### LIFE EXPERIENCE OF STROKE SURVIVORS AND CAREGIVERS

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Department of Physiotherapy CRP, Savar, Dhaka-1343 Bangladesh August -2018 We, the undersigned certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled **LIFE EXPERIENCE OF STROKE SERVIVORS AND CAREGIVERS.** 

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### DECLARATION

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistake or inaccuracy is my own. I also declare that for any publication, presentation or dissemination of information of the study. I would be bound to take written consent of my supervisor & Head from the Department of Physiotherapy of Bangladesh Health Professions Institute (BHPI).

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# ABBREVIATION

BHPI:	Bangladesh Health Professions Institute
<b>BMRC:</b>	Bangladesh Medical and Research Council.
CRP:	Center for the Rehabilitation of the Paralyzed.
DVT:	Deep Vein Thrombosis.
HSC:	Higher Secondary School Certificate.
RTI:	Respiratory Tract Infection.
IRB:	Institution of Review Board.
SSC:	Secondary school certificate
WHO:	World Health Organization
LOS:	Length of loss

# ABSTRACT

*Purpose:* The purpose of the study was to the quality of life experience of stroke survivors among stroke patients at CRR *Objectives*: The objectives are to find out the life experience of stroke servivors, to find out the socio-demographic information of the patients and caregivers. *Methodology*: The study was conducted by using of Qualitative method. 20 participants were selected and this qualitative study conducted in the Neurology Unit in CRP, which is a nongovernment organization, located in Savar Participants were selected by purposive convenience sampling. All data collected through face-to face interview by using a semi-structured research question and given freedom to explain their feelings in their own words. They also received opportunity to talk and described the feelings and real facts or incidents. The entire interviews were recorded by the audio recorder and transcribed the interview in Bangla. Finally, Bangla data were been translated into English and then the researcher coding and themes were made from the participants answer. Results: This study was found that male participants about 65% and 35% were female. Males were been affected than female. The most vulnerable age range is 30 to 90 years. Seven theme are the results Prior about knowledge, Staying at hospital, Access to Rehabilitation Including (Physiotherapy, Occupational Therapy and Speech and Language Therapy), Level of Independence Post Stroke, Rehab services at community, The Challenges of Returning Home and The Challenges Experienced by Caregivers. Conclusion: Speech problem, movement problems, cooking problem, bed mobility, communication problems, lonely life and others problems, are life experience of stroke survivors awareness and take steps to reduce the risk of developing.

Keywords: Stroke, caregivers, stroke survivors, rehabilitation

#### 1.1 Background

Stroke is defined by WHO as "Rapidly developed clinical signs of focal disturbance of cerebral function lasting for more than 24 hours or leading to death without any apparent cause other than vascular origin (Hossain et al., 2011).

Stroke is the second leading cause of death (Lozano et al, 2012) and third leading cause of disability (Murray et al, 2012) worldwide. In Asia, which holds 60% of the world's population (Venketasubramanian et al, 2017), stroke mortality is higher when compared to Western Europe, the Americas and Australasia (Feigin et al 2014).

Stroke is expected that as the control of infectious diseases improves, life expectancy in Bangladesh will increase. In turn, this may result in a higher exposure to risk factors associated with stroke and therefore higher incidence of stroke, if modifiable risk factors are not managed. Limited availability of healthcare may result in higher mortality rates and greater numbers of disabled survivors (Venketasubramanian et al., 2017).

In addition to the physical impairment caused by stroke, the emotional, social and economic impacts of stroke can be overwhelming stroke survivors and their families (Walsh et al., 2015). Post stroke depression (PSD) thought to be affect about one third of persons with chronic stroke, this condition is difficult to diagnose and therefore remains unrecognized and undertreated (Srivastava et al., 2010). PSD, along with factors such as social isolation, age and decreased function have been associated with a reduction in participation (Sturm et al 2004 and Chau et al., 2009). The majority of stroke survivors living at home 6 months after stroke reported a lack of social, recreational or meaningful activity (Mayo et al., 2002).

Caregivers have an important role supporting stroke survivors through these challenges. Therefore it is critical that we not only consider the effects of stroke on the patient but also those experienced by the caregiver, especially given the nature of sudden onset and unexpected change to lifestyle that is required to adapt to this situation. Balancing the dual responsibility of caring for the stroke survivor, whilst maintaining the necessary adjustments in their lifestyle, is challenging for caregivers (Bhattacharjee et al., 2012).

Understandably, this can result in chronic stress, compromising the caregiver's physical health (Schulz and Sherwood 2008), subjective well-being and self-efficacy (Pinquart and Sörensen, 2003). Although the effects of stroke on survivors and caregivers has been well documented, little we known about how these findings compare to a Bangladeshi population given the limited provision of rehabilitation services available to stroke survivors (Mamin et al., 2017).

While the relationship between physical functioning, disability and self-perceptions of health among stroke survivors is complex and strongly mediated by context and individual factors. Their impact on disability might be diminish and experiences of health enhanced by assessing self-perceptions in individual patients and tailoring rehabilitation. A simple question of 'how would you rate your health?' followed by a range of options (for example, poor, fair, good or excellent), can give a wealth of information to the healthcare professional, and aid in the targeting of interventions (Bergina et al., 2016). Worldwide, stroke is the second leading cause of death, responsible for at least 4.4 million (9%) of total 50.5 million deaths each year (Sudlow & Warlow, 2009).

Currently, Stroke is the second leading cause of death in the western world ranking after heart diseases and before cancer and causes 10% of deaths worldwide (Braunwald et al., 2006). According to the World Health Organization, 15 million people suffer stroke worldwide each year. 5 million die and another 5 million are permanently disabled (Engstrom et al., 2011).

Interventions that potentially enhance subjective health experiences after stroke, such as those that modify the social circumstances of stroke survivors, and those that focus on enhancing psychological outlook and resilience. Enabling .stroke survivors to cope with the stressors of rehabilitation and take control of their recovery are likely to be important to improving the overall health status of stroke survivors (Bergina et al., 2016).

The brain is an exciting area in neurology as it is complex in anatomy and in function. With the advancement of age in addition to decay, the brain becomes more prone to get many complicated life threatening diseases, these will need appropriate attention in time. Stroke is one of such condition, which is the burning topic in this new millennium, since it is not only a major killer, but also a cause of disability in the world as well as in Bangladesh (Mohammad, 2011).

Stroke is one of the major chronic illnesses worldwide that health-care organizations will need to address for the next several decades. The nerve cells are responsible for controlling various parts and processes within the body. If the cells cannot function properly, the body parts they are responsible for controlling also cannot functioning properly. About a third of all strokes are precede by transient ischemic attacks (TIA), or mini-strokes, that temporarily interrupt blood flow to the brain. While TIAs cause similar symptoms (such as sudden vision loss, or temporary weakness in a limb), they abate much more quickly than full flexed strokes, usually within a few hours, sometimes as quickly as a few minutes (Bruno, 2008).

Stroke can affected by the following effects of brain attacks like weakness or paralysis on one side of the body that may affect the whole side or just arm or leg and the weakness or paralysis is on the side of the body opposite the side of the brain. Stroke causes spasticity, stiffness in the muscles, painful muscles spasms, problems with balance or coordination, problems using language, having difficulty to understand the speech or writing (aphasia); and knowing the right words but having trouble saying them clearly (dysarthria). Being unaware of or ignoring sensations on one side of the body , pain, numbness or odd sensations problem with memory, thinking, attention or stroke, being unaware of the effects of a stroke, trouble swallowing (dysphasia), problem with bowel or bladder control, fatigue, difficulty controlling emotion, depression and difficulties with daily tasks (Murie-Fernandez et al.,2012).

There are some modifiable or preventable risk factors for stroke. These are -diet and nutrition, physical inability, smoking, substance/alcohol abuse, certain medical condition including: abnormal blood vessel connections, cerebral aneurysms, low cholesterol level, diabetes, hardening of the arteries, heart disease, high blood pressure, obesity, Transient Ischemic Attacks(TIA) And some non-modifiable risk factors are age, ethnicity, heredity/family history of stroke and gender (Maria, 2008).

#### **1.2 Rationale**

Stroke is a catastrophic event and one of the most common causes of severe disability following neurological damage. Stroke is an important health problem in Bangladesh due to high morbidity and Mortality rate. It is the one of the significant causes of physical Disability in our country. The number of affecting people is increasing day by day due to lack of awareness. It is affecting a large number of individual that creates devastating effect on a family a society as well as in whole country. It is be explained by broadly about the life experience of stroke survivors of the stroke patients and this is the most common scenery in the Bangladesh. The world health organization statistics that is, about 10% of the population are disabled by stroke large number of Populations suffer from stroke. Life experience of stroke survivors arise, due to lack of awareness of patients and family. Therefore, everyone about the life experience of stroke should know it. If enough knowledge about the life experience after stroke. It will be easy to prevent the further complication. The aim of the study is to find the out the life experience of stroke survivors. So it is help for our society and country in both socially and economically. This is very important for the stroke patients focusing on preventing the survivors and improving quality of life for people with stroke. Finally, for this study, participants may be beneficial and practitioner will gain knowledge from this study.

# 1.3 Research question

What are the life experience of stroke survivors and caregivers?

### 1.4 Aims

The aim of the study was to find the life experience of stroke survivors and caregivers.

### **1.5 Objectives**

### **1.5.1 General objective**

To identify the of life experience of stroke survivors and caregivers.

### **1.5.2 Specific objectives**

1. To find out the prevalence of life experience of stroke survivors and caregivers .

- 2. To identify the male female ratio.
- 3. To identify the more affected age group.
- 4. To find the occupation of patients with stroke.

5. To identify the patients influencing demographic factors for such exposure group in relation to name, age, sex, occupation, education, type of stroke, living area, etc.

6. To identify the caregivers influence demographic factors for such exposure group in relation to name, age, sex, occupation, education etc.

### **1.6 List of variables**

### **Independent Variables**

- 1. Socio Demographic factors, for example: Name, Age, Sex, Education, and Occupation.
- 2. Types of Diagnosis
- 3. Types of Treatment
- 4. Behavioral risk factor.
- 5. Physical inactivity

## **Dependent variables**

Life experience of stroke survivors and caregivers.

### **1.6 Operational definition Stroke**

The world Health Organization the stroke as: A rapidly developed clinical sign of focal disturbance of cerebral function of presumed vascular origin and of more than 24 hours duration.

#### **1.6 Survivors**

A person who survives, especially a person remaining alive after an event in which others have died. "He was the sole survivor of the massacre" the remainder of a group of people or things." A survivor from last year's team" A person who copes well with difficulties in their life. "She is a born survivor" The stroke usually refers to the patients who have had Cerebrovascular Accident (CVA) as the results in circulatory defects in which the symptoms have continued for more than 24 hours and it is due to a lesion affecting the opposite side of the cerebrum (Carr & Shepherd, 2006).

Stroke is characterized as a neurological deficit attributed to an acute focal injury of the central nervous system by a vascular cause, including cerebral infarction, intracerebral hemorrhage, and subarachnoid hemorrhage and is a major cause of disability and death worldwide. Despite its global impact, the term "stroke" is not defined in clinical practice, in clinical research, or in assessments of the public health. Advances in basic science, neuropathology, and neuro imaging have improved the understanding of ischemia, infarction, and hemorrhage in the central nervous system (Sacco et al., 2013).

A Stroke is an acute medical emergency. Stroke (also called "Brain Attack") is disease of the circulatory system caused by the rupturing or the blockage of an artery. In middle age older women, approximately 70% of strokes are thromboembolic (caused by a blockage from a blood clot), 15% consist of intracerebral hemorrhage, and 10% of subarachnoid hemorrhage. Depending on where the rupture or blocked artery leads, this part of the brain does not get oxygen. This can result in permanent brain damage, disability and sometimes death (Harari et al., 2008).

Cerebral vascular accident (CVA) or stroke is the most common disabling neurological disease of adulthood (Pedretti, 2007). It may be defined as an interruption in the blood flow so that an adequate supply of oxygen and nutrients faith reach portion of the brain. Medical practitioners use the term, often abbreviated as CVA, for stroke. A stroke can occur in any part of the brain the cerebral hemispheres, the cerebellum or the brainstem (Bierman, 2009). A cerebrovascular accident is a rapidly developed clinical sign of a focal disturbance of cerebral function of presumed vascular origin and o more than 24

hours duration (WHO, Foster, and Johnson, 2006). Clinical signs of stroke developed suddenly due to interruption of blood flow to the brain and lasts more than 24 hours. Warlow (2010) defined as the stroke or CVA as rapidly developing clinical symptoms and or signs of focal time's global loss of cerebral function with symptoms lasting more than 24 hours leading to death with no apparent cause other than that vascular origin. World health Organization (WHO) supports this definition of CVA. When the severity of stroke last less than 24 hours, it is known as transient ischemic attack (TIA). It is not a stroke but a warning for a fourth-coming stroke. In TIA no symptoms are found (Pedretti, 2007)

The most common type of stroke and it is responsible for about 80% of all first ever in a lifetime stroke. This takes place when a clot blocks blood vessels or become too narrow for blood to flow within the brain due to reduction in blood supply, brain cells die from lack of oxygen (Nayan, 2009).

The most important modifiable risk factors for stroke are high blood pressure and atrial fibrillation (although magnitude of this effect is small: the evidence from the Medical Research Council trials is that 833 patients have to be treated for 1year to prevent one stroke). Other modifiable risk factors include high blood cholesterol levels, diabetes, cigarette smoking (active and passive), heavy alcohol consumption and drug use, lack of physical activity, obesity, processed red meat consumption and unhealthy diet. Alcohol use could predispose to ischemic stroke and intracerebral and subarachnoid hemorrhage via multiple mechanisms (for example via hypertension, atrial fibrilation, rebound thrombocytosis and platelet aggregation and clotting disturbances). The drugs most commonly associated with stroke are cocaine, amphetamines causing hemorrhagic stroke, but also over-the-counter cough and cold drugs containing sympathomimetic (NINDS, 2005).

The stroke Centre (2012) has described the following risk factors of stroke are manageable or preventable. Risk Factors: Diet & Nutrition, physical inactivity, smoking, substance/alcohol abuse, certain medical conditions, including abnormal blood vessel connections (arteriovenous malformations and arteriovenous fistulas), cerebral aneurysms (enraptured), cholesterol level (high levels of bad cholesterol and/or low levels of good cholesterol), diabetes hardening of the arteries (atherosclerosis/arteriosclerosis), heart (cardiovascular) disease, high blood pressure (hypertension), obesity, transient ischemic attacks (TIAs). Unalterable Risk Factors: Age, ethnicity, heredity/family history of stroke, gender (TSC, 2012)

Stroke are be diagnosed by studying images of the brain (brain imaging) and carrying out physical tests. Doctor may check for the causes of stroke by taking blood tests to determine cholesterol and blood sugar levels, checking pulse for an irregular heartbeat and taking a blood pressure measurement. Even if the physical symptoms of a stroke are obvious, brain imaging should also be carried out to determine, if the stroke has been caused by a blocked artery or burst blood vessel, which part of the brain has been affected, how severe the stroke is, the risk of a transient ischemic attack (TIA). Different treatment is required for each type of stroke so a rapid diagnosis will make treatment more straight forward (Jakson et al., 2006).

The ability to define the world and our place in it distinguishes our humanity. Stroke or brain attack forever alters this world-making capacity. The stroke patient's world, once comprehensible and manageable, is be transformed into a confusing, intimidating and hostile environment. The skills of intellect, sensation, perception and movement, which are be honed over the course of a lifetime and which so characterize our humanity are the very abilities most compromised by stroke. Stroke can rob people of the most basic methods of interacting with the world. The specific abilities that will be lost or affected by stroke depend on the extent of therein damage and most importance where in the brain the stroke occurred. The brain is an incredibly complex organ, and each area within the brain has responsibility for particular function or ability. The brain is be divided into four primary parts: the right hemisphere (or half), the left hemisphere, the cerebellum and the brain stem (Drake, 2005). A stroke may result in a severe dramatic change to a person's life. It can be very hard to accept this and may result in unrealistic expectation and depression. People often feel a great physical and mental tiredness. Movements are not as autonomic and smooth as before the stroke. People who had a stroke use much more

energy than someone who has not. In relation with movement, the functional activities of the stroke patient become dependent. It influences in all aspects of daily living at home such addressing, toileting, bathing. Each stroke differs depending upon the brain injury, the severity of the injury, and the person's general health (Mondol, 2005).

Stroke is often followed by survivors, which add to the detrimental effect that loss of motor, sensory and autonomic function have on a person's health, social participation and quality of life Stroke typically induces devastating damages leading to a permanent loss of sensory and voluntary motor functions. In recent years, associated conditions or called secondary complications have received increasing attention from clinicians 'and scientists. It is generally recognized that many stroke patients will develop important and often life-threatening complications several months to several years post-trauma. For instance, muscle wasting, osteoporosis, cardiovascular problems, Immune deficiencies, hormonal imbalance, skin ulcers, anemia and urinary urgency are among the problems typically encountered by chronic ischemic individuals (Robert et al., 2013).

The incidence rates are reported to be between 29-67% in acute stroke patients. Some of the variability is be related to differences in the timing and method of swallowing assessment. The presence of dysphasia can be identified on the basis of clinical or radiographic examinations, or both patients (Martino et al., 2005). The most occurring voiding abnormalities associated with stroke have been identified as urinary frequency, urge incontinence and urinary retention (Marinkovic & Badlani 2011). There have been reports that 21%-47% of stroke patients experience urinary retention. The commonality and the importance/necessity for clinicians to address and manage these complications have been highlighted by three recent review articles on overactive bladder, urinary incontinence, and voiding dysfunctions in stroke patients, respectively (Linsenmeyer 2012; McKenzie & Badlani 2012; Mehdi et al., 2013).

A variety of risk factors for fecal incontinence has been identified by total anterior infarction (Barrett 2012). It identified problems with toilet access and constipating drugs as modifiable risk factors post stroke; however, the most powerful predictor of fecal

incontinence in the first few days following stroke appears to be the initial level of consciousness. These are followed Bladder distention spasms and catheter irrigation are the primary causes of autonomic dysreflexia. These are be followed by bowel impaction and rectal stimulation (Umphred, 2007).

The clinical diagnosis of pulmonary emboli is unreliable, being both insensitive and nonspecific. Many cases are clinically silent with only 30% having the clinical features of a DVT and only 70% demonstrating a DVT on demography. Patients with a massive pulmonary embolus who suffer compromise of more than 60% of the pulmonary circulation are critically ill. Right heart failure may progress to cardiovascular collapse with hypertension, coma and death. A submissive pulmonary embolus presents with tachycardia, tachypnea and signs of pulmonary infarction with consolidation, riles, hemoptysis, pleuritic chest pain, pleural friction rub, pleural effusion and fever. In most cases there are usually only a few clinical findings and the presentation may be nonspecific with the major clinical complaints malaise and a fever (Jensen & Lenz, 2005).

Post stroke seizures may occur soon after stroke or be delayed each appears to be associated with differing pathogeneses. Most seizures are single, either partial or generalized (Ferro & Pinto 2008). Wiebe and Butler (2008) noted that, Seizures are the clinical expression of excessive, hyper synchronous discharge of neurons in the cerebral cortex."Whether seizures worsen outcome remains unclear. Vernon et al., (2009) reported new-onset seizure among patients with ischemic stroke was an independent risk factor for mortality. However, the authors did not control for the confounding effects of stroke severity or co morbidity. Similarly, higher mortality risk at 30 days and 1 year was seen in patients with early seizures but the risk disappeared after adjusting for stroke severity and other confounding factors (Hamidou et al., 2013). reported to be between 4% and 15%, with the majority of fractures occurring on the both side. Moreover, Watanabe (2005) found that 40% of patients admitted for inpatient stroke rehabilitation already had osteoporosis. About one hundred years ago, a couple French neurologists described an abnormal pain disorder occurring subsequent to stroke (Segatore 2006).

Central post stroke pain (CPSP) is a syndrome characterized by sensory disturbances and neuropathic pain. The condition has received a significant amount of attention recently. One study reported that as many as 8% of all stroke patients had some form of CPSP. However, given the multitude of clinical impairments/disabilities suffered by stroke patients it is not unusual for pain to be ignored or given a lower priority. In 4060% of CPSP patients, the onset of central pain occurs more than one month following the stroke and may cause delays in diagnosis and treatment if the primary care providers are no longer actively involved in the patents' care at this point (Hansson 2005).

Although fatigue following stroke is common and may negatively affect progress during inpatient rehabilitation, it has not been well studied. Fatigue is a subjective term and there is no valid and accepted definition of fatigue (Choi-Kwon & Kim 2011; Van Eijsden et al., 2012). Abnormal, or pathological fatigue has been defined as a state of general tiredness characterized and shoulder hand syndrome by weariness unrelated to precious exertion levels and is usually not ameliorated by rest (De Groot et al., 2009). When people sustain Stroke they need prolonged meticulous care that starts with hospitalization and extend long after discharge. In stroke, the goals of rehabilitation include, optimizing physical function, facilitating social independence, minimizing medical complications, enhancing emotional adaptation, and promoting reintegration into the community. Rehabilitation involves the combined & coordinated use of medical, socials, educational & vocational measures for training & retraining the individuals to the highest possible level of functional activity. Rehabilitation has been defined by the World Health Organization as a progressive, dynamic, goal oriented and often time limited process, which enables an individual with an impairment to identify and reach his/her optimal mental, physical, cognitive and social functional level (Zeyda, 2009). Patients need to be transferred to specialist units for Stroke at the earliest opportunity so that they can achieve the greatest degree of functional independence possible, for it appears that delay causes more medical complications prolonging rehabilitation Concluded that optimal rehabilitation care, with regard to the prevention of complications during the acute phase, entails early admission to a specialized multidisciplinary facility (Roy et al., 2014).

#### 3.1 Study design

It was used a qualitative research model to extract the life experience of stroke survivors. A qualitative research design was used so that there would use large number of participants and therefore to collect data. The qualitative study carried out among patients who are suffering from life experience of stroke survivors Centre for the Rehabilitation of the Paralyzed (CRP) at Neurological unit.

#### 3.2 Study site

Data were collect from the Neurological unit of Centre for the Rehabilitation of the Paralyzed (CRP), which was the largest rehabilitation centre for the Stroke patients in the Bangladesh. It was a nonprofit organization, which is providing comprehensive rehabilitation of people with spinal cord injury in Bangladesh. CRP the person's impairment alone. CRP focuses on a holistic approach to rehabilitation, recognizing that all aspects were important for it success Physical rehabilitation, psychological rehabilitation, economic rehabilitation and planned discharge. Support was be extended once the person goes back to a live in the community. CRP also launch stroke rehabilitation of stroke patients. Approximately 20 stroke patients per day are receiving services from CRP as inpatient and outpatient. For that, reason CRP was consider as a study place.

#### **3.3 Study sampling and population**

The study populations were 20 stroke patients 20 caregivers who admitted in CRP for treatment. The sample was be chosen by convenience sampling. There was developed a semi structural type questionnaire for identifying the life experience of stroke survivors.

#### 3.4 Inclusion criteria

- 1. Both male and female patients would include.
- 2. Patient age range was between 30-90 years.
- 3. In caregivers:-

-Both male and female.

-Caregivers age range 16-75 years.

-Full primary care.

#### 3.5 Exclusion criteria

- 1. Patients who would medically unstable.
- 2. Participants who had not speaking problem.
- 3. Patients who had cognitive problem.
- 4. Patients who were not able to communicate.

### 3.6 Sample size

Due to limited set of time the number of the sample of the study was 20. For this study small sample size was taken. So, the researcher could analyze the data from the participant deeply & easily. Only 20 participants was have been chosen as sample until data saturation point was reached. Small numbers of potential study participants are appropriate for a qualitative methodology. They selected according to the researcher purpose and their willingness and accessibility for interview.

#### 3.7 Sampling technique

Data were collect from Neurological unit of CRP. Data is collected data from the patients who are admitted at CRP to take physiotherapy treatment or continuing their treatment. Sampling procedure was purposive convenience sampling technique. According to this sampling process, the researcher had the ability to select the sample towards the study purpose. By using this sampling procedure could make a judgment about sample & able to collect in depth data from participant according to research needs. Those who meets inclusion and exclusion criteria were select as the participants.

#### 3.8 Questionnaire

The questionnaire was structural type for collecting the date for the findings of the study.

### **3.9 Data collection method**

A study population was been selected by using the convenience sampling method. A small number of participants were appropriate for our qualitative study method, of those, twenty participants were sufficient to reach data saturation point. In addition to the inclusion and exclusion criteria, participants were select according to the researcher purpose and their willingness and accessibility for interview. CRP was one of the largest providers of stroke rehabilitation in Bangladesh. A semi-structured questionnaire was developed to guide researchers in their data collection during the interview. All socio-demographic information were collect and questionnaires completed during face-to-face interviews led by a final year physiotherapy student supported by academic and clinical physiotherapists. All interviews were carried out in Bengali and recorded on audiotape for later analysis and translation. Data was stored in the form of transcripts and voice recordings; any information with patient identifiable information was kept safe in a locked office.

### **3.10 Data collection procedure**

There is a questionnaire for acquiring the participant's demographic information including age, sex, marital status, educational status, occupation, history including types of occupation, disease condition related information such as neurological related, and others information. The questionnaire is provided to responsible physiotherapists for patients and also direct to the patients for finding the answers to the questions given in the questionnaire.

### 3.11 Data collection tools

- 1. Pen
- 2. Paper
- 3. Pencil
- 4. Android phone

#### 3.12 Data Analysis

Researchers began by transcribing the interviews in Bengali from the audio tape recorder. These transcriptions were reviewed multiple times and a qualitative content analysis was used to verify the data and decipher common themes. Information was then translated into English.

#### 3.13 Ethical Consideration

The research proposal was submitted to the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) & approval was obtained from the board. The whole process of this research project was been done by following the Bangladesh Medical Research Council (BMRC) guidelines and World Health Organization (WHO) Research guidelines. Verbal and written inform consent was taken from every participants and ensure every participants that they can leave any time during data collection, & it was ensured that participants were not influenced by data collector. The researcher strictly maintained the confidentiality regarding participant's condition. The study was been conducted in a clean and systematic way. Every subject had the opportunity to discuss their problem with the senior authority or administration of CRP and have any questioned answer to their satisfaction.

#### 3.14 Rigor

This study was conducted in systemic way. All the steps of research would followed by a sequent during data collection and analysis there was avoided influencing the whole process by own perspectives values and biases. When conducting the study it took help from the supervisors and physiotherapists. There was never influenced the participants by personal perception during data collection. A trustful relationship with participants was always maintained and the documents were kept confidential. During data analysis biasness was avoided.

The aim of the study is to find out perception about group therapy among the stroke patients. Results and discussion are carried out at the same time and presented together. The participant in this study offered some important insight on the perspective about group therapy. Participants responds according to their perception. There were 20 patients and caregivers from stroke rehabilitation unit from Stroke Rehabilitation Unit (SRU) of Neurology Department of Centre for the Rehabilitation of the Paralyzed (CRP).

### Socio-demographic information at a glance

20 patients and their caregivers participated in this study. Our sample represents patients from 30 to 90years old. (See Table 1) A majority of our study population were male (65%), living in urban areas (50%) and employed (70%). Most of the participants received some form of education, with only 5% having no formal education. All participants were married and described themselves as Muslim Each participant had a caregiver who supported them at home and in the community with various daily tasks. The Caregivers were aged between 16 and 75 years old. The youngest caregiver was a student and the daughter of the participant. A majority of the caregivers were female (70%) and were housewives (50%)

<b>Table-1: Patients and</b>	Caregivers	Socio-demographic	Information

Socio-demographic	Participants	Caregivers
Information		
Age		
11-20	0 (0%)	1 (5%)
21-30	0 (0%)	5 (25%)
31-40	5 (25%)	1 (5%)
41-50	6 (30%)	7 (35%)

51-60	4 (20%)	2 (10%)
61-70	3 (15%)	2 (10%)
71-80	1 (5%)	2 (10%)
81-90	1 (5%)	0 (0%)
Sex		
Male	13 (65%)	6 (30%)
Female	7 (35%)	14 (70%)
Residential area	I	
Rural	7 (35%)	7 (35%)
Semirural	3 (15%)	3 (15%)
Urban	10 (50%)	10 (50%)
Occupation	I	
Housewife	6 (30%)	10 (50%)
Self Employed	2 (10%)	0 (0%)
Employed(Public and Private	12 (60%)	9 (45%)
Sector)		
Student	0 (0%)	1 (5%)
Educational status	I	
No formal education	1 (5%)	2 (10%)
Primary School Certificate	2 (10%)	3 (15%)
Junior School Certificate	3 (15%)	2 (10%)
Secondary School Certificate	5 (25%)	7 (35%)
Higher School Certificate	3 (15%)	2 (10%)
Bachelor degree	6 (30%)	4 (20%)

#### Findings at a glance:

Theme 1: Prior about knowledge

Theme 2: Staying at hospital

Theme 3: Access to Rehabilitation Including Physiotherapy, Occupational Therapy and Speech and Language Therapy

Theme 4: Level of Independence Post Stroke

Theme 5: Rehab services at community

Theme 6: The Challenges of Returning Home

Theme 7: The Challenges Experienced by Caregivers

Seven themes were deciphered following analysis of the data collected from the interviews.

#### **Theme 1 - Prior Knowledge of Stroke**

Within our study population the awareness of stroke was poor, with only one participant reporting any insight into stroke and some of its associated risk factors prior to the event. This following statement was provided by this participant: "I know that hypertension, depression, fatty food, heart attack can cause a stroke." All participants were unaware they had had a stroke until this diagnosis was confirmed by a doctor. The majority of participants were found unconscious, while some reported that symptoms of weakness resulted in them seeking medical assistance. One stroke survivor described the following symptoms: "I was talking to my wife. Then suddenly my right hand started to feel heavy. I could not raise my arm. I could not speak. My wife helped me to lie down and poured water on my head."

#### **Theme 2 - Hospitalization Post Stroke**

Following the onset of stroke all patients attended hospital, 75% of which were supported by their spouse and the remainder receiving support from other family members such as their sons and brothers. One participant reflects on their experience of the event. "I was confused. I did not understand what was going on. My husband and my son took me to hospital." Participants were asked about their length of stay in hospital and to comment on their experience during their hospital admission. Participants' hospital admissions varied from 1 to 30 days, with an average length of stay of 12 days. For example: "In hospital, I gained consciousness. I was just lying in bed. During my stay, about 16 days, I did not move myself out of bed. I did everything in bed. I slept a lot. I was just on medication. I did not receive any rehabilitation services." None of the participants received therapy input (including physiotherapy, occupational therapy and speech and language therapy) during their initial hospital admission. When commenting on their experience whilst in hospital, 50% of participants reported no improvement in their physical, psychological or social well-being, whereas 40% of participants reported some improvement, specifically relating to their level of consciousness. Only 5% of participants reported an improvement in their well-being. The final 5% reported receiving solely medical treatment for their stroke, showing no physical improvement. One participant recalled their experience of hospital: "They treated my brain. I did a lot of tests and had medicine. I could not move my left arm and left leg. There were no improvements in my movement during my hospital stay. I asked doctors and nurses about my recovery, they assured me I would be able to walk again. No one advised me or helped me to move. All of them told me to lie down on the bed and not move."

# Theme 3 - Access to Rehabilitation Including Physiotherapy, Occupational Therapy and Speech and Language Therapy

The participants heard about CRP from different sources, 45% were recommended CRP by relatives and 40% of participants were referred by a doctor. The remaining 15% of participants were encouraged to attend by friends and neighbors who had previously received treatment from CRP. One participant described how they found out about

rehabilitation: "On discharge, no one from the hospital told me about rehabilitation services. They told me to do some exercise at home. One of my relatives informed me that he knew someone who had been to CRP after their stroke. That patient received therapy and regained his mobility. He encouraged me to go to CRP for therapy." All participants received physiotherapy intervention at CRP, with 60% receiving occupational therapy in addition to physiotherapy. 35% of participants received speech and language therapy alongside their physiotherapy and occupational therapy intervention. A participant reflects on their therapy: "As I had problems with my mobility, managing daily activities and my speech, I received physiotherapy, occupational therapy and speech therapy. All therapies were useful, particularly physiotherapy which helped me to walk again. When I initially came to CRP, I need help from 2 or 3 people to transfer myself from my wheelchair to the bed. I could not sit alone. My wife helped me with feeding, dressing and for everything. After one month of therapy, my situation improved a lot. I was able to sit and stand alone for a long time. I only required minimal help from someone during walking. All therapists helped me to gain this outcome."

#### **Theme 4 - Level of Independence Post Stroke**

All patients sought a full recovery from their stroke. However, on reporting functional level achieved at least 1 year post discharge from CRP, 18 participants reported being able to transfer from lying to sitting independently, 14 of these participants reported independence with some Activities of Daily Living. 8 participants reported the ability to mobilize unaided and 4 of these participants reported improvements in their mood. 1 participant reported regaining the movement only in his fingers and 1 participant reported no improvement in his function. One participant describes the positive outcome following therapy: "I gained about 80% of my mobility back after receiving physiotherapy at CRP. When I went back to my community, I did my daily activities; I did my cooking, washing and some other activities. It was a new life for me. I did not believe I could walk again or do something for my family." In contrast, another participant describes their negative experience: "I was fully dependent on my family. I started my therapy at CRP, 9 months after my stroke and I did not achieve much improvement. I always need someone to help me. At home my wife did all my activities. I was not able to go back to my job. I was not able to even visit the

nearby shop from my home. I felt like a prisoner. I could not go outside and meet people to speak to."

#### Theme 5 – Satisfaction with the Health care System Post-Stroke

Participants asked about their experience using the healthcare system in Bangladesh. 90% of participants reported poor perceptions about the health services however were unable to identify how the system could be improved. 10% of participants reported they had a good experience when using the healthcare system. One of these participants reported that having a CRP center in every district in Bangladesh would improve the healthcare system, and another felt the healthcare system needed to be more developed in order to provide better care. One participant describes their experience of the healthcare system: "My family and I had no idea what to do after stroke. I initially went to our nearby local hospital but they did not provide any treatment. They sent me to a bigger hospital in Dhaka. It took around 4 hours to get to Dhaka. I had to do lots of tests. No one explained to me or my family what to do. I was just lying in bed. After a week they discharged me but they did not tell me what I needed to do next. I could not move the right side of my body and I had some problems speaking. I did not have any information about rehabilitation services after stroke. I did not even receive any therapy during my stay at hospital. If therapy services were available at hospital I could get more benefits. When the hospital discharged me, I went back to my home. I was just lying down at home as I did in hospital. One of my family friends suggested I go to CRP, but CRP was far from my home. So my children brought me here. If therapy services were available at my nearby government hospital it would be better. I had to spend lots of money for therapy and staying near to CRP. A service near my home or in the community will definitely reduce my suffering and the cost."

#### **Theme 6** – **The Challenges of Returning Home**

All participants require some support from their caregivers as a result of their stroke. 80% of the participants were unable to access therapy once discharged home. For example: "When I went home from CRP, I still needed therapy. Unfortunately there was no facility for therapy in my community. In my nearby town there was a therapy centre and I went there only once. That centre was run by a non-qualified therapist. Once he was a patient

caregiver and claimed he had some short training. But he only treated me with some electrical devices. He used red light (Infrared Radiation). I did not continue treatment there." 10% were able to gain access to therapy treatment by attending a private therapy centre. One participant illustrates their experience of private physiotherapy: "At the town in my district I found one therapy centre run by a physiotherapist. I went there several times. It was far from my home and travelling to that centre was very difficult. I could not use public transport comfortably. I needed to hire private transport that was expensive. The quality of the therapy service was satisfactory but not as good as CRP." The remaining 10% continued to stay near CRP and seek treatment. For example: "CRP discharged me from its regular therapy services but I did not go back to my home, as I could not walk. So what would I do if I go back to home? I rented a house near by CRP and took extra therapy services from various therapy center around CRP." Participants were asked about how their stroke had affected their personal life. Some participants reported various restrictions to participation, including: "I cannot eat with my hand, cook or walk by myself". "I am not able to talk clearly and I cannot walk". "I cannot move. I stay in bed." Following their stroke, 70% of participants were unable to return to work and their previous household role, due to the physical, mental and social implications of their stroke. One participant describes her upsetting experience following her stroke: "I was a housewife. I used to do all sorts of activities at my home including cooking, washing and cleaning. After the stroke, I can't do anything. Now I am useless. I am a burden on my family. My husband, son, daughter always spend time with me. Most days my daughter cannot go to her college. My husband is depressed. He already spent enough money on me. Now our financial situation is bad. I do not know if I will be able to work again or not. I am always thinking and depressed. What is the future of my family? I cannot visit anywhere. No social activity. I have to depend on others for my washing and bathing. This is so frustrating and humiliating." The remainder of the population returned to work and their previous role in the household. For example: "I am lucky that I recovered very well. Though it is not 100%, I can do all of my work. Very occasionally I need help from someone. I returned to my work. I work for a private company. If I could not go back to my job my family would be in big trouble. Now my son and daughter are able to continue their study." All participants reported that their stroke had a negative impact on their household income. 65% reported

that they had lost money due to their stroke. The financial burden of stroke as described by one participant: "Treatment for stroke is costly. I had to spend lots of money in hospital after the stroke. The cost of different tests and medication was very expensive. Taking therapy services is also expensive. The cost for therapy is not so expensive but staying around CRP is much more expensive. The house rent is too much around CRP with the cost of food and travelling included. I am not currently involved in any work. I have no income. I have to spend extra money for the stroke. I already spent all my savings and now I have to borrow money from others." 35% felt they would get more treatment if they had more financial resources. For example: "Continuing therapy is expensive. I spent all of my savings and borrowed some money. Therapy not provided by CRP is not satisfactory. But living around CRP and having therapy is expensive. In my community no therapy service is available. If I had enough money I could continue my treatment here at CRP." Participants reported common challenges they experienced following their stroke, including financial problems: "I have lost a lot of money and now I have more problems in my family life". Social isolation: "I am lonely because my wife and children have given up on me". And some communication difficulties: "I have some communication problems which has led to me losing money and having issues with social participation".

#### Theme 7 - The Challenges Experienced by Caregivers

Caregivers were be asked by a series of questions about the impact of their relative's stroke on their life. Common challenges faced by caregivers included financial struggles and a lack of time for their social, educational and personal needs. One caregiver described the effects of the care giving role on her education: "I had to look after my mum. My mum could not do much for herself. I have to help her with her daily activities. I also need to cook, do washing and other activities for my family. I have little time for studying and to go to school. I have already dropped a year. I don't know what will happen next year." Another caregivers discussed the following financial challenges: "My father was the only member of our family earning. He did a small private job. After his stroke he is not able to go back to his job. He is not earning any more. We have already spent all of our savings and borrowed money from our relatives. We don't have enough land or any other sources of income. I am in the middle of my study. I am not sure if I will get a job or not. In addition, I need to spend a lot of time with my father. My mother's health is also not good. So I always feel helpless." When asked about how their health had been affected, only 10% reported having no physical problems. 55% of caregivers reported they have developed back pain with a further 25% of careers reporting neck pain from caring for their relative. 10% of caregivers reported upper limb paresthesia. One caregiver comments on the negative impact on her health: "My husband is dependent on me. I help him doing all basic activities. I help him doing exercises as the therapist instructed. I need to give a lot of physical effort. I am always busy doing something. I have very little time for rest. Initially I did not know how to move my husband; I use a lot of effort to move him. Now I have developed pain in my back. I am not feeling well. I have no rest in the day. I cannot sleep well as my husband wakes up in the middle of the night, so I have to wake up as well." When caregivers were asked how the healthcare system could be improved, most were unaware. However some felt that more preventative and rehabilitative care for caregivers should be more easily accessible. "Treating and taking care of stroke patients is really difficult. If an integrated health system was more established, it would be good and reduce the burden of patients on families. We need to develop facilities for stroke treatment in our nearby hospital. Travelling to Dhaka or big cities is not good. We have big problems with therapy services. We do not have facilities in our community to receive therapy services. We need to come to CRP. This is too far and staying here for a long time is expensive and difficult. As I have seen all stroke patients need care and therapy services for a long time. Two of my family members are always busy with my patient. We actually cannot do any other work. If therapy services were available in Upzila (sub district) Hospital or in the community it would be good for us. Therapy services must be provided in government hospitals then we can get this service for free or low cost. Private therapy services are expensive.

# **Comprehensive table-2:**

	Participants																			
Theme	P1	P2	P3	P4	P5	P6	<b>P</b> 7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20
Prior about Knowledge																				
Yes	$\checkmark$																			
No												$\checkmark$							$\checkmark$	
Hospitalization																				
Yes	$\checkmark$	$\checkmark$							$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$				$\checkmark$	
No																				
Access Rehab	ilita	tior	1																	
Improvement														$\checkmark$	$\checkmark$				$\checkmark$	
No																				
improvement																				
Level indepen	deno	ce p	ost	stro	oke															
Independent														$\checkmark$	$\checkmark$					
Dependent																				
Rehab service	e Co	mm	uni	ity																
PT									$\checkmark$					$\checkmark$	$\checkmark$				$\checkmark$	
OT																				
SLT																				
Return to wor	k			1			<b> </b>			L		1					L			
Yes																				
No																				
Challenges Ex	peri	ienc	ed o	care	egivo	ers						1					<u> </u>			
Problem in														$\checkmark$	$\checkmark$				$\checkmark$	
body function																				

Problem in	$\checkmark$	 			 $\checkmark$	$\checkmark$		$\checkmark$			
social											
participation											

Our study found that knowledge of stroke and its associated risk factors amongst participants prior to their stroke was poor. In 2013 stroke resulted in 6.5 million deaths, with approximately 25.7 million stroke survivors, resulting in 113 million disability adjusted life years (Feign et al, 2017). With such poor awareness of the risk factors associated with stroke, it is likely that very few understand the importance of seeking medical advice to manage any modifiable risk factors. Many of the strokes occurring could potentially be preventable if these risk factors are better managed. Previous research has shown that use of mass media and public education campaigns are effective for increasing awareness of stroke and its risk factors (Müller-Nordhorn et al., 2006 and Becker et al., 2001).

There are a number of barriers in Bangladesh that may affect how easy it is to disseminate information via media sources including low literacy levels (Bangladesh Bureau of Statistics, 2008) and difficulty accessing internet particularly in rural areas (Islam and Hoq, 2010). As stated previously by it is vital that government and health professionals work closely to educate the public to reduce this growing epidemic. (Venketasubramanian et al.,2017). Despite varying lengths of stay (1-30 days), none of our participants received any form of rehabilitation during their acute hospital admission. A previous review found that patients with acute stroke who receive multidisciplinary stroke rehabilitation were more likely to survive, regain independence and return home (Stroke Unit Trialists' Collaboration, 2013).

Greater functional outcomes on discharge and follow-up were associated with higher initial functioning following the stroke and early initiation of multidisciplinary stroke rehabilitation (Cifu and Stewart, 1999). Stroke describes the importance of rehabilitation professionals assessing stroke patients as soon as possible post-admission. This is supported by who found greater functional gain and shorter length of stay in hospital with patients who received stroke rehabilitation within 30 days of their first stroke (Salter et

al.,2006). The National Institute for Health and Care Excellence (2013) also suggests that health and social care professionals should work together to promptly assess patients prior to discharge from hospital. This guideline recommends that people with disability following stroke should receive a multidisciplinary approach to rehabilitation, including being offered 45 minutes of each relevant therapy for a minimum of 5 days a week in a stroke unit. Furthermore, rehabilitation should be continued once in the community by a specialist stroke team. The lack of provision of any form of rehabilitation whilst in hospital and lack of advice to seek rehabilitation on discharge, may have contributed to the patients' poor satisfaction level with the healthcare system. (Hebert et al., 2016)

In addition to the lack of rehabilitation whilst in hospital, there are several other factors feed into the delay of initiating rehabilitation. These include the inconsistent advice and low rate of onward referrals from medical professionals (40%) to commence rehabilitation and absence of a pathway linking patients into rehabilitation facilities on discharge. For instance, one participant did not receive any rehabilitation until 9 months post-stroke. This time delay results in an increased risk of secondary complications occurring without therapy intervention (Brandstater and Shutter, 2002). Studies have found that significant improvements are made in rehabilitation in the first 3 months following stroke, with the recovery rate decreasing between 3 and 6 months (Verheyden et al, 2008 and Lee et al,. 2015).

The life changing effects of stroke on patients, understandably results in challenges to readjust upon returning home. The personal, social and economic impact on stroke survivors has been well documented (Daniel et al, 2009 and Walsh et al, 2015). Common challenges in this study included financial problems, social isolation and difficulties walking. We found the most common challenge among participants and caregivers was the financial burden of stroke supported similar findings in their review. (Mishra et al,. (2016).

Previous research has shown that return to work was influenced by the ability to walk, cognitive function and occupation. Those who were able to return to work were more likely to achieve high subjective well-being and life satisfaction (Vestling et al, 2003). In our

study only 30% of participants returned to work or previous responsibilities. Similarly, Walsh et al 2015) found that less than a quarter of their participants returned to work following a stroke, however those that did, had to reduce their hours, adjust their roles or were unable to sustain employment. (Walsh et al., 2015). Although we did not investigate this issue in detail, possible challenges to returning to work may include the manual nature of work in Bangladesh (Kibri, 2012), the lack of accessible transport for people with disabilities (Abir and Hoque, 2011) and potential lack of workplace adjustments.

In addition to the financial problems caused by stroke, Walsh et al (2015) found that participation in social and psychosocial barriers and lack of transport affected leisure activities. Likewise, we found that the burden of supporting the stroke survivor through barriers such as these may have caused a shift in the relationship between caregiver and stroke survivor, with one caregiver referring to their affected family member as "my patient".

The main challenges faced by the caregivers in this study included financial struggles and a lack of time for their social, educational and personal needs. Although care giving can improve careers' self-efficacy, enable them to learn new skills and may strengthen family relationships, it often results in chronic stress, which in turn has a negative impact on the caregivers' physical and psychosocial health (Schulz and Sherwood, 2008). One example from the study is of a young caregiver having to take on the role of supporting both her mother and the rest of the family, resulting in her having no time to continue in education. Amongst the caregivers interviewed for the study a majority experienced some physical health problems as a result of caring for the stroke survivor. Back pain and neck pain were the most common complaints for our caregivers, indicating the need for further support and training in adapting to this new role.

These caregivers suggested that preventative and rehabilitative care should be available for caregivers in order to improve the healthcare system. This is supported by Cheng et al (2014) who suggested that caregivers should be supported throughout the stroke and this psychosocial intervention should focus on skills such as problem solving and stress coping.

Bhattacharjee et al (2012) concluded that it would be beneficial to provide caregivers with practical nursing training and counselling sessions in order to reduce caregiver burden.

#### Limitation

Each and every thesis paper has some limitations and some limitations may exist. Regarding this study, there we some limitations or barriers to consider the result of the study as listed below: The first limitation of this study is sample size. It is taken20 samples. There is a few research completed in Bangladesh, so there is little evidence to support the result of this project. Another major limitation is time. The period is very limited to conduct the research project on this topic. As the study period short so the adequate number of sample could not arrange for the study. As the study is conducted at Centre for the Rehabilitation of the paralyzed (CRP) which may not represent the whole country.

### Conclusion

The awareness of stroke and its risk factors is low in Bangladesh. This highlights the importance of educating the population about this topic to reduce the incidence of stroke. The government should work closely with healthcare professionals to achieve a better public awareness of stroke. Delays in accessing rehabilitation were common due to an absence of therapy in hospital and a lack of referrals made to rehabilitation services by medical professionals. For these reason it is also likely that many do not receive any rehabilitation following their stroke. Implementation of a stroke pathway that increases awareness of the rehabilitation services available and encourages referrals onto rehabilitation should be considered to improve access and reduce these delays, thereby improving possible outcomes for stroke survivors and potentially reducing caregiver burden. It is important to recognize the socio-economic, psychological and physical strains caregivers experience when caring for stroke survivors. Support and training should be available to all caregivers throughout their journey of care to reduce and where possible prevent these strains. Future research should broaden its investigation of the challenges faced by stroke survivors and their caregivers focusing on those who are unable to access rehabilitation. This would help to identify areas for development in the provision of healthcare and rehabilitation whilst working towards Bangladesh achieving its Sustainable Development Goals.

#### Recommendation

The recommendation evolves out of the content in which the study was conducted. Therefore main recommendation would be made. Further research of the different perspectives emerged from the study, is recommended: In Bangladesh, as a new profession physiotherapy practice should be strong evidenced based so that can develop a interrelationship with other professionals standard in comparison with the support of the global evidence of rigorous. This type of study should be considered that need to be collected adequate resources that knowledge on this area could be extended and later result can obtain to generalize to the population. During further research it is recommended to take more samples with adequate time to solve the recent problems areas for better result and perspectives.

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Ref. CRP-BIIPI/IRB/10/18/1252

Date: 2.2/10/2018

To Ummul Khayer Fatema B.Sc. in Physiotherapy Session: 2013-2014, Student ID: 112130200 BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

Subject: Approval of the thesis proposal "Quality of life experience of stroke survivors" by ethics committee.

Dear Ummul Khayer Fatema,

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 version & Bangla version)	
3	Information sheet & consent form.	

The purpose of the study is to determine quality of life experience of stroke survivors using a questionnaire that requires 20-25 minutes, the members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 10:00 AM on  $24^{th}$  January, 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,

Leverthanala

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

সিআরপি-চাপাইন, সাডার, 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

### **CONSENT STATEMENT**

#### Assalamualaikum,

I am Ummul Khayer Fatema student of physiotherapy department affiliated to university of Dhaka. I am conducting this study for 4<sup>th</sup> professional B.sc in Physiotherapy project study dissertation titled "Life experience of stroke survivors and caregivers" To fulfil my research project, I need to some information from you to collect data. So, you can be a respected participant of this research and the conversation time will be approximately 15-20 minutes. I would like to inform you that this is a purely academic study and will not be used for any other purpose. Your participation in the research will have no impact on your present workplace. All information provided by you will be treated as confidential and in the event of any report or publication it will be ensured that the source of information remains anonymous. Your participation in this study is voluntary and honorarium will not be provided for this purpose. I am conducting a study on Experience after stroke: survivors and caregivers perspectives. Participation in this study is completely voluntary and you can withdraw yourself at any time. Your participation in this study will not affect your treatment or any other services. If you want to know more please contact with us. Information collected from you will be used solely for research purpose. I will not disclose your information to others and all information will be kept confidential and stored safely. I am happy to answer any of your inquiry. Please do not hesitate to ask any question during at any time of your during interview

If you have any query about the study or your right as a participant, you may contact with me at Physiotherapy Department, BHPI, CRP, Savar, Dhaka-1343. Do you have any questions before I start? So, may I have your consent to proceed with the interview?

Name of participant	sig
Name of participant	sig
Name of interviewer	

## Questionnaire

## Experience after stroke: survivors and caregivers perspectives

Part I: Socio-demographic information of patients and caregivers

Patients information	
Gender	
Age	
Types of stroke	
Hemiplegia	
Date of stroke	
Occupation before stroke	
Occupation after stroke	
Level of education	
Residence (address/rural/ semi urban/ urban	
Caregivers relation	
Care givers information	
Gender	
Age	
Education	
Occupation	

### **P II:** (Open questions)

### Domain 1( Health care delivery )

- 1. Did you know what was stroke prior to this incidence
- 2. Did you know what the risk factors of stroke were prior to incidence
- 3. How did you recognized it was a stroke
- 4. what did you do immediately after the onset
- 5. what was the first profession you approach to help
- 6. How long did you stay at hospital? What is your experience during stay at hospital?
- 7. Who advised you to seek rehab

- 8. Why did you take rehabilitation (therapy) services? What rehabilitation services did you take?
- 9. What was your expectation of rehab
- 10. Overall experience of Bangladesh health care system for stroke
- 11. How do you think the health system can be improved

Domain 2: After discharge from rehab service (Home environment)

- 12. How did you mange at home after discharge from rehab service
- 13. Did you access any medical or rehabilitation services

Domain 3: personal life

- 1. How has stroke affected your personal life?
- 2. How has stroke affected your occupation
- 3. Has your stroke affected household income
- 4. What challenges are you facing now?

If resource and finance were not an issue would could improve the situation.

Domain 4:	Caregivers	specific of	questions

- 1. How has stroke of your relative affected your life?
- 2. How has your health been affected?
- 3. How accessible did you find the health care and rehabilitation services
- 4. How do you think the health system can be improved
- 5. If resource and finance were not an issue would could improve the situation.

সেট্রাকের পরের অভিজ্ঞতা : বেচেঁ থাকা এবং যত্নশীল দৃষ্টিকোণ রোগীর এ**বং** সেবাদানকারীর সামাজিক-জনসংখ্যার তথ্য

# রোগীর তথ্য :-

- ১. রোগীর নাম
- ২. বয়স
- ৩. লিঙ্গ
- 8. স্ট্রোকের ধরণ
- ৫. কত তারিখে সেট্রাক হয়েছে
- ৬. স্ট্রোকের আগের পেশা
- ৭. স্ট্রোকের পরের পেশা
- ৮. শিক্ষার স্তর
- ৯. ঠিকানা:- গ্রাম/শহর

# সেবাদানকারীর তথ্য:-

- সেবাদানকারীর নাম
- <u>২. বয়স</u>
- ৩. লিঙ্গ
- 8. শিক্ষা
- ৫. পেশা

# ডোমেন-১ (স্বাস্থ্যসেবা প্রদান)

- ১. স্ট্রোক কি? আপনি কি আগে স্ট্রোক সম্পর্কে জানতেন?
- ২. আপনি কি স্ট্রোক হওয়ার কারণ গুলো আগে জানতেন?
- ৩. আপনি কিভাবে বুঝলেন আপনার স্ট্রোক হয়েছে?
- 8. স্ট্রোক হওয়ার সাথে সাথে আপনি কি করলেন?

- ৫. কে প্রথম আপনাকে হাসপাতালে আসতে সাহায্য করেছিল?
- ৬. হাসপাতালে থাকার সময় আপনি কতটুকু ভাল হয়েছিল?
- ৭. কারা আপনাকে থেরাপী সেবা সম্পর্কে পরামর্শ দিয়েছিল?
- ৮. আপনি কোন থেরাপী সেবা গ্রহণ করছেন?
- ৯. আপনার থেরাপী সেবার প্রত্যাশা কি?

১০.আপনি কি জানেন স্বাস্থ্য সেবার উন্নতি কিভাবে করা যায়?

১১. স্ট্রোকের জন্য বাংলাদেশে যে স্বাস্থ্য সেবা দেওয়া হয় সে সম্পর্কে আপনি কি জানেন?

ডোমেন-২: থেরাপী সেবা থেকে বাড়িতে যাওয়ার পর (ঘরের পরিবেশ)

- ১. আপনি থেরাপী নিয়ে বাড়িতে যাওয়ার পর কিভাবে চলছেন?
- ২. আপনি বাড়িতে কোন থেরাপী সেবা গ্রহণ করছেন?

ডোমেন-৩ (ব্যক্তিগত জীবন)

- ১. স্ট্রোকের ফলে আপনার জীবনে কি কি সমস্যা হয়েছে?
- ২. স্ট্রোকের ফলে আপনার পেশার কি ক্ষতি হয়েছ?
- ৩.স্ট্রোকের ফলে আপনার পরিবারের আয়ের কোন সমস্যা হয়েছে?
- 8. আপনি কি কি সমস্যা সমমখীন?

ডোমেন-৪ (সেবাদানকারীর নির্দিষ্ট প্রশ্ন)

- ১. আপনার আত্মীয়ের সেট্রাক আপনার জীবনে কি কি সমস্যা তৈরি করেছে?
- ২. আপনার স্বাস্থ্যের উপর কেমন প্রভাব ফেলেছে?
- ৩. আপনি কি কোন থেরাপী সেবা নিছেন?
- ৪. আপনার স্বাস্থ্য কিভাবে ভাল রাখা যায় বলে আপনি মনে করেন?
- ৫. বাংলাদেশের স্বাস্থ্য সেবা কতটুকু উন্নতি করা প্রয়োজন বলে আপনি মনে করেন?