

**LINGUISTIC VALIDATION AND TRANSLATION
OF STROKE IMPACT SCALE VERSION 3.0 IN
BANGLADESH**



By

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Statement of Authorship

Except where is made in the text of the thesis, this thesis contains no materials published elsewhere or extracted in whole or in part form a thesis presented by me for any other degree or diploma or seminar.

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Dedication

Dedicated to my honorable and beloved parents, my respected all teachers of Bangladesh Health Professions Institute and my little sister and brother.

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List of Abbreviation

QOL: Quality of Life

HRQoL: Health related Quality of Life

SIS: Stroke Impact Scale

PRO: Patient Reported Outcome

COA: Clinical Outcome Assessments

ClinROs: Clinician Reported Outcome

ObsROs: Observer Reported Outcome

Abstract

Translation and Linguistic Validation has become very important for any Patient Reported Outcome Instruments. There is no specific quality-of-life scale for stroke patients has previously been translated and culturally adapted, for use in the Bangla language to detect accurate fact about their quality of life. Internationally, the instrument for this purpose is the Stroke Impact Scale 3.0 (SIS). The Use of SIS enables comprehensive analysis on the impact of stroke on patients' lives. The impact of stroke can be worse and may result in serious deficits, which may reduce quality of life (QOL). Specific QOL measurement is needed to give an account and quantify the impact of this condition. The purpose of this study is to establish translation and linguistic validation of this SIS 3.0 in Bangla language.

The objectives are to understand the actual meaning of each questionnaires to the patients, to identify the linguistic problematic which is face by patients, to determine that all the data collect by this scale are clean and conceptually equivalent to the instrument, to modify non-suitable items from the domain to improve the measurement of impact of stroke.

Native-speaking citizens of the target countries who reported stroke related problems were asked to review a translation of the SIS 3.0 questionnaire, which was harmonized in Bengali languages. During a cognitive debriefing interview, participants were asked to identify any words that were difficult to understand and explain in their own words the meaning of each sentence in the questionnaire. The qualitative analysis was conducted by local linguistic validation teams (original translators, back translator, clinical occupational therapist, interviewer, and another expert).

After analyzing the data found that Translation and linguistic validation of Stroke Impact Scale 3.0 has performed successfully by considering and adapting cultural context, patient's response and opinion of expert committee. After cognitive debriefing assumed that by using this translated scale data can be collected in short time and also use for research purpose. Further Psychometric Properties of the Stroke Impact Scale 3.0 will be carried out.

Key Words: Stroke, Translation and linguistic validation, Stroke Impact Scale 3.0, Quality of life.

Chapter 1: Introduction

1.1 Background:

The word “stroke” was apparently first introduced into medicine in 1689 by William Cole in A Physico-Medical Essay Concerning the Late Frequencies of Apoplexies (Sacco et al.,2013). Stroke is an aspect of cardiovascular diseases which is a major cause of disability in many Asian countries, with low-and middle-income countries carrying a higher burden of mortality (Global Health Insight, October 2017). World Health Organization (WHO) reported that, stroke is a global leading cause of morbidity and mortality with negative impact on health-related quality of life (HRQOL), and it is projected to worsen in developing countries over the next two decades (Hamza, Nabillah & Loh, 2012).Health related quality of life of a stroke survivors has impact on different dimensions which varies during the recovery phase when an individual try to adjust to life (Hamza, Al-Sadat, Loh, and Jahan, May 2014).Bangladesh is ranked 84 according to WHO’s mortality rate index (out of 163 countries) and stroke is the third leading cause of death (Global Health Insight, October 2017). Worldwide, the developing country estimated that approximately 75% of stroke related deaths and 81% of stroke related disability-adjusted life-years (DALYs) (Mamin, Islam, Rumana, & faruqui,2017). Brandão et al., (2017) stated that When death does not come, stroke has various negative outcome on individuals’ lives, like organizational, loss of independency and cognitive and communicative impairment. Stroke can have substantial adverse effects on functioning and well-being (Jenkinson et al.,2013). A study reported that Various studies of Quality of life in stroke show that In Quality of life physical disabilities often have a negative impact, but this is not happening in all the case. A compromised QL with little or no physical dysfunction can also experience in stroke patients (Xie, Wu, Zheng, Croft, Greenlund, Mensah, and Labarthe, 2006). The impact of stroke in stroke survivor’s quality of life may poor. Measurements of impairments and disability of a stroke patient is not as relevant as the measurement of QOL (Brandão et al.,2017) This is important to measure QOL because these are patient centered which is represent patient’s perspective of health fairly and exactly and also a

given treatment (sonrasi et al.,2010). QOL is one of the predictive indicators for stroke as a vast description of the disease can find out by it (Brandão et al.,2017).

Many stroke survivors have changes in their physical, cognitive, and emotional abilities that impede them from independently performing their daily activities related to work, school, parenting, or leisure (The American Occupational Therapy Association, Inc [AOTA], n.d.) It is very important to know that how different dimensions of HRQoL change over time among the stroke survivors (Hamza, Al-Sadat, Loh, and Jahan, May 2014). For improving quality of life and increasing independency occupational therapy always focus on ensuring that the client will function as well as possible after discharge (The American Occupational Therapy Association, Inc [AOTA], n.d.). Occupational therapy performs a central role in health care professions while many other professions assess function in health care, which is always focus to evaluate a person's performance of everyday tasks or occupations (Wales et al., 2016). For that reason, it is important to measure that how much improvement is show after receiving occupational therapy of a stroke survivor patient. Several instruments have been developed to assess their multiple dimensions of their life (Brandão et al.,2017). Though there are many instruments have been developed but many of them have not been enough validated (de Souza, Alexandre, & Guirardello,2017). Worldwide Bengali is one of the sixth most widely spoken languages with nearly 300 million users and also estimated that in 2050 Bengali speaking population will be nearly 400 million (Arafat,2015). At present according to Bangladeshi perspective Stroke Impact scale 3.0 should be linguistically valid.

Stroke Impact Scale 3.0 is use to assess quality of life. It has been widely used to measure the outcome to visualize the extent and domains of QOL betterment after stroke rehabilitation. (Lin et al.,2010). This is a specific HRQoL tool which was developed by Duncan et al at the University of Kansas Medical Center (Javier, Carod-Artal, Coral, Trizotto, & Moreira,2008). Stroke impact Scale (SIS)3.0 is a 59-item self-report assessment of stroke outcome which is used to assess HRQoL and it has 8 domains: strength, hand function, mobility, physical and instrumental activities of daily living (i.e., ADLs and IADLs), memory and thinking, communication, emotion, and social participation. (Kamwesiga, Koch, Kottorp, and Guidetti,2016) Scores for each

domain range from 0 to 100, and higher scores indicate a better HRQoL. (Kamwesiga, Koch, Kottorp, and Guidetti,2016).

In researches, clinical practice and to assess the population's health a rising number of questionnaires or measurement instruments that assess psychosocial characteristics and several outcomes in health are available to be used. (de Souza, Alexandre, & Guirardello,2017) Linguistic validation is commonly used for Clinical Outcomes Assessments (COAs), such as Patient Reported Outcomes (PROs), Clinician Reported Outcomes (ClinROs) and Observer Reported Outcomes (ObsROs) and for Quality of Life (QOL) questionnaires ("Language Scientific",2018). These are often called "instruments" and include instructions, items (also known as questions) and response categories or response choices to those items/questions. (Language Scientific,2018). The instruments must be accurate, valid and interpretable data for the people's health assessment before it is account as worthy (de Souza, Alexandre, & Guirardello,2017). To ensure that all components of the questionnaire have the same constitute value and are conceptually equivalent across multiple languages and locales is the ultimate goal of linguistic validation ("Language Scientific",2018). Linguistic Validation of Stroke Impact Scale 3.0 is very important. That's why researcher was interested to establish the Stroke Impact Scale 3.0 linguistically valid.

1.2. Justification

Stroke is a neurological condition. Occupational therapy is an important aspect of stroke rehabilitation. Every year many people are affected by stroke and also become disable by stroke. They become functionally dependent on their caregivers or family members. Their quality of life become poor after having stroke. It is highly very important to measure the QOL in stroke. This quality of life includes different dimensions such as physical, cognitive, psychosocial, social. Stroke Impact Scale 3.0 is self-reported instrument which is used to measure QOL of stroke patient. To find out accurate and conceptually equivalent data the instrument should be valid and also linguistically valid. But this Stroke Impact Scale is not valid in Bangladesh. Investigator feel that, this study will help to establish a valid tool for measuring QOL according to Bangladeshi perspective. Occupational Therapist of Bangladesh can use this scale to measure the state of QOL after provide occupational therapy treatment and also can find out in which area and problem they should give more focus for stroke patients. The

beneficial purpose of this research is it will take less time to collect data for the therapist because it will culturally be adapted and the language of this scale will be Bangla. A culturally adapted Bengali version will be necessary in future studies with stroke in Bangladesh.

It is the first study of Occupational Therapy profession in Bangladesh. The study aim is to establish the Linguistic Validation of a stroke impact scale. A Scale or tool or instrument have to be valid before apply for research purpose. Without linguistic validation of an instrument clinical research trials can be rejected due to patient misunderstanding of poorly translated clinical instruments. This Study will consider all the aspect of local language of Bangladesh to meet the patients understanding of each questionnaires and account for actual outcome. This tool also can be used for stroke patients QOL related research as a valid tool. This study will be helpful for the professions and professionals of Occupational therapy and other professionals. Establishing a tools validation will also strengthen the Occupational therapy profession.

1.3. Operational Definition:

Stroke: Strokes are brain attacks. They occur when the blood supply to the brain becomes blocked. The sudden death of brain cells due to lack of oxygen, caused by blockage of blood flow or rupture of an artery to the brain. Sudden loss of speech, weakness, or paralysis of one side of the body can be symptoms. A stroke is a medical emergency that needs immediate medical attention (“What is Stroke”,2018).

Validation: Validity is the credibility of the study or the genuineness of the study. Result of a test should be corrected by ensuring that what is being measured and the tools used to measure are what is required

Linguistic Validity: Linguistic validation is the process by which an instrument or patient questionnaire is simultaneously translated by different translators, both translations are reconciled into a single version and then that version is back-translated by other translators into the original language to evaluate the quality of the reconciled translation in comparison with the source document.

Health related Quality of Life: HRQL is a broad concept of physical, psychological with social functioning and well-being that includes both positive and negative aspects. Health-related quality of life (HRQL) focuses on the impact of health on a person's ability to live a fulfilling life. ("What is Health Related Quality of Life",2015)

Stroke Impact scale: It is a 5-point Likert scale which is used to measure health related quality of life according to point of view of stroke survivors. (Lin et al.,2010). An instrument to measure the effect of a stroke on a person's mobility, speech, social activities, manual dexterity, strength, emotions, memory, and daily activities. SIS is part of a recommended battery of assessments for tracking patient outcomes, the Stroke Toolbox. (Stroke Impact Scale & Stroke Toolbox (SIS V2.0) Duncan PW; Lai SM; Studenski S)

1.4 Research Question

Does the Stroke Impact Scale is linguistically Valid in Bangladesh?

1.5. Aim: To establish the Linguistic Validity of Stroke Impact Scale version 3.0 in Bangladesh

1.6. Objectives

- To understand the actual meaning of each questionnaires from stroke patients through interview
- To identify the linguistic problem which is faced by stroke patients
- To determine that all the data is collected by this scale are clean and conceptually equivalent to the instrument
- To modify non-suitable items from the domain to improve the measurement of impact of stroke
- To identify if there is any additional opinion or question about questionnaire from the patient

Chapter 2: Literature review

Stroke

Stroke is classically characterized as a neurological deficit which is imposed to an acute focal injury of the central nervous system (CNS) by a vascular cause, also including cerebral infarction, intracerebral hemorrhage (ICH), and subarachnoid hemorrhage (SAH), and worldwide it is a leading cause of disability and death. (Sacco et al.2013). It is a "brain attack" and when it happens blood flow to an area of brain is cut off. When this happens, brain cells are deprived of oxygen and begin to die. When brain cells die during a stroke, the area of the brain who perform different types of function, also control different type of functions such as memory or muscle control are being lost. (What is stroke,2018)

When a blood vessel carrying blood to the brain is blocked by a blood clot. This causes blood not to reach the brain ischemic stroke occurs. Ischemic strokes account for about 87% of all strokes., About only 15 percent of all strokes are hemorrhagic as hemorrhagic stroke are less common, but they are responsible for about 40% of all stroke deaths. This stroke is either a brain aneurysm burst or a weakened blood vessel leak. Swelling and pressure creates, and blood spills into or around the brain and damaging cells and tissue in the brain. (National Stroke Association,2018). Transient Ischemic Attack (TIA) include focal insufficiency of an ischemic stroke and a clear vascular disturbance however it is reversible because there is no cerebral infarction occur and it must resolve within 24 hours (Gillen & Burkhardt,2004). Sometimes TIA doesn't cause durable damage, it's often ignored and this is considered as a big mistake. TIAs may act as signal of complete stroke ahead (American Stroke Association,2018). Person who has had a TIA must need a complete evaluation for Cerebrovascular disease and origin of Embolism because 35% of persons become the victim of stroke within 5 years who have had TIAs (Gillen & Burkhardt,2004). Islam et al. (2012) stated that hospital-based studies conducted in past decades have indicated that hypertension is the main cause of ischemic and hemorrhagic stroke in Bangladesh and others reason followed by heart disease (24%), diabetes mellitus (DM) (21%), and hyperlipidaemia

(7%) (Islam et al.2012). In the vascular territory wise, it is very important to know the symptomatology of stroke but this is very complex. For the sake of simplicity, there has some common features which will help to recognize this condition. Stroke patients commonly present with such as hemiplegia/monoplegia which is most common in stroke patients, patient face difficulties in speech (dysarthria/dysphasia) and swallowing, headache, vomiting, Convulsion, blurring of vision/double vision etc. The prevalence and incidence of stroke is increasing day by day in Bangladesh in comparison to developed country. (Mohammad,2013)

Prevalence of Stroke

The prevalence of stroke depends on incidence, mortality, and mean length of survival after stroke (Centers for Disease Control and Prevention,2012). Worldwide stroke is a leading cause of mortality. Stroke is the fifth leading cause of death in the United States, which is killing about 140,000 Americans each year and that is 1 of every 20 deaths. In the United States anyone has a stroke every 40 seconds and estimated that every four minutes, someone dies of stroke (Centers for Disease Control and Prevention,2017). The prevalence of stroke survivors including incomplete recovery has been estimated at 460/100,000, and one third demand care in at least one activity of daily living (ADL) (Opara et al.,2010). Bangladesh is a developing country where stroke has been ranked as the third leading cause of death after coronary heart disease and infectious diseases and the mortality rate of stroke which was 6.00% in 2006 reached to 8.57% in 2011 with an age-adjusted mortality rate of 108.31 per 100 000 people (in 2011) (Islam et al.2012). There is no sufficient data on incidence and mortality from stroke in Bangladesh. Among stroke, ischemic infraction comprises 85% to 90% and 15% to 10% is caused by intracranial hemorrhages in the western world, whereas hemorrhages comprise a larger percentage in Asia (Hossain et al.,2011). Worldwide, this stroke has impact on different dimensions of health-related quality of life (HRQoL) of stroke survivors when an individual attempt to adjust to life (Hamza et al.,2016).

Impact of Stroke

Each and every stroke is unique, but however it is, it tends to affect people in common ways (American Stroke Association,2018). Nayan et al. (2016) reported that in Bangladesh prevalence of stroke is 0.3% and a high number of people which is disability adjusted life years lost because of stroke indicate that stroke severely impacts Bangladesh's economy. A large number of people were affected by stroke and also becoming disable by stroke. It is estimated that 70% of strokes can be restrained and patient's awareness to the risk factors is crucial for stroke prevention (Hossain et al.,2012) Caroline stated that, from stroke the most common types of disability shows restriction in physical activities, imperfect use of limbs, difficulties to grip or hold any type of items, and speech difficulties (AIHW 2011) and stroke is an ongoing burden to the individuals who are affected, and also to the health systems (Fryer et al.,2016). To complete a person's everyday life activities which amount of ability needs, a stroke survivor cannot complete it because of decreased capability, their disease also interfere in social life, damages the independent activities of oneself, which is followed by resultant stress and lower self-esteem. For this reason, a stroke victim's quality of life goes down (Park,2017). Stroke generate a significant burden in an economic and social perspective, and this burden is progressing. Patients mostly demand individualized long-term care and rehabilitation services (Mamin et al.,2017). It gives enhance to an extensive need for care, since it affects human functions, and it's not only disrupts the patient's life but also the lives of the entire family because of its sequelae. Most stroke survivors who are required constant and ongoing care are left with permanent sequelae (Brandão et al.,2017). Stroke survivors who are in position of the third highest length for stay in rehabilitation following spinal cord injuries and brain dysfunction (Sonrasi,2005). There has been usually limitation in neurological impairment and disability on evaluations of stroke. A spectrum of related answers for the many issues surrounding stroke could be provided by measuring the quality of life (QOL) after stroke (Brandão et al.,2017). Stroke disables almost all quality-of-life (QOL) functions, including insufficiency in motor and sensory function and impairments in cognitive function, and can result in poststroke depression, therefore, QOL becomes a significant index of stroke rehabilitation (Lin et al.,2010).

Quality of life of Stroke Patients

QOL as a construct has been assumed as a multidimensional approach which covers the physical, functional, psychological, and social health dimensions and derived its theoretical framework based on modifications from the WHO's International Classification of Impairment, Disabilities, and Handicaps (Mohammad et al.,2014). Stroke is a very prevalent clinical condition that exposes a great economic burden to the society as well as affect to the QOL(Sonrasi,2005). This stroke has a mountainous impact on the patients' lives it also affect on the lives of their caregivers and the carers of stroke patients provide informal custody ranging from physical help to psychosocial support. According to this, the caregivers of stroke patients may experience high levels of burden, associated with characteristics of the patients and of the carers themselves (Pinedo et al.,2017). The person who are suffers from stroke, the consequences of stroke include having to depend on others to perform their activities of daily living (ADL) and disruption of their social life. The reality of stroke exposes a negative impact on the quality of life (QOL) of patients and also of their relatives or family members who usually become their main caregivers (Sonrasi,2005). Moreover, the majority of stroke survivors have incurable stroke related disabilities and require ongoing lifetime assistance. For example, in Australia, it is estimated that the people live in Australia who had stroke merely over a third (131,100) had a disability from their stroke and were significantly more likely to be profoundly limited ("always need help") in core activities (56%) than people with other disabilities (AIHW 2013) (Fryer et al.,2016). Approximately 1/3 of stroke victims will die in the medium term and another 1/3 will recover completely or with minor impairments. Consequently, the rest of the 30-40% will experience moderate to severe impairments which will require special care and skilled care or long-term care facility (Sonrasi,2005). Health-related QOL which is investigated through self-evaluation by patients' broad wise multiple dimensions that are just not limited to physical, social and emotional concepts. QOL which is also become a significant prognostic indicator for stroke, and it enables a broader statement of the disease (Brandão et al.,2017). There are many studies which examining quality of life among patients who are sustaining a stroke have shown that stroke has a detrimental effect on both short-term and long-term health-related quality of life (HRQoL) and that disability is a strong determinant of HRQoL among this group of stroke survivors(Sonrasi,2005).It is very important to know how different dimensions of health related Quality of Life vary over time among the persons who are suffers from

stroke. Henceforth, HRQoL has become one of the key indicators to measure the poststroke outcome (Hamza et al.,2016).

Importance to Measure QOL of Stroke Survivors

In healthcare evaluation, health-related quality of life (HRQoL) and subjective well-being these two outcomes that are being increasingly incorporated, even though functional outcome measures are very important in stroke rehabilitation (Javier et al.,2008). In the last years, Patient outcomes such as self-perception, subjective well-being and health-related quality of life (HRQoL) have been increasingly assimilate to the stroke literature. In a recent search in Medline until March 2008, there is 1,940 articles which were obtained by using the key words ‘quality of life’ and ‘stroke’ (Carod-Artal & Egado,2009). It is very important to learn how various dimensions of HRQoL vary over time among the stroke survivors. Even though, evidence on the consequences of stroke and its determinants on HRQoL among long term stroke survivors had already been generated in developed country; research has been sparse in developing countries (Hamza et al.,2016). There is one way to assess patients’ wellbeing and that is quality-of-life questionnaires. The instruments which is use for measuring quality of life are an obligate way to transform subjective measurements into objective data that can be quantified and analyzed, and are important for checking the impact of interventions on patients’ health and quality of life (Brandão et al.,2017). QOL data in stroke research will prove valuable in providing information and strategies which take advantage by health care providers and professionals in their attempt to improve the QOL of stroke patients with therapeutic interventions (Mohammad et al.,2014). To assess HRQoL in stroke patients suitable and psychometrically tested instruments are still lacking (Javier et al.,2008).To assess QOL may also be expensive in providing researchers/professionals with a global look of recovery following stroke, development of more comprehensive rehabilitation interventions, resource allocation, policy formulation in a resource poor country, planning of rehabilitation services, and specific therapeutics (Mohammad et al.,2014). Stroke Impact Scale 3.0 is a QOL assessment tools which is worldwide use for stroke patients (Kamwesiga. et al.,2016).

Stroke Impact Scale 3.0

The Stroke Impact Scale (SIS) is a stroke specific QOL instrument that measures the consequences of stroke,³ and it has been widely used as the outcome measure to determine the extent and domains of QOL improvement after stroke rehabilitation (Lin et al.,2010). This scale is developed by Pamela Duncan, Dennis Wallace, Sue Min Lai, Stephanie Studenski, Dallas Johnson, and Susan Embretson. This scale is published from University of Kansas Medical Center. This scale required 15-20 to administered with the patients (Javier et al.,2008).The SIS is designed to assess or evaluate physical aspects and dimensions of health-related quality of life: emotion, communication, memory and thinking, and social role function and covers perceptions by the individual with stroke on daily functioning in 8 domains (Guidetti et al.,2014).The strength items are rated in terms of strength; memory, communication, ADLs/IADLs, mobility, and hand function items are rated in terms of amount of difficulty; emotion and social participation items are rated in terms of frequency(Kamwesiga. et al.,2016). To detect consequences of stroke, especially mild to moderate stroke on Quality of Life across multiple It is also designed to track changes over time. The assessment is a self-report questionnaire 5 Likert rating scale from 1 (no deficit) to 5 (large amount of deficit). It has a total of 59 questions (Mohammad et al.,2014). Its administration is very easy, respondents should see as well as hear the question before answering. It can be administered in this like person, mail-administered, or taken by proxy (Lin et al.,2010). According to SIS guideline which was given by Mapi research Trust (2011) its scoring procedure is added up the total raw scores for each domain, add up the lowest possible raw score for the domain and subtract from actual raw score, add up and divide score by highest total possible score for domain and multiple by 100 for final score. This client's score can be compared against the normative score of 50. Calculation is-
[(Actual raw score-lowest possible raw score) /Possible raw score range] x100.This 3.0 version of Stroke Impact Scale has proved valid, reliable and useful in describing changes after stroke. (Guidetti et al.,2014)

Translation and Linguistic Validation

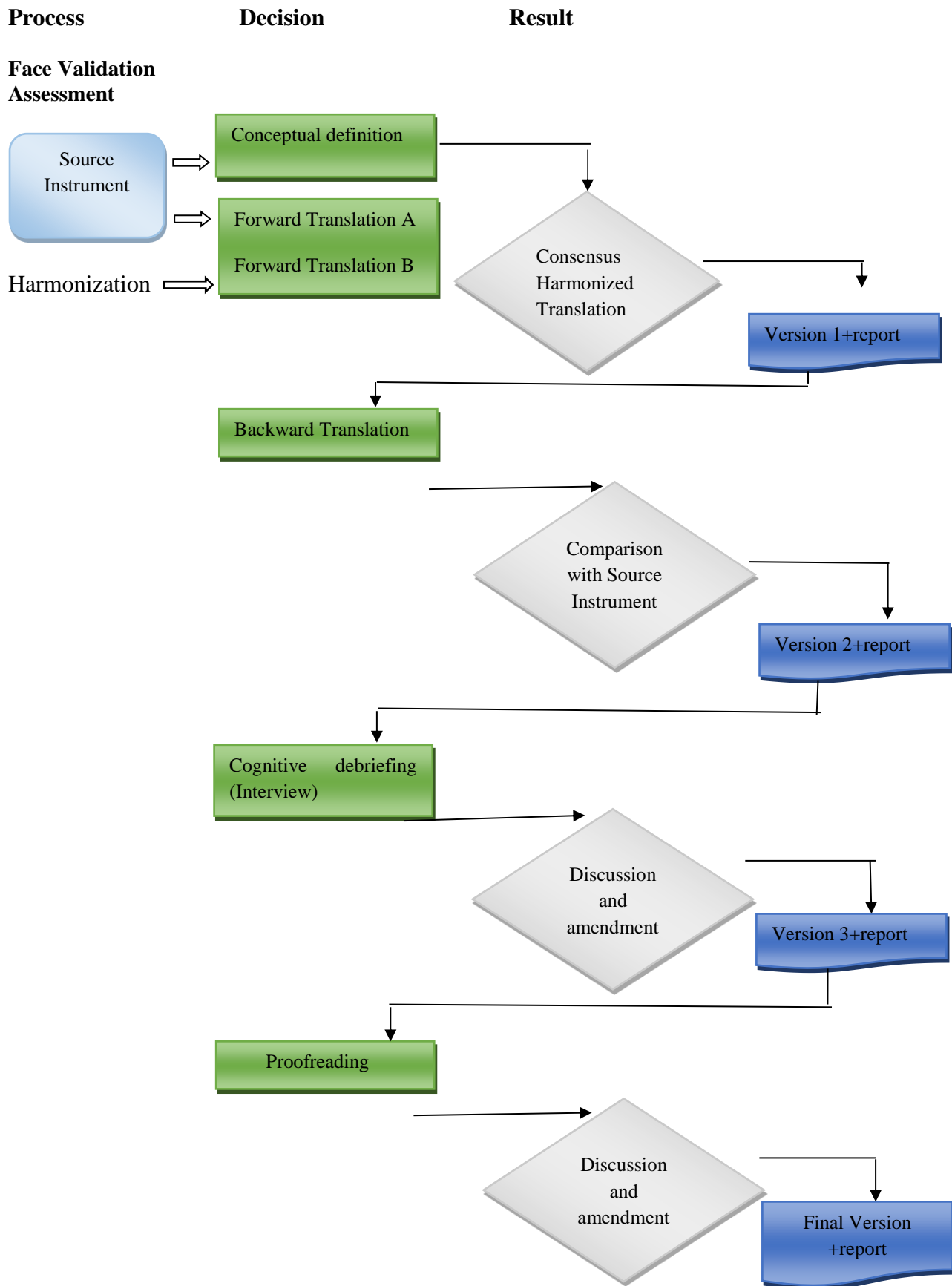
The Translation and Cultural Adaptation (TCA) group met at the ISPOR Third Annual European Congress in Antwerp for the first time in 1999. The Congress was presided over by representatives of the pharmaceutical industry, academia, and contract research organizations (CROs); presented of all participants were either interested or involved in the translation and cultural adaptation of patient reported outcomes (PRO) measures which is use in clinical trials or other forms of outcomes research (Guidetti et al.,2014). The ISPOR Health Science Policy Council authorized and recommended the Translation and Linguistic Validation Task Force in January 2007. This policy was accepted by the ISPOR Board in March 2007(Wild et al.,2005). Literature has alerted researchers for the need of a deep evaluation of the measurement properties of questionnaires. The researcher has to diligently select the adequate and accurate tool, in order to ensure the quality of their research results and it is necessary to know the about the using instruments in details – items, domains, assessment forms, and, specially, measurement properties –, before using them. The quality of the information provided by the instruments depends, at least partially, on their psychometric properties (de Souza, Alexandre, & Guirardello,2017). To increasing internationalization of clinical trials, the need to translate and adapt PRO instruments for use in countries rather than that of the source language has grown rapidly and continues to develop with the increasing involvement of new countries such as India and China in clinical trials. Most of the instruments are developed in English-speaking countries, and therefore, it should be translated and adapted for use in other countries (Wild et al.,2005). A multi-professional committee form with five experts who carried out the translation and linguistic validation of the SIS 3.0 in accordance with the Mapi Research Institute format and guidelines for cultural adaptation of questionnaires (Hamza et al.,2014). The Linguistic Validation followed an internationally-accepted translation methodology and was performed using a well-recognized methodology which includes of the following standard steps-

Forward Translation

The destination of this step is to produce a version in the target language which is close to the original questionnaire in meaning and also close in conceptually. The process includes the concepts of each item in the original questionnaire are clearly defined in collaboration with the author and ensures that translators in various languages have a common understanding of the concepts and items, thereby ensuring that the translations continue faithful to the original meaning (Hamza et al., 2014). Two professional translators, native speakers of the target language and fluent in the source language, take on independent forward translations of the original questionnaire into the target language. A reconciled language version is developed on the basis of that two forward translations (Seventer et al., 2010).

Backward Translation

A backward translation of the reconciled language version is obtained in the source language by a professional translator who is a native target language speaker and fluent in English, and had no prior knowledge of the instrument. Then the backward translated version is compared with the original instrument by the multidisciplinary team leading to the production of the second reconciled version in target language. Similarly, during this process, translation discrepancies and linguistic issues arose, and modifications has made accordingly (Hamza et al., 2014)



Algorithm of the linguistic validation processes

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Clinical Review and Cognitive Debriefing (Pilot testing)

The second version of the questionnaire (obtained after backward translation) has to undergo cognitive debriefing. The subjects should be native speakers of the target language. The apprehension test should be performed through individual interviews during which the interviewer should inquire whether the participant had any difficulty in understanding the questionnaire and check the participant's interpretation of all items (Kamwesiga. et al.,2016). In case of any issue, the interviewer can mention or test alternatives of translations (if this issue has been anticipated), or ask the participant to propose alternatives.

A report on the interviewed should be produced in English: it should determinant the number of subjects interviewed, their age, the difficulties encountered, the solutions suggested and retained and how the third version of the questionnaire was produced (Seventer et al.,2010).

Proofreading

This stage avoids any typing, spelling or grammatical mistakes remain in the most recent target language version. This proofreading of the third version of the questionnaire has done by a proofreader whose native language is the target language and who is skillful in English. Production of the ultimate target language version together with a report on the proofreading step (Kamwesiga. et al.,2016)

Practical Details

Linguistic validation process is time-consuming rather than a single straightforward translation. This requires sufficient time to plan for each step for the production of the translations, meeting with the translators, interviews with patients, discussions and production of reports. According to the Guideline of Mapi research trust (2018) require this minimum timeframe-Forward translation step (2 weeks), Backward translation step (2 weeks), Testing on patients (3 weeks) and Proofreading and finalization (1 week).

Chapter 3: Methodology

3.1. Conceptual Framework:

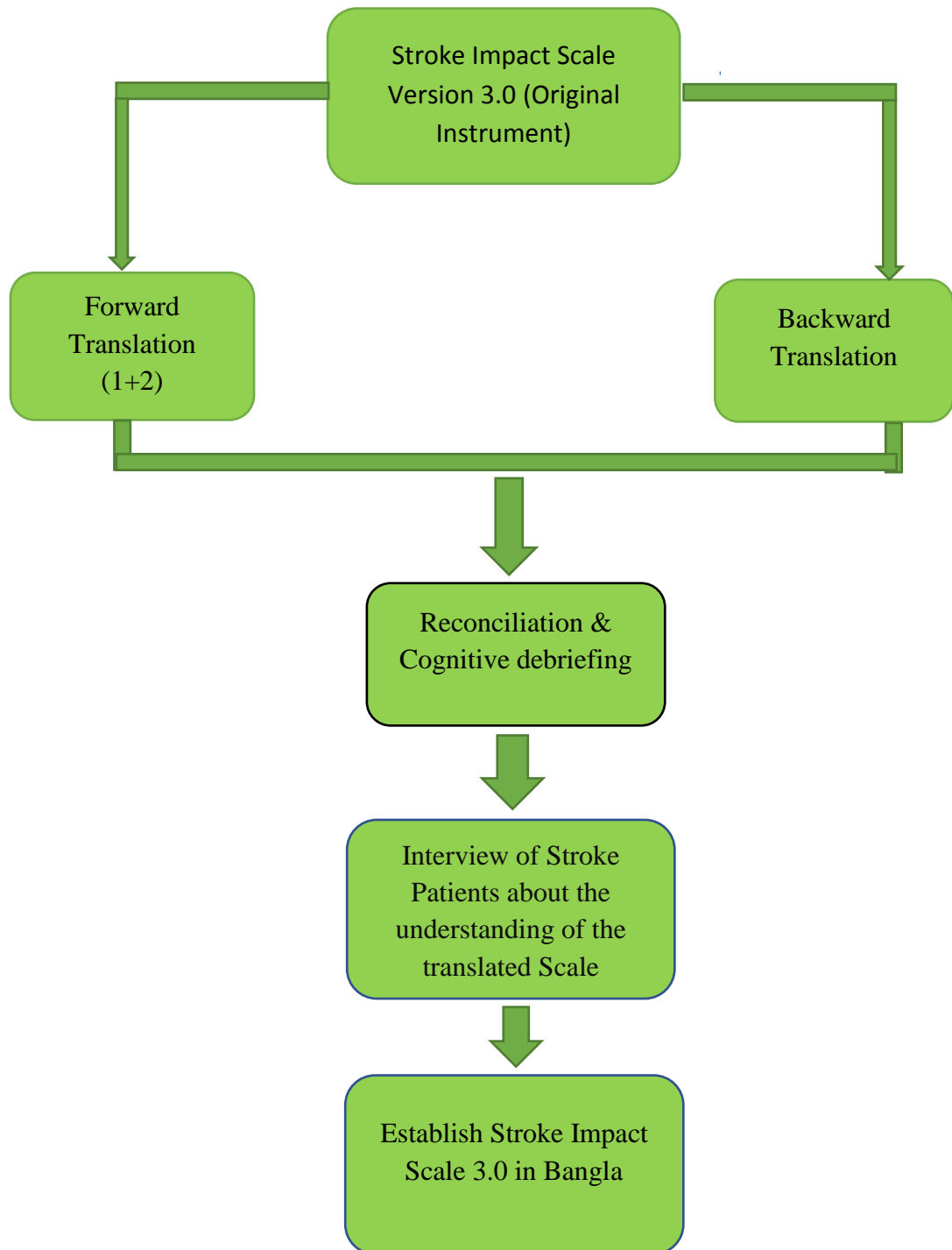


Figure: Conceptual Framework

3.2. Study Design:

Permission was accessed for the cultural adaptation and linguistic validation of the SIS 3.0 into Bangla from the original questionnaire developers and the copyright owners (Duncan et al.,2003)²³ via Mapi Research Trust (Lyon, France). Native-speaking citizens of the target countries who reported stroke related problems were asked to review a translation of the SIS 3.0 questionnaire, which was harmonized in Bengali languages. During a cognitive debriefing interview, participants were asked to identify any words that were difficult to understand and explain in their own words the meaning of each sentence in the questionnaire. The qualitative content analysis was conducted by local linguistic validation teams (original translators, back translator, clinical occupational therapist, interviewer, and another expert). Qualitative research refers to an understanding of the human condition in different contexts and of a perceived situation. In 1952, Berelson defined content analysis as “a research technique for the objective, systematic and quantitative description of the manifest content of communication” (Bengtsson,2016). This is a methodological study with a view to translation and linguistic validation of the Stroke Impact Scale- Version 3.0, following the particular steps of this method: initial translation, translation synthesis, back-translation, review by a committee of judges and finally, pretest of the final version(Reis et al.,2015).In order to successfully complete the present study, permission to use the index was taken from the Mapi Research Trust by email. The translated version was back-translated into the original language by a blind procedure, in which the translators did not have access to the English version (original) of the index. The two translators responsible for the back-translation were bilingual, with English as mother tongue, and were informed of the concepts explored.

3.3. Study population

The study population was the stroke survivors of Bangladesh who has at least one-month stroke incident.

3.4. Study setting

This study was conducted in Centre for the Rehabilitation of the Paralysed (CRP) (Neuro rehabilitation unit). For data collection the researcher used that places which were recommended by the participants and where the participants feel comfortable to express their experiences.

3.5. Study period:

The period of this study was from August, 2018 to April 2019. However, the researcher got time to collect data from 1st January to 30th January, 2019.

3.6. Sample size

The aim of this study was to establish the Bangla version of this scale according to culture of Bangladesh. The researcher used purposive sampling for this study who met the inclusion criteria. Purposive sampling usually used to get in depth information of an issue. (Goyal,2013). The purposive sampling technique, also called judgment sampling, is the deliberate choice of a participant due to the qualities the participant possesses. It is a nonrandom technique that does not need underlying theories or a set number of participants. (Etikan et al.,2016). Data was collected from a wide range of population. For this study,12 participants were selected. Purposive sampling according to criteria to conduct the study and the sample.

3.7. Inclusion criteria

- All men and female stroke survivors
- Both Ischemic and Hemorrhagic strokes have included
- Stroke survivors who has at least one-month experience of stroke

Exclusion criteria:

- Patients with transient Ischemic Attack
- Impaired ability to understand the questionnaires (e.g.-due to severe aphasia, dementia, or decreased level of consciousness)
- Stroke with cognitive impairment
- Severe illness

3.8. Sampling Technique:

Investigator selected purposive sampling technique to collect data. The investigator selected stroke survivors as sample for this study purposively based on inclusion criteria. This technique was selected because it involves the deliberate selection of the individuals by the investigator based on pre-defined criteria and getting of those sample whose criteria were concerned with the study purpose. Purposive sampling method is used in qualitative studies to study about experienced of a specific population by using specific selection criteria. Purposive sampling is a non-probability sampling method which occurs when elements selected for the sample are chosen by the judgment of the researcher. (Etiken et al.,2016)

3.9. Data collection tools/ materials

- Audio recorder was used to record interview of the participants for judgment and it is the most appropriate method for recording interview.
- Paper and pen were used to write down the observation note or any other information that was obvious needed to research study.
- Bangla Stroke Impact scale 3.0 and questionnaires
- Consent form & Information sheet
- Clip board
- Mobile phone for recorder

3.10. Data collection methods

All data of this research was collected through face-to-face in-depth interview by using a semi-structured research question. In this study, the investigator has explored the experience of understanding of translate Stroke Impact Scale 3.0. In-depth interview has conducted in this study to collect data thoroughly from the participants. With in-depth interview participants would be given freedom to explain their feelings and experience or perception in their own words. This interview procedure would provide the opportunities to observe the facial expression of participants and would help the investigator to determine their understanding of the questions. The question was written in Bengali so it would be easily under stable for all participants. The researcher started from the initial stage of the data collection procedure. At first, the researcher would verbally present the details of the study such as, aim, objectives and purpose of the study then explain the rights, roles, benefits and importance of the written consent form in a descriptive way and arranged the interview in a suitable place. Before starting the interview, the researcher asked the participants about the place of interview. When the participant agreed with the researcher and they felt comfort with the place, then the researcher started to interview. During the interview, a recorder was used to record the conversations and discussion between the participants and interviewer. Recorder, paper and pens also used during interview for writing the additional information from the participants

3.11. Data management and analysis

The researcher selected Qualitative Content Analysis (QCA) method for analyzing data. QCA follows the three steps (coding, categorizing and generating theme) to present the result of the study. Qualitative methodologies contribute the philosophical perspectives, assumptions, postulates, and approaches which are serve to render their work open to analysis, critique, replication, repetition, and/or adaptation and to choose research methods by researchers(Bengtsson,2016).Bloor and Wood,2006 stated that the purpose of content analysis is to describe the characteristics of the document's content by examining who says what, to whom, and with what effect (Vaismoradi et

al.,2013).At first researcher complete forward, backward cognitive debriefing and pilot testing. Then the analysis of data began with transcription of interviews. At first the researcher transcribed the entire interview in Bangla from recordings. By formulating the transcription, it was given to 2 individuals who are competent in English to translate the data from Bangla to English. Then the researcher verified the data and read several times to find out theme.

The researcher organized the data according to each interview questions. Then each participants answer was analyzed and find out some major categories and under those major categories some coding were come out. Each coding was separate from other coding. Then themes are taken from categories and coding. The researcher found four categories in this study by content analysis. These are-

Category:01. Understanding the actual meaning of each questionnaires.

Category:02. Additional opinion or question about the translated questionnaire

Category:03. Identify difficulties to understand the sentence or word.

Category:04. Collected data by translated scale were clean and conceptually equivalent to the environment.

Category:05. Modify non-suitable and challenging item from the questionnaires.

Summary of Data Analysis

Objectives	Code	Categories	Theme
To understand the actual meaning of each questionnaires to the patients	Research Questionnaires 01	Understanding the actual meaning of each questionnaire	Participants were able to understand the actual meaning of each questionnaire.
To identify the linguistic problematic which is face by patient	Research Questionnaires 04	Identify difficulties to understand the sentences and word	As all of the questions was in Bangla it was easy to understand.
To determine that all the data collect by this scale are clean and conceptually equivalent to the instrument	Research Questionnaires 01	Collected data were clean and conceptually equivalent to the environment	Participants answer was directly related to the question and indicate actual answer to the questions.
To modify non-suitable items from the domain to improve the measurement of impact of stroke	Research Questionnaires 03	Modify non-suitable and challenging items from the Questionnaires	There was no word which would objectionable and feel comfort to answer all of the questions.

To identify if there is any additional opinion or question about questionnaire from the patient	Research Questionnaires 02	Identify additional opinion or question about questionnaire	Participants have not any type of opinion or question about questionnaire
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Table-3.1: Summary of data analysis

3.12. Quality control & quality assurance

All data collection should be appropriately done with the concern of respective supervisor along with follow all instructions. It must be ensuring that, the methods which have been using there that's are validated fit for the purpose before use the text. From the beginning of data collection, the researcher completed a field test with 2 participants for the survey question, and face- to - face interviews conducted to ensure whether them question and translated scale were understand by the participants. It is important to carry out a field test before collecting the final data because it helps the researcher to refine the data collection plan and to justify the reliability and validity of the questionnaire fit with Bangladeshi context. This field test was performed to identify any difficulties that exist in the questionnaires. Then the researcher got chance to rearrange the questionnaires to make it more understandable, clear and enough for the participants and the study.

3.13. Ethical considerations

The researcher has maintained some ethical considerations like:

- The researcher got permission from the ethical committee to conduct the research.
- Ethical consideration has ensured by means of an informed consent letter from BHPI and IRB.

- Every personal data (e.g. name, address) has recorded and it must be confidential.
- All sources have cited and acknowledged appropriately.
- All participants were informed about the aim of the study.
- A written consent form which has written in Bangla (Appendix 3) used to take the permission of each participants of the study.
- The researcher has ensured that all participants were informed about their rights and reserves and about the aim and objectives of the study.
- All kinds of confidentiality would be highly maintained. The researcher would have to ensure not to leak out any type of confidentialities.
- The researcher would be eligible to do the study after knowing the academic and clinical rules of doing the study about what should be done and what should not be.
- All rights of the participants would be reserved and researcher was accountable to the participant to answer any type of study related question

3.14. Field test: A field test was conducted with two participants. Before the time of final data collection, it was necessary to conduct a field test to help the researcher for purifying the data collection plan

3.15. Rigour

This study was conducted through rigorous manner or trustworthiness. The entire study was carried out in a systematic way by following research steps under the supervision of an experienced supervisor. At the time of data collection and data analysis, the researcher never be biased and never tries to influence the result by her own value or perspectives. The researcher accepted all the answers of the participants whatever the participants delivered. The researcher prepared transcript from the field notes and audio recording. Soon after the interview it was written. Translation has completed by three people to avoid biasness then researcher completed the same translation and record to reduce mistake and compare it with the Bangla transcript. The researcher has checked translated data for several times so that all information would be include. All of notes kept safe to maintain confidentiality. In the result chapter, the researcher would not influence the result by personal view.

Result and Discussion

4.1. Result

In this result chapter, it has presented that, during cognitive debriefing interview Which issues regarding SIS 3.0 were identified with patients are shown with a table. All the item of the scale was defined with patient’s comprehension. Also showed the questions which needed to be revised. The qualitative analysis was also conducted by local linguistic validation teams (original translators, back translator, clinical occupational therapist, interviewer, and another expert).

Table 4.1.1. Issues regarding SIS 3.0 Questions identified in cognitive interviews with patients (n=12) and item revised

Items in the English version	Patients comprehension of the pre-final Bangla Stroke Impact Scale 3.0	Questions revised
Q1. In the past week, how would you rate the strength of your....	Overall Good comprehension (12/12).3-4 patients were also rate their strength by percentage.	No
1.a. Arm that was most affected by your stroke?	Good comprehension by all patients (12/12). The word “weak hand” are felt more comfort rather than “affected “word at least to 6-7 patients.	No
1.b. Grip of your hand that was most affected by your stroke?	Good comprehension by all patients (12/12).	No
1.c. Leg that was most affected by your stroke?	Good comprehension by all patients (12/12).	No
1.d. Foot/ankle that was most affected by your stroke?	Good comprehension by all patients (12/12).	No
Q2.In the past week, how difficult was it for you to...	Good comprehension by all patients (12/12).	No

2.a. Remember things that people just told you?	Good comprehension by all patients (12/12).	No
2.b. Remember things that happened the day before?	Good comprehension by all patients (12/12).	No
2.c. Remember to do things (e.g. Keep scheduled appointments or take medication)?	Overall good comprehension. All patient except 1 was clear about examples (11/12).	No
2.d. Remember the day of the week?	Good comprehension by all patients (12/12).	No
2.e. Concentrate?	Overall good comprehension (10/12). But two patients did not understand. Patient was confused that if it is whether holding concentration or being attentive.	Yes
2.f. Think quickly?	Good comprehension by all patients (12/12). But 1-2 patients felt difficult to identify that.	No
2.g. Solve everyday problems?	Good comprehension by all patients (9/12). But 2-3 patients could not indicate the everyday problem. They became confused between usual problem or significant problem.	Yes
Q.3. In the past week, how often did you...	Good comprehension by all patients (12/12).	No
3.a. Feel sad?	Good comprehension by all patients (10/12). But 3 patients stuck with that it is “feeling cry”.	No
3.b. Feel that there is nobody you are close to?	Good comprehension by all patients (12/12).	No
3.c. Feel that you are a burden to others?	Good comprehension by all patients (12/12).	No
3.d. Feel that you have nothing to look forward to?	Good comprehension by all patients (12/12).	No
3.e. Blame yourself for mistakes that you made?	Good comprehension by all patients (12/12).	No
3.f. Enjoy things as much as ever?	Good comprehension by all patients (12/12). But most of the patient feel sad when they answer this question.	No

3.g. Feel quite nervous?	Good comprehension (10/12) However, this nervous is not commonly used in local community. They understand this as being angry.	Yes
3.h. Feel that life is worth living?	Some patients felt difficulties to understand this question (9/12).	Yes
3.i. Smile and laugh at least once a day?	Good comprehension by all patients (12/12).	No
Q.4. In the past week, how difficult was it to...	Good comprehension by all patients (12/12).	No
4.a. Say the name of someone who was in front of you?	Good comprehension by all patients (12/12).	No
4.b. Understand what was being said to you in a conversation?	Good comprehension by all patients (11/12). Some patients mixed between if he understands others talk and understand what was saying to him.	No
4.c. Reply to questions?	Good comprehension by all patients (12/12).	No
4.d. Correctly name objects?	Good comprehension by all patients (12/12)	No
4.e. Participate in a conversation with a group of people?	Good comprehension by all patients (12/12).	No
4.f. Have a conversation on the telephone?	Good comprehension by all patients (12/12).	No
4.g. Call another person on the telephone, including selecting the correct phone number and dialing?	Good comprehension by all patients (12/12).	No
Q.5. In the past 2 weeks, how difficult was it to...	Overall good comprehension by all patients.	No
5.a. Cut your food with a knife and fork?	Patients were not known with cutting food with fork and knife. The Bangla term “Eating management by using hands” as a replacement and showed good comprehension (3/12)	Yes

5.b. Dress the top part of your body?	Overall good comprehension by all patients (12/12).	No
5.c. Bathe yourself?	Overall good comprehension by all patients (12/12).	No
5.d. Clip your toenails?	Overall good comprehension by all patients (12/12).	No
5.e. Get to the toilet on time?	Overall good comprehension by all patients (12/12)	No
5.f. Control your bladder (not have an accident)?	Good comprehension by all patients (12/12).	No
5.g. Control your bowels (not have an accident)?	Good comprehension by all patients (12/12).	No
5.h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	Good comprehension by all patients (12/12).	No
5.i. Go shopping?	This question for most of the female patient was not suitable as they are housewives, lives in rural area and they did not go for shopping. However, when asking “go for buying vegetables just near to their house” showed good comprehension (7/12)	No
5.j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	Overall good comprehension. But example “Vacuum” is not commonly used in Bangladesh. However, the term “Cleaning” for its replacement showed good comprehension (9/12).	Yes
Q.6. In the past 2 weeks, how difficult was it to...	Good comprehension by all patients (12/12).	No
6.a. Stay sitting without losing your balance?	Overall good comprehension (9/12). This “Balance” word can be difficult to understand so “Support” is added with this.	No
6.b. Stay standing without losing your balance?	Good comprehension by all patients (12/12).	No
6.c. Walk without losing your balance?	Good comprehension by all patients (12/12).	No
6.d. Move from a bed to a chair?	Good comprehension by all patients (12/12).	No

6.e. Walk one block?	Most of the patient did not understand. However, the term “area/village/ around your home “for its replacement showed good comprehension (4/12).	Yes
6.f. Walk fast?	Good comprehension by all patients (12/12).	No
6.g. Climb one flight of stairs?	Good comprehension by all patients (12/12).	No
6.h. Climb several flights of stairs?	Good comprehension by all patients (12/12).	No
6.i. Get in and out of a car?	Good comprehension by all patients (12/12).	No
Q.7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	Overall good comprehension by all patients (12/12).	No
7.a. Carry heavy objects (e.g. bag of groceries)?	Good comprehension by all patients (12/12) .	No
7.b. Turn a doorknob?	Good comprehension by all patients (12/12).	No
7.c. Open a can or jar?	Good comprehension by all patients (12/12).	No
7.d. Tie a shoe lace?	Good comprehension by all patients (12/12).	No
7.e. Pick up a dime?	Good comprehension by all patients when it is replaced with coin (12/12).	No
Q.8. During the past 4 weeks, how much of the time have you been limited in...	Overall good comprehension by all patients (12/12).	No
8.a. Your work (paid, voluntary or other)	Good comprehension by all patients (12/12).	No
8.b. Your social activities?	Some patients did not which activities indicate as social activities. However, for this added some example to clarify the social activities and showed good comprehension. (4/12).	Yes

8.c. Quiet recreation (crafts, reading)?	Some patients did not understand. The term “Leisure” for its replacement showed good comprehension (5/12).	Yes
8.d. Active recreation (sports, outings, travel)?	Good comprehension by all patients (12/12).	No
8.e. Your role as a family member and/or friend?	Good comprehension by all patients (12/12).	No
8.f. Your participation in spiritual or religious activities?	Good comprehension by all patients (12/12).	No
8.g. Your ability to control your life as you wish?	Good comprehension by all patients (12/12).	No
8.h. Your ability to help others?	Good comprehension by all patients (12/12).	No
Q.9. Stroke Recovery (On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?)	Overall good comprehension by all patients. All patients except 2-3 patient were rate their recovery percentage (12/12).	No

On the other hand, in result and discussion chapter, it has presented the result of the research study and presented the findings by using different literature. In qualitative studies, it is usually common practice to present result and discussion together in one section. The result part of this section has described as completely so that it is possible to judge the findings of the study. By using tables and figures it has demonstrated the findings of the study.

4.1.2. Major themes that emerged from the study:

Theme One: Participants were able to understand the actual meaning of each questionnaire.

Theme Two: As all of the questions was in Bangla it was easy to understand.

Theme Three: Participants answer was directly related to the question and indicate actual answer to the questions.

Theme Four: There was no word which would objectionable and feel comfort to answer all of the questions.

Theme Five: Participants have not any type of opinion or question about questionnaire

4.2. Discussion

In this discussion session it would be easy to understand the participants comments which used as codes because under each table the interview findings are described. The tick was given only for those columns where the participants spoke about that issue. Here “p” was used for participants. At each table the interview findings are described with coding.

Table - 4.2.1. Category: Understanding the actual meaning of each questionnaire

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Questions are clear and understandable	√		√	√	√		√	√	√	√	√	√
Questions are taken short time to understand actual fact.		√				√						

The participants were asked for their understanding about the questionnaire which was used to translated. Most of the participant said that all of the questionnaire of the translated scale was understandable. Another participant also said that it takes short time to understand the questionnaires.

One participant said-

“I have understood all the questions clearly what you mean...”

Another Participant said-

“The questionnaires you have asked me I understand quickly...”

Overall participants understand the question and their actual meaning.

A study mentioned that, Translation of instruments consent for more current and idiomatic usage. There will be significant much less risk that patients will misunderstand wording used, including terms used for cultural references. This translation in target language might be very important and related for older patients who are accustomed or habituated to more traditional language with fewer loan words rather than other countries languages. Require time schedule may be reduce than with the worldwide approach because time is not spent waiting for consensus from all country representatives. (Wild et al.,2005)

Table - 4.2.2. Category: Identify difficulties to understand the sentences a

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
There have no difficulties to understand the questionnaires	√		√	√						√	√	√
All the questionnaires' was in Bangla so there are no difficulties to understand in questionnaire		√				√	√	√	√			

From this table seen that, most of the participant do not face any type of linguistic problem to understand or give answer to the questions.

Participant 3 said that-

“No, there was no problem to me to understand. I have understood properly...”

A study stated that- The aim of the linguistic validation is to consider all cultural context and a simple grammatical issue. A simple grammatical issue can change the meaning of the questionnaires. (Hamza et al.,2012)

Participant 7 said that-

“As you asked me all of the questionnaires' in Bangla, so I don't face any difficulties...”

The translated linguistically validated scale in target language will be helpful to assess the and patients Quality of life and helps in clinical practice, research, public health, and primary health care in Bangladesh. (Arafat,2016)

Table - 4.2.3. Category: Collected data were clean and conceptually equivalent to the environment

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
As questions were clear, understand the actual meaning of the questionnaires	√	√	√	√	√	√	√	√	√	√	√	√

From this table seen that, all of the participants data which are collected by translated scale was clean as the participants answer was directly relevant to the questions and indicate actual meaning to the questions.

One participant said that-

“I understand your questions that you want to understand me...”

Cultural adaptation of patient reported outcome (PRO) instruments using standard procedures is becoming increasingly important day by day in different countries and across different cultures. This is to ensure the optimal disposal of the original and actual message and indicate to measuring what is actually intended to be measured. (Hamza et al.,2012)

One study revealed that, as clinical trials are increasing in number in most of countries, it becomes necessary to select the language versions required for PROs effectively. Most of the instruments are developed in English-speaking countries, and therefore, the instruments translation and adaptation for use in other countries are extremely needed to expose the actual fact of the instruments. (Wild et al.,2009)

Table - 4.2.4. Category: Modify non-suitable and challenging items from the Questionnaire

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
There was no objectionable or irritative question among the questionnaires	√		√	√	√	√		√	√	√	√	√
Since the purpose for asking questions was clearly defined, did feel bad or uneasy about the questionnaire.		√					√					

From this table seen that, maximum participants did not feel uneasy or feel irritate to answer the questions. There was not present any type of question which seems to be objectionable or annoying questions to the participants.

Participant 6 said that-

“I have no objection and don’t feel bad about your questionnaires...”

To be linguistically valid and translate a questionnaire into a version from one language to another language is not straightforward, and differences in cultures and customs among the populations who use each language have to be considered during translation. (Reis et al.,2015)

Participant 02 said that-

“You, already told me your purpose and it is for your educational purpose, I did not feel bad...”

Any type of measurement error source that would be exposed through the translation process and minimized by identify questionable items, terms, or response options that were either hard to understand or misconceived by the respondents during their interview. Because the response choices of the words may affect the translation of the items, (Brandão et al.,2017)

Table- 4.2.5. Category: Identify additional opinion or question about questionnaire

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
There has no opinion about the Questionnaire which has asked.	√	√	√	√		√	√	√	√	√		√
This questionnaire is for well-being, so there is no opinion.					√						√	√

From this table seen that, participants have no additional opinion or say about the questionnaire. They feel that it is for their well being and they show interest to answer the questions.

One Participant said that,

“I have no opinion about these questionnaires, all question is good...”

One study stated that Respondents or participants better comprehend the meaning of the expressions when they understand the questions. (Guidetti,2014)

One participant said that-

“You are asking these questions for my benefit, so I have no opinion about your questionnaire.”

The same question is asked to all type of patients; therefore, there is less likelihood of bias from asking differently worded questions. There may be practical and logistical advantage in only having one language version available. (Wild et al.,2009)

4.3. Domain description of the translated scale

Translation and Transcultural Adaptations of Stroke Impact Scale 3.0 (the linguistic validation process)

The recommendation of 5 stage from MAPI's which consists of translation, synthesis, back translation, expert committee review and pilot testing was used. A multi-professional expert committee was included to complete the translation process.

Forward Translation

The translation was completed by two bilingual translators, whose mother tongue was Bangla and who were efficient in English. The two translators worked independently to prevent influence on each other's translation. The investigator had meeting with expert for review and comparison of the two drafts. The two drafts were then reconciled and the investigator and expert committee decided on which translation was more equivalent to the original meaning and appropriate for Bangla speakers. A single reconciled Bangla version was obtained thereafter.

Backward Translation

This translation of the reconciled language version was done in the source language (U.S. English) by a translator who was a native Bangla speaker and fluent in English, and had no prior knowledge of the instrument. The backward translated version was compared with the original SIS 3.0. During this process, translation clash and linguistic issues arose, and modifications were also made accordingly.

Pilot testing

Pilot testing was conducted with 12 stroke patients. Took average of about 15-20 minutes to complete the questionnaire and conduct this testing to ensure the acceptability of the scale.

Final Translation of the Domain

Title of the Instrument: “Stroke Impact Scale (SIS) 3.0”

The title of the scale in Bangla Language literally translated into” স্ট্রোক প্রভাব নির্ণয়ের মানদণ্ড - সংস্করণ ৩.০”

Domain Description (Terms and Reflexion Within the Items)

Culturally sufficient equivalents had to be found for the terms and expressions which were identified as problematic by the committee and replacement and added similar word for better understanding were agreed upon.

Respondents easily comprehend the meaning of the expressions when they are alternatively stated as the phrases following the arrows as illustrated below:

- Arm that was most affected by your stroke in Bangla translated and adapted in - স্ট্রোক দ্বারা আপনার যে হাত সবচেয়ে বেশি দুর্বল / আক্রান্ত হয়েছে?
- Stay sitting without losing your balance in Bangla translated and adapted as- ভারসাম্য না হারিয়ে বা সাহায্য ছাড়া বসে থাকা?
- Cut your food with a knife and fork in Bangla translated and adapted in- ছুরি এবং কাটা চামচ এর সাহায্যে খাবার কাটা? / হাত ব্যবহারের মাধ্যমে খাবার ব্যবস্থা পরিচালনা করা?
- Walk one block in Bangla translated and adapted in- নিজের এলাকা বা কলোনি বা বাড়ির আশেপাশে হাঁটতে পারা?
- Concentrate in Bangla translated and adapted in – মনোযোগ ধরে রাখা ?

- Solve everyday problems in Bangla translated and adapted in – প্রতিদিনের সাধারণ সমস্যা সমাধান করা?
- Feel quite nervous in Bangla translated in- কিছুটা রেগে/ ঘাবড়ে যান?
- Open a can or jar in Bangla translated in- বয়্যম বা কৌটা খুলতে পারা?
- Your social activities in Bangla translated and added example for understanding in a while- সামাজিক কার্যক্রম? (মসজিদে যাওয়া, বন্ধুদের সাথে ঘুরতে যাওয়া, আত্মীয়-স্বজন এর বাড়িতে যাওয়া ইত্যাদি)
- Quiet recreation (crafts, reading) in Bangla translated in- অবসর সময় কাটানো (কারুশিল্প, বই পড়া)?
- Active recreation (sports, outings, travel) in Bangla translated in- বিনোদন (খেলাধুলা, বাইরে যাওয়া, ভ্রমণ)?

Response Options

Throughout the linguistic validation process there were no difficulties encountered regarding the response options.

Chapter 5: Conclusion

5.1 Limitation

Limitations are potential weaknesses in a study and are out of control (Simon, 2011). There is a single limitation which was the researcher absolutely taken into account during the time of study. Researcher tried to best systematic way to conduct the research. By considering these limitations, the researcher conducted this study. The limitations are given below:

- Lack of time, reliability and validity of this scale could not be produced
- In Bangladeshi context, it is a new study. So, there was a lack of available information related to this study such as, research study

As a result, there are many strength points of this study such as researcher tried to find out related literature about just linguistic validation and establish a linguistically valid tool for the use of Occupational therapist in clinical setting in Bangladesh. This study is absolutely directed as a new conception in the context of Bangladesh. That was why there are no such type of work has been found to compare with the study in Bangladesh.

5.2 Conclusion

Stroke might have substantial adverse effects on activities of daily living and well-being (Jenkinson,2013). Stroke can limit a person's general life activity and can limit or decrease Quality of life. Worldwide Stroke impact scale 3.0 vastly used to assess QOL of a stroke patient. To know about a person's quality of life in depth should consider their language. Because by their own language a person can describe herself and her circumstance. This study aimed to perform the linguistic validation of this scale.

The participants of this study are indicated that they have not face any type of difficulties to answer the questionnaires. They feel easy to understand the questionnaires. They don't feel any type of hesitation to answer the question of the Bangla Stroke Impact Scale 3.0.

In Bangladesh, Valid tool of patient reported outcome instruments can improve Occupational Therapy profession by accurately measuring patient's quality of life. Also, can apply a valid tool for research purpose.

5.3 Recommendation

Linguistic validation is very important for health professionals. Every health professions should use a valid tool for clinical practice. It will enhance their validity of their clinical practice. Recommendation for this study should be-

- Further Reliability and validity should be performed.
- Sample size should increase for further research.
- Stroke related all the other instrument should valid and culturally adapted.
- Validation studies should increase in number.

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Appendix A

Approval Letter from IRB

**বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)**
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

CRP-BHPI/IRB/10/18/1238 Date: 17/10/2018

To
Afsana Arafine
B.Sc. in Occupational Therapy
Session: 2014-2015, Student ID: 122140166
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of thesis proposal "Linguistic Validation of Stroke Impact Scale Version 3.0 in Bangla Language" by ethics committee.


Dear Afsana Arafine,

Congratulations,
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the Principal investigator. The following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Dissertation Proposal
2	Questionnaire (English and Bengali version)
3	Information sheet & consent form.

Since the study involves "Stroke Impact Scale Version 3.0 Questionnaire" questionnaire that takes 20 to 25 minutes and have no likelihood of any harm to the participants, the members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 09:00 AM on September 1, 2018 at BHPI.

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

Muhammad Millat Hossain
Assistant Professor, Dept. of Rehabilitation Science
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন : ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স : ৭৭৪৫০৬৯
CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org

Appendix B

Approval Letter from Author



afsana arefin <afsana.ot18.edu@gmail.com>

152405: Translation Agreement for SIS scale

3 messages

Djebabli, Farah <Farah.Djebabli@iconplc.com>
To: afsana arefin <afsana.ot18.edu@gmail.com>

Tue, Oct 16, 2018 at 6:20 PM

Dear Afsana,

You are now authorized to perform the translation of the SIS 3.0 in Bengali for Bangladesh.

Please find attached the material to be used for your translation:

- US English original versions
- Linguistic validation guidelines

You can use the English original versions of the SIS as templates for your translations.

We greatly appreciate your collaboration and hard work; it will be extremely useful to future researchers wanting to use the Bengali for Bangladesh version of the SIS in future studies.

I would be very grateful if you could inform me if you decide to abandon this translation.

We wish you all the best in translating and in your research. Please do not hesitate to contact me if you have any questions.

I would be most grateful if you could please kindly confirm safe receipt of this message and documents attached.

Best regards

Farah Djebabli
Information Resources Specialist

Tel: +33 (0)4 72 13 66 66
Farah.Djebabli@mapi-trust.org
www.mapi-trust.org, <https://eprovide.mapi-trust.org/>

Please, note my email address has changed to Farah.Djebabli@mapi-trust.org Please update your directory with my new information



Appendix C

Informed Consent Form for the Stroke Patients

Title: Linguistic Validation of Stroke Impact Scale Version 3.0 in Bengali Language.

Investigator: Afsana Arafine, Student of B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP- Savar, Dhaka- 1343

Place: Centre for the Rehabilitation of the Paralysed (CRP), Outpatient Unit, Savar, Bangladesh.

Part I: Information Sheet Introduction

I am Afsana Arafine, B.Sc. in Occupational Therapy student of Bangladesh Health Professions Institute (BHPI); have to conduct a thesis as a part of this Bachelor course, under thesis supervisor, Nayan kumer Chanda. You are going to have details information about the study purpose, data collection process, ethical issues.

You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. If this consent form contains some words that you do not understand, please ask me to stop. I will take time to explain.

Background and Purpose of the study

You are being invited to be a part of this research because Stroke has an adverse effect on functioning and well-being of a stroke survivor patient. Stroke can affect on Quality of life of a stroke survivor. It can affect on physical abilities, activities of daily living of a stroke patient. Quality of life assessment has been important part of the evaluation of stroke patients and their treatment. The impact of stroke on health-related quality of life may be disastrous; stroke can affect multiple domains of life. To assess these consequences several instruments have been developed. Most of them are questionnaires based on a patient's subjective self-report or self-evaluation. Stroke Impact Scale version 3.0 is one of them. It is a questionnaires-based scale. The purpose of this questionnaire is to evaluate how stroke has impacted on health and life. It is very important to include in rehabilitation service. It should be important to know about their quality of life for a health professional. But this scale should

be valid in Bengali language. It must be happened by considering cultural acceptance and understanding level of patients so that an accurate evaluation can come. So, your experience as a stroke survivor will be best to reveal your impairments, disabilities, experience after your stroke as well as how stroke has affected your quality of life. The general purpose of the study is to Linguistic Validation of stroke Impact scale version 3.0 in Bengali language. We also know about the process of linguistic Validation and pilot testing of the translated Scale.

Research related information

The research related information will be discussed with you throughout the information sheet before taking your signature on consent form. After that participants will be asked to complete a questionnaire which may need 15-20minutes to fill. In this questionnaire there will be questions on socio-demographic factors (for example-Age, Sex, Experience). It will contain some specific questions. Particularly, in this research we have selected stroke patient as they know about their health-related quality of life.

The data collection period will be two months followed by the date of approval. During that time, the investigator will come to you and do face to face interview. If you do not wish the questions included in the survey, you may skip them and move on to the next question. The information recorded is confidential, your name is not being included on the forms, only a number will identify you, and no one else except Nayan Kumer Chanda, Supervisor of the study will have access to this survey.

Voluntary Participation

The choice that you make will have no effect on your job or on any work-related evaluation or reports. You can change your mind at any time of the data collection process even throughout the study period. You have also right to refuse your participation even if you agreed earlier.

Right to Refuse or Withdraw

I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Risks and benefits

We are asking to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not need to answer any question or take part in the discussion interview/survey if you don't wish to do so, and that is also okay. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. On the other hand, you may not have any direct benefit by participating in this research, but your valuable participation is likely to help us to establish the Stroke Impact Scale Version 3.0 in Bengali Language as it is an essential part for this study.

Confidentiality

Information about you will not be shared to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone except Nayan kumer Chanda, study supervisor.

Sharing the Results

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you before it is made widely available to the public. Each participant will receive a summary of the results. There will also be small presentations and these will be announced. Following the presentations, we will publish the results so that other interested people may learn from the research.

Who to Contact

If you have any questions, you can ask me now or later. If you wish to ask questions later, you may contact any of the following: Afsana Arafine, Bachelor science in Occupational Therapy, Department of Occupational Therapy, e-mail: afsana.ot18.edu@gmail.com, Cell phone- 01631991696. This proposal has been reviewed and approved by Institutional Review Board (IRB), Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh, which is a committee whose task it is to make sure that research participants are

protected from harm. If you wish to find about more about the IRB, contact Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh. You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Can you withdraw from this study:

You can cancel any information collected for this research project at any time. After the cancellation, we expect permission from the information whether it can be used or not.

Withdrawal Form

Participants Name:

ID number:

Reason of Withdrawal

Participants Name:

Participants Signature:

Day/Month/Year:

Part II: Certificate of Consent

Statement by Participants

I have been invited to participate in research titled Linguistic Validation of Stroke Impact Scale Version 3.0 of Bangla Language. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of Participant _____

Signature of Participant _____

Date _____

Statement by the researcher taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

- 1.
- 2.
- 3.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Name of Researcher taking the consent _____

Signature of Researcher taking the consent _____

Date _____

Appendix D



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) অকুপেশনাল থেরাপি বিভাগ

সিআরপি- চাপাইন, সাভার, ঢাকা-১৩৪৩. টেলি: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪, ফ্যাক্স: ০২-৭৭৪৫০৬

অংশগ্রহণকারীদের তথ্য এবং সম্মতিপত্র

গবেষনার বিষয়: স্ট্রোক ইমপ্যাক্ট স্কেল ৩.০ এর ভাষাগত বৈধতা স্থাপন

গবেষক: আফসানা আরেফিন, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪তমবর্ষ), সেশন: ২০১৪-২০১৫ ইং, বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

তত্ত্বাবধায়ক: নয়ন কুমার চন্দ, লেকচারার, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট।

গবেষনার স্থান: বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট, পৰাঘাতগ্রস্থদের পূর্নবাসন কেন্দ্র (সিআরপি), সাভার, ঢাকা-১৩৪৩ বাংলাদেশ।

পর্ব ১ তথ্যপত্র:

ভূমিকা:

আমি আফসানা আরেফিন, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্রী হিসেবে স্নাতক শির্ষাকার্যক্রম (২০১৪-২০১৫ ইং) সেশনে অধ্যয়নরত আছি। বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শির্ষাকার্যক্রমটি সম্পন্ন করার জন্য একটি গবেষণা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের লেকচারার নয়ন কুমার চন্দ স্যার এর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এই অংশগ্রহণকারী তথ্যপত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগ্হের প্রণালী ও গবেষণাটির সাথে সংশ্লিষ্ট বিষয় কিভাবে র্ষিত হবে তা বিস্তারিতভাবে আপনার কাছে উপস্থাপন করা হবে। যদি এই গবেষণায় অংশগ্রহন করতে আপনি ইচ্ছুক থাকেন, সেবেত্রে এই গবেষণার সম্পৃক্ত বিষয় সম্পর্কে স্বচ্ছ ধারণা থাকলে সিদ্ধান্ত গ্রহন সহজতর হবে। অবশ্য এখন আপনার অংশগ্রহন আমাদের নিশ্চিত করতে হবে না। যে কোন সিদ্ধান্ত গ্রহনের পূর্বে, যদি চান তাহলে আপনার আত্মীয়-স্বজন, বন্ধু অথবা আস্থাজন যে কারো সাথে এই ব্যাপারে আলোচনা করে নিতে পারেন। অপরপর্বে, অংশগ্রহনকারী তথ্যপত্রটি পড়ে, যদি কোন বিষয়বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছু সম্পর্কে আরোবেশি জানার প্রয়োজন হয়, তবে নির্দিধায় প্রশ্ন করতে পারেন।

গবেষনার প্রেক্ষাপট ও উদ্দেশ্য:

এই গবেষণাতে পৰাঘাতগ্রস্থদের পূর্নবাসন কেন্দ্রের অকুপেশনাল থেরাপি বর্ষিবিভাগের স্ট্রোক রোগীদের অন্তর্ভুক্ত হবার জন্য আমন্ত্রন জানানো হবে। এর অংশ হিসাবে, আপনাকেও উক্ত গবেষণা প্রকল্পে অংশগ্রহনের জন্য আমন্ত্রণ জানানো হলো। কারণ, আপনি নিশ্চয় অবগত আছেন যে, স্ট্রোক নিরাময়ে অকুপেশনাল থেরাপিস্ট এর অনেক গুরুত্বপূর্ণ অবদান রয়েছে। স্ট্রোক এ আক্রান্ত রোগীদের জীবনের মান সম্পর্কে ধারণা থাকা খুবই জরুরী। স্ট্রোক রোগীদের জীবনমান পরিমাপের জন্য একটি স্কেল- স্ট্রোক ইমপ্যাক্ট স্কেল ৩.০ রয়েছে। এটি দ্বারা একজন স্ট্রোক রোগীর জীবনের বিভিন্ন স্তর যেমন- শারীরিক সমস্যা, চিন্তা

শক্তি, আবেগ, দৈনন্দিন কর্মক্ষমতা ইত্যাদিতে তার ক্ষমতা কতটুকু তা পরিমাপ করা হয়। এই স্কেলটির বর্তমান ভাষা ইংরেজী। যা বাংলাদেশের প্রেক্ষাপটে বাংলা ভাষা ব্যবহারকারী দের জন্য বোধগম্য নয়। এর ফলে স্কেলের প্রশ্নগুলোর সঠিক এবং সংগতিপূর্ণ উত্তর পাওয়া যায়না। তাই এটি সম্পূর্ণ বাংলা ভাষায় পরিবর্তন করা অত্যাাবশ্যিক। এই স্কেলটি বাংলাদেশের প্রেক্ষাপটে ভাষাগত বৈধতা স্থাপন করা হয়নি। অতএব গবেষণাটির সাধারণ উদ্দেশ্য হল: স্ট্রোক ইমপ্যাক্ট স্কেল ৩.০ এর ভাষাগত বৈধতা স্থাপন। আপনার কার্যকারী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

এই গবেষণা কর্মটিতে অংশগ্রহনের সাথে সম্পৃক্ত বিষয়সমূহ সম্পর্কে জানা যাক

আপনার থেকে অনুমতিপত্রে স্বাক্ষর নেবার আগে, এই অংশগ্রহনকারী তথ্যপত্রের মাধ্যমে গবেষণা প্রকল্পটির পরিচালনা করার তথ্যসমূহ বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। আপনি যদি এই গবেষণায় অংশগ্রহন করতে চান, তাহলে সম্মতিপত্রে আপনাকে স্বাক্ষর করতে হবে। আপনি অংশগ্রহন নিশ্চিত করলে, আপনার সংরবনের জন্য সম্মতিপত্রটির একটি অনুলিপি দিয়ে দেয়া হবে। পরবর্তীতে গবেষক কর্তৃক গঠিত তথ্য-উপাত্ত সংগ্রহের একটি দলের প্রতিনিধি আপনার কাছে যাবে। আপনার থেকে চেয়ে নেওয়া যে কোন একটি নির্দিষ্ট সময়ে একটি প্রশ্নপত্রের মাধ্যমে তথ্য সংগ্রহ করা হবে। এই গবেষণার প্রকল্পে আপনার অংশগ্রহণ ঐচ্ছিক। যদি আপনি সম্মতি প্রদান না করেন তবে আপনাকে অংশগ্রহন করতে হবে না। আপনি সম্মতি প্রদান করা সত্ত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন।

অংশগ্রহনের সুবিধা ও ঝুঁকিসমূহ কি ?

গবেষণা প্রকল্পটিতে অংশগ্রহনের জন্য আপনি সরাসরি কোন সুবিধা পাবেন না। তবে আমরা আশাবাদী যে, গবেষণার মাধ্যমে প্রাপ্ত উপাত্ত পরবর্তীতে এই স্কেলের ব্যবহার বাংলাদেশের প্রেক্ষাপটে আরো নিখুঁত, সুনির্দিষ্ট ও ভাষাগত জরুরতা অর্জন করবেএখানে সংশ্লিষ্ট গবেষণায় অংশগ্রহনে কোন ধরনের বাড়তি ঝুঁকি, বিপত্তি অথবা অস্বস্তি নেই বলে আশা করা যাচ্ছে।

তথ্যের গোপনীয়তা কি নিশ্চিত থাকবে?

এই সম্মতিপত্রে স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষণা প্রকল্পে অধ্যয়নরত গবেষণা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষণা প্রকল্পের জন্য সংগৃহীত যেকোন তথ্য, যা আপনাকে সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষণের কাজে ব্যবহৃত হবে। তথ্যপত্রগুলো নিরাপদ স্থানে সংগ্রহ করা হবে। বিএইচপিআই এর অকুপেশনাল থেরাপি বিভাগে ও গবেষকের ব্যক্তিগত ল্যাপটপে উপাত্তসমূহের ইলেকট্রনিক ভার্সন সংগৃহীত থাকবে।

প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার বেধে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোন ভাবেই সনাক্ত করা না যায়। তথ্য-উপাত্ত প্রাথমিক ভাবে কাগজপত্র সংগ্রহ করা হবে।

গবেষণা সম্পর্কে জানতে কোথায় যোগাযোগ করতে হবে?

গবেষণা প্রকল্পটির বিষয়ে যোগাযোগ করতে চাইলে অথবা গবেষণা প্রকল্পটির সম্পর্কে কোন প্রশ্ন থাকলে, এখন অথবা পরবর্তীতে যে কোন সময়ে তা জিজ্ঞাসা করা যাবে। সেবেধে আপনি গবেষকের সাথে উল্লেখিত ০১৬৩১৯৯১৬৯৬ (আফসানা আরেফিন) নাম্বারে যোগাযোগ করতে পারেন। এই গবেষণা প্রকল্পটি বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক ঞ্চনিকতা পরিষদ থেকে (সিআরপি-বিএইচপিআই/আইআরবি/১০/১৮/১২৩৮) পর্যালোচিত ও অনুমোদিত হয়েছে। এই

গবেষণা প্রকল্প পরিচালনা প্রসঙ্গে যেকোন উদ্ভিগ্ন অথবা অভিযোগকারী ব্যক্তি প্রাতিষ্ঠানিক ঐনতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগ করবেন।

গবেষণা থেকে নিজেকে প্রত্যাহার করা যাবে কি?

আপনি সম্মতি প্রদান করা স্বত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহনকারীর প্রত্যাহারপত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

অংশগ্রহনকারীর প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহনকারীর নাম:

প্রত্যাহার করার কারণ:

.....
.....
.....
.....
.....

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহনকারীর নাম:

অংশগ্রহনকারীর স্বাক্ষর:

তারিখ:

*নিরবর হয় যদি

অংশগ্রহনকারীর আঙ্গুলের ছাপ

স্বাক্ষরকারীর নাম:

স্বাক্ষরকারীর স্বাক্ষর

তারিখ:

সম্মতি পত্র:

স্ট্রোক ইমপ্যাক্ট স্কেল ৩.০ এর ভাষাগত জ্ঞান স্থাপন- শীর্ষক গবেষণায় অংশগ্রহণের জন্য আমাকে আমন্ত্রন জানানো হয়েছে। আমি পূর্বলিখিত তথ্য পত্রটি পড়েছি বা এটা আমাকে পড়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ ছিল এবং যে কোন প্রশ্নের আমি সম্মতজনক উত্তর পেয়েছি। এই গবেষণায় একজন অংশগ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর নাম:

তারিখ :

অংশগ্রহনকারীর স্বাক্ষর:

*নিরবর হয় যদি

অংশগ্রহনকারীর আঙ্গুলের ছাপ

স্বাক্ষর নাম:

স্বাক্ষর স্বাক্ষর:

তারিখ:

গবেষক ও সম্মতিকারীর বিবৃতি:

আমি অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্যপত্রটি পড়ে শুনিয়েছি এবং আমার সর্বোচ্চ সামর্থ অনুযায়ী নিশ্চিত করেছি যে, অংশগ্রহনকারীর বোধগম্য হয়েছে যে, নিম্নোক্ত বিষয়সমূহ করা হবে।

- ১) সকল তথ্য গবেষণার কাজে ব্যবহৃত হবে।
- ২) তথ্যসমূহ সম্পূর্ণভাবে গোপনীয় করা হবে।
- ৩) অংশগ্রহনকারীর নাম ও পরিচয় প্রকাশ করা হবে না।

আমি নিশ্চিত করেছি যে, এই বিষয় সম্পর্কে অংশগ্রহনকারীকে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেয়া হয়েছে এবং অংশগ্রহনকারী যে সকল প্রশ্ন জিজ্ঞাসা আমার সর্বোচ্চ সামর্থ অনুযায়ী, সেগুলোর সঠিক উত্তর প্রদান করা সম্ভব হয়েছে। আমি নিশ্চিত করেছি যে, কোন ব্যক্তিকে সম্মতি দান করতে বাধ্য করা হয়নি। তিনি অবাধে অথবা স্বেচ্ছায় সম্মতি দিয়েছেন।

অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্য ও সম্মতিপত্রের একটি অনুলিপি দেওয়া হয়েছে।

গবেষকের নাম:

গবেষকের স্বাক্ষর :

তারিখ:

Appendix-E

Stroke Impact Scale Version 3.0

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from YOUR POINT OF VIEW how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your....	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was most affected by your stroke? _____	5	4	3	2	1
b. Grip of your hand that was most affected by your stroke? _____	5	4	3	2	1
c. Leg that was most affected by your stroke? _____	5	4	3	2	1
d. Foot/ankle that was most affected by your stroke? _____	5	4	3	2	1

These questions are about your memory and thinking.

2. In the past week, how difficult was it for you to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

3. In the past week, how often did you...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

4. In the past week, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

**The following questions ask about activities you might do
during a typical day.**

5. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

**The following questions are about your ability to be mobile,
at home and in the community.**

6. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

8. During the past 4 weeks, how much of the time have you been limited in...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?

_____ 100 Full Recovery

—
_____ 90

—
_____ 80

—
_____ 70

—
_____ 60

—
_____ 50

—
_____ 40

—
_____ 30

—
_____ 20

—
_____ 10

_____ 0 No Recovery

Appendix F

Final Bangla Translation (Stroke Impact Scale 3.0)

স্ট্রোক প্রভাব নির্ণয়ের মানদণ্ড - সংস্করণ ৩.০

এই প্রশ্নাবলীর উদ্দেশ্য হল স্ট্রোক কিভাবে আপনার জীবন এবং স্বাস্থ্য এর উপর প্রভাব ফেলেছে তা মূল্যায়ন করা। আপনার দৃষ্টিকোণ থেকে আমরা জানতে চাই স্ট্রোক কিভাবে আপনাকে আক্রান্ত করেছে। আমরা আপনাকে জিজ্ঞাসা করব, আপনার বিকলতা এবং প্রতিবন্ধিতা সম্পর্কে, যা আপনার স্ট্রোক এর কারণে হয়েছে, পাশাপাশি কিভাবে স্ট্রোক আপনার জীবনের মানকে প্রভাবিত করেছে। অবশেষে, আমরা আপনাকে জিজ্ঞাসা করব আপনার মতে স্ট্রোক থেকে আপনি কতটুকু পরিমাণ নিরাময়তা লাভ করেছেন।

নিম্নোক্ত প্রশ্ন গুলো আপনার শারীরিক সমস্যার সম্পর্কে যা স্ট্রোক এর ফলাফল হিসেবে হতে পারে

১। গত সপ্তাহে আপনি কিভাবে আপনার শক্তির হার পরিমাপ করবেন-	অনেক শক্তি	ভাল শক্তি	অল্প শক্তি	খুবই অল্প শক্তি	কোন শক্তিই নেই
স্ট্রোক দ্বারা আপনার যে হাত সবচেয়ে বেশি দুর্বল / আক্রান্ত হয়েছে?	৫	৪	৩	২	১
স্ট্রোক দ্বারা আপনার যে কজি সবচেয়ে বেশি দুর্বল / আক্রান্ত হয়েছে?	৫	৪	৩	২	১
স্ট্রোক দ্বারা আপনার যে পা সবচেয়ে বেশি দুর্বল / আক্রান্ত হয়েছে?	৫	৪	৩	২	১
স্ট্রোক দ্বারা আপনার যে পায়ের পাতা/ গোড়ালি সবচেয়ে বেশি দুর্বল / আক্রান্ত হয়েছে?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার প্রতি শক্তি এবং চিন্তা শক্তি সম্পর্কে

২। গত সপ্তাহে, কতটুকু কঠিন ছিল আপনার জন্য-	কঠিন নয়	সামান্য কঠিন	সহনীয় কঠিন	কঠিন	অনেক বেশি কঠিন
তাৎক্ষণিক ভাবে কেউ কিছু বললে তা মনে করতে পারা?	৫	৪	৩	২	১
গতকাল যা ঘটেছে তা মনে করতে পারা?	৫	৪	৩	২	১
কোন কাজ করতে মনে থাকা (যেমন- নির্ধারিত সময়সূচী মনে রাখা, ঔষধ সেবন করা)?	৫	৪	৩	২	১
সপ্তাহের নামগুলো মনে রাখা?	৫	৪	৩	২	১
মনোযোগ ধরে রাখা ?	৫	৪	৩	২	১
দ্রুত চিন্তা করা?	৫	৪	৩	২	১
প্রতিদিনের সাধারণ সমস্যা সমাধান করা?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার ভাব পরিবর্তন এবং আবেগ নিয়ন্ত্রনের ক্ষমতা সম্পর্কে যা আপনি স্ট্রোক এর পর অনুভব করে থাকেন

৩। গত সপ্তাহে, আপনি কখন	কখনই না	হঠাৎ	মাঝে মাঝে	প্রায়শই	সবসময়
দুঃখবোধ করেছেন?	৫	৪	৩	২	১
আপনি কি মনে করেন আপনার কাছের কেউ নেই?	৫	৪	৩	২	১
আপনি কি মনে করেন আপনি অন্যদের জন্য বোঝা?	৫	৪	৩	২	১
আপনি কি ভাবেন জীবনে সামনের দিকে এগিয়ে যাওয়ার জন্য আপনার কিছু নেই?	৫	৪	৩	২	১
জীবনের ঘোঁটে যাওয়া ভুল গুলোর জন্য নিজেকে দায়ী ভাবেন?	৫	৪	৩	২	১
আগের মতই সবকিছু উপভোগ করেন?	৫	৪	৩	২	১
কিছুটা রেগে/ ঘাবড়ে যান?	৫	৪	৩	২	১

আপনি কি মনে করেন জীবন মূল্যবান?	৫	৪	৩	২	১
দিনে অন্তত একবার প্রাণ খুলে হাসেন?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার অন্যদের সাথে যোগাযোগ করার ক্ষমতা সেই সাথে একটি আলোচনায় আপনি কি বুঝতে পারছেন এবং আপনি কি শুনছেন তার ক্ষমতা সম্পর্কে

৪। গত সপ্তাহে আপনার জন্য কতটুকু কঠিন ছিল-	কঠিন নয়	সামান্য কঠিন	সহনীয় কঠিন	কঠিন	অনেক বেশি কঠিন
আপনার সামনে উপস্থিত কারও নাম বলতে পারা?	৫	৪	৩	২	১
সবার সাথে কথাবার্তার মধ্যে আপনাকে কি বলা হচ্ছে তা বুঝতে পারা?	৫	৪	৩	২	১
প্রশ্নের উত্তর দেয়া?	৫	৪	৩	২	১
সঠিকভাবে জিনিসের নাম বলতে পারা?	৫	৪	৩	২	১
কতোগুলো মানুষের সাথে কোন আলোচনায় অংশ গ্রহণ করতে পারা?	৫	৪	৩	২	১

টেলিফোনে কথা বলা?	৫	৪	৩	২	১
সঠিক ফোন নাম্বার বাছাই করে একজনকে টেলিফোন করা?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার একটি সাধারণ দিনের কর্মসূচী সম্পর্কে যা আপনি করে থাকেন

৫। গত দুই সপ্তাহে, কতটুকু কঠিন ছিল আপনার জন্য-	কঠিন নয়	সামান্য কঠিন	সহনীয় কঠিন	কঠিন	অনেক বেশি কঠিন
ছুরি এবং কাটা চামচ এর সাহায্যে খাবার কাটা? হাত ব্যবহারের মাধ্যমে খাবার ব্যবস্থা পরিচালনা করা?	৫	৪	৩	২	১
শরীরের উপরের অংশে কাপড় পরা?	৫	৪	৩	২	১
নিজে নিজে গোসল করা?	৫	৪	৩	২	১
পরিচ্ছন্নতা যেমন পায়ের নখ কাটা?	৫	৪	৩	২	১
সময়মত বাথরুমে যাওয়া?	৫	৪	৩	২	১

প্রসাব/মূত্রনালি ধরে রাখা?(দুঘটনা ব্যাতিত)	৫	৪	৩	২	১
পায়খানা/ মূত্রনালি ধরে রাখা?(দুঘটনা ব্যাতিত)	৫	৪	৩	২	১
ঘরের হালকা কাজ গুলো করা (যেমন-খুলা পরিষ্কার করা,বিছানা তৈরি করা,রান্না করা,ময়লা বাহিরে নেয়া)?	৫	৪	৩	২	১
কেনাকাটা বা বাঁজার করতে যাওয়া?	৫	৪	৩	২	১
ঘরের ভারী কাজ গুলো করা (যেমন- পরিষ্কার করা, কাপড় ধোওয়া অথবা উঠানের কাজ)?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার বাড়ি এবং জনসমাজে চলাফেরা করার ক্ষমতা সম্পর্কে

৬। গত দুই সপ্তাহে কতটুকু কঠিন ছিল আপনার জন্য-	কঠিন নয়	সামান্য কঠিন	সহনীয় কঠিন	কঠিন	অনেক বেশি কঠিন
ভারসাম্য না হারিয়ে বা সাহায্য ছাড়া বসে থাকা?	৫	৪	৩	২	১
ভারসাম্য না হারিয়ে বা সাহায্য ছাড়া দাঁড়িয়ে থাকা?	৫	৪	৩	২	১
ভারসাম্য না হারিয়ে বা সাহায্য ছাড়া হাঁটতে পারা?	৫	৪	৩	২	১
বিছানা থেকে চেয়ারে যাওয়া?	৫	৪	৩	২	১
নিজের এলাকা বা কলোনি বা বাড়ির আশেপাশে হাঁটতে পারা?	৫	৪	৩	২	১
দ্রুত হাঁটা?	৫	৪	৩	২	১
একধাপ সিঁড়ি উঠতে পারা?	৫	৪	৩	২	১

কয়েকখাপ সিঁড়ি উঠতে পারা?	৫	৪	৩	২	১
গাড়িতে প্রবেশ করা এবং গাড়ি থেকে বের হওয়া?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্নগুলো স্ট্রোক দ্বারা আপনার সবচেয়ে বেশি আক্রান্ত হাত এর ব্যবহার সম্পর্কে

৭। গত দুই সপ্তাহে, কতটুকু ছিল আপনার জন্য স্ট্রোক দ্বারা, আপনার সবচেয়ে বেশি আক্রান্ত হাতটি ব্যবহার করে-	কঠিন নয়	সামান্য কঠিন	সহনীয় কঠিন	কঠিন	অনেক বেশি কঠিন
ভারি বস্তু বহন করা (যেমন- বাজারের ব্যাগ)?	৫	৪	৩	২	১
দরজার হাতল ঘুরানো?	৫	৪	৩	২	১
বয়্যম বা কৌটা খুলতে পারা?	৫	৪	৩	২	১
জুতার ফিতা বাধা?	৫	৪	৩	২	১
পয়সা / টাকা উঠানো?	৫	৪	৩	২	১

নিম্নোক্ত প্রশ্ন গুলো আপনার,আপনি সাধারানত যে কাজ গুলো করেন তার ক্ষমতা ,যা আপনার কাছে গুরুত্বপূর্ণ এবং যা আপনার জীবনে উদ্দেশ্য খুজতে সাহায্য করে তার উপর স্ট্রোক কিভাবে প্রভাব ফেলে সে সম্পর্কে-

৮। গত চার সপ্তাহ ধরে আপনি কয়বার বা কত সময় সীমাবদ্ধতায় ছিলেন-	কখনই না	হঠাৎ	মাঝে মাঝে	প্রায়শই	সবসময়
নিজের কাজ (বিনময়, সেচ্ছায় অথবা অন্যান্য)?	৫	৪	৩	২	১
সামাজিক কার্যক্রম? (মসজিদে যাওয়া, বন্ধুদের সাথে ঘুরতে যাওয়া, আত্মীয়- স্বজন এর বাড়িতে যাওয়া ইত্যাদি)	৫	৪	৩	২	১
অবসর সময় কাটানো (কারুশিল্প, বই পড়া)?	৫	৪	৩	২	১
বিনোদন (খেলাধুলা , বাইরে যাওয়া ,ভ্রমন)?	৫	৪	৩	২	১
পরিবারের একজন সদস্য অথবা বন্ধু হিসেবে আপনার ভূমিকা?	৫	৪	৩	২	১

আত্মিক এবং ধর্মীয় কার্যক্রমে আপনার অংশগ্রহণ?	৫	৪	৩	২	১
আপনার ইচ্ছা অনুযায়ী আপনার জীবন নিয়ন্ত্রণ করার ক্ষমতা?	৫	৪	৩	২	১
অন্যকে সাহায্য করার ক্ষমতা?	৫	৪	৩	২	১

৯। স্ট্রোক নিরাময়

০ থেকে ১০০ মানদণ্ডের ক্ষেত্রে, ১০০ দ্বারা সম্পূর্ণ নিরাময় এবং ০ দ্বারা কোন নিরাময় হয়নি বুঝায়, আপনি আপনার স্ট্রোক থেকে কতটুকু নিরাময় হয়েছেন-

----- ১০০ পূর্ণ নিরাময়

----- ৯০

----- ৮০

----- ৭০

----- ৬০

----- ৫০

----- ৪০

----- ৩০

----- ২০

----- ১০

----- ০ কোন নিরাময় হয়নি

Appendix G

Final Backward Translation of Bangla Stroke Impact Scale 3.0 Stroke Impact Scale Edition 3.0

The purpose of these questionnaires is conferring importance of how stroke creates impact on your life and health. We want to know from your point of view how stroke affects you. We will ask you about your impairment and disability which are appear by stroke besides how stroke creates impact on the standard of your life. At length, we will ask you, according to you how much cured you have achieved from your stroke.

The following questions are about your physical difficulties due to stroke

1.How could you measure your strength for last week-	Heavy strength	Good strength	Moderate strength	Minimum strength	No strength
a. Which part of your body more affected by Stroke?	5	4	3	2	1
b. Which wrist are more affected by stroke?	5	4	3	2	1
c. Which lower limb/leg more affected by Stroke?	5	4	3	2	1
d. Foot/ ankle which one more affected by stroke?	5	4	3	2	1

The following questions are about memory and cognitive abilities

2. In last week, how much difficult to you	No difficulties	Minimum difficulties	Moderate difficulties	difficulties	Very difficulties
a.Could you remember anything after talking with someone?	5	4	3	2	1
b.Can you remember previous day's events?	5	4	3	2	1

c. Recall any activities (such as- follow the routine, take drugs properly)	5	4	3	2	1
d. Recall the days of the week	5	4	3	2	1
e. Holding concentrate?	5	4	3	2	1
f.Immediate thinking?	5	4	3	2	1
g.Problems solving in daily life issues?	5	4	3	2	1

The following questions are about your mood change and controlling emotions power after having stroke which you can feel

3. Last week when you,	Never ever	Suddenly	Sometimes	Irregularly	Regularly
a.You feel sorry or sad?	5	4	3	2	1
b.Feel no one beside of you?	5	4	3	2	1
c.Feel that you are burden to others?	5	4	3	2	1
d.You feel you can't participate in future life?	5	4	3	2	1
e.Blame yourself for your mistake?	5	4	3	2	1
f.Enjoy everything like previous?	5	4	3	2	1
g.Feel angry/ nervous?	5	4	3	2	1

h.You feel, life has value?	5	4	3	2	1
i.Smile every day?	5	4	3	2	1

The following questions are about communication power and yours understanding ability including listening with other people

4. last week, how much it was difficult for you	No difficulties	Minimum difficulties	Moderate difficulties	Difficulties	Very difficulties
a.Call anyone name in front of you?	5	4	3	2	1
b.Understand what is saying to you during a conversation?	5	4	3	2	1
c.Give answer?	5	4	3	2	1
d.Name the objects correctly?	5	4	3	2	1
e.Participate in a discussion with many people?	5	4	3	2	1
f.Talk over telephone?	5	4	3	2	1
g.Identify the correct phone number and call one correctly?	5	4	3	2	1

The following questions are about your daily life activity which you perform

5. last two week, how much it was difficult for you	No difficulties	Minimum difficulties	Moderate difficulties	Difficulties	Very difficulties
a.Perform eating activity with fork and knife? / Eating activity manage. (Such as:	5	4	3	2	1

cutting food with knife and fork and hand use)					
b.Upper half dressing?	5	4	3	2	1
c.Bathing?	5	4	3	2	1
d.Cleaning like cutting your nail?	5	4	3	2	1
e.Go to washroom?	5	4	3	2	1
f.Bladder control?	5	4	3	2	1
g.Bowel control?	5	4	3	2	1
h. Perform light home activity (such as: cleaning, arrange bed sheet, cooking, take garbage in outside)	5	4	3	2	1
i.Shopping?	5	4	3	2	1
jPerform heavy home activities like-cleaning, washing cloth, weeping the floor	5	4	3	2	1

The following question are about locomotion power at your home and society

6.In last two weeks, how much difficult to you	No difficulties	Minimum difficulties	Moderate difficulties	Difficulties	Very difficulties
a.Sitting without support or loosing balance?	5	4	3	2	1
b.Standing without support or loosing balance?	5	4	3	2	1
c.Walking without support?	5	4	3	2	1
d.Transferring from bed to chair?	5	4	3	2	1

e.Walking ability on your area/village/ around your home?	5	4	3	2	1
f.Quick walking?	5	4	3	2	1
g.Staring (one step)?	5	4	3	2	1
h.Staring (few steps)?	5	4	3	2	1
i.Get in and get off in the car?	5	4	3	2	1

The following questions are about your mostly affected hand and its impact during function

7.Last two weeks how it was difficulties to use your affected hand	No difficulties	Minimum difficulties	Moderate difficulties	Difficulties	Very difficulties
a.Carry heavy object (such as: shopping bag)?	5	4	3	2	1
b.Twisting door handle?	5	4	3	2	1
c.Opening Box?	5	4	3	2	1
d.Tie down shoe band?	5	4	3	2	1
e.Collect money or coin?	5	4	3	2	1

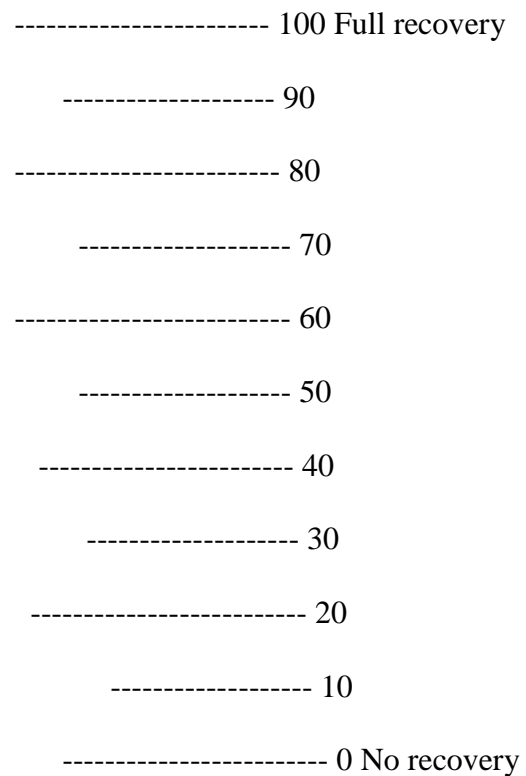
The following question are about, your daily living work performance ability which is meaningful to your life that is affected by stroke

8.For last four weeks, how many times you were in limit-	Never ever	Suddenly	Sometimes	Irregularly	Regularly
a.Self-activity (paid, willingly or others)?	5	4	3	2	1

b.Social activity (visit at relatives, going to masjid, outing with friends)?	5	4	3	2	1
c.Leisure (crafting, reading book)?	5	4	3	2	1
d.Active participation (play, outing, traveling)?	5	4	3	2	1
e.Role as a family member and /or friend?	5	4	3	2	1
f.Spiritual and religious activity participation?	5	4	3	2	1
g.Ability to control your life?	5	4	3	2	1
h.Ability to help others?	5	4	3	2	1

9. Stroke recovery.

0 to 100, 100 is total recovery and 0 is no recovery, how much you recover from your stroke?



Appendix H

স্কেল পরবর্তী প্রশ্নাবলীঃ(রোগীর জন্য)

- ১। কোন প্রশ্ন বুঝতে গিয়ে আপনার কি কি ধরনের সমস্যা হয়েছে?
- ২। আপনাকে যা জিজ্ঞাসা করা হয়েছে সে সম্পর্কে আপনার কোন ধরনের প্রশ্ন আছে?
- ৩। কোন প্রশ্ন কি আপনার কাছে আপত্তিকর/ অস্বস্তিকর মনে হয়েছে?
(মনে হয়ে থাকলে, কোনটা বলুন)
- ৪। কোন প্রশ্ন কি আপনার কাছে বুঝতে অনেক বেশি কঠিন মনে হয়েছে?

Appendix I

Questionnaire:

1. Did you face any type of difficulties to understand the questionnaire (scale)?
2. Did you have any opinion about the questionnaire you have asked?
3. Did you feel hesitation or have objection with any question?
4. Did you think that questions were hard to understand?