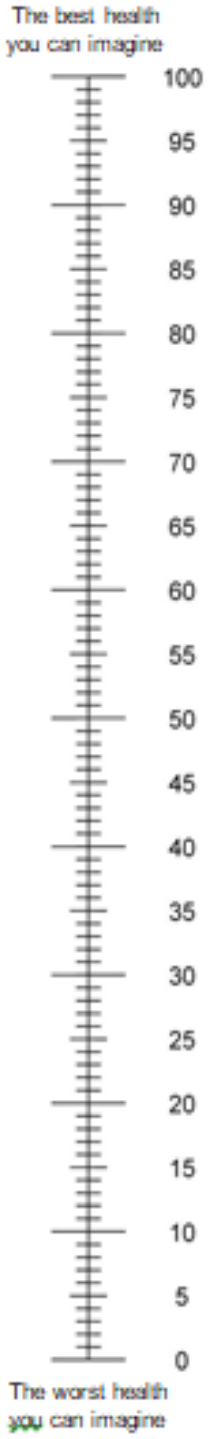
I would like you to picture in your mind a vertical line that is numbered from 0 to 100.
(Note to interviewer: if interviewing face-to-face, please show the proxy the VAS line.)

100 at the top of the line means the best health you can imagine.

0 at the bottom of the line means the worst health you can imagine.

I would now like you to tell me the point on this line where you would put the person's health TODAY.
(Note to interviewer: mark the line to indicate how the proxy thinks the person's health is TODAY. Now, please write the number you marked on the line in the box below.)

THE PERSON'S HEALTH TODAY = ☐



Thank you for taking the time to answer these questions.

Under each heading, please tick the ONE box that you think best describes the person's health TODAY.

MOBILITY

- No problems in walking about ❑
- Slight problems in walking about ❑
- Moderate problems in walking about ❑
- Severe problems in walking about ❑
- Unable to walk about ❑

SELF-CARE

- No problems washing or dressing him/herself ❑
- Slight problems washing or dressing him/herself ❑
- Moderate problems washing or dressing him/herself ❑
- Severe problems washing or dressing him/herself ❑
- Unable to wash or dress him/herself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

- No problems doing his/her usual activities ❑
- Slight problems doing his/her usual activities ❑
- Moderate problems doing his/her usual activities ❑
- Severe problems doing his/her usual activities ❑
- Unable to do his/her usual activities ❑

PAIN / DISCOMFORT

- No pain or discomfort ❑
- Slight pain or discomfort ❑
- Moderate pain or discomfort ❑
- Severe pain or discomfort ❑
- Extreme pain or discomfort ❑

ANXIETY / DEPRESSION

- Not anxious or depressed ❑
- Slightly anxious or depressed ❑
- Moderately anxious or depressed ❑
- Severely anxious or depressed ❑
- Extremely anxious or depressed ❑

We would like to know how good or bad you think the person's health is TODAY.

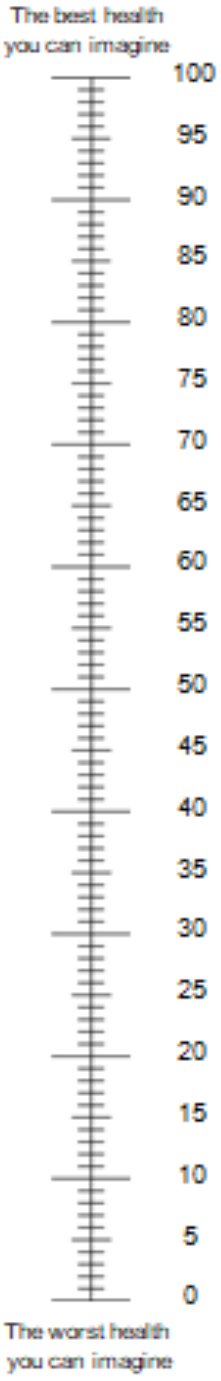
This scale is numbered from 0 to 100.

100 means the best health you can imagine.
0 means the worst health you can imagine.

Please mark an X on the scale to indicate how you think the person's health is TODAY.

Now, write the number you marked on the scale in the box below.

THE PERSON'S HEALTH TODAY = ☐



Annex II

In-Depth Interview

Informed Consent Form	
Study Title: *Assessment of psychometric properties, feasibility and usefulness of the EQ-5D-5L in Ethiopian stroke patients*	
Introduction and study objective	
I want to thank you for taking the time to meet with me today. My name is Ewennat Wehib and I am the principal investigator of the study. I am conducting this interview to understand better the issues of QoL on people with certain neurological conditions, such as stroke and to *provide possible explanation for the difference in response for directly reported and recalled HRQoL.. Your participation is purely voluntary and wouldn't take greater than 30 minutes of your time. Direct quotes might be taken from your response to be used in written and verbal reports of the paper. However, tape recorder may be used during the interview. Your honest response to the question is of paramount importance for the successful completion of the study. There was no right or wrong answers to the questions. You do not have to answer all questions you do not wish to and you can withdraw from the interview at any time. Your responses was be integrated with many other participants to ensure a broader understanding of QOL of stroke patients and the use of EQ-5D in stroke patients.*	
Confidentiality	
We were maintain the information you provide completely confidential. Your name was never be written and aggregate responses from different respondents was only be identified only by codes	
Risks and benefit	
Benefits include helping the research team to understand how to measure health-related quality of life. We do not think there are risks involved in taking part in this research. However, some participants may feel uncomfortable when asked to think about different aspects of their health. Although we believe the questions are unlikely to cause you to feel uncomfortable, if this did happen, we would to take a break from the interview and it is your choice to stop the interview entirely. If you do feel unsettled or upset during or after the interview, we encourage you to discuss this with your usual health care professional.	
Who to contact	
If you decide to participate in this interview and you have additional doubts or questions, you can communicate with the principal investigator at 0920577504	
Verbal consent and agreement	
If you would like to participate, please confirm that you understood everything I have told you about this study. Do you have any questions?	
Agrees to participate	
Does NOT agree to participate	
I understand the study aims and objectives and have decided to allow the interview to go forward.	
Signature:	*Day/Month/Year*
Person Obtaining Consent:	
Name:	
Signature:	*Day/Month/Year*

Interview guide for patients and their proxy caregivers on EQ-5D-5L as health-related quality of life measure for stroke patients. [English version]

Dear interviewer:

Before starting the interview, explain the following to the patient and proxy:

This interview aims to understand your experiences as patients and/or caregivers in the early and later stages of the interview. I would also like to discuss if the patients and caregivers have any differences in reported health status of the person experiencing a stroke – and what you think about any differences if these occur. I will explain this carefully as we go along, and you can ask me questions at any stage. You also have the right not to answer any question or questions.

1. What was your experience during the EQ-5D-5L interview? How easy or difficult was it?
   Probe: As a patient or a proxy, how did they feel during the previous interview? How easy was it to respond to the questions or match the health conditions to the questions? How easy was it for the proxy to imagine the patient's health condition?

2. What do you think the reasons are for the differences in your responses to the EQ-5D-5L descriptive profile (between the patient and proxy) as well as for EQ-VAS scores? (**Interviewer:** Please show them the completed questionnaires and ask them to discuss these differences).
   Probe: Show them how their responses to EQ-5D questions and EQ-VAS scores differ for the same health state of the patient and ask them what they think the reasons for the discrepancies could be. Why did the proxy or the patient choose this particular response? What are their thoughts on the reasons for the differences in their responses? Finally, enquire as to whether the patient agrees with the proxy's responses (and vice versa) and explanations, and if not, why not?

Dear Participants, thank you for your time and cooperation throughout the study!

Annex III (Amharic version)

በዕወቀትላይየተመሠረተየፍቃደኝነት ትስምማ ትቅጽ
የጥናቱርዕስ፦ በስትሮክ ህመምተኞችወስጥከጠፍ ጋር ተያያዝነ ትያላቸውን የኦሮጥራትለማ ምጣመከይቅ የማጠቀምአ ዋጩ ት
መግቢያና የጥናትዓላማዎች
ሰላም፣ ስሜ _እውንናት ውሂብ ነው። በዚህ ጥናት ውስጥ ለመሳተፍ ፈቃደኛ ስለሆኑ እናመሰግናለን። ለመሳተፍ ከመወሰንዎ በፊት ጥናቱ ለምን እየተካሄደ እንደሆነ እና ምን እንደሚያካትት መገንዘቡ አስፈላጊ ነው፡. በአሁኑ ወቅት በኢትዮጵያ የስትሮክ ህመምተኞች የጤና ሁኔታ በተሻለ ለመለካት መጠይቅን (ኢክዉ-5ዲ-5ኤል) የመጠቀም አዋጭነት ላይ ጥናት እያደረግን ነው። ለጥናቱ በቂ መረጃ ለማግኘት ትብብርዎ ጠቃሚ ነው። ቃለመጠይቁ እስከ 20 ደቂቃዎች ሊወስድ ይችላል እና በዚህ ጥናት ውስጥ ያለው ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው። ለመሳተፍ ቢስማሙም በማንኛውም ጊዜ መውጣት ይችላሉ። በዚህ ጥናት ውስጥ መሳተፍ ወይም በጥናቱ ለመሳተፍ ፈቃደኛ አለመሆን ከጤና ተቋም በሚያገኟቸው አገልግሎቶች ላይ ምንም ተጽዕኖ የለውም። ከአሁኑ ቃለ-መጠይቅ በተጨማሪ በ3 ኛ እና በ6 ኛ ወር በሁለት ቃለ-መጠይቆች ላይ እንዲሳተፉ እንጋብዝዎታለን። በቃለ መጠይቁ ወቅት ስለእርስዎ አንዳንድ ጥያቄዎችን (ለምሳሌ፥ ዕድሜዎ) እንዲሁም ስለ ጤናዎ ጥያቄዎች እንጠይቅዎታለን። ማንኛዉንም ያልተመቸዎትን ጥያቄ የመዝለል መብት አለዎት ወይም በማንኛውም ጊዜ ከጥናቱ መውጣት ይችላሉ። ለቃለ መጠይቁ ጥያቄዎች ትክክለኛ ወይም የተሳሳተ መልስ የለም።
ሚስጥራዊነት
የእርስዎ ተሳትፎ እና የሰጡት መረጃ ሁሉ ሚስጥራዊ ይሆናል እናም በማንኛውም ሪፖርቶች ወይም ህትመቶች ውስጥ ስለ እርስዎ አንጠቅስም። የተጠናቀቁ ጥናቶች በአዲስ አበባ ዩኒቨርሲቲ ዋና ተመራማሪ እና የምርምር ቡድኑ አባላት ብቻ በሚደርሱበት በተቆለፈ ቦታ ላይ ይቀመጣሉ። ሊታወቅ የማይችል መረጃ (ያለእርስዎ ስም እና የእውቂያ ዝርዝሮች) በይለፍ ቃል የተጠበቀ ኮምፒተር ላይ በኤሌክትሮኒክ መንገድ ይገባል። የተሰበሰበዉ መረጃ የመጨረሻውንእትም ከታተመ በኋላ ቢያንስለ 5 ዓመታት ያህል እናቆያለን ፣ ከዚያ በኋላ የኤሌክትሮኒክ ፋይሎች እና የወረቀት ቅጂዎች ይወገዳሉ።
በማ ተፍሊገ ኙየ ሚችሉጠቀሜታዎች እና ሊከሰቱየ ሚችሉችግሮች
ከጥናቱ የጤና ሁኔታን በተሻለ እንዴት እንደምንለካ ጠቃሚ መረጃ እናገኛለን። በዚህ ምርምር ውስጥ መሳተፍ ምንም ችግር የለዉም። አንዳንድ ተሳታፊዎች ስለጤንነታቸው የተለያዩ ገጽታዎች እንዲያስቡ ሲጠየቁ ምቾት የማይሰማቸውም ከሆነ ከቃለ መጠይቁ እረፍት መውሰድ ወይም ቃለመጠይቁን ሙሉ በሙሉ መተው ይችላሉ። በቃለ መጠይቁ ወቅት ወይም በኋላ አለመረጋጋት ወይም መረበሽ ከተሰማዎት ይህንን ከተለመደው የጤና እንክብካቤ ባለሙያዎ ጋር እንዲወያዩ እናበረታታዎታለን ።
ሚጀቢፈልጉ
ማንኛውም ጥያቄዎች ወይም አሳሳቢ ጉዳዮች ካሉዎት ዋናኢንቨስቲጌተር ከሆኑ _ከእውንናት ውሂብ ጋር በሥልክ ቁጥር 0920577504 መነጋገር ይችላሉ።
በቃል የማ ለጽየ ፍቃደኝነት ትስምማ ት
መሳተፍ የሚፈልጉ ከሆነ፣ እባክዎ ስለዚህ ጥናት የተነገረዎትን ነገር በሙሉ መረዳትዎን ያረጋግጡ። ጥይቄ አለዎት? (ተጠያቂው ጥያቄ ካላቸው እንዲጠይቁ ያበረታው)
የመረጃው ባለቤት ማንነት የማይገለጽበትን ይህን የጥናት ሂደት እንድንጀምር ፍቃደኛ ነዎት?
ለመሳተፍ ይስማማሉ |
ለመሳተፍ አይስማሙም |
የጥናቱን ዓላማዎችና ግቦች ተረድቻለሁ፤ እናም እናም የአጋሮች ጥናት ሂደቱ ላይ ለመሳተፍ ወስኛለሁ።
ሥም፦
ፊርማ፦ | *ቀን/ ወር/ ዓ.ም* |
ፍቃደኝነቱን ያገኘው ሰው፦ |
ሥም፦ |
ፊርማ፦ | *ቀን/ ወር/ ዓ.ም* |

ስለተሳታፍዉ ጠቅላላ መረጃ

እርስዎን በተመለከተ አጠቃላይ መጠይቅ	መልስ
1. ጾታ	1. ወንድ 2. ሴት
2. እድሜ	_____ዓመት
3. የጋብቻ ሁኔታ	1. ያላገባ/ች 2. ያገባ/ች 3. አግብቶ/ታ የፈታ/ች 4. የትዳር ጓደኛን በሞት ያጣ/ች
4. የትምህርት ደረጃ	1. መደበኛ ትምህርት ያልቀሰመ 2. ከ 1ኛ-4ኛ ክፍል 3. ከ 5ኛ-8ኛ ክፍል 4. ሁለተኛ ደረጃ/መሰናዶ ትምህርት (ከ 9ኛ-12ኛ ክፍል) 5. የተክንክና ሙያ ስልጠና /የኮሌጅ ድፒሎማ 6. የመጀመሪያ ዲግሪና ከዚያ በላይ
5. የስራ ቅጥር ሁኔታ	1. ተቀጣሪ 2. የግል ስራ 3. ጡረተኛ 4. ተማሪ 5. የቤት እመቤት 6. ሌሎች፣ይግለፁ _____
6. ባለፈው ዓመት ውስጥ አጠቃላይ የቤትዎ ገቢ የዕለት ተዕለት ፍላጎቶችዎን እንደ ማረፊያ ፣ ምግብ ፣ አልባሳት ያሉ እና ሌሎች ፍላጎቶች ምን ያህል ያሟላ ነበር?	1. በቂ አይደለም 2. ይበቃል 3. ከበቂ በላይ

በእያንዳንዱ ርዕስ ስር፣ እባክዎ **ዛሬ** ያለዎትን ጤንነት በተሻለ ሁኔታ የሚገልጸው **አንድ** ሳጥን ላይ ምልክት ያድርጉ።

እንቅስቃሴ

የመረመድ ችግር የለብኝም	❑
አነስተኛ የሆነ የመረመድ ችግር አለብኝ	❑
መጠነኛ የሆነ የመረመድ ችግር አለብኝ	❑
ከባድ የሆነ የመረመድ ችግር አለብኝ	❑
ምንም መረመድ አልችልም	❑

ራስን መንከባከብ

ለመታጠብም ሆነ ለመልበስ ምንም ችግር የለብኝም	❑
ለመታጠብም ሆነ ለመልበስ አነስተኛ የሆነ ችግር አለብኝ	❑
ለመታጠብም ሆነ ለመልበስ መጠነኛ ችግር አለብኝ	❑
ለመታጠብም ሆነ ለመልበስ ከፍተኛ የሆነ ችግር አለብኝ	❑
ራሴ ልታጠብም ሆነ ልለብስ አልችልም	❑

መደበኛ ተግባራት *(ለምሳሌ፦ ስራ፣ ትምህርት፣ የቤት ውስጥ ስራ፣ ቤተሰባዊ ወይም የእረፍት ጊዜ ተግባራት)*

መደበኛ ተግባራቶቼን ያለ ምንም ችግር አከናውናለሁ	❑
መደበኛ ተግባራቶቼን ለማከናወን አነስተኛ ችግር አለብኝ	❑
መደበኛ ተግባራቶቼን ለማከናወን መጠነኛ ችግር አለብኝ	❑
መደበኛ ተግባራቶቼን ለማከናወን ከፍተኛ ችግር አለብኝ	❑
መደበኛ ተግባራቶቼን ለማከናወን አልችልም	❑

የሕመም ስሜት/ምቾት ማጣት

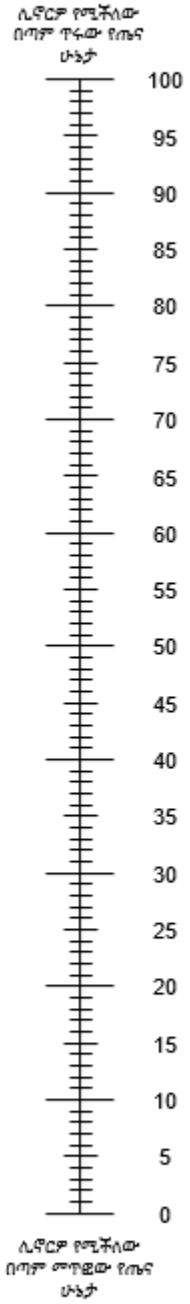
የሕመም ስሜትም ሆነ የምቾት ማጣት ስሜት የለኝም	❑
አነስተኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለኝ	❑
መጠነኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለኝ	❑
ከባድ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለኝ	❑
የከፋ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለኝ	❑

ጭንቀት/ድብርት

ጭንቀትም ሆነ ድብርት የለብኝም	❑
አነስተኛ ጭንቀት ወይም ድብርት አለብኝ	❑
መጠነኛ ጭንቀት ወይም ድብርት አለብኝ	❑
ከባድ ጭንቀት ወይም ድብርት አለብኝ	❑
እጅግ ከባድ ጭንቀት ወይም ድብርት አለብኝ	❑

- **ዛሬ** የጤና ሁኔታዎ ምን ያህል ጥሩ ወይም መጥፎ መሆኑን ለማወቅ እንፈልጋለን፡፡
- መለኪያው ከ0 እስከ 100 ድረስ ቁጥሮች አሉት፡፡
- 100 ማለት ሊኖርዎ የሚችለው በጣም ጥሩው የጤና ሁኔታ ነው።
  0 ማለት ሊኖርዎ የሚችለው በጣም መጥፎው የጤና ሁኔታ ነው።
- በመለኪያው ላይ **ዛሬ** ጤንነትዎ ያለበትን ሁኔታ ለማሳየት የ X ምልክት ያድርጉ፡፡
- አሁን፣ከስር ባለው ሳጥን ውስጥ በለመኪያው ላይ ምልክት ያደረጉበትን ቁጥር ይጻፉ፡፡

የዛሬ ጤንነትዎ =



EQ-5D ጥላም ስርዓት

በቅድሚያ፣ ስለ እንቅስቃሴ ልጠይቅዎት እፈልጋለሁ። ስለሚከተለው አጠቃላይ ሁኔታ ምን ይላሉ፡

1. የመራመድ ችግር የለብዎትም? ❑
2. አነስተኛ የሆነ የመራመድ ችግር አለብዎት? ❑
3. መጠነኛ የሆነ የመራመድ ችግር አለብዎት? ❑
4. ከባድ የሆነ የመራመድ ችግር አለብዎት? ❑
5. ምንም መራመድ አይችሉም? ❑

በመቀጠል፣ ራስን ስለመንከባከብ ልጠይቅዎት እፈልጋለሁ። ስለሚከተለው አጠቃላይ ሁኔታ ምን ይላሉ፡

1. ራስዎትን ችለው ለመታጠብም ሆነ ለመልበስ ምንም ችግር የለብዎትም? ❑
2. ራስዎትን ችለው ለመታጠብም ሆነ ለመልበስ አነስተኛ የሆነ ችግር አለብዎት? ❑
3. ራስዎትን ችለው ለመታጠብም ሆነ ለመልበስ መጠነኛ ችግር አለብዎት? ❑
4. ራስዎትን ችለው ለመታጠብም ሆነ ለመልበስ ከፍተኛ የሆነ ችግር አለብዎት? ❑
5. ራስዎትን ችለው ሊታጠቡም ሆነ ሊለብሱ አይችሉም? ❑

በመቀጠል፣ ስለ መደበኛ ተግባራት ልጠይቅዎት እፈልጋለሁ፤ ለምሳሌ፡ ስራ፣ ትምህርት፣ የቤት ውስጥ ስራ፣ ቤተሰባዊ ወይም የአረፍት ጊዜ ተግባራት። ስለሚከተለው አጠቃላይ ሁኔታ ምን ይላሉ፡

1. መደበኛ ተግባራቶችዎን ያለ ምንም ችግር ያከናውናሉ? ❑
2. መደበኛ ተግባራቶችዎን ለማከናወን አነስተኛ ችግር አለብዎት? ❑
3. መደበኛ ተግባራቶችዎን ለማከናወን መጠነኛ ችግር አለብዎት? ❑
4. መደበኛ ተግባራቶችዎን ለማከናወን ከፍተኛ ችግር አለብዎት? ❑
5. መደበኛ ተግባራቶችዎን ለማከናወን አይችሉም? ❑

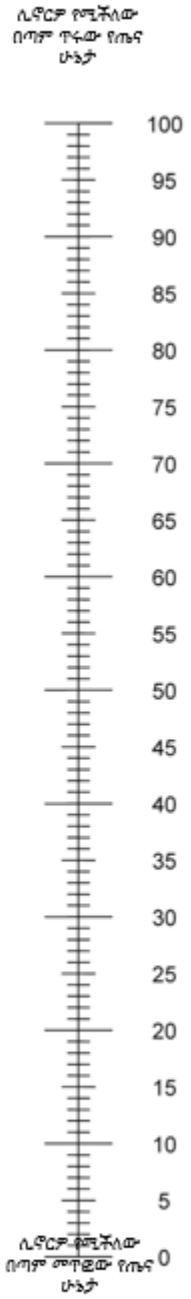
በመቀጠል፣ ስለ የሕመም ስሜት ወይም ምቾት ማጣት ልጠይቅዎት እፈልጋለሁ። ስለሚከተለው አጠቃላይ ሁኔታ ምን ይላሉ፡

1. የሕመም ስሜትም ሆነ የምቾት ማጣት ስሜት የለዎትም? ❑
2. አነስተኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለዎት? ❑
3. መጠነኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለዎት? ❑
4. ከባድ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለዎት? ❑
5. የከፋ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አለዎት? ❑

በመጨረሻ፣ ስለ ጭንቀት/ድብርት ልጠይቅዎት እፈልጋለሁ። ስለሚከተለው አጠቃላይ ሁኔታ ምን ይላሉ፡

1. ጭንቀትም ሆነ ድብርት የለብዎትም? ❑
2. አነስተኛ ጭንቀት ወይም ድብርት አለብዎት? ❑
3. መጠነኛ ጭንቀት ወይም ድብርት አለብዎት? ❑
4. ከባድ ጭንቀት ወይም ድብርት አለብዎት? ❑
5. እጅግ ከባድ ጭንቀት ወይም ድብርት አለብዎት? ❑

EQ-5D VAS



- **አሁን ደግሞ፣ <u>የዛሬው</u> የጤና ሁኔታዎ ምን ያህል ጥሩ ወይም መጥፎ መሆኑን በተመለከተ እንዲናገሩ አጠይቅዎታለሁ።**

- **ከ0 እስከ 100 ድረስ ቁጥሮች ያሉትን ተጸፋት መስመር በአእምሮዎ ውስጥ እንዲስሉ እፈልጋለሁ።**
  (ማስታወሻ ሊቃለ መጠይቅ አድራጊ፡ ቃለ መጠይቅ የሚያደርጉት ፊት ለፊት ከሆነ፣ አባክዎ ለመልስ ሰጪው የ VAS መስመርን ያሳዩ።)

- **ከመስመሩ አናት ላይ ያለው ቁጥር 100 ከሆነ፣ ሊኖርዎ የሚችለው <u>እጅግ የተሻለው</u> የጤና ሁኔታ ግለት ነው።**

  ከመስመሩ ግርጌ ላይ ያለው ቁጥር 0 ከሆነ፣ ሊኖርዎ የሚችለው <u>በጣም መጥፎው</u> የጤና ሁኔታ ግለት ነው።

- **አሁን ደግሞ <u>ዛሬ</u> ጤንነትዎ ያለበትን ሁኔታ በዚህ መስመር ላይ የሚያሳየውን ነጥብ እንዲነግሩኝ እፈልጋለሁ።**
  (ማስታወሻ ሊቃለ መጠይቅ አድራጊ፡ የመልስ ሰጪውን የዛሬ ጤንነት የሚያመለክተው ነጥብ ላይ መስመሩን ምልክት ያድርጉበት። አሁን፣ አባክዎ ከስር ባለው ሳጥን ውስጥ በመስመሩ ላይ ምልክት ያደረጉበትን ቁጥር ይጻፉ።)

የመልስ ሰጪው የዛሬ ጤነነት =

ጊዜዎን ወስደው እነዚህን ጥያቄዎች ስለመለሱ እናመሰግናለን።

በእያንዳንዱ ርዕስ ስር፣ እባክዎ ግለሰቡ **ዛሬ** ያላቸውን ጤንነት በተመለከተ እርስዎ የሚያስቡትን በተሻለ ሁኔታ የሚገልጸው **አንድ** ሳጥን ላይ ምልክት ያድርጉ።

እንቅስቃሴ

የመረመድ ችግር የለባቸውም	❑
አነስተኛ የሆነ የመረመድ ችግር አለባቸው	❑
መጠነኛ የሆነ የመረመድ ችግር አለባቸው	❑
ከባድ የሆነ የመረመድ ችግር አለባቸው	❑
ምንም መረመድ አይችሉም	❑

ራስን መንከባከብ

ራሱን/ራሷን ችላ/ችሎ ለመታጠብም ሆነ ለመልበስ ምንም ችግር የለባቸውም	❑
ራሱን/ራሷን ችላ/ችሎ ለመታጠብም ሆነ ለመልበስ አነስተኛ የሆነ ችግር አለባቸው	❑
ራሱን/ራሷን ችላ/ችሎ ለመታጠብም ሆነ ለመልበስ መጠነኛ ችግር አለባቸው	❑
ራሱን/ራሷን ችላ/ችሎ ለመታጠብም ሆነ ለመልበስ ከፍተኛ የሆነ ችግር አለባቸው	❑
ራሱን/ራሷን ችላ/ችሎ ራሳቸው ሊታጠቡም ሆነ ሊለብሱ አይችሉም	❑

መደበኛ ተግባራት *(ለምሳሌ፦ ሰራ፣ ትምህርት፣ የቤት ውስጥ ስራ፣ ቤተሰባዊ ወይም የአረፍት ጊዜ ተግባራት)*

መደበኛ ተግባራቶቻቸውን ያለ ምንም ችግር ያከናውናሉ	❑
መደበኛ ተግባራቶቻቸውን ለማከናወን አነስተኛ ችግር አለባቸው	❑
መደበኛ ተግባራቶቻቸውን ለማከናወን መጠነኛ ችግር አለባቸው	❑
መደበኛ ተግባራቶቻቸውን ለማከናወን ከፍተኛ ችግር አለባቸው	❑
መደበኛ ተግባራቶቻቸውን ለማከናወን አይችሉም	❑

የሕመም ስሜት/ምቾት ማጣት

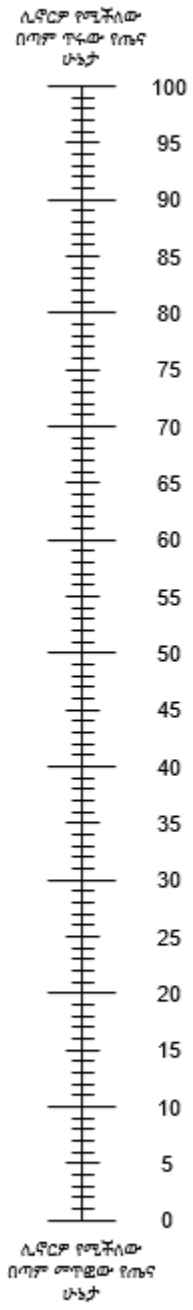
የሕመም ስሜትም ሆነ የምቾት ማጣት ስሜት የላቸውም	❑
አነስተኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው	❑
መጠነኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው	❑
ከባድ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው	❑
የከፋ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው	❑

ጭንቀት/ድብርት

ጭንቀትም ሆነ ድብርት የለባቸውም	❑
አነስተኛ ጭንቀት ወይም ድብርት አለባቸው	❑
መጠነኛ ጭንቀት ወይም ድብርት አለባቸው	❑
ከባድ ጭንቀት ወይም ድብርት አለባቸው	❑
እጅግ ከባድ ጭንቀት ወይም ድብርት አለባቸው	❑

- **የዛሬው** የግለሰቡ የጤና ሁኔታ ምን ያህል ጥሩ ወይም መጥፎ መሆኑን በተመለከተ እርስዎ ምን እንደሚያስቡ ለማወቅ እንፈልጋለን።
- መለኪያው ከ0 እስከ 100 ድረስ ቁጥሮች አሉት።
- 100 ማለት ሊኖርዎ የሚችለው በጣም ጥሩው የጤና ሁኔታ ነው።
  0 ማለት ሊኖርዎ የሚችለው በጣም መጥፎው የጤና ሁኔታ ነው።
- እባክዎ የግለሰቡን **የዛሬ** ጤንነት ያለበትን ሁኔታ ለማሳየት በመለኪያው ላይ የ X ምልክት ያድርጉ።
- አሁን፣ ከስር ባለው ሳጥን ውስጥ በለመኪያው ላይ ምልክት ያደረጉበትን ቁጥር ይጻፉ።

የግለሰቡ የዛሬ ጤንነት =



EQ-5D ጎላም ስርዓት

በቅድሚያ፣ ስለ እንቅስቃሴ ልጠይቅዎት እፈልጋለሁ። እርስዎ ግለሰቡን እንደሚያስቡት፦

1. የመራመድ ችግር የለባቸውም? ❑
2. አነስተኛ የሆነ የመራመድ ችግር አለባቸው? ❑
3. መጠነኛ የሆነ የመራመድ ችግር አለባቸው? ❑
4. ከባድ የሆነ የመራመድ ችግር አለባቸው? ❑
5. ምንም መራመድ አይችሉም? ❑

በመቀጠል፣ ራስን ስለመንከባከብ ልጠይቅዎት እፈልጋለሁ። እርስዎ ግለሰቡን እንደሚያስቡት፦

1. ራሱን/ራሷን ችሎ/ችላ ለመታጠብም ሆነ ለመልበስ ምንም ችግር የለባቸውም? ❑
2. ራሱን/ራሷን ችሎ/ችላ ለመታጠብም ሆነ ለመልበስ አነስተኛ የሆነ ችግር አለባቸው? ❑
3. ራሱን/ራሷን ችሎ/ችላ ለመታጠብም ሆነ ለመልበስ መጠነኛ ችግር አለባቸው? ❑
4. ራሱን/ራሷን ችሎ/ችላ ለመታጠብም ሆነ ለመልበስ ከፍተኛ የሆነ ችግር አለባቸው? ❑
5. ራሱን/ራሷን ችሎ/ችላ ሊታጠቡም ሆነ ሊለብሱ አይችሉም? ❑

በመቀጠል፣ ስለ መደበኛ ተግባራት ልጠይቅዎት እፈልጋለሁ፤ ለምሳሌ፦ ስራ፣ ትምህርት፣ የቤት ውስጥ ስራ፣ ቤተሰባዊ ወይም የአረፍት ጊዜ ተግባራት። እርስዎ ግለሰቡን እንደሚያስቡት፦

1. የእሱን/የእሷን መደበኛ ተግባራቶች ያለምንም ችግር ያከናውናሉ? ❑
2. የእሱን/የእሷን መደበኛ ተግባራቶች ለማከናወን አነስተኛ ችግር አለባቸው? ❑
3. የእሱን/የእሷን መደበኛ ተግባራቶች ለማከናወን መጠነኛ ችግር አለባቸው? ❑
4. የእሱን/የእሷን መደበኛ ተግባራቶች ለማከናወን ከፍተኛ ችግር አለባቸው? ❑
5. የእሱን/የእሷን መደበኛ ተግባራቶች ማከናወን አይችሉም? ❑

በመቀጠል፣ ስለ የሕመም ስሜት ወይም ምቾት ማጣት ልጠይቅዎት እፈልጋለሁ። እርስዎ ግለሰቡን እንደሚያስቡት፦

1. የሕመም ስሜትም ሆነ የምቾት ማጣት ስሜት የላቸውም? ❑
2. አነስተኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው? ❑
3. መጠነኛ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው? ❑
4. የከፋ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው? ❑
5. በጣም የከፋ የሕመም ስሜት ወይም የምቾት ማጣት ስሜት አላቸው? ❑

በመጨረሻ፣ ስለ ጭንቀት/ድብርት ልጠይቅዎት እፈልጋለሁ። እርስዎ ግለሰቡን እንደሚያስቡት፦

1. ጭንቀትም ሆነ ድብርት የለባቸውም? ❑
2. አነስተኛ ጭንቀት ወይም ድብርት አለባቸው? ❑
3. መጠነኛ ጭንቀት ወይም ድብርት አለባቸው? ❑
4. ከባድ ጭንቀት ወይም ድብርት አለባቸው? ❑
5. እጅግ ከባድ ጭንቀት ወይም ድብርት አለባቸው? ❑

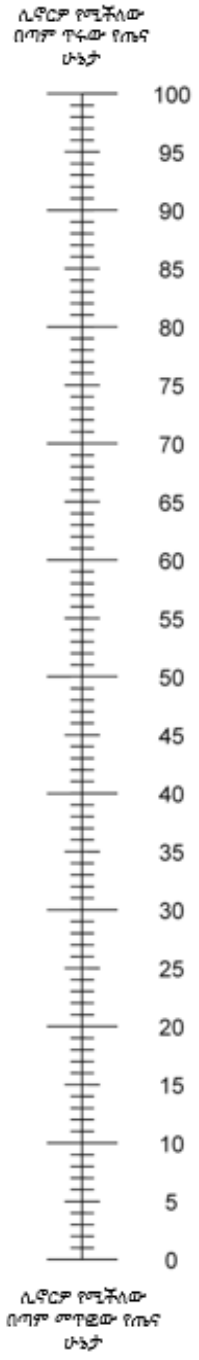
EQ-5D VAS

- **አሁን <u>የዛሬው</u> የግለሰቡ የጤና ሁኔታ ምን ያህል ጥሩ ወይም መጥፎ መሆኑን በተመለከተ እርስዎ ምን እንደሚያስቡ ለመጠየቅ እንፈልጋለን።**
- **ከ0 እስከ 100 ድረስ ቁጥሮች ያሉትን ተጸፋት መስመር በአእምሮዎ ውስጥ እንደሰሉ እፈልጋለሁ።**
  (ማስታወሻ ሊቃለ መጠይቅ አደራጊ፡ ቃለ መጠይቅ የሚያደርጉት ፊት ለፊት ከሆነ፣ አባክዎ ለወኪሉ የ VAS መስመርን ያሳዩ።)
- **ከመስመሩ አናት ላይ ያለው ቁጥር 100 ከሆነ፣ ሊኖርዎ የሚችለው <u>እጅግ የተሻለው</u> የጤና ሁኔታ ማለት ነው።**

  ከመስመሩ ግርጌ ላይ ያለው ቁጥር 0 ከሆነ፣ ሊኖርዎ የሚችለው <u>በጣም መጥፎው</u> የጤና ሁኔታ ማለት ነው።
- **አሁን ደግሞ የግለሰቡን <u>የዛሬ</u> ጤንነት ያለበትን ሁኔታ በዚህ መስመር ላይ የሚያሳየውን ነጥብ እንዲነቀሩኝ እፈልጋለሁ።**
  *(ማስታወሻ ሊቃለ መጠይቅ አደራጊ፡ የግለሰቡ **የዛሬ** ጤንነት በተመለከተ ወኪሉ ምን እንደሚያስብ የሚያመለክተው ነጥብ ላይ መስመሩን ምልክት ያድርጉ፣ አባክዎ ከለር ባለው ሳጥን ውስጥ በመስመሩ ላይ ምልክት ያደረጉበትን ቁጥር ይጻፉ።)*

የግለሰቡ የዛሬ ጤነነት = ☐

ጊዜዎን ወስደው እነዚህን ጥያቄዎች ስለመለሱ እናመሰግናለን።



በዕውቀት ላይ የተመሠረተ የፍቃደኝነት ስምምነት ቅጽ
የጥናቱ ርዕስ፡- በስትሮክ ህመምተኞች ውስጥ ከጤና ጋር ተያያዥነት ያላቸውን የኑሮ ጥራት ለመገምገም መጠይቅ የመጠቀም አዋጭነት
መግቢያና የጥናት ዓላማዎች
ጤና ይስጥልኝ፣ ሥሜ_እውንናት ውሂብ ይባላል የጥናቱ ዋና ተመራማሪ ነኝ። በአሁኑ ወቅት በኢትዮጵያ የስትሮክ ህመምተኞች የጤና ሁኔታ በተሻለ ለመለካት መጠይቅን(ኢክዉ-5ዲ-5ኤል) የመጠቀም አዋጭነት ላይ ጥናት እያደረግን ነው። ይህንን ቃለ ምልልስ የማቀርበው እንደ‹stroke› ያለ የነርቭ በሽታ በሰዎች የኑሮ ጥራት ላይ የሚያሳድረውን ተጽእኖ በተሻለ ለመረዳት እና በቀጥታ ሪፖርት በሚያደርጉት እና አስታውሰው በሚናገሩት የኑሮ ጥራት ምላሽ ላይ ለተስተዋለው ልዩነት ማብራሪያ ለመስጠት ነው ።ቃለ- መጠይቁ ከ30 ደቂቃዎች ያልበለጠ ይወስዳል ። ከምላሽዎ የተወሰዱ ቀጥተኛ ንግግሮች በወረቀቱ የቃል ሪፖርቶች ውስጥ ጥቅም ላይ የሚውሉ ሊሆኑ ይችላሉ ። ሆኖም በቃለ መጠይቁ ወቅት የቴፕ መቅጃ ጥቅም ላይ ሊውል ይችላል ። ለጥያቄው በሐቀኝነት የሰጡት ምላሽ ለጥናቱ ስኬታማነት ከፍተኛ ጠቀሜታ አለው ። ለጥያቄዎቹ ትክክለኛ ወይም የተሳሳቱ መልሶች አይኖሩም ። ለማይፈልጋቸው ጥያቄዎች ሁሉ መልስ መስጠት የለብዎትም እናም በማንኛውም ጊዜ ከቃለ መጠይቁ መውጣት ይችላሉ። ስለ ስትሮክ ህመምተኞች የኑሮ ጥራት ሰፋ ያለ ግንዛቤን እና በስትሮክ ህመምተኞች ውስጥ EQ-5D ን መጠቀሙን ለማረጋገጥ የእርስዎ ምላሾች ከብዙ ሌሎች ተሳታፊዎች ጋር ይቀናጃሉ
ሚስጥራዊነት
የእርስዎ ተሳትፎ እና የሰጡት መረጃ ሁሉ ሚስጥራዊ ይሆናል እናም በማንኛውም ሪፖርቶች ወይም ህትመቶች ውስጥ ስለ እርስዎ አንጠቅስም። የተጠናቀቁ ጥናቶች በአዲስ አበባ ዩኒቨርሲቲ ዋና ተመራማሪ እና የምርምር ቡድኑ አባላት ብቻ በሚደርሱበት በተቆለፈ ቦታ ላይ ይቀመጣሉ። ሊታወቅ የማይችል መረጃ(ያለእርስዎ ስም እና የእውቂያ ዝርዝሮች) በይለፍ ቃል የተጠበቀ ኮምፒተር ላይ በኤሌክትሮኒክ መንገድ ይገባል።
በመሳተፍ ሊገኙ የሚችሉ ጠቀሜታዎች እና ሊከሰቱ የሚችሉ ችግሮች
የስትሮክ ህመምተኞችን የኑሮ ጥራት በተሻለ እንዴት እንደምንለካ ጠቃሚ መረጃ እናገኛለን። በዚህ ምርምር ውስጥ መሳተፍ ምንም ችግር የለዉም። አንዳንድ ተሳታፊዎች ስለጤንነታቸው የተለያዩ ገጽታዎች እንዲያስቡ ሲጠየቁ ምቾት የማይሰማቸውም ከሆነ ከቃለ መጠይቁ እረፍት መውሰድ ወይም ቃለመጠይቁን ሙሉ በሙሉ መተው ይችላሉ። በቃለ መጠይቁ ወቅት ወይም በኋላ አለመረጋጋት ወይም መረበሽ ከተሰማዎት ይህንን ከተለመደው የጤና እንክብካቤ ባለሙያዎ ጋር እንዲወያዩ እናበረታታዎታለን ።
መረጃ ቢፈልጉ
ማንኛውም ጥያቄዎች ወይም አሳሳቢ ጉዳዮች ካሉዎት ዋና ኢንቨስቲጌተር ከሆኑ_ከእውንናት ውሂብ ጋር በሥልክ ቁጥር 0920577504 መነጋገር ይችላሉ።
በቃል የሚገለጽ የፍቃደኝነት ስምምነት
*መ*ሳተፍ የሚፈልጉ ከሆነ፣ እባክዎ ስለዚህ ጥናት የተነገረዎትን ነገር በሙሉ መረዳትዎን ያረጋግጡ። ጥይቄ አለዎት? (ተጠያቂው ጥያቄ ካላቸው እንዲጠይቁ ያበረታቱ)
የመረጃው ባለቤት ማንነት የማይገለጽበትን ይህን የጥናት ሂደት እንድንጀምር ፍቃደኛ ነዎት?

ለመሳተፍ ይስማማሉ	
ለመሳተፍ አይስማሙም	

የጥናቱን ዓላማዎችና ግቦች ተረድቻለሁ፤ እናም እናም የአጋሮች ጥናት ሂደቱ ላይ ለመሳተፍ ወስኛለሁ።		
ሥም፡-		
ፊርማ፡-	*ቀን/ ወር/ ዓ.ም*	
ፍቃደኝነቱን ያገኘው ሰው፡-		
ሥም፡-		
ፊርማ፡-	*ቀን/ ወር/ ዓ.ም*	

የቃለ መጠይቅ መመሪያ ለታካሚዎች እና ለ ተንከባካቢዎቻቸው በ EQ-5D-5L ላይ የስትሮክ ህመምተኞች ከጤና ጋር ተያያዥነት ያላቸውን የኑሮ ጥራት ስለመገምገም [አማርኛ ስሪት]

ውድ ጠያቂ፡-

ቃለ መጠይቁን ከመጀመርዎ በፊት የሚከተሉትን ለታካሚው እና ለተንከባካቢው ያብራሩ፡-

ይህ ቃለ መጠይቅ አላማው እንደ ታካሚ እና/ወይም ተንከባካቢ በቃለ መጠይቁ መጀመሪያ እና ቀጥሎ ባሉት መጠይቆች ላይ ያለዎትን ልምድ ለመረዳት ነው። እንዲሁም ታካሚዎች እና ተንከባካቢዎች ስትሮክ በተያዘው ሰው ላይ በተገለጸው የጤና ሁኔታ ላይ ምንም አይነት ልዩነት ካላቸው ለማወቅ - እና ካለም ስለማንኛውም ልዩነት ምን እንደሚያስቡ መወያየት እፈልጋለሁ። ይህንን በሂደት በደንብ አስረዳለው, እና በማንኛውም ሰአት ጥያቄዎችን ሊጠይቁኝ ይችላሉ. እንዲሁም ማንኛውንም ጥያቄ ወይም ጥያቄ ያለመመለስ መብት አለዎት።

1. በEQ-5D-5L ቃለ መጠይቅ ወቅት ልምድዎ ምን ይመስል ነበር? ምን ያህል ቀላል ወይም ከባድ ነበር?

ምርመራ፡ እንደ ታካሚ ወይም ተንከባካቢ ፣ በቀድሞው ቃለ መጠይቅ ወቅት ምን ተሰማዎት? ለጥያቄዎቹ ምላሽ መስጠት ወይም የጤና ሁኔታዎችን ከጥያቄዎቹ ጋር ማዛመድ ምን ያህል ቀላል ነበር? የታካሚውን የጤና ሁኔታ መገመት ለተንከባካቢው ምን ያህል ቀላል ነበር?

2. ለ EQ-5D-5L **ገላጭ ስርዓት** (በታካሚው እና በተንከባካቢው መካከል) እንዲሁም ለ EQ-VAS ውጤቶች ምላሾችዎ ልዩነት ምክንያት ምን ይመስልዎታል? (ጠያቂ፡ እባኮትን የተሟሉ መጠይቆችን ያሳዩዋቸው እና በእነዚህ ልዩነቶች ላይ እንዲወያዩባቸው ይጠይቋቸው) ።

ምርመራ፡- ተመሳሳይ ለሆኑ የታካሚው የጤና ሁኔታ ላይ ለEQ-5D ጥያቄዎች እና የEQ-VAS መለኪያዎች ምላሾቻቸው እንዴት እንደሚለያዩ ያሳዩዋቸው እና የአለመግባባቶቹ ምክንያቶች ምን ሊሆኑ ይችላሉ ብለው እንደሚያስቡ ይጠይቋቸው። ለምን ታካሚው ወይም ተንከባካቢው ይህን ልዩ ምላሽ መረጡ? በምላሾቻቸው ውስጥ ለተፈጠሩት ልዩነቶች ምክንያቶች ሀሳባቸው ምንድን ነው? በመጨረሻም፣ ታካሚው በተንከባካቢው ምላሾች (እንዲሁም ተንከባካቢው በታካሚው ምላሾች) እና ማብራሪያዎች ይስማማ እንደሆነ ይጠይቁ፣ እና ካልሆነ፣ ለምን እንዳልተስማሙ ይጠይቁ?

ስለ ጊዜዎ እና ስለ ትብብርዎ
በጣም አመሰግናለሁ !!!