# PERCEPTION OF PATIENT'S CARER ABOUT HOME BASED REHABILITATION THERAPY (HBRT) SERVICE FOR THE STROKE PATIENTS AT CRP

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We, the under signed certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled

# PERCEPTION OF PATIENT'S CARER ABOUT HOME BASED REHABILITATION THERAPY (HBRT) SERVICE FOR THE STROKE PATIENTS AT CRP

Submitted by **Farhana Faruqui,** for the partial fulfillment of the requirements for the degree of Bachelor of Science in Physiotherapy (B.Sc.PT).

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# Declaration

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistakes or inaccuracies are 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 of Physiotherapy Department, Bangladesh Health Professions Institute (BHPI).

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# Contents

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# Acronyms

| | |
|---|---|
| **ADL** | Activities of Daily Living |
| **BHPI** | Bangladesh Health Professions Institution |
| **BMRC** | Bangladesh Medical and Research Council |
| **CRP** | Centre for the Rehabilitation of the Paralysed |
| **ESD** | Early Supported Discharge |
| **HBRT** | Home Based Rehabilitation Therapy |
| **IRB** | Institutional Research Board |
| **MDT** | Multi – Disciplinary Team |
| **WHO** | World Health Organization |

# List of Tables

# List of Figures

## Abstract

*Purpose:* To explore the perception of patient's carer about the Home Based Rehabilitation Therapy (HBRT) at CRP. *Objectives:* To know about the benefits of HBRT, to find out whether the training given to the carers is adequate or not, to see whether the carers face any difficulty or not during giving HBRT and to know about the carers suggestions to make HBRT more beneficial. *Methodology:* A qualitative study design was used to conduct the study. Twelve carers of stroke patients were recruited in this study. The samples were selected by convenience sampling method. The data were collected by using a semi-structured questionnaire form and coded by seven themes; finally the coded data are analyzed and presented qualitative analysis. *Result:* Following themes have been emerged on the basis of data analysis. These include, Knowledge regarding the HBRT among carers is poor, HBRT is beneficial for stroke patients, HBRT treatment cost is not affordable by maximum stroke patients, Carers are satisfied with the patient's condition and therapy, Carers face very much little problem during giving HBRT, Training given to the carers regarding the HBRT is not sufficient and Some recommendations of the carers to make the program more beneficial.


*Keywords:* Home Based Rehabilitation Therapy, Stroke, Carer.

# CHAPTER-I INTRODUCTION

## 1.1 Background

The third leading cause of death and disability in adults in Bangladesh is stroke (Islam et al., 2012). The World Health Organization (WHO) defined stroke as "*rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin*."(Ralph et al., 2013). Survival after stroke initially can depend on the acute phase of specialist hospital care. However, the greatest impact on patient's health and well-being is from the long-term consequences faced when stroke survivors leave the hospital. Optimal recovery requires the provision of coordinated specialist rehabilitation, not only in the early stages of returning home, but also, usually many months after the stroke (Walker et al., 2013).

Rehabilitation plays an important part in comprehensive management of stroke. Studies have shown that rehabilitation is responsible for most of the recovery experienced by patients after a stroke and without it, little or no improvement can be accomplished (Mercy Stroke Center, 2013). Stroke rehabilitation provides a targeted and organized plan to re-learn functions lost in the shortest period of time possible. Improvements in function after stroke are the result of recovery within the ischemic penumbra, resolution of cerebral edema, neuroplasticity and compensatory strategies learnt by the patient (Hebb et al., 2013). Rehabilitation after stroke is a continuous process starting within days of stroke onset and ending only when it no longer produces any positive effect (Heart and stroke foundation, 2013). More than half the 75% of patients who survive the first month after a stroke will require specialized rehabilitation. Effective rehabilitation relies on a coordinated, multidisciplinary team approach (Clarke & Forster, 2015).

Stroke rehabilitation services are offered in both inpatient and community-based sites. Inpatient care may be provided in rehabilitation centers such as units attached to acute hospitals or nursing facilities. Outpatient rehabilitation services can be provided in hospital-based or independent clinics, in day hospital setting or in the home (Ottenbacher & Jannell., 2013). Eligibility requirements, the services provided and costs vary across sites of care. Delivery of stroke specialist care by HBRT is

increasing, particularly as health services face the challenge of reducing costs and are moving care out of expensive hospitals. There is also evidence that rehabilitation in the home environment is more beneficial for patients (Christine et al., 2013).

HBRT is to provide an in-home rehabilitation alternative to in-hospital rehabilitation. Advantages of HBRT include elimination of patient's travel resulting in decreased cost, fatigue and therefore, increasing treatment effectiveness (Parker et al., 2011). Patients are more relaxed and co-operative in their home environment. Family awareness of progress and ability increase resulting in increased continuity of the rehabilitation process. The disadvantages include increased frequency of patients' depression and isolation, increased travel time for the therapists and increased isolation of therapist from the multidisciplinary team (Parker et al., 2011).

HBRT at CRP is a joint session where an evaluation is done by physiotherapist and occupational therapist regarding patient's condition, patient's home environment and the way he/she functions in the home environment. Clinical measurement tools are used to get an idea of the patients' starting situation. Patients are visited two times in a week in the home situation and treated following the guidelines. Healthcare professionals will communicate the first one/two weeks every other day in a multidisciplinary meeting which will thereafter be held once a week. In these meeting participants are ought to discuss their findings and will come a consensus on aims during the treatment. The improvements are observed by two supervisors and they intervene when guidelines are not met. They attend the meetings to have an idea of the quality that is delivered.

## 1.2 Rationale

Stroke ranks third among the leading causes of death in Bangladesh (Islam et al., 2012). The World Health Organization ranks Bangladesh's mortality rate due to stroke as number 84 in the world (Islam et al., 2012). The reported prevalence of stroke in Bangladesh is 0.3%, although no data on stroke incidence have been recorded. Hospital-based studies conducted in past decades have indicated that hypertension is the main cause of ischemic and hemorrhagic stroke in Bangladesh. The high number of disability-adjusted life-years lost due to stroke (485 per 10,000 people) show that stroke severely impacts Bangladesh's economy (Islam et al., 2012).

Besides medical management, stroke rehabilitation is an integral part in the management of stroke patients which can be provided inpatient basis, hospital supervised outpatient basis and also through HBRT. Highly individualized therapies around a person's specific goals are provided by HBRT teams to a person's household environment and focus on improving activities of daily living to optimize function (Seenan et al., 2007). This approach may be quite effective as a person's home is often the most appropriate and effective setting for this recovery to take place and to improve or maximize independence. In this way, stroke patients are better able to cope with and overcome barriers specific to their home environments. This client centered approach to stroke rehabilitation can be effective and is often valued highly by the stroke survivor (Logan et al., 2014). Family carers usually do major caregiving tasks while caring for their stroke survivors at home. Sufficient preparation of the carers by providing training before discharge is positively related to quality of care. After completing the study we came to know the benefits, constraints and cost of HBRT. Knowledge of HBRT and carers recommendations is also known which will help us to modify the HBRT program to make it more beneficial.

## 1.3 Research Question

What are the perceptions of patients' carers about the HBRT service in stroke patients at CRP?

## 1.4 Objectives

### 1.4.1 General Objective

To explore the perceptions of patient's carers about the Home-Based Rehabilitation Therapy (HBRT) in stroke patients at CRP.

### 1.4.2 Specific Objectives

1. To know about the benefits of the HBRT.
2. To find out the perception whether the training given to them is beneficial or not.
3. To find out the difficulties faced during giving HBRT.
4. To know about the suggestions to make HBRT more beneficial.

## 1.5 Operational Definition

### Perception

Perception is the ability to see, hear or become aware of something through the senses or the way in which something is regarded, understood or interpreted.

### Rehabilitation

Rehabilitation describes specialized healthcare dedicated to improving, maintaining or restoring physical strength, cognition and mobility with maximized results. Typically, it helps people gain greater independence after illness, injury or surgery.

### Home Based Rehabilitation Therapy (HBRT)

Rehabilitation in the patients' home environment after stroke given by Multi - Disciplinary Team (MDT).

### Carers

Carers refer to any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition (Gibson, 2012).

# CHAPTER- II LITERATURE REVIEW

In the majority of health care systems, stroke care is initially offered in the inpatient hospital setting. Many individuals, upon discharge are able to receive ongoing rehabilitation in the hospital-based outpatient setting. However, these outpatient services are not available to all stroke survivors with ongoing needs (Duncan et al., 2005). The idea of HBRT has developed to deliver specialized stroke therapy services following discharge from hospital. This type of service is often directed at individuals who have ongoing rehabilitation needs and for whom traditional hospital-based outpatient rehabilitation services are not available, not accessible or simply as an alternative to traditional facility-based outpatient services (Allen, 2015).

HBRT teams provide services directly in a person's home. These teams most often limit their therapy setting to a person's household environment (Allen, 2015). These HBRT programs often structure their highly individualized therapies around a person's specific goals and focus on improving activities of daily living to optimize function (Allen, 2015). HBRT may be quite effective as a person's home is often the most appropriate and effective setting for this recovery to take place (Allen, 2015). In this way, stroke patients are better able to cope with and overcome barriers specific to their home environments. This client centered approach to stroke rehabilitation can be effective and is often valued highly by the stroke survivor (Allen, 2015).

HBRT programs differ greatly in their professional make up, client inclusion criteria and organization of services. They may also vary in the intensity of therapies and length of services offered (Allen, 2015). HBRT teams most often consist of some combination of team coordinator, physiotherapist, occupational therapist, speech-language therapist, social worker, nurse and recreational therapist (Allen, 2015). In the majority of cases, however, teams consist of a physiotherapist and occupational therapist as their core component. In a systematic review, eight of the included studies involved these two disciplines as a part of their multidisciplinary team structure. Five of the examined studies also included a registered nurse as a part of their offered services and a speech language therapist was included in four teams. In two studies, social workers were permanent members of the rehabilitation team but were included only on a consultation basis in several other programs (Winkel et al., 2008). A number of studies also included the direct involvement of a physician (Allen, 2015).

Upon further examination of the literature on HBRT teams, additional health care professionals such as psychologists, dieticians, therapy aides and physical medicine physicians also have been included as members of these interdisciplinary teams (Allen, 2015). Additionally, some HBRT teams are offered in combination with personal support worker and other home care services for influencing their functionality and impact (Allen, 2015).

Eligibility criteria are wide in the majority of HBRT programs as described in the literature. Most programs offer therapy to any adult stroke survivor who has rehabilitation needs as a result of their stroke and is able to participate in therapy (Allen, 2015). Other programs limit services to only those with acute stroke. Some HBRT programs may offer services in the form of Early Supported Discharge (ESD) from hospital which allows patients to return to their own homes with support days and even weeks sooner than may otherwise would have occurred in the absences of such a program (Allen, 2015).

The intensity of therapy provided to clients served by HBRT teams may also vary widely. In many cases, the amount and duration of therapy provided is highly individualized to each client (Allen, 2015). Other structures consist of a predetermined maximum of anywhere from two to five sessions per week and include a maximum duration of services. Programs may also incorporate a period of self-management in which stroke survivors are able to practice the skills they have acquired during the period of rehabilitation (Sirbu, 2012).

Although HBRT provides a unique opportunity for recovery in the most useful and practical environment, evidence of the effectiveness of HBRT programs is still incomplete. Many of the currently available Randomized Controlled Trials and observational studies compare HBRT to hospital-based outpatient rehabilitation, with the majority of studies conducted in the United Kingdom, Australia and Scandinavia. Furthermore, the majority of this literature compares HBRT with an Early Supported Discharge (ESD) approach to inpatient rehabilitation. Both inpatient rehabilitation and traditional outpatient services are efficacious in improving patient outcomes post stroke (Teasell et al., 2013).

The majority of studies of the efficacy of HBRT post stroke have looked at areas of disability, physical function and improvement in Activities of Daily Living (ADL) as primary outcomes. These outcomes are important measures of the disability level of an individual. Significant improvements in ADLs in HBRT groups have been observed in the majority of studies examining this outcome (Maddalena et al., 2015). In one study, although there were no significant differences between study groups, an earlier improvement was noted in the HBRT group (Hartman et al., 2007). Some studies have been able to demonstrate a significant improvement in favour of HBRT groups when compared with hospital-based controls.

HBRT programs are able to demonstrate significant improvement in motor function and also improvement in ADLs over time. However, when between groups comparisons are examined, no superiority of HBRT was observed over hospital-based therapy (Allen, 2015). Along with motor function and independence in ADLs, mobility is typically assessed as a measure of overall physical functioning in the stroke patient. Once again, HBRT has repeatedly been demonstrated to show significant improvements in mobility, although it has not been shown to be superior to control participants receiving hospital-based services (Banks & Marotta, 2007).

Overall function is also often assessed when examining the effectiveness of in-home rehabilitation. Although significant improvements are typically observed in overall health, daily activities, mobility and social functioning, they have not been observed to be superior to improvements seen in individuals accessing traditional outpatient or community services (Bjorkdahl et al., 2006). Furthermore, when compared with individuals receiving limited community rehabilitation services, a Canadian study by Reid et al. (2011) was not able to observe any superiority of the HBRT program on this particular outcome. Additionally, two studies have shown dominance of HBRT on improvements in overall measures of function as was observed in a study of young stroke survivors (Bjorkdahl et al., 2006). Superiority of hospital over HBRT in functional improvement was also observed, although authors acknowledge a substantial risk of bias with this result (Crotty et al., 2008). Overall, HBRT has been widely demonstrated to be effective at improving physical outcomes of stroke patients including improving independence in activities of daily living, motor function and mobility. There is conflicting evidence that HBRT is able to improve an individual's

overall function when compared with a hospital-based outpatient population (Allen, 2015).

In the majority of studies, as with physical and functional outcomes, improvement in the psychosocial domain was not found to have improved to a greater degree in a sample receiving HBRT when compared with outpatient therapy services (Teasell et al., 2013). One study looking at HBRT compared with a control group receiving limited services was not able to detect any difference in depression and anxiety symptoms (Hall et al., 2014). Conversely, Chaiyawat and Kulkantrakorn (2012) was the only study to detect a significant improvement in a treatment group compared with a control group who had limited access to post stroke rehabilitation services. This suggests that HBRT is not inferior to hospital-based treatment in improving symptoms of depression and anxiety in stroke survivors. An improvement in coping skills was examined in one study in the context of Early Supported Discharge and was found not to be significantly better in the treatment group versus controls discharged early from inpatient rehabilitation. (Quinn et al., 2009).

Many HBRT programs also provide support to family members and friends of stroke survivors, aiming to improve caregiver outcomes following stroke. These most often focus on psychosocial wellbeing as well as overall health status. In an RCT, caregivers of persons who suffered a stroke who received services from HBRT programs reported considerably less burden and reported more knowledge of stroke than the hospital outpatient-based control group (Teasell et al., 2013). Several other investigators have not been able to show any improvement in treatment groups over controls when examining caregiver outcomes (Schumi & Wittes, 2011). Converse to outcomes of physical and psychosocial recovery in stroke patients, studies that examine improvements in caregiver outcomes have been able to show more benefit in favor of HBRT groups when compared with standard rehabilitation controls.

Improvements in cognitive functioning are also often assessed. As before, very few studies have demonstrated any superiority of HBRT when compared with traditional rehabilitation services, although statistically significant improvements in these outcomes are observed in both groups, particularly on the Mini Mental State Examination. One study was not able to find superiority of HBRT in improving

cognitive outcomes when compared to a no or limited therapy group (Willems, 2006). Furthermore, one study found no improvement in cognition in either the intervention or the control group on the Barrow Neurological Institute Screen for Higher Cerebral Functions. Conversely, a Randomized Controlled Trial showed significant improvement in several cognitive domains when compared to a control group (Boudreau et al., 2006). Between admission and study end, significant improvements were observed in expression and problem solving. Furthermore, between admission and 4 week follow up, significant improvements were seen in comprehension, problem solving and memory domains on tests of neurological status and cognitive functioning (Boudreau et al., 2006).

Allen et al. (2015) observed a significant reduction in the length of hospital stay in individuals discharged to in-home rehabilitation. It has also been reported that home-based rehabilitation therapy can result in increased satisfaction in services for both patients and caregivers. Home-based therapy enabled patients and family to be involved in the planning process and allowed for greater opportunity to set relevant and achievable rehabilitation goals through a greater understanding of the needs and context of the programs clients. This resulted in greater client and caregiver satisfaction. Further benefits include a person's opportunity to make their own choices, which may further lead to the potential to be more active and motivated.

Meta-analysis of outcomes related to in-home rehabilitation is a challenge due to heterogeneity between programs, therapy intensities, structures, services provided and outcomes examined. In a meta-analysis of RCT comparing home-based and centre-based stroke rehabilitation facilities, home-based services were associated with greater client satisfaction, reduced caregiver strain, lower readmission rates and increased function and ADLs in a broad summary of results (Teasell et al., 2013). Analysis of six month follow up scores also revealed significant improvements compared with controls on this measure. This review noted that home-based rehabilitation may be superior from a patient outcome perspective, in part because individuals have the opportunity to immediately transfer skills they have learned in their own living environment (Allen et al., 2013). Although the majority of these studies did not demonstrate superior improvements when compared to traditional services, the preponderance of analyses demonstrated significant improvements in

level of disability, psychosocial well-being, caregiver outcomes, general health and well-being, and a variety of other positive benefits in study groups who received home-based rehabilitation compared to baseline. This supports the evidence for the efficacy of home-based stroke rehabilitation. However, evaluations of ongoing programs are warranted to further validate the efficacy of this treatment approach.

Few economic reviews have examined the costs of home-based programs in the post-acute stage. The majority of these studies examined the costs of these programs in the context of an early supported discharge program. Far fewer looked at cost differences in comparison to hospital based outpatient programs. Most studies have found that home-based services are no more costly than outpatient hospital based programs and in some cases are more cost-effective, looked at both health and social service costs accrued by participants during the study period and found that there were no statistically significant differences between those accessing in-home rehabilitation and individuals in an outpatient program (Allen, 2015). While similar overall health service costs were observed in the two groups, slightly higher social service costs were noted in the home-based group. Similar cost outcomes were also noted by Smith et al. (2013) with slightly lower health service costs observed in the hospital-based cohort. Tummers et al. (2012) also examined the costs of home-based rehabilitation as an alternative to an outpatient hospital program. This study solely examined the costs of the two programs themselves, and did not include any additional health care costs. The authors found that the program cost of home rehabilitation was less than half (42%) of hospital based rehabilitation. A systematic review of the economic impact of home-based rehabilitation programs including those with an early supported discharge component found that overall home-based rehabilitation reduced hospital stays by 13 days (Tummers et al, 2012). Furthermore, overall mean costs for community stroke rehabilitation care in combination with early discharge from hospital resulted in an overall mean cost reduction of 15% without compromising patient outcomes (Duncan et al., 2005).

In general, there is substantial heterogeneity of results when examining the effectiveness of home-based stroke rehabilitation programs in terms of patient outcomes in relation to cost savings (Stokes, 2008). This is likely due to the fact that the majority of studies examining home-based rehabilitation for stroke patients differ

on aspects of the programs themselves, structure of the interdisciplinary teams, as well as the differences in health care system structures between countries around the world. Furthermore, studies generally have small sample sizes and limited follow up. This may also have implications for extrapolating the effectiveness of results and the cost.

# CHAPTER-III METHODOLOGY

## 3.1 Study Design

Qualitative research approach was applied to gain understanding and explore the perception of the carers of stroke patients about the HBRT. Semi-structured face to face interview was conducted among the carers for getting a clear idea about their perception on HBRT, its effectiveness, their opinions regarding cost, difficulties facing therapy and their suggestions regarding the improvement of the program.

## 3.2 Study Site

The study was conducted in one rehabilitation center named 'Centre for the Rehabilitation of the Paralysed (CRP) at Savar, Dhaka, Bangladesh.

## 3.3 Study Population

Carers of stroke patients getting HBRT at Centre for Rehabilitation of the Paralysed (CRP).

## 3.4 Sampling Method

The samples were selected by convenience sampling method.

## 3.5 Inclusion Criteria

1. Carers of stroke patients taking HBRT service at CRP
2. Carers with age 15 to 50 years
3. Male and female carers both were the participants
4. Both literate and illiterate carers were included in the study

## 3.6 Exclusion Criteria

1. Those who were not interested.
2. Age <15 years and >50 years

## 3.7 Sample Size

Twelve carers were interviewed from the patient's guest house, private room and nursery hostel at Centre for the Rehabilitation of the Paralyzed (CRP). **3.8 Data**

## Collection Tools

A tape recorder was used during the interviews to record the conversation. Simultaneously pen and papers were also used to write down field notes.

## 3.9 Method of Data Collection

Data were collected by conducting face to face interviews providing a semi structured questionnaire form.

## 3.10 Procedure of Data Collection

Semi-structured interview questions were used in this study. The interview was recorded using a tape recorder by taking permission from the patient's carers. Audiotape was used to record the all interviews to discover exact feeling, attitude and emotions of the participants during interviews. The interview was conducted in bengali as though they can understand the questions easily. Face to face interview was conducted because this may provide higher response than other data collection methods. Every interview lasted for 30-40 minutes. Interview continued until saturation point was reached, that is no major new insights were being revealed and there was repetition of the same issues with different respondents. Data was collected in between 12$^{th}$ September 2015 to 5$^{th}$ October 2015. Each data was collected carefully and confidentiality was maintained. Each participant provided particular time to collect data. Each questionnaire took approximately 30-40 minutes to complete.

## 3.11 Data Analysis

The data analysis mainly involved the transcript of the interviews, identifying themes and then incorporating those themes into the next stage of data collection. Same questions were asked to the participants by preparing a semi structure questionnaire. The questions were analyzed as the first step of data analysis. For a better analysis, the individual responses were read thoroughly for several times to identify the actual meaning and themes from the responses. Finally seven themes were listed and codes were developed from the list. According to the codes, the differences between each other were detected. The codes were also defined clearly with their actual meaning.

For that reason, overtime the participant's perceptions were coded carefully according to their actual meaning and followed in each question. The next step is the content analysis of the topic. Here the researcher carefully divided the topic into some categories. Finally theme will be known from each category.

## 3.12 Ethical Consideration

Researchers have ethical responsibility to recognize and protect the rights of human research participants. Human rights that require protection in research are the right to self-determination, right to privacy, right to anonymity and confidentiality, right to fair treatment and protection from discomfort and harm (The British Psychological Society, 2010). These five principles of human rights also guided ethical consideration for this research. The ways of protecting the five human rights were divided into three parts: before, during and after data collection. Before data collection, the research was approved by Review Committee of BHPI. After obtaining approval, the research process was begun. For the participants, the researcher provided detailed information to protect the five human rights as described in the consent form. The information included: A detailed description of the purpose and procedure of the research; the benefits and risks of joining this research. There were no expected risks for participants during the research period. The only inconvenience for participants was they might feel uncomfortable and inconvenienced while answering questions during interviews and the researcher's presence in their living places. They had the right to decide to participate in this research, and they could withdraw from this research at any time. If they decided not to participate, their decisions would not impact on the quantity and quality of care for their family member from HBRT team. The collected information was kept confidentially and only the researcher could access those data. The collected data would not be disclosed or identified with an individual's name. After data collection, all collected data was transcribed and entered into one computer and two back-up copies in two portable hard drives. All of the printed documents or raw data were locked in a file box and only the researcher could access those data. Those data were deleted or shredded and discarded after the research was finished. The Research was approved by Institutional Research Board.

### 3.13 Rigor

Researcher always tried not to influence the process by her own value and biases. No leading questions were asked or no important question is avoided. While conducting the study the author took help from her supervisor and follows her direction appropriately.

# CHAPTER-IV RESULTS

## 4.1 Participant's Details

Twelve carers both male and female were included in this study. Among the participants, seven participants were female and five were male. The average age was 34 with minimum age 26 years and maximum 43 years (Table-1).

| Carer's ID No | Age | Sex |
|---|---|---|
| C1 | 36 | Female |
| C2 | 43 | Female |
| C3 | 39 | Male |
| C4 | 28 | Female |
| C5 | 40 | Male |
| C6 | 42 | Male |
| C7 | 26 | Female |
| C8 | 35 | Female |
| C9 | 27 | Male |
| C10 | 30 | Female |
| C11 | 33 | Female |
| C12 | 42 | Male |

**Table-1** Participant's details

### 4.2 Socio-demographic information at a glance

Among twelve participants 20-40 years old participants were 09 and (>40) year's old participants were 0 3 (Figure-01).

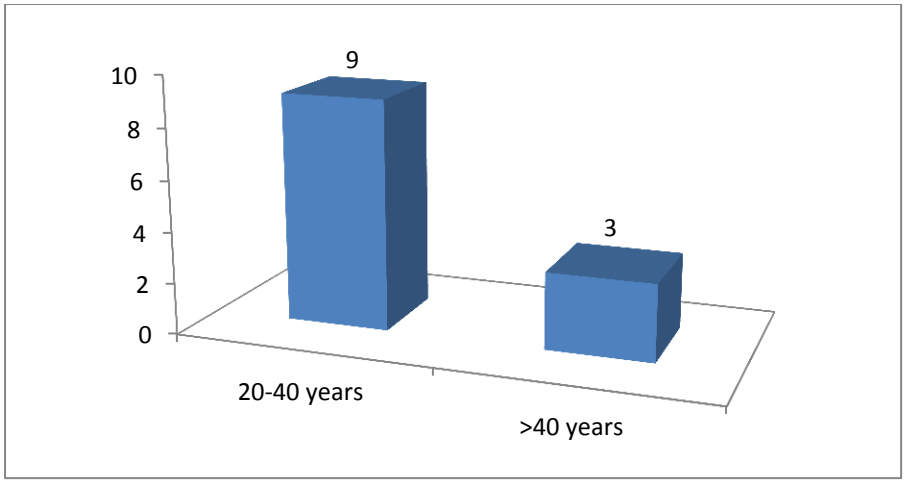


**Figure-1** Age Distribution of Carers

Among the participants, female were 07 and male were 05 (Figure-02).

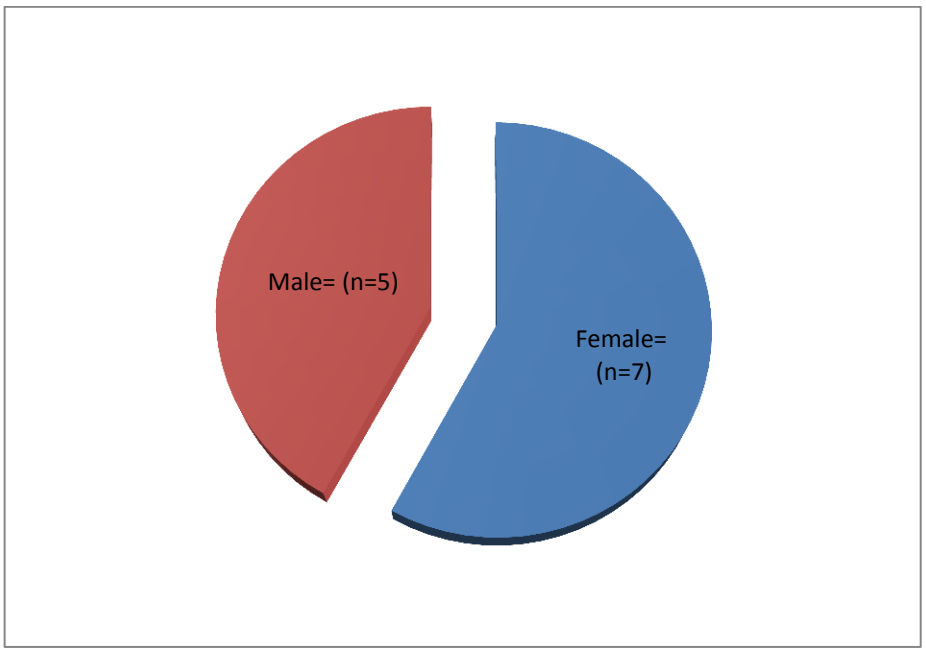


**Figure-2** Sex Distribution of Carers

Among the 12 participants, 04 participants were illiterate, 03 participants had primary education, 04 participants completed secondary education, and 01 participant had Bachelor degree (Figure-03).

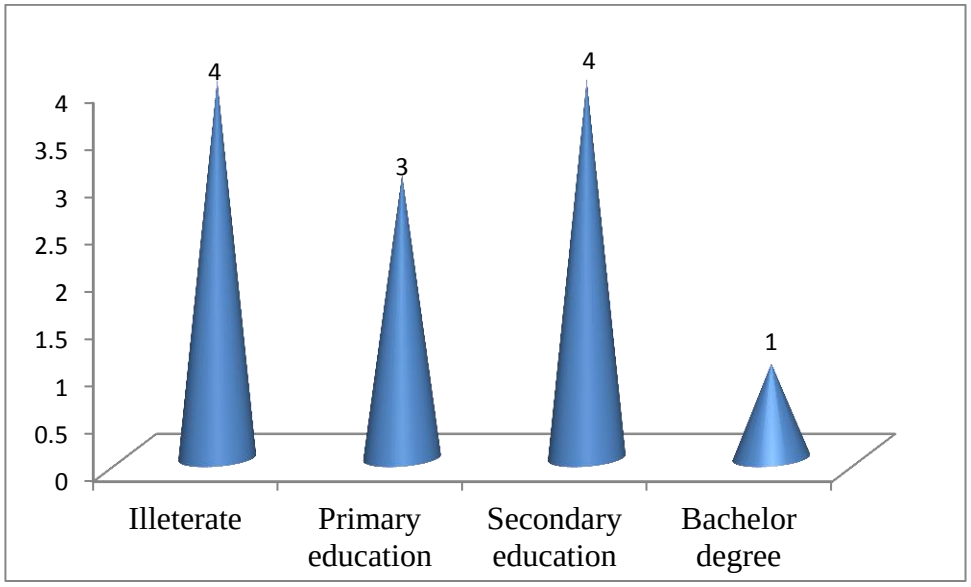


**Figure-3** Educational Distribution of Carers

Among the 12 participants, 04 participants were housewife 03 participants were farmer and 05 participants were service holder (Figure-4).

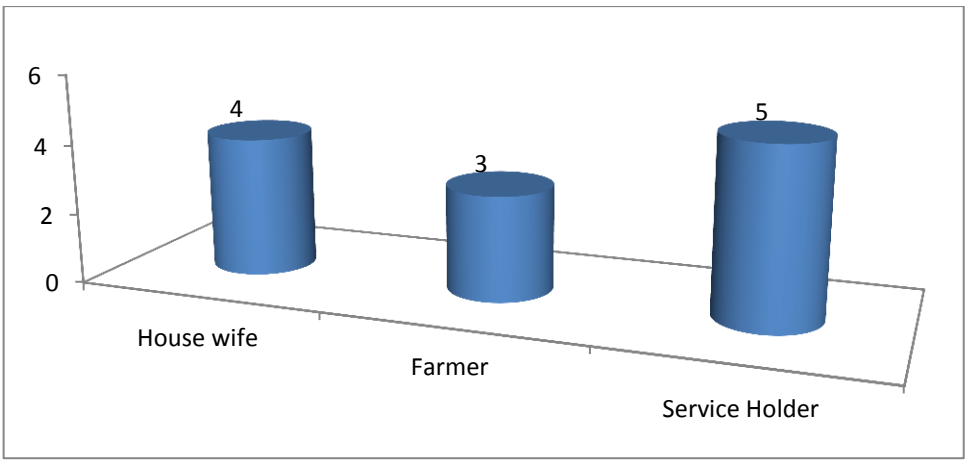


**Figure- 4** Occupations of Carers

## 4.3 Following Themes are emerged on the basis of data analysis

1. Knowledge regarding the HBRT among carers is poor.
2. HBRT is beneficial for stroke patients.
3. HBRT treatment cost is not affordable by maximum stroke patients.
4. Carers are satisfied with the patient's condition and therapy.
5. Training given to the carers regarding the HBRT is not sufficient.
6. Carers face very much little problem during giving HBRT.
7. Some recommendations of the carers to make the program more beneficial

### 4.3.1 Knowledge regarding the HBRT among carers is poor

This theme relates to the carers knowledge about home based rehabilitation therapy. The participant responses are displayed below (Figure-5).

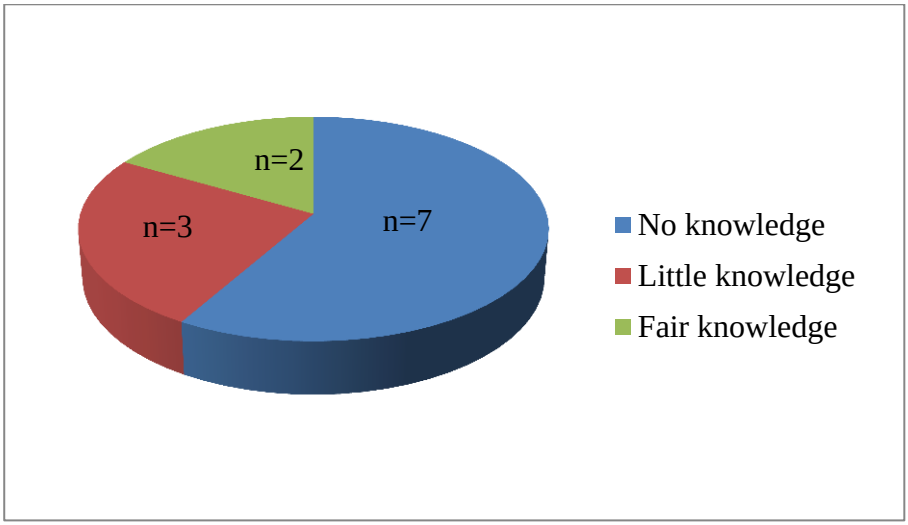


**Figure-5** Knowledge regarding the HBRT among carers

According to the transcripts, 07 of the participants stated that they had no knowledge regarding HBRT, 03 participants had some idea regarding HBRT but 02 participants had sound knowledge.

### 4.3.2 HBRT is beneficial for stroke patients

To find out the every participant was asked the same question. The participant responses are displayed at below (Table-2).

| Carers ID No | HBRT Beneficial | HBRT Not Beneficial |
|---|---|---|
| C1 | ✓ | - |
| C2 | ✓ | - |
| C3 | ✓ | - |
| C4 | ✓ | - |
| C5 | ✓ | - |
| C6 | ✓ | - |
| C7 | ✓ | - |
| C8 | ✓ | - |
| C9 | ✓ | - |
| C10 | ✓ | - |
| C11 | ✓ | - |
| C12 | ✓ | - |

**Table-2** HBRT among stroke patients is beneficial

In this table all the participants stated that, HBRT is a most beneficial treatment for their patients.

### 4.3.3 HBRT treatment cost is not affordable by many of the stroke patients

Here the researcher wanted to know the carers perception of the cost for their patients care. The participant responses are displayed below (Figure-6).

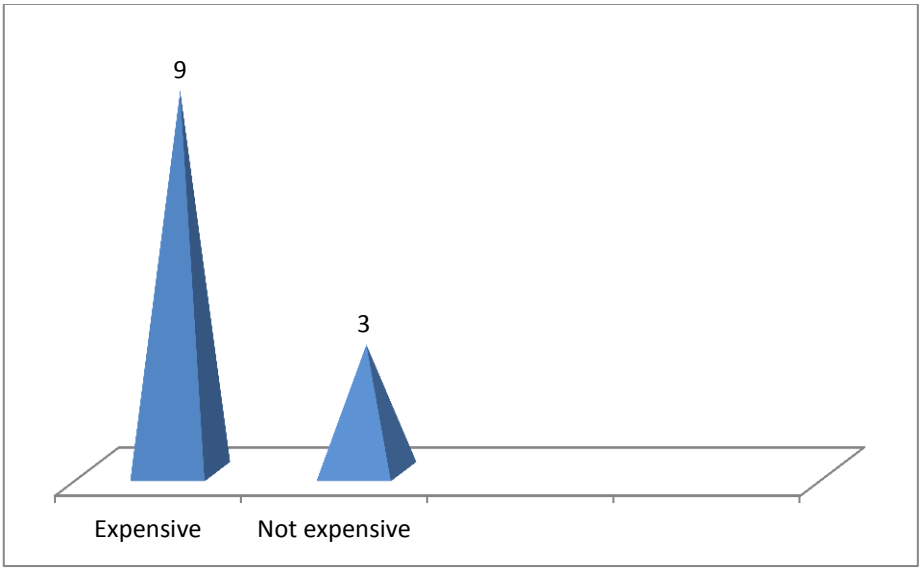


Figure-6 HBRT treatment cost

This table represents the participants view about expenditure of HBRT at CRP. Among 12 participants, 09 participants reported that the "cost of treatment is not affordable". 03 participants stated that, "HBRT cost is not expensive".

### 4.3.4 Carers are satisfied with the patient's condition and therapy

The researcher wanted to find out whether the carers were satisfied with the patient's condition and therapy. The participant responses are displayed at below (Table-3).

| Carers ID NO | Satisfied | Not Satisfied |
|---|---|---|
| C1 | ✓ | - |
| C2 | ✓ | - |
| C3 | ✓ | - |
| C4 | ✓ | - |
| C5 | ✓ | - |
| C6 | ✓ | - |
| C7 | ✓ | - |
| C8 | ✓ | - |
| C9 | ✓ | - |
| C10 | ✓ | - |
| C11 | ✓ | - |
| C12 | ✓ | - |

**Table-3** Satisfaction of the carers regarding HBRT

This table represents all the 12 participants said that they are satisfied about the patient's condition and therapy provided by HBRT.

### 4.3.5 Training given to the carers regarding the HBRT is not sufficient

The researcher wanted to find out whether the training given to the carers is sufficient or not. The participant responses are displayed below (Table-4).

| Carers ID NO | Sufficient | Not Sufficient |
|---|---|---|
| C1 | ✓ | - |
| C2 | - | ✓ |
| C3 | - | ✓ |
| C4 | ✓ | - |
| C5 | ✓ | - |
| C6 | ✓ | - |
| C7 | - | ✓ |
| C8 | ✓ | - |
| C9 | ✓ | - |
| C10 | - | ✓ |
| C11 | ✓ | - |
| C12 | ✓ | - |

**Table-04** Training given to the carers regarding the HBRT

### 4.3.6 Carers face very much little problem during giving HBRT

This theme covers the issues whether the carers face any difficulty during giving HBRT.

Among 12 participants one of them said that, *"The behavior of both Physiotherapist and Occupational therapist is good, therapists are very communicative during treatment time".*

Above statement reflect that the therapist developed trust of the patients showing professional attitude which is very important to express their problem without any hesitation.

Another one participant stated, *"The behavior of the therapist is good. My patient's therapist is very cooperative and friendly. She gives lot of effort in order to make patient's condition improved."*

This statement reflects that carers are satisfied with the behavior of the therapist.

One of the participant stated, *"Here I am alone with my father. It is very difficult for me to give all the therapy. I am giving those therapies regularly that are possible in lying condition."*

This statement reflects that it is not possible for a carer to give all the therapies properly without the help of others.

### 4.3.7 Some recommendations of the carers to make the program more beneficial

According to one participant, *"Health care professional should instruct the carers about the appropriate procedures of the exercises and also should explain which exercise for which problem so that we can easily understand."*

One of the 12 participants stated, *"Therapist should inquire regularly whether we are giving the therapy appropriately or not."*

According to another participant, *"Authority should give written instruction including pictorial form of exercise so that we can understand properly."*

Another participant stated, *"Authority should reduce per session treatment cost as this type of patient is to take regular therapy for prolonged period of time."*

Another participant said, *"Therapist should give per session treatment for full one hour."*

# CHAPTER-V DISCUSSION

The aim of this study was to explore the perception of patients' carer about the Home Based Rehabilitation Therapy (HBRT) at CRP. A qualitative study design was used to conduct the study. Twelve carers of stroke patients were recruited in this study. The samples were selected by convenience sampling method. The data were collected by using a semi-structured questionnaire form and coded by seven themes; finally the coded data are analyzed and presented qualitative analysis. Following themes have been emerged on the basis of data analysis. These include, Knowledge regarding the HBRT among carers is poor, HBRT is beneficial for stroke patients, HBRT treatment cost is not affordable by maximum stroke patients, Carers are satisfied with the patient's condition and therapy, Carers face very much little problem during giving HBRT, Training given to the carers regarding the HBRT is not sufficient.

12 carers both male and female were included in this study. Among the participants, 07 participants were female and 05 were male. The average age was 34 with minimum age 26 years and maximum 43 years; 20-40 years old participants were 09 and >40 year's old participants were 03. Among the participants, female were seven 07 and male were 05; 04 participants were illiterate, 03 participants had primary education, 04 participants completed secondary education and 01 participant had Bachelor degree. Among the 12 participants, 04 participants were housewife, 03 participants were farmer and 05 participants were service holder.

7 of the participants stated that they had no knowledge regarding HBRT. 3 participants had some idea regarding HBRT but 2 participants had sound knowledge. Among twelve participants one of them reported that, "I heard that HBRT is a project in which there are some facilities for the patients. Therapists will visit home of each patient and teach us about the therapy. " Another one participants stated that, "I have no idea regarding HBRT. As far I understand about HBRT that patients of HBRT get some extra facilities in counter, therapists also take extra care about them. They come to patient's room, give therapy and teach us how to give therapy and how to take care of the patient." These statements reflect that the carers knowledge is poor

regarding HBRT. Mary et al. (2012) found that poor knowledge is probably due to their poor educational background and also the amount of time and hospital resources to prepare the carers were inadequate.

All the participants stated that HBRT is the most beneficial treatment for their patients. One of the carers stated that, *"I think HBRT is a*n *effective treatment. After receiving HBRT my patient is gradually improving. He can now move his paralyzed limbs and can walk with minimum support"*. Another respondent express that, *"Before receiving HBRT my patient's right hand and leg were very stiff and painful but now pain subsided and stiffness reduced after getting HBRT"*. These statements are supported by a study in which it is said that rehabilitation in home environment is more beneficial for the patients (Christine et al., 2013).

Among 12 participants, 9 participants reported that the "cost of treatment is not affordable". 3 participants stated that, "HBRT cost is not expensive". Different participants expressed their opinion in different ways. Among 12 participants one of them stated that, *"Per session treatment cost is 250 taka which is not affordable for me. Authority should reduce the treatment cost after a certain period of time".* Another one stated that, *"HBRT cost should not exceed more than 100 taka per session"*. Another participant said, *"We have no problem to bear therapy cost because Samajkallayan supported me financially. Now my treatment cost is 100 taka per session"*. These statements reflect that HBRT treatment is not affordable for most of the patients. The last statement also reflect that, if any patients find it difficult to pay the treatment cost, CRP provides financial support through Samajkallayan which is the social welfare department of CRP to help the poor patients. The findings are supported by a study in which it is said that HBRT treatment is costly (Egglestone et al., 2009).

All the 12 participants said they are satisfied about the patient's condition and therapy provided by HBRT. One participant stated, *"My patient could not walk without support after stroke. After receiving HBRT my patient's condition is much better. Now he can walk independently"*. According to another participant, *"My patient's condition is much better following HBRT. He is feeling better today".* Another one said, *"I think HBRT is effective treatment for my patient because*

*after taking HBRT for six sessions his condition is much better than before".* Another participant stated, *"My father was not able to move his right side and there was tingling sensation in his right side. But after receiving HBRT he is now improving. Now he can move his right upper and lower limb. His tingling sensation is also reduced."* According to another participant, *"The mouth of my patient was curved before, now it is straight. Now her speech is clear. She did not lose her memory. She can hear a word and can speak."* These statements reflect that the outcome of HBRT satisfied all of the participants which are consistent with the study by Christine et al. (2013) stated, *'carers expressed great satisfaction about receiving rehabilitation within the home environment'.*

One of the participants stated, *"Training given to us is sufficient, but it would have more effective if therapists inquire regularly whether we are able to give therapy appropriately."* Another participant told, *"I am doing up and down of the head, raise the hip and foot as per advice of the therapist. I move the fingers, raise the hand, bend up the knee and straight it, move the toes etc. I also practice standing exercise to her and then try to move her hip as therapists told."* This state reflects that as per training all carers are not able to give therapy to their patients and training given to the carers were not adequate.

Among 12 participants one of them said that, *"The behavior of both Physiotherapist and Occupational therapist is good, therapists are very communicative during treatment time".*Above statement reflects that the therapist developed trust of the patients showing professional attitude which is very important to express their problem without any hesitation. Another one participant stated, *"The behavior of the therapist is good. My patient's therapist is very cooperative and friendly. She gives lot of effort in order to make patient's condition improved."* This statement reflects that carers are satisfied with the behavior of the therapist.

One of the participant stated, *"Here I am alone with my father. It is very difficult for me to give all the therapy. I am giving those therapies regularly that are possible in lying condition."* This statement reflects that it is not possible for a carer to give all the therapies properly without the helpf others. According to one participant, *"Health care professional should instruct the carers about the appropriate procedures of the*

*exercises and also should explain which exercise for which problem so that we can easily understand."*

One of the 12 participants stated, *"Therapist should inquire regularly whether we are giving the therapy appropriately or not."* According to another participant, *"Authority should give written instruction including pictorial form of exercise so that we can understand properly."* Another participant stated, *"Authority should reduce per session treatment cost as this type of patient is to take regular therapy for prolonged period of time."* Another participant said, *"Therapist should give per session treatment for full one hour."* If we consider the carers recommendations and incorporate these recommendations as practicable, then HBRT will be more helpful for stroke patients.

## Limitations

The researcher was a 4th year B.Sc. in physiotherapy student and this was her first research project. She had limited experience with techniques and strategies in terms of the practical aspects of research. As it was the first research of the researcher so might be there were some mistakes that overlooked by the supervisor and the honorable teachers.

# CHAPTER-VI CONCLUSION AND RECOMMENDATION

## 6.1 Conclusion

This study explored the perception of the carers of stroke patients about the home based rehabilitation therapy. The study demonstrated some common problems of stroke patients from the perception of the carers. It is found in this study that a common expectation of the carers is that the stroke survivors will be getting a near normal life by taking home based rehabilitation therapy. Various types of improvement also found from their perception in this study. Most of the participants thought that if home based rehabilitation therapy is given properly, it will be more helpful for getting the improvement quickly. The participants also observed some problems that they faced during delivery of home based rehabilitation therapy. But taking this home based rehabilitation therapy for their patients satisfies all the participants. As they got some improvement by taking this therapy, they are more hopeful to get more improvement so that their patients will lead a better life.

## 6.2 Recommendation

The health professionals should pay attention not only to the stroke patients but also to the attitude and beliefs of the carers both in the treatment and rehabilitation phase. It would secure a better recovery and rehabilitation of the stroke patients. If no attention is paying to the values, beliefs and attitudes of the carers, the impact of recovery will be slow. It is not possible to make any judgement on the home based rehabilitation therapy of the stroke patients from this study. This study can be useful for the health professional to understand what the carers actually think about the home based rehabilitation therapy that is given for their patients. This will be helpful for making goal setting for stroke patients. It will be easier to understand for the health professionals that what the best therapy is for stroke patients. Further study is needed to specify the home based rehabilitation therapy that is recommended for stroke patients.

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# Appendix

## VERBAL CONSENT FORM

(Please read out to the participant)

Assalamualaikum, my name is Farhana Faruqui, I am conducting a study for partial fulfillment of Bachelor of Science in Physiotherapy degree, titled on

**"PERCEPTION OF PATIENTS CARER ABOUT HOME BASED REHABILITATION THERAPY (HBRT) SERVICE FOR THE STROKE PATIENTS AT CRP"**

From Bangladesh Health Professions Institute (BHPI) under medicine faculty of University of Dhaka. I would like to know some information related to my study. This will take approximately 30-40 minutes. I need to meet you just once to collect entire information.

I would like to inform you that this is a purely academic study and obtain information will not be used for any other purpose. All information provided by you will be kept confidential and also the source of information will remain anonymous.

Your participation in this study is voluntary and you also have the right not to answer a particular question that you don't like or do not want to answer during interview.

Do you have any questions before I start?

So may I have your consent to proceed with the interview?

Yes ☐ No ☐

Signature of the witness…… Date……..

Signature of the participants…….Date……

Signature of the researcher……....Date……...

# মৌখিক অনুমতি পত্র

## (অংশগ্রহনকারীকে পড়ে শোনাতে হবে)

আস্সালামু আলাইকুম/নমস্কার, আমার নাম ফারহানা ফারুকী , আমি এই গবেষনাটি বাংলাদেশ হেলথ্ প্রফেশনস্ ইনস্টিটিউট (বি,এইচ,পি,আই), ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদ- এর অধিনে করছি যা আমার ফিজিওথেরাপী স্নাতক কোর্সের আংশিক অধিভুক্ত, যার শিরোনাম হল- ''সিআরপিতে স্ট্রোকে আক্রান্ত রোগীর পরিচর্যাকারীর হোম বেইজড রিহাবিলিটেশন থেরাপী সম্পর্কে ধারণা '' । আমি এক্ষেত্রে কিছু ব্যক্তিগত এবং আপনার সমস্যা সম্পর্কে আনুষাঙ্গিক কিছু তথ্য জানতে চাচ্ছি যা আনুমানিক ৩০-৪০ মিনিট সময় নিবে। আমি এই তথ্য সংগ্রহের জন্য শুধুমাত্র একবারই আপনার সাথে সাক্ষাৎ করব।

এই গবেষনার প্রধান উদ্দেশ্য হল সি আর পিতে স্ট্রোকে আক্রান্ত রোগীর পরিচর্যাকারীর হোম বেইজড রিহাবিলিটেশন থেরাপী সম্পর্কে ধারণা।

আমি আপনাকে অবগত করছি যে, এটা কেবল মাত্র আমার অধ্যায়নের সাথে সম্পর্কযুক্ত এবং এই তথ্যগুলো অন্য কোন উদ্দেশ্যে ব্যবহৃত হবে না। আমি আপনাকে আরও নিশ্চয়তা প্রদান করছি যে, আপনার এবং আপনার দেওয়া সকল তথ্যের গোপনীয়তা বজায় থাকবে।

এই অধ্যয়নে আপনার অংশগ্রহন স্বেচ্ছাপ্রণোদিত এবং আপনি যে কোন সময় এই অধ্যয়ন থেকে কোন নেতিবাচক ফলাফল ছাড়াই নিজেকে প্রত্যাহার করতে পারবেন। এছাড়াও আপনি যদি চান তবে এই সাক্ষাৎকারের যে কোন প্রশ্নের উত্তর নাও দিতে পারেন যেটা আপনার পছন্দ না।

এই সাক্ষাৎকার শুরু করার আগে আপনার কি কোন প্রশ্ন আছে?

আমি আপনার অনুমতি নিয়ে এই সাক্ষাৎকার শুরু করতে যাচ্ছি।

হ্যাঁ ☐ না ☐

সাক্ষীর স্বাক্ষর : ..... তারিখ.....

সাক্ষাৎকার প্রদানকারীর স্বাক্ষর ঃ..... তারিখ.....

সাক্ষাৎকার গ্রহনকারীর স্বাক্ষর ঃ..... ..তারিখ ঃ.....

## Questionnaire

Demographic information:

Name: Age: Sex:

Address: Phone no:

Occupation:

Educational status:

1. What do you know about Home Based Rehabilitation Therapy?
2. How long your patient having Home Based Rehabilitation Therapy Service at CRP?
3. How many days your patient having Home Based Rehabilitation Therapy in a week?
4. Do you think the time that HBRTS team providing is sufficient? Yes/ No
   If no, will you please mention why?
5. What is your opinion regarding the cost of HBRTS?
6. What were the problems your patient faced prior to Home Based Rehabilitation Therapy?
7. Do you find Home Based Rehabilitation Therapy Service beneficial for your patient? Yes/No
   Would you please mention why?
8. How you found about the training you get from the therapist regarding your patient? Yes/No
   If No, would you please mention why?
9. Is the patient cooperative with you when you provide the suggested treatment? Yes/no
   If No, would you please mention why?
10. Is there any problems do you found regarding HBRTs? Yes/No
    If yes, would you please mention?
11. What are the suggestions you recommend to make the program more effective?

## প্রশ্নমালা

সামাজিক অবস্থা

নাম :  বয়স :  লিঙ্গ :

ঠিকানা :  ফোন নং :

পেশা :

শিক্ষাগত যোগ্যতা :

১. হোম বেজড রিহ্যাবিলিটেশন থেরাপী সমন্ধে আপনি কী জানেন?

২. আপনার রোগী কতদিন ধরে হোম বেজড রিহ্যাবিলিটেশন থেরাপী নিচ্ছে?

৩. আপনার রোগী সপ্তাহে কতদিন হোম বেজড রিহ্যাবিলিটেশন থেরাপী পাচ্ছে?

৪. হোম বেজড রিহ্যাবিলিটেশন থেরাপীর দল আপনার রোগীকে যে সময় দিচ্ছে, আপনি কি সেটা যথেষ্ট মনে করেন? হ্যাঁ/না।

যদি না হয়, তাহলে কেন ব্যাখ্যা করুনঃ

৫. হোম বেজড রিহ্যাবিলিটেশন থেরাপীর ব্যয় সম্পর্কে আপনার মতামত কী?

৬. হোম বেজড রিহ্যাবিলিটেশন থেরাপী নেওয়ার আগে আপনার রোগী কী কী সমস্যার সম্মুখীন হয়েছে?

৭. আপনি কি আপনার রোগীর জন্যে হোম বেজড রিহ্যাবিলিটেশন থেরাপীটকে উপকারী মনে করেছেন। হ্যাঁ/না।

তাহলে কেন ব্যাখ্যা করুনঃ

৮. আপনার রোগীর থেরাপী বিষয়ে থেরাপীস্টগণ আপনাকে যে প্রশিক্ষণ দেয়, সেটা কি আপনি যথেষ্ট মনে করেন? হ্যাঁ/না।

যদি না হয়, তাহলে কেন ব্যাখ্যা করুনঃ

৯. আপনাকে শেখানো থেরাপী গুলো যখন আপনার রোগীকে করান তখন কি আপনার রোগী আপনাকে সহযোগিতা করে? হ্যাঁ/না।

যদি না হয়, তাহলে কেন ব্যাখ্যা করুনঃ

১০. আপনি কি হোম বেজড রিহ্যাবিলিটেশন থেরাপী পাওয়ার সময় কোন সমস্যার সম্মুখীন হয়েছেন? হ্যাঁ/না।

যদি হ্যাঁ হয়, তাহলে কী ব্যাখ্যা করুনঃ

১১. এই প্রোগ্রামটিকে আরও ফলপ্রসু করার জন্যে আপনার পরামর্শ কী?

September 12, 2015 **Permission letter**

The Head of the department

Department of physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain,Savar,Dhaka-1343.

**Through:** Head, Department of Physiotherapy, BHPI.

**Subject:**Seeking permission of data collection to conduct my research project.

Dear Sir,

With due respect and humble submission to state that I am Farhana Faruqui student of 4th Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI).The ethical committee has approved my research project entitled on "Perception of patients' carers about home based rehabilitation therapy service for the stroke patient at Center for the Rehabilitation of the Paralyzed (CRP)"under the supervision of Farzana Sharmin, In charge of Neurology unit of physiotherapy Department, CRP, Savar. Conducting this research project is partial fulfillment of the requirement for the degree of B.Sc. in Physiotherapy. I want to collect data for my research project from thecarers of stroke patients` who are stayed in the private room, guest house and nursery hostel of CRP. So, I need permission for data collection from the private room, guest house and nursery hostel of CRP-Savar. I would like to assure that anything of my study will not be harmful for the participants.

I, therefore, pray & hope that you would be kind enough to grant my application & give me permission for data collection and oblige thereby.

Sincerely

Farhana Faruqui

4th Professional B.Sc. in Physiotherapy

Roll-35, Session: 2010-2011

Bangladesh Health Professions Institute (BHPI)

(An academic Institute of CRP)

CRP, Chapain, Savar,Dhaka-1343.

She may be allowed for data collection.
12.09.15

Rumana
Sr. PT
12.09.15

Approved
16/09/15